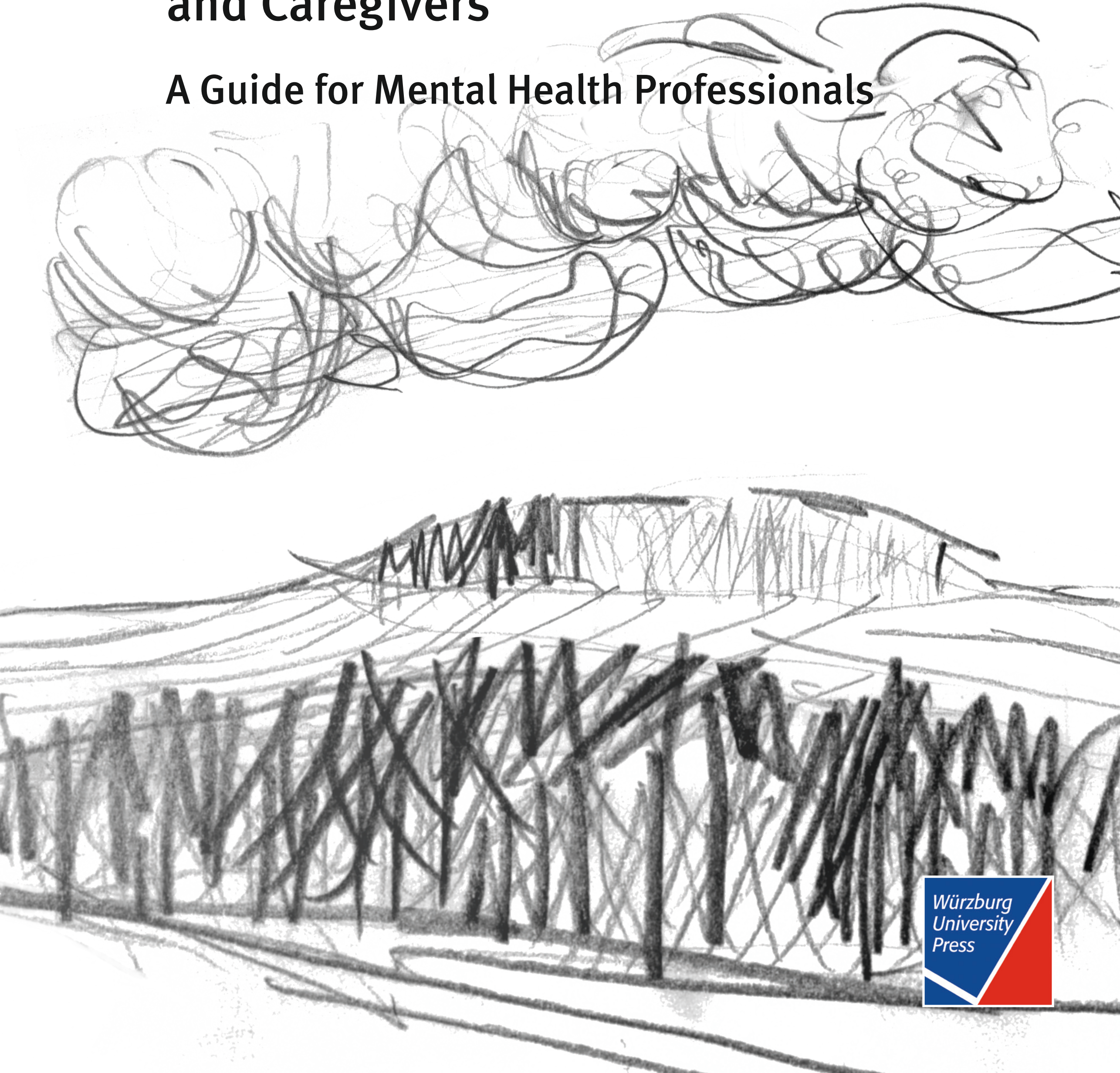
Marcia Smith Pasqualini, Michael Macht,
Heiner Ellgring

Cognitive Behavioral Therapy for People with Parkinson's Disease and Caregivers

A Guide for Mental Health Professionals



Würzburg University Press

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Preface

> "Can I live a happy life with a progressive neurological disease?"
> "How can I cope when Parkinson's disease makes me feel hopeless?"

As clinical psychologists who work with people with Parkinson's disease (PD) and their family members, these are questions we have often been asked. While scientists search for a medical cure, people with PD face challenges that can affect all aspects of their lives. Mental health professionals need solutions for people dealing with a wide range of challenges that cannot be fixed by medical treatment alone. This book provides a blueprint. Based on techniques of cognitive behavioral therapy and backed by research, our aim is to help people with PD and their caregivers embrace new ways of living with PD, under the professional guidance of qualified professionals.

We provide background information about PD together with practical instructions for the delivery of psychological interventions, either in a group format or on an individual basis. This book is not meant to be used as a rigid training manual, but rather as a foundation that can be adapted by therapists to address individuals' needs.

Our focus is primarily on nonmotor functions, although psychological interventions may benefit motor symptoms as well. Psychological interventions for people with PD should always be used in conjunction with ongoing medical care, not as a replacement. Other services including physical therapy, occupational therapy, and speech-language therapy can provide additional help, and our programs can be coordinated with these services as needed.

Our overall goal is to enable people with PD and their families to live full and meaningful lives by facilitating the use of psychologically-based treatments for PD, as well as to promote continued research on the efficacy of these treatments.

This book is intended primarily for *mental health practitioners* who work with people with PD and their caregivers. These practitioners would typically include psychologists, counselors, clinical social workers, psychiatric nurses, and neurological nurses. We provide a flexible toolkit to address a variety of issues that can occur with PD. We assume that practitioners have basic skills in psychological assessment, cognitive behavioral therapy, and experience working with family members (for caregiver programs), in order to use these methods appropriately.

People with PD and their caregivers may also benefit directly from the information we provide. Understanding how PD can affect not only movement, but also thoughts, feelings, and behaviors, can enable those who are dealing with these issues to identify possible courses of action, and to understand how seeking assistance from professionals may help.

Clinical researchers can use the treatment programs in this book as the basis for developing intervention protocols. Just as medical treatments continue to evolve, so do psychological interventions. We hope that this book will not only support people with PD and their caregivers, but will also encourage further systematic research on psychological interventions for PD.

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Marcia Smith Pasqualini, Michael Macht, Heiner Ellgring

Addresses

Prof. Marcia Smith Pasqualini
Avila University
School of Psychology
11901 Wornall Road
Kansas City, Missouri 64145
United States
Email: marcia.pasqualini@avila.edu

Prof. Dr. Michael Macht
University of Würzburg
Department of Psychology
c/o Psychological Practice
Zeller Str. 45 b
907082 Würzburg, Germany
Email: michael.macht@uni-wuerzburg.de

Prof. Dr. Heiner Ellgring
University of Würzburg
Department of Psychology
c/o Angererstr. 7c
80796 Munich, Germany
Email: ellgring@uni-wuerzburg.de

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Important Notes and Limits of Liability

Diagnostic evaluation of people with Parkinson's disease must be conducted by appropriate medical and mental health practitioners. In particular, an independent review of diagnoses and drug dosages is essential, due to rapid advances in medical science and treatment. The therapeutic techniques described in this book should be used only by appropriately qualified professionals.

To the fullest extent permitted by the law, the authors accept no liability whatsoever with respect to injury and/or damage to persons or property, with regard to product liability, negligence or otherwise. This applies equally for any application or use of the methods, products, instructions or concepts listed or described in this book.

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Table of Contents

SECTION 1: Background

Chapter 1: Introduction

People with Parkinson's disease (PD) and the people who care for them are looking for help in dealing with this disease. Although PD is a neurological disorder that can be treated with drugs and other medical treatments, the disease typically causes psychological challenges in everyday life. Medical treatments can reduce only some of the symptoms, some of the time, and often have unwelcome side effects. Fortunately, people with PD and caregivers can improve their well-being using psychology-based interventions. Psychotherapy protocols developed for use with other diseases or difficulties may be beneficial; however, the unique characteristics of PD, particularly the potential effects of PD on daily activities, emotions, and social relationships, create a need for specialized treatment approaches.

Psychosocial functioning is the most important predictor of quality of life for people with PD (van Uem et al., 2015). The motor symptoms of PD can fluctuate from day to day and throughout the day, impeding daily activities. Psychological factors such as stress and excitement can make motor symptoms worse. The visibility of some symptoms can affect social interactions. Reduced facial expressions can create a dissociation between emotional experience and expression of feelings. Caregivers and friends must learn new ways of interacting with the person with PD, while often feeling psychologically burdened themselves.

Evidence that psychological symptoms of PD often arise from the same constellation of pathophysiological changes that cause motor dysfunction has led to a broader awareness and appreciation of the reciprocal influences of biological, psychological and social factors on the clinical course of PD. Accordingly, efforts to develop and evaluate psychosocial interventions that can be used in conjunction with medical treatment have increased.

One approach is to provide educational programs that teach essential information about PD and provide guidance in using psychological practices to improve quality of life. For example, we developed a structured, group-based, educational program for people with PD and their caregivers (Macht et al., 2007; Smith Pasqualini & Simons, 2006), together with a European consortium. This program is available in seven languages, and has been implemented successfully in a variety of settings (see Chapter 4).

For some individuals, however, a standard educational program is not suitable or sufficient. A comprehensive psychological approach is needed, including in-depth, flexible treatment for a wider range and severity of problems and situations. The purpose of this book is to present such a treatment approach, designed specifically for mental health practitioners to treat people with PD and their caregivers.

Treatment Philosophy and Goals

The set of training programs described in this book are based primarily on principles and techniques of cognitive behavioral therapy (CBT) that have been supported by empirical research findings, together with our own clinical experience helping people with PD.

While psychological interventions cannot “cure” PD, they can have positive effects on individuals’ daily lives. The International Parkinson and Movement Disorder Society

Evidence-Based Medicine Committee's most recent recommendations for treatments of PD suggest that CBT is "likely efficacious" for treatment of nonmotor aspects of PD (Seppi et al., 2019). These interventions empower people with PD and caregivers by enabling them to become active participants in their own care (van der Eijk et al., 2013).

Given the impact of psychological interventions across a range of symptoms, the majority of people with PD are likely to benefit. The most important criteria for initiating treatment are the psychological state and living situation of the person with PD and their family, rather than the duration of illness, type of symptoms, or severity. Expert psychological support is particularly important for clients who need more than routine medical help, and for those who feel hopeless or do not know what to do when confronted with challenging situations. The assessment of each person's difficulties and strengths is important for targeting the treatment that will be most useful and effective at a given time, as well as for evaluating the effectiveness of treatment.

Client and Therapist Terms

Throughout this book, we use the term "participants" for clients who take part in our programs. We use the term "caregivers" for those who support people with PD. Typically, the caregiver is a partner or spouse who lives with a person with PD, but caregivers could also be adult children, other relatives, or any individuals who care for a person with PD.

When describing the implementation of the programs, we address the therapist as "you," assuming that the reader is leading the therapy sessions (except in session scripts, where "you" refers to the participants). However, people with PD and caregivers may also benefit from applying these principles and exercises on their own.

Therapy Format

We typically conduct our training programs in a structured, weekly group format (see Chapter 5). Group therapy is our preferred mode of delivery not only because it is economical, but also because it enables participants to exchange information and role-play interpersonal situations. Although we normally run the sessions with only one therapist, two therapists could work together to lead the sessions, and may be preferable if the group is large or has diverse needs.

At times, groups are not possible either for practical reasons or because they are not appropriate for particular clients or problems. For example, people with marked depression or cognitive impairment may have difficulty participating in and profiting from some aspects of the programs, particularly in a group setting (see Chapter 3). The majority of the exercises presented here can be used in psychotherapy with individual clients, except for those that require interaction with other participants. The therapist can select elements of treatment that correspond to the specific goals of the client.

Similarly, people with PD and caregiver partners who have significant relationship concerns may benefit from couples therapy instead of or in addition to the group training programs. Careful assessment is always the key to identifying the best treatment approach.

The Training Programs

Our training programs are practical guides to treatment intended to address particular sets of participant needs. Each program is designed as a structured, stand-alone sequence of sessions. The sessions are composed of components, each targeting a specific issue.

Three programs are for people with PD:

Coping with stress and illness (Stress Program; 11 sessions; Chapter 6). Stress can increase PD-related movement problems, and difficulties with movement can increase stress. In addition, people with PD may experience feelings of depression and anxiety, including fear of disease progression. These psychological issues can occur due to the disease itself, as a reaction to the disease, and as side effects of medication. The Stress Program includes training in relaxation, changing negative thought patterns, coping strategies, and activity planning to address these concerns.

Communicating about PD (Communication Program; 6 sessions; Chapter 7). PD can affect communication in a variety of ways, both in relationships and in public. The way a person communicates about PD reflects their attitude about it. This program offers ways to assess and improve communication, with an emphasis on communicating about the disease.

Emotional expression (Emotions Program; 6 sessions; Chapter 8). PD can affect movement in ways that diminish a person's expression of their personality and feelings, thus increasing difficulties with social interactions. In this program, participants learn how to communicate their feelings despite these motor changes.

A fourth program is designed specifically for caregivers:

Interventions for caregivers (Caregiver Program; 9 sessions; Chapter 9). PD affects not only the person with the disease, but also those who live with, care for, and care about the person. This program offers help for caregivers to cope with their own psychological and physical stress in dealing with the disease.[*]

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[*] Although severe cognitive impairment can sometimes occur in later stages of PD (see Chapter 3), causing considerable challenges for caregivers, our programs do not directly target these issues. For help with these concerns, other resources are available, including websites for caregivers of people with dementia from Alzheimer's disease, such as https://www.nia.nih.gov/health/managing-personality-and-behavior-changes-alzheimers.

In addition, in Chapter 10, we describe special problems that can occur with PD (freezing, impulse control, hallucinations/delusions), together with guidelines for treatment. We typically address these problems with individual clients rather than in a group.

Flexibility of Interventions

Individuals with PD have different challenges, and successful interventions reflect these differences. The components within each session can be modified as needed to meet the characteristics and needs of the groups or individuals to increase their effectiveness.

In addition, the program sessions can be combined in different ways. Components from one training program can be added to complement another, depending on the needs of the participants. For example, sessions from the Communication Program could be combined with sessions from the Emotions Program for particular groups or individuals.

The Structure of this Book

This book has two main sections, plus accompanying appendices with assessment instruments (Appendix A), and program handouts (Appendix B).

In Section I, we provide foundational information about the clinical course and etiology of PD (Chapter 2), psychological changes associated with PD (Chapter 3), and research on psychological interventions for PD (Chapter 4). We recommend that all therapists review this information carefully before beginning work with people with PD or caregivers.

In Section II, we present our assessment plan and interventions. In Chapter 5 we describe our assessment approach and protocol, followed by an overview and guidelines for delivering the training programs. We then present the programs themselves (Chapters 6, 7, 8, 9), followed by a chapter about treatment for special problems in PD (Chapter 10).

Chapter 2: General Information about Parkinson's Disease

Symptoms and Medical Diagnosis

Parkinson's disease (PD) was first called paralysis agitans ("shaking palsy") by James Parkinson in 1817, and is often thought of primarily as a disease that causes tremor in older adults. Although tremor is common, it is not required for diagnosis: in fact, about 30% of people with PD do not experience tremor (Olanow et al., 2009). Furthermore, although the prevalence of PD increases with age, it can occur in younger people as well (Hirsch et al., 2016).

PD is characterized by three main types of motor symptoms. The first type, considered the cardinal feature of PD, involves a reduction in the speed and size of movements. Changes may include motor slowing (bradykinesia), smaller movements (hypokinesia), and the absence of movements (akinesia). These symptoms can manifest as shuffling gait, small handwriting (micrographia), reduced facial expression (hypomimia or "masked facies"), and soft voice (hypophonia). In addition, people with PD may experience "freezing" when walking (sudden, temporary inability to move), hastening of steps (festination), and difficulties actively stopping once started. On clinical examination, they may show difficulty repeating simple movements, such as touching the thumb and index finger together.

The second main type of motor symptom is rigidity, which refers to an increase in muscle tension at rest, and is experienced as stiffness. When a limb is passively moved by a clinician, there is higher than normal resistance to the movement, which can be manifest as either jerky, start-and-stop movements ("cogwheel rigidity") or continuous high resistance ("lead-pipe rigidity"). The consequences of rigidity are progressive postural anomalies (stooped posture with the head and upper body bent forward, arms bent and knees bent) and painful pressure on the joints.

The third main type of motor symptom is tremor, which occurs mainly at rest, and typically in the extremities (hands and arms more often than legs, and more rarely head, chin or tongue). Tremor frequency is generally 4 to 7 Hz per second, and is usually absent during voluntary movements and during sleep. Because the public perception of PD is often a person with tremor, it can be comparatively easy for a person with PD to explain this symptom to other people, compared with other symptoms.

In addition to the primary motor symptoms, postural instability (instability while standing or walking due to loss of postural reflexes) occurs in a smaller subset of people with PD. When this symptom is present early in the course of the disease, it is associated with an increased risk of falls and other complications (Palakurthi & Preetham Burugupally, 2019; Zach et al., 2017).

Motor symptoms can also contribute to speech problems (Moustafa et al., 2016), which affect up to 90% of people with PD (Moya-Gale & Levy, 2019). Difficulties with speech production include monotone voice, slurred speech, breathiness, and dysfluencies or stuttering, in addition to reduced volume, all of which can reduce intelligibility for listeners (Barnish et al., 2017). In later stages of the disease, changes in motor function can also make swallowing difficult, a condition known as dysphagia (Barichella et al., 2009).

Non-motor symptoms may include sensory changes (unusual sensations, pain, reduced ability to smell), problems regulating bodily function (disorders of blood pressure and temperature regulation, constipation) and psychological changes (depressive moods, anxiety, cognitive changes, sleep disorders; see Chapter 3).

Table 2.1 presents a summary of symptoms in PD. The occurrence and intensity of symptoms vary between individuals and over time.

Table 2.1. Summary of symptoms in Parkinson's disease

Motor symptoms	**Person may experience**
Bradykinesia	Slowness
Hypokinesia/Akinesia	Shuffling gait Small handwriting Reduced facial expression Soft voice, slurred speech, dysfluencies Difficulty swallowing "Freezing" of gait Inability to turn over in bed
Rigidity	Stiffness Stooped posture Pressure on joints
Tremor	Shaking, primarily at rest
Postural instability	Falls
Non-motor symptoms	**Person may experience**
Sensory/autonomic changes	Reduced sense of smell Pain Dysregulated blood pressure Sweating Constipation
Psychological changes	Depression Anxiety Cognitive changes

Parkinson’s disease vs “Parkinson’s syndrome”

The terms “Parkinson's syndrome” or “Parkinsonism” refer to a constellation of symptoms that can occur in a heterogeneous group of diseases.

Parkinson's disease, also called idiopathic Parkinson's disease, is a specific disease with no known cause, and is the most common form of Parkinson’s syndrome. A clinical diagnosis of idiopathic PD requires the presence of bradykinesia in combination with rigidity and/or tremor at rest, in the absence of other specific exclusionary criteria. The most recent set of diagnostic guidelines of the Movement Disorders Society (Zach et al., 2017) includes ten exclusionary criteria for PD (e.g., possible frontotemporal dementia or symptoms present only in the lower extremities). In addition, at least two supporting criteria must be present (e.g., a clear response to dopaminergic therapy or reduced sense of smell). Finally, a diagnosis of idiopathic PD requires that there be no indication of an atypical or secondary Parkinson's syndrome (e.g., severe autonomic dysregulation).

Diagnosing PD is not always easy, even for specialists, and the onset of non-motor symptoms can occur years before a diagnosis is made (Corti et al., 2011). A thorough neurological examination and behavioral observation of the person are critical. This challenge is further complicated by the existence of two primary clinical subtypes of PD. The first subtype is characterized by tremor as the main symptom. This subtype is more commonly observed in younger people and tends to progress slowly. The second subtype is characterized by akinesia and rigidity as the main symptoms, occurs more often in older people, and tends to progress more quickly. These differences in presentation have led some to suggest that idiopathic PD may not be a single disease (Obeso et al., 2010). There is evidence, however, that people with one subtype can “convert” to the other over the course of the disease (von Coelln & Shulman, 2016).

In cases of secondary Parkinson’s syndromes, the causes of damage are known. Some examples include strokes, brain tumors, neuroleptic medication used to treat psychosis (e.g., Haloperidol, trade name Haldol®), poisons (e.g., manganese, carbon monoxide), and post-encephalitic Parkinson’s syndrome caused by encephalitis lethargica (sleeping sickness). In addition, parkinsonian symptoms can overlap with those of other neurodegenerative diseases, including Lewy body dementia, Alzheimer's disease, progressive supranuclear palsy, and multiple system atrophy.

Although the focus of this book is idiopathic PD, many of the principles and techniques may be applicable to people with other types of Parkinson’s syndrome.

Epidemiology and Course

PD is one of the most common neurodegenerative diseases, second in the United States only to Alzheimer’s disease (Kowal et al., 2013), and its prevalence worldwide is increasing more quickly than other neurological disorders (Armstrong & Okun, 2020). The overall prevalence of PD in North America in people aged 45 years and older is believed to be 572 per 100,000 people, with projected conservative estimates of over 1,200,000 cases in 2030 (Marras et al., 2018). Men are more likely than women to be diagnosed with PD, particularly within older age groups (Hirsch et al., 2016). In addition, men and women may show different patterns of clinical symptoms and response to treatment, although research in this area has as yet been inconclusive (Picillo et al., 2017).

PD is a chronic disease that can last many years, and does not directly cause death. It is believed to have a long prodromal period (Siderowf et al., 2023), although the symptoms and rate of progression of disease vary greatly from person to person. Since the introduction of dopamine treatment in the early 1970's, life expectancy has been about the same as in the general population. The most frequent causes of death in people with PD do not differ from those without PD.

The severity and course of disease can be classified using stages described by Hoehn and Yahr (1967), as shown in Table 2.2.

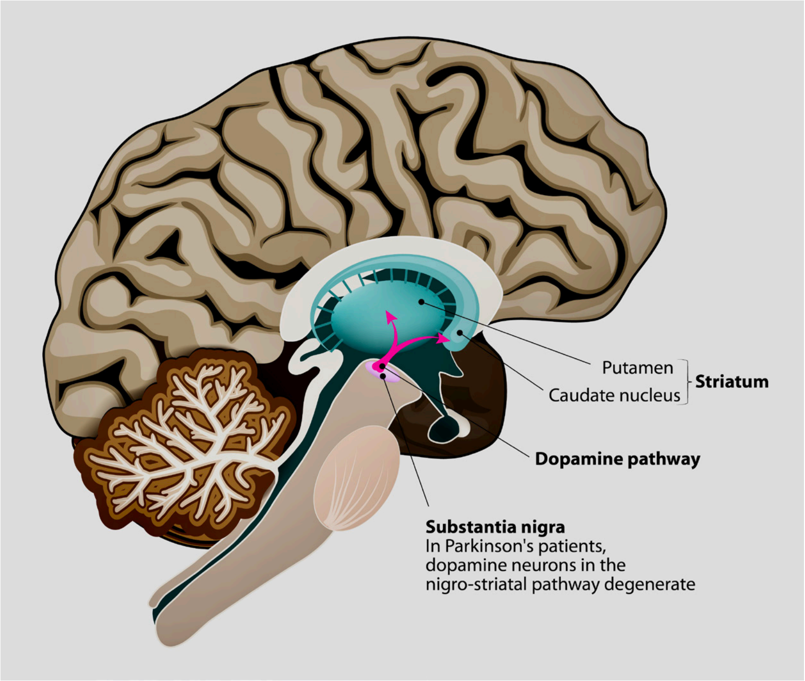
Table 2.2. Hoehn and Yahr scale

Stage	Symptoms and impairment
1	Motor symptoms occur on only one side of the body. No significant impairment.
2	Motor symptoms appear on both sides or in the midline. Other symptoms such as problems speaking or swallowing. No impairment of balance. Slight disability.
3	Difficulty in walking and maintaining balance. Physically independent, with mild to moderate disability.
4	Severe disability, but able to walk or stand unassisted. The person is dependent on help for most daily activities.
5	The person is bedridden or dependent on a wheelchair unless aided.

Pathophysiology

Pathophysiologically, PD is associated with the progressive death of neurons (nerve cells) in the pars compacta region of the substantia nigra, a small area within the midbrain. The neurons of the substantia nigra supply a neighboring subcortical area, the striatum (caudate and putamen), with the neurotransmitter dopamine. This pathway is thus known as the nigrostriatal dopamine pathway, and it in turn projects to the globus pallidus. The striatum and globus pallidus together are referred to as the basal ganglia. The loss of neurons in the substantia nigra leads to a lack of dopamine in the striatum. The first symptoms of disease typically do not appear until more than 70% of the nigral cells have died.

Figure 2.1. Human Brain



Cross-section of the human brain showing the substantia nigra, the region affected by Parkinson's disease. Designua/Shutterstock.com.

The presence of Lewy bodies (abnormal deposits of alpha-synuclein and other proteins) within the neurons of the substantia nigra and other brain areas is a hallmark of PD, and a marker for cell loss (Gibb & Lees, 1988). The specific neural substrates and mechanisms underlying PD symptoms are not clear-cut, however. Nondopaminergic neurotransmitter systems and brain areas beyond the substantia nigra may be important (Moustafa et al., 2016), particularly for understanding nonmotor aspects of the disease (Olanow et al., 2009).

According to an influential theory by Braak et al. (2003), PD begins in the lower brain stem (medulla and olfactory structures) before affecting the substantia nigra and gradually progressing to higher brain regions. More recent evidence suggests that two distinct patterns of disease progression may exist: a "brain-first" pattern originating in the brain and spreading to the autonomic nervous system, and a "body-first" pattern originating in the enteric nervous system (within the digestive system) and spreading to the brain, characterized by REM-sleep difficulties as an early symptom, and greater autonomic dysfunction (Horsager et al., 2022).

Causes of PD

As indicated by the term “idiopathic PD,” the cause of PD is unknown, despite intensive research. Several theories of etiology of the disease have been proposed, but to date none are considered conclusive.

One potential cause is exposure to toxic substances. This hypothesis is based in part on observations about the effect of the chemical MPTP (1-methyl-4-phenyl-1,2,3,6-tetrahydropyridine). In 1982, a “designer drug” version of heroin was accidentally contaminated with MPTP, and triggered a parkinsonian syndrome in people who ingested the drug. In follow-up lab experiments with non-human animals, MPTP led to selective destruction of dopaminergic neurons of the substantia nigra (Langston, 1985). The extent to which similarly acting environmental substances play a role in the development of idiopathic PD remains to be clarified, but could be a factor contributing to the increase in prevalence (Armstrong & Okun, 2020).

A second potential cause is infection. The basis of this model is the encephalitis lethargica (“sleeping sickness”) pandemic of 1917-1927, which caused many of those afflicted to later develop “post-encephalitic” Parkinson's syndrome.

Third, hereditary factors are believed to play a direct role in rare forms of familial PD (Corti et al., 2011). In addition, however, genetic factors may increase the risk of PD more widely (Corti et al., 2011; Nalls et al., 2019). For example, genetic and epigenetic factors appear to be related to a reduced number of dopamine-producing neurons present in the substantia nigra at birth (von Linstow et al., 2020).

A fourth potential cause relates to changes in the microbiome, which consists of microorganisms that live in the human body, particularly in the gastrointestinal tract. This “gut microbiome” could be implicated directly or indirectly in the pathogenesis of PD, through the microbiome-gut-brain axis. Consistent with this idea, constipation often appears prior to the diagnosis of PD, and intestinal inflammation is often present in people with PD (see Elfil et al., 2020, for a review). Relatedly, nutrition may play a role in the clinical course of PD, with certain nutrients acting as potential risk factors, and others as protective factors (see Seidl et al., 2014).

In view of the findings to date, it is most likely that PD develops as a result of a complex interaction of multiple genetic and environmental factors (Jahanshahi & Marsden, 2000; Obeso et al., 2010).

Medical Treatment

Although there is presently no cure for PD, several medications are used to treat the symptoms. The most effective treatment is levodopa (L-DOPA), the chemical precursor of dopamine, which is converted to dopamine in the brain and thus acts directly on dopamine receptors. Medications containing L-DOPA as the active ingredient usually include other drugs, such as peripherally acting dopa-decarboxylase inhibitors (carbidopa), to enhance the effects of L-DOPA in the brain and to reduce side effects (e.g., trade name Sinemet®).

Certain foods may affect the absorption of L-DOPA; dietary management, particularly with regard to timing of the consumption of protein, can help (Barichella et al., 2009).

The beneficial effects of L-DOPA usually decrease over the years. People with PD report more frequent and burdensome "off" periods, which typically include a sharply reduced ability to move, functional deficits such as difficulty getting up from a chair, and emotional changes such as fear, frustration, and anger (Chahine et al., 2020). Other debilitating motor complications such as dyskinesias (involuntary movements) and "freezing" of gait (see Chapter 10) may occur as medication loses its effectiveness and neurodegeneration continues. Efforts to prolong the beneficial effects of L-DOPA have focused on alternative modes of delivery, such as extended-release medication (Margolesky & Singer, 2018) as well as delivery in the form of a gel through an intestinal pump (Antonini et al., 2021).

Other drugs act as dopamine agonists by inhibiting enzymes that normally break down dopamine, thus increasing the dopamine supply. This class of drugs includes MAO-B (monoamine oxidase-B) inhibitors and COMT (catechol-O-methyltransferase) inhibitors. NDMA (N-methyl-D-aspartate) antagonists and anticholinergic drugs may also be used.

Another approach is to use medications that offer neuroprotective effects to slow the natural progression of disease. To date, these efforts have not yet yielded clinically useful results (Potashkin & Seidl, 2011; Salamon et al., 2020). However, efforts are continuing, including clinical trials of medications that trigger insulin signaling in the brain (e.g., GLP-1 receptor agonists), which are approved for treatment of Type 2 diabetes. Insulin is important for neuron health and repair, and appears to be desensitized in the brains of people with PD (Mulvaney et al., 2020).

Neurosurgical procedures have been used for people whose symptoms cannot be controlled with medication. One approach that garnered a great deal of attention and controversy was the transplantation of fetal midbrain tissue. Despite early promise, effects of this treatment have not been shown to be better than effects of placebo (McRae et al., 2004; Obeso et al., 2010). Transplantation of stem cells may have greater therapeutic potential but thus far has shown variable outcomes (Fričová et al., 2020).

A different neurosurgical approach, deep brain stimulation (DBS), is now an established procedure in the treatment of idiopathic PD. DBS typically targets the subthalamic nucleus, a structure that modulates basal ganglia activity. DBS appears to be more effective for the control of tremor than for akinesia, although beneficial effects may depend on target placement (Moustafa et al., 2016). DBS may also be useful for reducing behavioral disturbances associated with dopaminergic medication (Lhommée et al., 2012). These interventions involve risks, and patients normally still require medication, albeit at a reduced level. In addition, DBS may make some problems worse, such as speech production (Phokaewvarangkul et al., 2019).

Research continues to progress with regard to the prevention and cure of PD. One promising development is the identification of a biochemical marker in the cerebrospinal fluid that can potentially identify people with PD before they become symptomatic (Siderowf et al., 2023). Despite recent advancements, however, current medical treatments do not yet provide a solution for many of the difficulties faced by people with PD.

Implications for Therapists

Learning about the current state of knowledge regarding PD and the limited long-term effectiveness of medical treatment can be frustrating for people with PD and caregivers. Thus, helping individuals to focus on controllable factors that can improve symptom management, and to learn strategies and approaches that will improve their quality of life while "living with PD," is of utmost importance and the fundamental task of psychotherapy.

In addition, because PD is associated with changes across a wide range of systems, some of which may not seem obvious or related (e.g., gastrointestinal problems, anosmia, depression, sleep disturbances, impulse control problems), awareness of these potential symptoms and clear communication between people with PD/caregivers and medical personnel are critical for optimal management of the disease. Assessing a client's ability to effectively ask questions, describe changes in symptoms, and communicate needs is therefore an important part of our evaluation (and see Chapter 7 for our Communication Training Program).

Further information about the symptoms, diagnosis, etiology and treatment of PD and Parkinson's syndrome can be found in Armstrong and Okun (2020), in books written for the general public, such as those by Jahanshahi and Marsden (2000) and Weiner et al. (2013), and from the websites of non-profit organizations such as the Parkinson's Foundation (https://www.parkinson.org/understanding-parkinsons), the American Parkinson Disease Association (https://www.apdaparkinson.org/what-is-parkinsons), Parkinson's UK (https://www.parkinsons.org.uk), and the Michael J. Fox Foundation (https://www.michaeljfox.org/parkinsons-101).

Chapter 3: Psychological Changes in Parkinson's Disease

Psychological functions—thinking, feeling, and behaving—are basic to our existence. People with PD may show changes in some or all of these functions, with considerable impact on their lives (cf. Table 3.1). In fact, many people with PD report that nonmotor symptoms are their greatest challenge (Boersma et al., 2016), while caregivers report that they contribute significantly to their own burden (Chahine et al., 2021). Yet psychological changes have received relatively little research attention, and many studies are conducted on people with PD while they are optimally medicated. Thus, there is a gap between the research literature and clinical observations.

Furthermore, the majority of people with PD and caregivers never receive psychological help. An analysis of healthcare utilization patterns of Medicare beneficiaries in the USA in 2019 revealed that less than 2% of people with PD had been seen by a clinical psychologist, despite over half having a diagnosis of depression, anxiety, or both (Pearson et al., 2023). Although individuals who paid out-of-pocket would not have been included in this analysis, overall these findings suggest that many people with PD may not be aware of the potential value of psychotherapy or do not have easy and affordable access to treatment.

Table 3.1 shows frequently mentioned concerns in people with PD.

Table 3.1. Concerns in people with PD*

Concerns related to physical changes	
Reduced dexterity	97%
Slowing of movement	96%
Reduced motivation and drive	90%
Reduced gestures and other body language	86%
Emotional stress	
Helplessness	93%
Increase in symptoms with minor stressors	90%

Social concerns	
Fear of being in a crowd of people	84%
Uneasiness in social interactions	83%
Fewer social activities with partner	83%
Concerns about causing stress to partner	70%
*Results of a nationwide survey in Germany of 325 people with PD and their relatives. Percentage of people with PD who reported the concern (Ellgring et al., 1989).	

Cognitive Function

Studies of the effects of PD on cognitive functions have produced complicated and sometimes conflicting results (Biundo et al., 2016), and the fear of cognitive decline can itself be disruptive for people with PD and their caregivers. The most commonly affected cognitive abilities are executive skills, such as planning, abstract thinking, task switching, adapting to new situations, and mentally holding and manipulating information (Russ & Seger, 1995; Steinke et al., 2020; Vlagsma et al., 2016). These cognitive functions can be disrupted in early stages of the disease due to dysfunction of dopaminergic pathways between the striatum and the frontal lobes (Kehagia et al., 2010).

Difficulties in executive function may be associated with a slowing of thought processes, known as "bradyphrenia." In neuropsychological testing, cognitive slowing is manifest as greater response latencies and slower processing speeds; in daily life, this slowing can cause difficulties for friends, family, and caregivers, as conversations become laborious. The person with PD may feel that their thoughts are "disconnected," and they may withdraw from conversations.

Some people with PD experience reduced sensory perception, particularly reduced ability to perceive odors (Doty, 2012; Saku & Ellgring, 1992). In fact, deficits in odor identification may be useful as an early biomarker of PD (Fullard et al., 2017). In addition, changes in visual function can occur (Ekker et al., 2015; Hipp et al., 2014; Weil et al., 2016), ranging from disruption of early stages of visual processing due to reduced dopamine innervation in the retina, to difficulties with a broader range of visuoperceptual abilities if more brain areas are affected. Visual disturbances may be associated with sleep disorders, visual hallucinations, and emotion recognition deficits (Weil et al., 2016).

Nevertheless, higher level cognitive abilities and cognitive processing speed may be relatively intact, even for those who show slowing on psychomotor tasks (Smith et al., 1998) or lower-level perceptual processing tasks (Arroyo et al., 2021). Yet the need to consciously focus on previously routine tasks, such as walking, may require a person with PD to divide their attention and cognitive resources, reducing their ability to respond flexibly to the environment (Moustafa et al., 2016). Without careful neuropsychological assessment, motor slowing and divided attention can lead to an overestimation of cognitive deficits. These apparent deficits may then be incorrectly interpreted as signs of dementia, a term used to describe a pattern of global cognitive impairment.

A subset of people with PD, however, do develop more severe cognitive problems, and PD is associated with a higher risk of dementia (Aarsland et al., 2008). For these individuals, neuropathology beyond the disruption of dopamine pathways in the substantia nigra is likely to be present (Kehagia et al., 2010).

Depression and Anxiety

Depression is the most common mental health problem in people with PD, occurring in about 35% of those diagnosed with PD (Reijnders et al., 2008). The causes are still not clear, and most likely include premorbid depression, depression as a reaction to dealing with the disease, and depression directly related to the disease process itself (Even & Weintraub, 2012), such as changes in neurotransmitter systems or the appearance of Lewy bodies in the limbic system. Additional psychological factors, such as social stress and dysfunctional coping strategies, can also contribute (Aarsland et al., 2012; Brown & Jahanshahi, 1995). For example, problems in the partnership are associated with higher rates of depression in people with PD (Seiler et al., 1992; Tanji et al., 2008).

Anxiety is common in people with PD as well, with an estimated prevalence of 31-69%; anxiety may often co-occur with depression (Broen et al., 2016; Richard, 2005).

Dakof and Mendelsohn (1989) identified two psychological "clusters" or subtypes of people with PD who had mild to moderate physical symptoms, using factor analysis on interview data. As shown in Table 3.2, differences in beliefs and attitudes about coping with PD were associated with differences in depression and anxiety, despite comparable severity of physical symptoms.

Table 3.2. Ways of coping in people with PD (Dakof & Mendelsohn, 1989)

Cluster 1: "Sanguine and engaged"	Cluster 2: "Depressed and worried"
Deliberately attempts to put negative thoughts out of mind and to remain optimistic	Has intrusive anxiety about the future
Can laugh at self and the disease	Is embarrassed by symptoms
Believes that some aspects of current and future disease status are within their control and that actions and attitudes can affect course of disease	Struggles against disease, resulting in anxiety, frustration, and depression
Believes there are worse fates than having PD	Resents losses and limitations

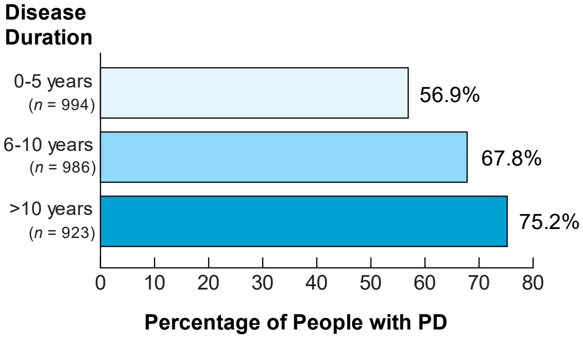
Stress

The physical symptoms of PD and the limitations associated with these changes can be stressful psychologically for people with PD as well as for their family and friends. In a survey of more than 3,000 people with PD, Macht et al. (2005) found four distinct groups of individuals with regard to psychosocial stress:

1. Generally low psychological stress (30-40%)
2. Generally high psychological stress (approximately 20%)
3. Sexual problems and marital/partnership problems (approximately 30%)
4. High psychological stress without sexual and partnership problems (approximately 10%).

The majority of people with PD in Macht et al.'s (2005) survey reported a significant increase in symptoms during times of stress, with the likelihood increasing with longer disease duration (see Figure 3.1; Macht et al., 1999a, 2005).

Figure 3.1. Increase in Parkinson's Disease Symptoms in Stressful Situations by Disease Duration



This exacerbation can occur even when the increase in arousal is so mild that that the person does not consciously perceive it. For example, they may decide to leave the house, and then suddenly are unable to button their coat. This phenomenon is so common it is known as "the Parkinson's effect" (Macht et al., 1999a). Although the most common problem is an increase in tremor, other symptoms may also be affected. For example, stress can trigger "freezing" of gait (Fahn, 1995; Giladi et al., 1992; Macht & Ellgring, 1999; Nutt et al., 2011). We address specific methods for coping with freezing of gait in Chapter 10.

Our training programs for dealing with stress can be found in Chapter 6 (people with PD) and Chapter 9 (caregivers).

Fatigue and Sleep Disruption

For people with PD, every activity requires greater effort. Half of people with PD report higher than normal levels of fatigue (Siciliano et al., 2018), which can be manifest physically, cognitively, and emotionally (Mantri et al., 2020). A related problem is daytime drowsiness, which can take the form of "unintended sleep episodes" (Olanow et al., 2009; formerly called "sleep attacks"), especially when taking dopamine agonist medications (Davie, 2008).

Fatigue may be related in part to sleep disturbances (Smith et al., 1997). Even relatively normal sleep patterns, such as occasional wakening during the night, can be experienced as stressful if the person with PD is unable to move; they may not be able to turn over alone, and may require help to go to the bathroom. Thus, the sleep quality of caregivers may also be negatively affected (Smith et al., 1997; Viwattanakulvanid et al., 2014).

Apathy

Cognitive and motor slowing, combined with increased fatigue, can contribute to the impression that people with PD lack drive or motivation, even when that is not the case. Early descriptions of the behavior of post-encephalitic patients showed how appearances can be deceiving: "seen from the inside," many patients had normal levels of drive (Hauptmann, 1922).

However, 40% of people with PD develop a clinically significant level of apathy including both cognitive (reduced interest in new experiences) and behavioral (reduced initiative and social interaction) components (den Brok et al., 2015; Pagonabarraga et al., 2015; Santangelo et al., 2013). Apathy is more likely to occur in individuals who experience neuropsychological changes such as reduced cognitive flexibility and inhibition (Santangelo et al., 2018), or depression (den Brok et al., 2015), and high levels of apathy can be predictive of future cognitive impairment (Martin et al., 2020). Nevertheless, apathy can occur without either cognitive changes or depression (den Brok et al., 2015).

When apathy is present, it should not be viewed as reduced conscious "willingness" to act, but rather as a behavioral feature of the disease process, as evidenced by the association of apathy with a blunted neural response in the areas of the brain important for experiencing reward (Lawrence et al., 2011).

Communication

The majority of people with PD report problems with communication, which can be compromised by a combination of factors (Schalling et al., 2017), including vocal characteristics (soft voice, dysarthria), language difficulties (e.g., word finding problems), and problems spontaneously joining conversations. People with PD who have more severe speech difficulties may benefit from targeted speech and language therapy, which can be used in conjunction with our programs (Behrman et al., 2020; Gillivan-Murphy et al., 2019; Levy et al., 2020; Ramig et al., 2018; Tamplin et al., 2019). The capacity to convey emotions may be particularly affected, as described in the next section.

Emotions

When discussing emotions and emotional dysfunction, researchers often distinguish between several aspects: the experience of emotions, the expression of emotions, the recognition of emotions in others, and the ability to regulate emotional experience and expression. These aspects may be differentially affected by PD. A disruption in any of these areas can have a negative impact on social relationships.

Experience of emotion

People with PD generally report normal levels of emotional experience in response to eliciting stimuli (Ille et al., 2016; Schienle et al., 2015; Simons et al., 2004; Smith et al., 1996; Vicente et al., 2011), despite evidence of reduced startle response (Bowers et al., 2006) and lower arousal ratings (Wieser et al., 2006). However, some people with PD reportedly experience alexithymia, which refers to difficulty interpreting one's own emotional experiences (Enrici et al., 2015).

Expression of emotion

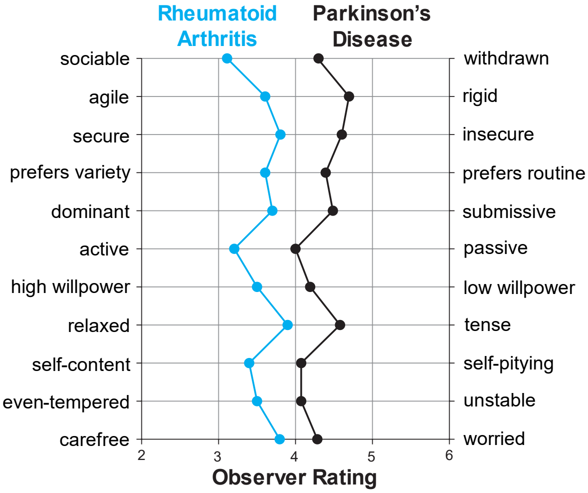
Expressions of emotion can be considered spontaneous (e.g., in response to a specific stimulus or during a conversation) or posed. Posing expressions can include intentionally trying to display a specific emotion in a situation that appears to call for it (e.g., deliberately smiling or trying to sound happy when you receive a present, even if you do not like it) or in response to experimenter instructions in a laboratory setting (e.g., "show me how you smile" or "show me how you look happy"). For facial expressions, different neural pathways are used depending on whether movements are spontaneous or posed (Buck, 1984; Simons et al., 2004), due to the presence of separate but overlapping areas in the brain for the generation of different types of facial movements (Bologna et al., 2013; Rinn, 1984).

People with PD may exhibit reduced quantity and intensity of expression for both spontaneous and posed facial movement (Novotny et al., 2022; Simons et al., 2003), with greater reduction for spontaneous than posed expressions (Simons et al., 2003; Simons et al., 2004; Smith et al., 1996). For example, when PD participants were asked to taste and smell stimuli that were pleasant or unpleasant, observers had difficulty identifying from their facial expressions which stimuli they were experiencing (Walter, 2000). Other studies have shown that people with PD mimic emotional expressions less (Livingstone et al., 2016), and display fewer non-emotional facial movements, such as eye blinks (Bologna et al., 2013). A person with PD may thus appear to have a “poker face” with little interest in the environment. Nevertheless, spontaneous expressivity may still be tied to emotional experience and context (Griffin & Greene, 1994; Simons et al., 2004; Takahashi et al., 2010). In other words, changes in expressivity may appropriately reflect social situations, despite a reduction in size, speed, and quantity of facial movements.

Expression of emotion through the voice may also be reduced in PD (Scott et al., 1984). When people with PD were asked to convey specific emotions when reading sentences, listeners were less able to identify the emotional state the person was trying to express (Barnish et al., 2017; Walter, 2000).

These difficulties in communicating emotion may lead others to judge the personality of a person with PD in a more negative way. For example, Walter (2000) filmed people as they read a fairy tale, and observers rated personality characteristics of the readers. People with PD were generally rated more negatively than those of a control group of people with rheumatoid arthritis. See Figure 3.2.

Figure 3.2. Observer Ratings of People with Parkinson's Disease and People with Rheumatoid Arthritis



Walter's (2000) results are consistent with the findings of a study of nurses, who rated people with PD as less intelligent and generally less positively than people with ischemic heart disease, based on their voices (Pitcairn et al., 1990a) and facial expressions (Pitcairn et al., 1990b). These findings clearly show the difficulty that people with PD have in "expressing their personality" and the negative effects reduced expression can have on other people's opinions of them.

Furthermore, people with PD may not be aware of the extent to which their expressivity has changed. In Walter's (2000) study, PD participants rated their own personality characteristics, and how they thought they came across to others. Discrepancies between self and observer ratings were then compared with those of the rheumatoid arthritis control group. For the PD group, these discrepancies were much more pronounced. Specifically, PD participants rated the impression they made on others more positively than observers rated them for the descriptions *interested*, *sympathetic*, *active*, *optimistic*, *flexible* and *empathetic*.

Similarly, people with PD may not notice that their voice is softer than usual, although the research on voice perception is mixed (Kwan & Whitehill, 2011). People with PD often report that they feel they are using the same "effort" as always, yet the motor output is reduced (Simons et al., 2004).

Emotion recognition

People with PD can have difficulty recognizing others' emotions through the voice (Dara et al., 2008; Scott et al., 1984) and the face (Enrici et al., 2015; Gray & Tickle-Degnen, 2010; Kwan & Whitehill, 2011; Narme et al., 2013; Ricciardi et al., 2017), particularly negative emotions (Argaud et al., 2018; Narme et al., 2013), even when well-medicated (Palmeri et al., 2020). Deficits in one modality are likely to be associated with deficits in the other (Buxton et al., 2013), and with caregiver ratings of the person's empathy (Narme et al., 2013). These effects on caregivers suggest that emotion recognition deficits can disrupt social relationships. However, emotion recognition may be largely intact in the early stages of disease (Hipp et al., 2014; Ille et al., 2016), and for more intense expressions (Buxton et al., 2013).

Emotion regulation

Although there is little research directly testing how well people with PD can regulate their emotions, Simons et al. (2003) found that people with PD were less successful than healthy controls in masking or intensifying negative facial expressions. Anecdotally, some of our clients with PD have reported that they react more emotionally than in the past. For example, they may be more likely to cry over seemingly minor events, or to experience an increase in motor symptoms when watching a suspenseful movie, similar to the effects reported during any increase in arousal (Macht et al., 1999a).

Implications for treatment

Effective communication of feelings and intentions between individuals with PD and their family members is crucial for well-being as they all adapt to changing roles and navigate new challenges (Roger & Medved, 2010). Difficulties can be further compounded when the person with PD does not perceive that their expressivity has changed. By increasing their awareness of these changes, they may be able to develop new ways of communicating.

Although it might be possible to enhance the facial expression of emotion in people with PD by increasing facial mobility through physiotherapy (Katsikitis & Pilowsky, 1996), this line of research has received limited attention. In addition, because some people with PD have difficulty posing facial expressions, trying to increase facial expressivity may not always be a viable compensatory strategy. Alternative methods, such as stating feelings that were previously communicated through nonverbal expression, may be more effective.

One strategy for caregivers is to learn to identify expressivity cues that are still present, rather than relying on cues they used in the past. However, when people with PD encounter acquaintances outside of the immediate family circle, or deal with strangers or authority figures in public situations, they may need additional means of communicating and coping.

Chapter 7 (Communication) and Chapter 8 (Emotions) describe training programs that address these problems. For a review of issues related to social and emotional communication in PD, see Prenger et al. (2020).

Other Behavioral Changes

Some people with PD may experience sexual problems that are linked to PD motor difficulties (Beier et al., 2000; Bronner et al., 2004). In a study using retrospective self-report, Buhmann et al. (2017) reported that PD negatively affected sexuality for both men and women, with men reporting more difficulties than women. Conversely, certain anti-parkinsonian medications can increase sexual drive (Garcia-Ruiz et al., 2014).

Impulse control problems have been associated with dopaminergic medication in about 14% of people with PD (Voon et al., 2011). Impulsivity can be manifest as difficulty inhibiting movements, impulsive decisions, and hasty reactions. Behaviors may include problematic gambling and compulsive sexual behavior (more common in men), as well as compulsive shopping and eating disorders (more common in women). Psychosocial factors, such as level of distress, can contribute to problems with impulse control (Delaney et al., 2012).

Additional non-motor side effects of medications can include psychotic symptoms, particularly visual hallucinations. However, hallucinations and delusions (false beliefs) can also result from the disease itself (Fredericks et al., 2017).

Intervention techniques for dealing with hallucinations and impulse control problems are described in Chapter 10.

Psychological Changes Over Time

Psychological symptoms and challenges may change over time with disease progression. Most people with PD live with the disease for 10, 20 or more years after diagnosis. A newly-diagnosed person may have difficulty talking to others about the disease, and appearing in public. After a few years, their focus may center on unpredictable symptom fluctuations, or tensions with caregivers. Typically, people with PD experience three phases in the course of the disease:

1. Noticing first symptoms, and coming to terms with the diagnosis of PD
2. Adjusting to using medication, and taking advantage of improvements brought about by the medication

3. Coping with increases in symptoms and progressive disability

Each phase is associated with different pressures and needs. The following example describes the reactions of a younger woman receiving her diagnosis.

To be effective, psychological interventions for people with PD as well as for caregivers must take the evolving nature of challenges into account, yet standardized group programs have seldom targeted people in different stages (Tennigkeit et al., 2020).

Case Study: Anxieties about PD

A 40-year-old woman was given the diagnosis of PD in a hospital hallway, when her doctor happened to be passing by. During the next two months, she lived in a state of shock. She then began to try to educate herself about the disease. When she discovered that many questions about the causes and treatment of PD were still unanswered, her stress levels increased. She also began to wonder if her introverted and cautious personality might have contributed to why she got the disease. She experienced many disease-related fears:

- Fear that friends would withdraw when the symptoms became more noticeable
- Fear of loss of attractiveness
- Fear of no longer being able to enjoy sex
- Fear of attracting negative attention in public
- Fear of people thinking she is an alcoholic because of her unsteady gait
- Fear of being consumed by daily tasks due to increasing disability
- Fear of cognitive decline
- Fear of financial problems due to future needs for assistance
- Fear that the disease would be rapidly progressive and untreatable
- Fear of her handwriting ("an expression of her personality") deteriorating
- Fear of not being considered for new promising treatments

Effects on Caregivers

PD affects not only the person with the disease, but also family members and friends. However, relatively little research has investigated the effects of PD on caregivers.

Table 3.3 lists stressors that were reported by at least 70% of respondents in a survey of 200 relatives of people with PD (Ellgring et al., 1993).

Table 3.3. Stressors for caregivers of people with PD

Stress due to physical symptoms	
Restriction of activities due to partner's PD	86%
Assuming duties and decision-making	72%
Emotional stress	
Fear of being alone	94%
Fear of disease progression for the person with PD	90%
Relationship problems	
Oversensitivity of person with PD	90%
Impatience in dealing with person with PD	83%
Person with PD's increased anxiety	82%
Difficulty in dealing with the lack of independence of the person with PD	80%
Fewer joint activities	76%
*Results of a nationwide survey in Germany of 200 caregivers of people with PD. Percentage of caregivers who reported experiencing the stressor (Ellgring et al., 1993).	

In a research review, Martinez-Martin et al. (2012) reported several factors that were associated with decreased quality of life in caregivers. These factors included depression (both in the caregivers and in people with PD they were caring for; see also Santos-Garcia et al., 2022, for a longitudinal analysis), neuropsychiatric symptoms such as apathy and delusions in the person with PD, severity and duration of PD, the degree of care needed, sleeping difficulties, and social isolation. One study (Tanji et al., 2008) found that stress in the marital relationship increased as the severity of PD symptoms increased, particularly symptoms of greater gait disturbance, balance problems, motor fluctuations, and urinary incontinence. Grun et al. (2016), however, showed that motor symptoms were not significantly correlated with caregiver burden; instead, nonmotor symptoms such as sleep disruption were most predictive. This finding was supported by a large, online survey of caregivers, which showed that the major contributors to caregiver burden were the person with PD's agitation, apathy, anxiety, disinhibition, and nighttime waking (Chahine et al., 2021). An additional factor highlighted in a study of caregivers of people with moderate to advanced PD was "time dependency"—the need to complete many caregiving tasks and watch the person constantly—often combined with fatigue due to lack of sleep (Hand et al., 2021).

Conversely, factors that have been associated with better caregiver outcomes include having a good relationship with the person with PD, perceived social support, and formal support services (Hand et al., 2021; Martinez-Martin et al., 2012). McRae et al. (2009) found that caregivers who attended support groups reported less loneliness and more perceived support than those who did not. McRae et al. also showed that loneliness was better predicted by caregiver variables than by patient variables, noting that direct interventions for caregivers may therefore be needed to reduce loneliness.

While research in this area is limited, the available evidence suggests that the impact of PD on the quality of life of caregivers is an important consideration for any treatment program for PD. In particular, enhancing the ability of caregivers to cope with disease-specific stressful situations at different stages in the course of the disease may be valuable.

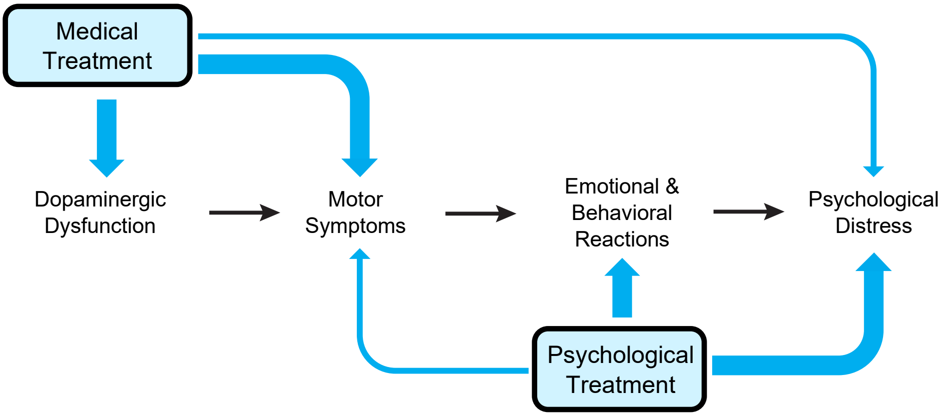
Chapter 4: Psychological interventions for Parkinson's Disease

Objectives

The goal of psychological interventions for PD is to improve the well-being of the person with PD, their family, and their caregivers. People with PD typically exhibit behaviors and symptoms that are visible to others, yet easily misunderstood.

The idea that psychological treatment can benefit people with PD is not new. Back in 1955, Chafetz et al. introduced group therapy for people with PD. In 1964, the psychiatrist Walter Schulte recommended psychotherapy after finding that it helped his PD patients relax and cope with disease-related stress, even if the illness itself could not be overcome. Since that time, psychotherapeutic methods have improved and received empirical support, and the use of psychological interventions for people with PD has increased. While medical treatments have focused primarily on motor symptoms and the underlying dopaminergic dysfunction, psychological approaches have typically targeted emotional and behavioral reactions to the illness, coping with motor symptoms, social interactions, and how to deal with stress (See Figure 4.1).

Figure 4.1. Medical and Psychological Treatment for Symptoms of Parkinson's Disease



We will briefly examine evidence for the effectiveness of psychological interventions for people with PD and for their caregivers, with an emphasis on CBT (cognitive behavioral therapy)-based programs.

Interventions for People with PD

Psychoeducation programs

The most common aims of psychoeducation programs for people with PD are to provide information about the illness, and to teach skills such as problem-solving, communication, and stress management strategies. The programs are usually presented in a group format, and can be particularly useful and efficient for people in earlier or less severe stages of disease.

For example, our eight-week group education program (see Ellgring et al., 2006; Smith Pasqualini & Simons, 2006) included the following components: general information, self-monitoring symptoms and behaviors, increasing pleasant activities, managing stress, managing anxiety and depression, increasing social competence, and increasing social support. A parallel session for caregivers was provided. This program was shown to have positive effects for people with PD and caregivers across several studies in different countries, both by our research partners and other clinical research groups using adapted versions of the program (A'Campo, Spliethoff-Kamminga, et al., 2010; A'Campo, Wekking, et al., 2010; A'Campo et al., 2012; Chlond et al., 2016; Hellqvist, Berterö, Dizdar, et al., 2020; Hellqvist, Berterö, Hagell, et al., 2020; Macht et al., 2007; Mosley et al., 2021; Navarta-Sanchez et al., 2020; Simons et al., 2006; see review in Tennigkeit et al., 2020).

Other education programs for PD that have shown promising results include those by Canivet et al. (2016), Guo et al. (2009), and Pappa et al. (2017). Education alone, however, may not be appropriate or sufficient for all people with PD (Dobkin et al., 2008; Zarotti et al., 2020), especially those with depression or low self-esteem (Viwattanakulvanid & Kittisopee, 2017).

CBT-based psychotherapy programs

The focus of CBT is to change maladaptive thoughts, feelings, and/or behaviors. CBT has received increasingly widespread empirical support as a treatment for improving mental health, including treatment for people with chronic health conditions (Veazey et al., 2009).

Berardelli et al. (2018) compared a group education program with a group CBT program, for people with PD who also met criteria for a psychiatric disorder. The education group received information about the effects of PD on psychological well-being, specifically targeting illness awareness, adherence to treatment, early detection of symptoms, and maintenance of a healthy lifestyle. The CBT program was described as a "standard group CBT," with an emphasis on the connections between psychological and physical symptoms. The CBT group showed a reduction in depression, anxiety, and other non-motor symptoms of PD, whereas the education group did not improve. Limitations of the study included small sample sizes and unequal numbers of treatment sessions. Although these results should therefore be viewed as preliminary, Berardelli et al. suggested that CBT is likely to be more useful than education alone for changing complex behaviors associated with depression and anxiety in people with PD.

Dobkin and colleagues (Dobkin, Mann, et al., 2019; Dobkin, Menza, et al., 2011) conducted relatively well-powered studies comparing CBT with standard clinical monitoring, and found that CBT was useful for treating depression in people with PD. As reported in the 2019 study, the largest effect sizes were for cognitive and behavioral indices, as opposed to somatic aspects of depression.

Other research studies using randomized assignment of people with PD to treatment and comparison groups have also reported promising results, albeit often with very small sample sizes. For instance, Calleo et al. (2015) found that individual CBT, delivered either in person or by telephone, was more effective than "enhanced usual care" for people with PD who had depression and anxiety. Similarly, Veazey et al. (2009) reported that telephone CBT was more effective than a support group in reducing depression and anxiety. Troeung et al. (2014) found that group CBT reduced depression and anxiety compared to waitlist controls, while Okai et al. (2013) reported a reduction in impulse control problems in people with PD using CBT compared to a waitlist control condition, although no reduction in caregiver burden was observed.

Evidence of the effectiveness of CBT for PD has also been shown through case studies. For example, Macht et al. (2007) reported that CBT was effective for three people with PD who had different presenting issues: depression and social anxiety, sexual problems, and "freezing" gait. Reynolds et al. (2020) used a multiple baseline single-case experimental design for people with PD and anxiety, and found that a 12-week CBT program reduced these symptoms.

Individual components of CBT, such as social skills and communication training (Macht et al., 1999b), relaxation and music to improve motor skills and well-being (Macht et al., 2000), and mindfulness training (Advocat et al., 2016; Vandenberg et al., 2018), have also received empirical support for treatment of people with PD.

Zarotti et al. (2020) conducted a scoping review of available evidence for psychological interventions in PD. They noted that CBT was the most common type of intervention, and was found to be effective primarily for treating depression and sleep disorders in PD. Several review articles specifically about the use of CBT for PD provide additional information, including Armento et al. (2012), Dobkin et al. (2008), and Koychev and Okai (2016).

Psychological interventions to reduce PD motor symptoms

Although the focus of most psychological interventions has been on non-motor aspects of PD, several studies have successfully targeted specific motor symptoms. These efforts include relaxation to reduce tremor (Chung et al., 1995; Lundervold et al., 1999) and to overcome motor "freezing" (Macht & Ellgring, 1999); a combination of progressive muscle relaxation with other behavioral treatments to improve posture, gait, and movement initiation (Müller et al., 1997); Alexander technique to decrease disability (Stallibrass, 1997); and meditation to decrease dyskinesias (Szekely et al., 1982).

A related approach is to use biofeedback, often in combination with other techniques. Studies have shown positive effects of biofeedback and systematic desensitization to reduce tremor (Nusselt & Legewie, 1975), frontal electromyography biofeedback and relaxation to improve motor symptoms (Shumaker, 1980), electroencephalographic (EEG) and respiratory sinus arrhythmia biofeedback to improve dystonia and "freezing" (Thompson & Thompson, 2002), and tactile biofeedback to increase voice volume (Schalling et al., 2013).

The need for continued research on psychological interventions

Pigott et al. (2022) performed a meta-analysis on self-management interventions for people with PD. The study analyzed the effects of education-based, CBT, and exercise-focused interventions on quality of life, well-being, and functional abilities. Although the findings were promising, Pigott et al. concluded that more large-scale, controlled studies were needed. One issue found across nearly all of the studies analyzed was either a lack of long-term assessment of effects, or diminishing effects for programs that did provide follow-up assessment. Follow-up is particularly important given the progressive nature of PD.

Interventions for Caregivers

Few published studies of the effects of psychologically-based interventions for caregivers of people with PD are available. Several of the group education programs described previously included caregivers as well as PD groups, with generally positive results when assessed immediately following the programs.

Dobkin et al. (2012) showed that caregiver participation in an education program predicted which people with PD would respond well to CBT treatment, suggesting that treatment for caregivers may help both partners. Secker and Brown (2005) compared a caregiver CBT group to a no-treatment control group, and reported improvement in the caregivers on a general health questionnaire. Dissanayaka et al. (2016) found a reduction in caregiver burden after a CBT program for PD/caregiver dyads to treat anxiety, although there was no control group.

Despite the paucity of research on interventions for caregivers of people with PD, there is evidence of the effectiveness of CBT with caregivers of other patient groups, such as people with dementia (Hopkinson et al., 2019). On the basis of a systematic review and meta-analysis, Hopkinson et al. concluded that CBT for caregivers of dementia patients can significantly reduce caregivers' depression and stress, and recommended a group format of eight sessions for cost-effective treatment.

SECTION 2: Assessment and Training Programs

Chapter 5: Assessment and Overview of Programs

In this chapter, we present (1) a description of our assessment approach and the instruments we use, and (2) an overview of the basic structure and implementation of our training programs.

Assessment Approach

As a first step, we meet individually with clients to collect demographic and medical information, and where appropriate, to describe the training programs. These meetings are useful for identifying whether an individual is suitable for a group, confirming that they understand the procedures, and ensuring that they feel comfortable with the therapist.

Our assessment is never intended as a replacement for clinical medical or psychopathological testing and diagnosis. People with PD have normally already undergone diagnostic testing before beginning psychotherapy. Ongoing clinical contact with a physician is critical, especially because improvements in psychological functioning may affect the timing or dosage of medical treatments.

Clinical interviews are always an important component of our assessment. In addition, we typically give a variety of standardized questionnaires, which we select based on a client's needs and goals in relation to the topics they would like to address.

For the therapist, assessment results are a key source of information for targeting interventions to clients and improving treatment delivery. Except when conducting a clinical research study, there is less need to have a standard protocol for assessment across groups, or even for all participants within a group. For the clinical researcher, however, a standard assessment protocol will enable collection of the empirical evidence needed to advance the field.

In addition to more formal assessment at intake and at the end of the program, it is important to monitor the changing needs of the person with PD and their family as treatment progresses. We do this in part via weekly homework assignments. Whenever we ask participants to complete a questionnaire or other types of homework to bring back to the following session, we make a point to discuss the results before starting on a new topic. Showing interest in the participants' responses and providing specific feedback demonstrates respect for their time and effort, and can increase compliance with any kind of homework.

We describe here the questionnaires that we typically use. The instruments themselves, scoring information, and a summary sheet for organizing participants' individual data, are provided in Appendix A.

Assessment of people with PD

Demographics: Participant Information Form

We use the *Participant Information* form to collect basic demographic information, the history of disease onset, and disease progression. Most people with PD can complete the form on their own. However, we recommend going through the sheet individually with each person if possible, to learn first-hand about the client's concerns, type and severity of motor symptoms, and how their symptoms affect their ability to communicate.

Disease stage classification: Hoehn & Yahr (modified)

To estimate the relative severity of disease, we use a self-rating modification of the *Hoehn and Yahr* (1967) classification system. The disease is divided into five stages, with Stage 1 being the mildest and Stage 5 the most severe form of the disease.

Depression: Zung Self-Rating Depression Scale

We assess depressive symptoms with the 20-item *Zung Self-rating Depression Scale* (SDS; Zung, 1965, 1973). Note that the SDS contains items related to physical changes that can occur in PD even without depressive thoughts and feelings. Therefore, for people we PD we calculate affective and somatic subscores in addition to the total score. Although the SDS is useful for estimating a person's level of depression, it is not a substitute for clinical assessment by a psychologist or psychiatrist. We advise clients whose scores suggest a high level of depression to discuss this issue with their physician, who may recommend medication. In addition, we may suggest that the person participate in individual psychotherapy instead of, or in addition to, group treatment.

Daily life: Activities of Daily Living

We use a modified form of the *Activities of Daily Living Scale* (Schwab & England, 1969) to measure impairment in daily activities in people with PD. This one-item, 11-point scale consists of a set of statements that each describe an overall level of ability to perform activities such as dressing, personal hygiene, work activities, and household chores. An additional independent rating by family/caregivers can be useful.

Psychosocial changes: Stress Questionnaire for People with PD

To measure psychosocial changes and problems in people with PD, we use a 19-item short form of the *Stress Questionnaire for Parkinson's Disease Patients (SQPD-P)*. The questionnaire was originally developed in German (*Belastungsfragebogen für Parkinson-Patienten* [BELA-P]; Ellgring et al., 1989; Ellgring, Seiler, Nagel, et al., 1990). A short form of the scale was translated into Dutch and validated in a Dutch sample (Spliethoff-Kamminga et al., 2003b), and then validated and used in a variety of studies in several languages (A'Campo, Spliethoff-Kamminga, et al., 2010; A'Campo, Wekking, et al., 2010; Ellgring et al., 2006; Macht & Ellgring, 2003). To increase clarity and reduce the load for English-speaking respondents, we modified the short form in the following ways: we improved the wording by translating the scale into English from the original German, reduced the response options from a 5-point to a 4-point scale, and eliminated the "need for help" parallel rating (which was not typically used in earlier studies).

Communicating about PD

We assess the ability of people with PD to communicate with other people about their disease with the *Communicating about PD* scale (CPD). This 20-item scale was developed and tested by M. Hinrichs (1992) in an unpublished Diploma Thesis (Free University of Berlin, Institute for Psychology, *Fragebogen zur krankheitsbezogenen Kommunikation bei Parkinson-Patienten*). Because this scale has not been validated in published research, results should be interpreted with caution; however, we have found it to be useful clinically in the absence of well-validated measures.

Impulsivity: Questionnaire for Impulsive-Compulsive Disorders in Parkinson's Disease- Rating Scale

When impulsive/compulsive behaviors are suspected, we use the *Questionnaire for Impulsive-Compulsive Disorders in Parkinson's Disease* (QUIP; Weintraub et al., 2009), or a revision of the scale that also measures severity (QUIP-RS; Weintraub et al., 2012; reviewed in Evans et al., 2019). This scale measures thoughts, urges, control, and efforts to engage in seven behavior types (gambling, sex, buying, eating, hobbies, repeating activities, taking PD medications). See Chapter 10 for more information about assessment of impulse control problems.

Neuropsychological evaluation

For some individuals with PD, a more comprehensive neuropsychological evaluation may be needed (Ringendahl et al., 2000). Although motor difficulties associated with PD may sometimes masquerade as cognitive deficits, the risks of mild cognitive impairment as well as more global cognitive deficits are increased in people with PD (see Chapter 3). Neuropsychological assessment can be used to identify strengths as well as problem areas, both of which are important for tailoring psychological interventions to the individual's current status and support systems. A sensitive discussion of test results is essential with regard to assessment of cognitive abilities, emphasizing how the person's relatively intact abilities and external support can be used in service of areas that have been affected by the disease.

Assessment of caregivers

For caregivers, we typically use the same or parallel standardized assessment instruments as those used for people with PD.

Demographics: Caregiver Information Form

We use the *Caregiver Information Form* to collect basic demographic information and a description of concerns.

Depression: Self-Rating Depression Scale

We assess depressive symptoms with the *Self-rating Depression Scale* (SDS; Zung, 1965, 1973).

Psychosocial changes: Stress Questionnaire for PD Caregivers

To measure psychosocial changes and problems in caregivers of people with PD, we use a 15-item short form of the *Stress Questionnaire for Parkinson's Disease Caregivers* (SQPD-C). The questionnaire was originally developed in German (*Belastungsfragebogen für Angehörige von Parkinson-Patienten* [BELA-A]; Ellgring et al., 1989; Ellgring, Seiler, Nagel, et al., 1990). As with the BELA-P, a short form of the scale was translated into Dutch and validated in a Dutch sample (Spliethoff-Kamminga et al., 2003a), and then validated and used in a variety of studies in several languages (A'Campo, Spliethoff-Kamminga, et al., 2010; A'Campo, Wekking, et al., 2010; Ellgring et al., 2006; Macht & Ellgring, 2003). We then improved the wording by translating the scale into English from the original German, reduced the response options from a 5-point to a 4-point scale, and eliminated the "need for help" parallel rating (which was not typically used in earlier studies).

End of program assessment

In an end-of-program or post-training session, we re-administer the questionnaires to all participants. In addition, we ask participants to complete an informal training program evaluation (see *Program Evaluation for People with PD* and *Program Evaluation for Caregivers* in Appendix A for examples). Participants have the opportunity to reflect on improvements and concerns. Results from these questionnaires allow us to assess the usefulness of the program both for follow-up with individual participants and to improve our programs for the future.

Overview of Training Programs

We present four complete training programs: three programs for people with PD (Stress, Chapter 6; Communication, Chapter 7; Emotions, Chapter 8) and one for caregivers (Chapter 9). As noted in Chapter 1, program components can be used flexibly depending on the needs of the group and the training setting.

In addition, in Chapter 10, we describe methods for dealing with specific symptoms that we would typically address on an individual basis rather than in a group: "freezing" of gait, impulse control issues, hallucinations and delusions.

Some topics and activities are covered in more than one program (e.g., goal-setting, relaxation). In these cases, we have intentionally repeated the full information needed within each program to eliminate the need for referring between programs.

Selecting treatment options

People with PD: Any person with PD is a potential candidate for psychological intervention. The results of a client's assessment, and their subjective needs, guide us in helping them choose whether an individual or group format would be more suitable. We have conducted our training programs primarily in an outpatient setting with people who meet criteria for Hoehn and Yahr Stages 1-3 (see Disease Stage Classification, Chapter 2). Individual therapy rather than group treatment may be needed for clients with more complex or unique difficulties, particularly for people with more advanced disease or cognitive impairments. We typically discuss the format options during the pre-session individual meeting with the person with PD and/or caregiver.

Assessment of each individual's specific challenges also informs which training program would be most useful. Not every intervention is appropriate or necessary. For example, one person with PD may feel good emotionally, but have difficulty dealing with motor "freezing." Another may have difficulties with interpersonal relationships. A third may feel depressed or even suicidal. Clients may benefit from different programs at different stages of the illness. Individual issues can be brought up within the group, allowing for both therapist and group feedback. Issues that may not be appropriate for the group can be addressed in individual sessions.

Caregivers: Caregivers of people with PD of any level of disease severity are normally suitable for the caregiver program. Caregivers can participate whether or not the person they are caring for is also participating in a group. In some cases (e.g., when the person with PD has impulse control problems, see Chapter 10), we recommend couples therapy instead of or in addition to group training sessions.

Size and composition of groups

We recommend that people with PD and caregivers participate in separate groups, rather than combining them into a single group. In this way, people with PD have more time to speak, and caregivers can proceed at a faster pace than is typically possible with groups for people with PD. However, an introductory seminar for people with PD and caregivers together can be useful. In this case, we would still dedicate a portion of the time in the middle of the session to meet with people with PD and caregivers separately in order to give everyone a chance to ask questions, concluding with an overall summary for everyone together.

It may also be practical to run PD and caregiver training groups in parallel, with different therapists leading the groups. Certain topics have components that potentially allow joint sessions. For example, communication training for caregivers could be conducted in conjunction with training on the same topics for people with PD.

The groups ideally comprise 4-7 people with PD, or 4-12 caregivers. If a large number of clients are interested in participating in a particular program, we might divide the group into two to keep the size of each group small enough to provide targeted interventions and to reduce time pressure. An alternative is to form subgroups for some of the sessions. For example, we might form subgroups for clients at different stages of illness, as people with PD who have more advanced disease tend to be less active, with less chance to speak, if they are in a group with people at earlier stages of disease. Subgroups can also be useful for people with different living situations, such as those living alone vs. with a family member.

In general, it is not important for group members to be similar to each other with regard to their demographic characteristics. Individuals with different backgrounds can work well together and complement each other due to their common experience of illness.

Training program format for groups

The groups typically progress as follows:

- *Introductory group session*: In this meeting, we present an overview of the program, introduce participants to each other, and informally assess the problems and skills of the participants in the group setting.
- *Weekly sessions*: The number of sessions varies depending on the program. Throughout the program, participants record their experiences and behaviors, enabling them to track their progress.
- *End-of-training or post-training session*: Either in a group or individually, participants discuss the effects of their participation in the program, and provide feedback. Based on this information, we make follow-up recommendations, which could include an additional training program, individual therapy, or couples therapy.
- *Booster sessions*: If feasible, booster sessions help to enhance longer-term motivation and skills, particularly with regard to applying new strategies to daily life. We recommend at least one booster session 4-8 weeks after training. We tailor the information covered in the booster session to the needs of the participants. What did they learn in the program that was helpful? What information/skills could benefit from review? Are they having any new problems that could be addressed with skills they have already learned, or that may require additional psychological or medical interventions?

Structure of group sessions

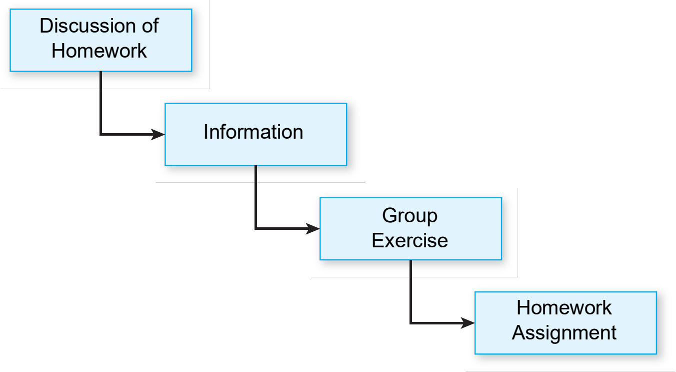
Groups typically meet weekly, for approximately 90 minutes. Although longer sessions are possible, they can be tiring, and participants may require frequent breaks.

With the exception of the first and last meetings (Introduction, Review), each group session is divided into the following components (Figure 5.1):

1. *Discussion of homework.* The homework exercises are geared toward applying new skills in everyday life, and/or as preparation for the following session. In the discussion, participants report briefly on their experience with the homework, and how they might use what they are learning.
2. *Information.* The therapist presents information about a new topic.
3. *Group exercise.* Exercises and role-plays enable participants to apply the information to their problems and goals, and practice skills.

4. *Homework assignment*. The therapist introduces and discusses the next homework assignment.
5. *Feedback Round*. Participants provide feedback, without discussion.

Figure 5.1. Components of a Group Session



We have found that this structure is useful for promoting a transfer of skills to everyday life. The amount of time devoted to each component within a session will vary depending on the topic and the needs of the participants. However, if a specific component or topic is taking significantly longer than planned, we typically bring the activity to a close by presenting a brief summary of the situation, making a note on the flip chart, and saying that this topic will be reviewed at a later time (which might be in the group, or with a specific individual).

Defining goals and target behaviors for each participant

For people with PD, selecting concrete goals is usually the first step in realistically facing and dealing with the effects of PD. A *goal* is defined here as a specific, desired outcome, as opposed to more abstract hopes or wishes. Goals provide direction, and can be achieved by changing specific behaviors, which we call *target behaviors*. Therefore, an essential aspect of every training program is for participants to formulate individual goals and to identify target behaviors that will enable them to achieve those goals.

Target behaviors must be well-defined and observable, and can include self-observable thoughts as well as concrete actions. It is important for participants to recognize that different levels of improvement are possible: success is not “all or nothing.”

Changes in target behaviors should be achievable in a relatively short period of time. Although the behavior changes all lead to an overall goal (e.g., speak so that other people can understand me), they may differ qualitatively (e.g., talking to a good friend, talking to a stranger, asserting myself in a restaurant) and/or in degree of difficulty (e.g., talking to one person, talking to two people, addressing a small group).

Goal-setting has the following characteristics:

- *Individualized:* Goals are specific to the person and the problem.
- *Measurable behaviors:* Each target behavior is described as concretely as possible.
- *Realistic:* Goals must be realistic to be useful. Some individuals may want to set goals that are too ambitious, whereas others may be reluctant to set goals at all, and therefore will benefit from encouragement to set small goals.
- *Rewards for achievement:* Motivation can be enhanced by choosing rewards for successful changes in target behaviors.
- *Flexibility:* Individuals' needs and goals may change over time. Participants are encouraged to modify their goals and target behaviors during the training program to fit their current challenges, unless consistent or uniform goals are needed for a research protocol.

To help participants visualize goals and target behaviors, we often use a *Goal Staircase*, based on Goal Attainment Scaling (GAS, Turner-Stokes, 2009). The staircase represents a specific target behavior, and each step is a level of achievement toward the target.

The original GAS uses a 5-point scale: 3 levels to describe improvement (0 = target; +1 = better than expected; +2 = much better than expected, and two levels below the target (-2, -1). This structure allows discrimination between changes in both directions, and is particularly useful for systematic evaluation and research on the effects of rehabilitation measures when different, individualized contents are to be compared.

To simplify the procedure for use with clients, however, we typically modify the GAS by creating a *Goal Staircase* with only four steps, i.e., a 4-point scale. We set the current situation as 0 and the desired target level as +1, which is easier for clients to envision as improvement (compared to a target of 0 in the original scale). Improvement beyond the target is +2. If the situation worsens, the rating would be -1.

+2: better than expected
+1: TARGET
0: unchanged
-1: worse

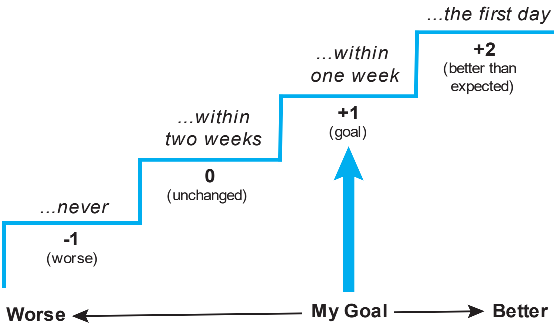
The following case study shows how levels of achievement can be depicted as a *Goal Staircase*.

Case Study: Individual goals

While on an annual vacation at a bed and breakfast with her husband, Ms. D (61 years old, diagnosed with PD for about a year), found it very stressful to eat in the dining room. She sensed that the other diners could see her tremor when she tried to eat. The feeling of being observed was very unpleasant and intensified the tremor. After more than half of the vacation had passed, she finally explained to the others that her tremor was caused by PD. Confiding in them was a great relief, and the atmosphere during meals became more pleasant. Because she felt more relaxed, the tremor decreased. Ms. D's goal is to enjoy her future vacations, and her specific target behavior is to share information about her PD earlier on. She developed a *Goal Staircase* to help herself do that (see Figure 5.2).

Figure 5.2. Example of a *Goal Staircase*: Talking to Another Person about Parkinson's Disease

"I will talk with a fellow diner about my Parkinson's disease…"



The simplified *Goal Staircase* helps participants to see small but important steps to success. We have found that *Goal Staircases* are most useful when introduced early in the training program, usually in the second or third session. In subsequent sessions, participants can discuss progress on goals and possible modifications during the discussion of homework.

In addition, we may refer to participants' *Goal Staircases* during other activities within the session, such as discussion of role plays. For example, we might ask participants whether they already have or would like to add an overall goal, or add target behaviors to a current goal, relating to skills being learned and practiced in the session.

In sum, *Goal Staircases* can be used as reminders of participants' priorities, and as measures of the degree to which they are meeting their targets. Their use for particular issues will be described in more detail within each training program. However, the essential element is for participants to set specific, achievable target behaviors that lead to goals that are important for the individual, whether or not *Goal Staircases* are used for visualizing progress.

Guidelines for the Design and Implementation of Programs

Consider participant characteristics and needs

The characteristics of the participants (including social/living situation, educational history, cognitive capacities, individual needs), and the time frame of the program, should ultimately govern decisions about what content and how many topics to include.

Participants may vary widely in their general knowledge about PD, and in their desire to know details about specific issues. In particular, when describing or discussing PD and its typical progression, be sure to consider the psychological state of all participants. Some participants, especially those who have been diagnosed recently, may find it difficult to be confronted with information about symptoms that they may or may not experience in the future. Therefore, approach with caution any information about PD that might increase distress before individuals are prepared to cope with that information.

Questions about medical treatments

Participants often ask questions about medications and other medical treatments for PD. It is important to be familiar with therapeutic effects, risks, and side effects of common treatments. Unless you are a physician, however, you should never give medical advice or make medical treatment a topic within the program. This caveat applies equally to medical treatment for depression and other psychological symptoms and conditions. Instead, direct the individual to discuss these questions with their physician. If appropriate, the questions can serve as starting point for discussions about how to interact with health care professionals, including the use of role-play exercises (see Communication training program, Chapter 7).

Group rules and confidentiality

During the initial meeting, discuss the “rules of the group” that every participant will agree to follow. Depending on the group, these rules may be more or less detailed and may include rules that are suggested by individual group members and then discussed. For all programs, a critical rule is that any personal information that comes up during the sessions must be kept confidential within the group. Inform participants that if they do not want to talk about a particular issue in the group, they always have the option not to speak. If desired, they can talk about the issue with the therapist later in private.

If a participant expresses concerns about self-injury or suicidal thoughts during a session, address the issue with the person individually at the end of the session, and refer for additional professional help as needed.

Practical tips for running sessions

Bring/set up prior to the session

- A flip chart, with markers. In the descriptions of the training programs in this book, we refer to flip charts because they are widely available and portable, but any type of system that allows you to write information to display to participants during the session will work.
- A large clock visible to participants to monitor the time during the session.
- Water to drink (people with PD often suffer from dry mouth).
- Handouts summarizing key information to provide to participants at the end of the session or digitally (See Appendix B). Alternatively, provide writing paper and pens for participants to take notes. However, many people with PD have slow or impaired writing, which may make note-taking difficult.

In the first session

- Because some participants may have limited or incorrect information about PD, it can be useful to ask what they already know about the disease, what they regard as important, and what is still unclear to them. Make notes on the flip chart, and then integrate relevant information into the sessions where appropriate. In addition, you can refer participants to current books and websites about PD written for lay audiences, such as those listed in Chapter 2. For questions about medication, however, always refer participants to their physician.

At the beginning of each session

- Present a short overview of the exercises and contents of the session.

During each session

- When presenting information, avoid long, detailed descriptions or explanations: it is tiring to participants when the group session becomes a seminar instead of an active group process. Try to arouse interest and pick out the most important points from the material. Encourage participants to ask questions, and to engage actively during the Information component, as it will set the tone for the rest of the session.
- For most sessions, a “script” is provided for portions of the Information or Exercise components, in order to more easily illustrate our typical delivery of the content, and to enable greater standardization for research protocols. Unless standardization is needed, however, you should adapt the information to suit your individual style and the needs of the participants. In any case, the script should never be simply “read” to

participants; always carefully review the information in advance and deliver the information with an appropriate conversational tone. Furthermore, intentionally alternating between providing information and eliciting input from participants will increase both the liveliness and relevance of the sessions.
- Give participants sufficient time to understand the information and ask questions. A good way to check understanding is to encourage participants to contribute their own examples.
- Write key points on the flip chart throughout the session. In addition to ensuring that participants are focusing on the most important aspects, writing on the flip chart will help you to slow down when presenting information.
- Use simple language, avoiding jargon (e.g., "changing thoughts" instead of "cognitive restructuring"), although the technical term can also be mentioned when appropriate.
- Tell participants that they will receive a summary sheet at the end of each session; they do not need to try to write down or memorize information. Except where indicated, we do not normally distribute the handouts during the session, to avoid dividing the participants' attention.
- For discussions, introduce and end the topics. Structure and summarize the contributions of group members. Re-focus the discussion back to the main topic if necessary.
- Ensure that every participant is involved in the exercises and takes part in the feedback round at the end of the session.
- Schedule short breaks between the sections of a session, which will allow participants (as well as you) some time to relax and refocus.
- If you recognize that participants are becoming sleepy or having other difficulties sustaining attention, ask for a short round of comments and then take an additional short break.

At the end of each session

- Present a short summary of the most important points. Hand out summary sheets of key points (or provide digitally); see Appendix B.
- Reinforce the importance of implementing the exercises in daily life. Without continued practice, it is difficult to make lasting changes.

Guiding Principles

When developing and implementing psychological interventions for PD, we have followed these seven principles, which we believe are important for all therapists who use our programs to work with people with PD:

Principle 1: Go step by step. A step-by-step approach means starting with small changes. Instead of focusing on coping with "the disease," address specific problems and issues in daily life.

Principle 2: Be flexible. Select the topics and problem areas that are most important, pressing, or difficult for the participants. The highest priority is for the program to be useful, and flexibility is key.

Principle 3: Be patient. People with PD may need a longer time to initiate and respond to questions during a session as a function of their disease symptoms. It is therefore important to be patient even with simple questions or activities—to wait a bit longer for an answer or reaction. In addition, people with PD may need time to come to grips with the changes occurring as a result of their diagnosis. Spend whatever time is needed to go through the information and to practice the exercises, rather than trying to cover everything. Acceptance and acknowledgment of each participant's strengths and challenges is critical.

Principle 4: Prepare for difficult situations. Participants may raise problems and questions in a group setting that do not fit the intended focus of a session. As the therapist, you must strike a balance. On one hand, it is important to respond to individuals' immediate needs and requests for help; on the other hand, it is important not to lose sight of the goals of the session. If a participant brings up an urgent issue, offer an individual session outside of the group setting.

Principle 5: Make it relevant. In every session, consider how the information can be used in daily life. If participants do not see the personal relevance of the content or activities, you may need to re-think which topics to address.

Principle 6: Help participants to focus on what is possible. Emphasize what works, not what doesn't work. Adopting a positive, problem-solving orientation may sometimes be difficult in the face of a chronic progressive disease. However, we have found that this mindset is critical for participants to maintain a sense of achievement throughout all phases of the disease.

Principle 7: Empower participants for the long term. The treatment programs are just the beginning of a new approach to living with PD. The overall goal is for participants to use these principles and techniques when facing new situations in the future, to be able to find information and resources when different problems arise or scientific advances are made, and to ask for additional help and support when needed.

Chapter 6: Coping with Stress and Illness

The training program for stress and disease management can be useful for anyone with PD, as we all experience stress. This program is particularly suitable for people who often experience emotional and physical stress, and for those who find it difficult to deal with problems brought on by their illness.

Participants learn what stress is, how to identify stressful situations and their own stress responses, and how to cope with stress in daily life. They then use this knowledge as a basis for improving their ability to cope with the disease itself.

Table 6.1 shows examples of problems and solutions that are covered in the program. (Note: If participants have a particular problem with "freezing" of gait under stress, refer to Chapter 10.)

Table 6.1. Stress and disease management: Examples of problems and possible solutions

Topic	Problem	Solutions
Stressors in everyday life	Symptoms increase with excitement and stress	• Relaxation techniques • Cognitive coping strategies
	Feeling overwhelmed, exhausted	• Relaxation techniques • Scheduling activities
	Symptom fluctuations	• Keeping daily record of symptoms • Scheduling activities
Coping with illness	Negative emotions upon learning of diagnosis	• Learning more about PD and ways to cope • Talking about feelings
	Depressed mood	• Changing negative thought patterns • Planning pleasant activities
	Anxiety about disease progression	• Distinguishing between realistic and unrealistic fears • Confronting fears

Structure of the Stress Program

This training program consists of 11 group sessions, beginning with an introduction in Session 1, and concluding with a review in Session 11. Sessions 2-10 each include a progress report about the previous session's homework, presentation of new information, group exercises, preparation for new homework, and a feedback round about the session.

Table 6.2 provides an overview of the group sessions and individual components, which can be adjusted as needed.

Table 6.2. Stress and disease management training: Components at a glance

Session	Information	Group Exercises	Homework
1. Introduction	• Overview of program • PD and stress • Problems and solutions	• Getting acquainted	• Introductory questions
2. Stressful events and self-observation	• Stressful events • Techniques to manage stress • Self-observation	• Body Awareness Exercise	• Body Awareness Exercise • Stress Journal[1]
3. Coping with stress in everyday life	• Effects of stress in people with PD: Negative and positive stress cycles • Setting goals with a Goal Staircase	• My reactions in stressful situations • Setting goals with a Goal Staircase	• My reactions in stressful situations • Setting goals
4. Relaxation I: Relaxation at rest	• Principles of relaxation	• Relaxation at rest	• Relaxation at rest
5. Relaxation II: Relaxation in stressful situations	• Using relaxation techniques in stressful situations	• Brief relaxation techniques • Brief relaxation in imagined stressful situations	• Relaxation practice
6. Cognitive Therapy I: Self-instruction	• Self-talk and self-instructional training • Combining self-instruction with relaxation techniques	• Self-instruction before, during, and after stressful events • Self-instruction and relaxation while re-imagining the past	• Self-instruction and relaxation in stressful situations

7. Cognitive Therapy II: Changing attitudes about PD	• Attitudes about disease	• Observing and changing attitudes in stressful situations	• Observing and changing attitudes
8. Cognitive Therapy III: Coping with disease	• Coping with disease	• Disease management	• My life with PD
9. Activity planning	• Activity planning	• Activity planning	• Activity planning • Bring something pleasant
10. Pleasant activities	• Increasing pleasant activities	• Engaging in pleasant activities	• Have some fun! • Program review
11. Program review		• Review of the program and "pack your bags"	
[1] Participants keep the Stress Journal during the entire program.			

Stress Session 1: Introduction to the Stress Program

Overview of session
Information: • Overview of program • PD and stress • Problems and solutions
Group Exercise: • Getting acquainted
Homework assignment: • Introductory questions
Handouts: • Overview and Schedule • Stress Session 1 Summary Sheet

Information: Overview of program

Hand out the *Overview and Schedule* sheet (or give to participants during the introductory meeting). Describe the program by carefully going through each point on the sheet and answering questions.

Group Exercise: Getting acquainted

In this exercise, participants get to know each other. The participants interview each other in pairs. These interviews work better if participants are paired with someone they don't know well. For odd-numbered groups, you can take on the role of an interview partner. If desired, provide paper and pens for participants who would like to take notes about their partner; note, however that many people with PD have difficulty with handwriting.

In the first round, one member of each pair asks their partner about themselves, which might include questions such as the following (write the questions on the flip chart):

- Name, age, living situation
- Duration of PD
- How has PD changed your life?
- How has PD changed the lives of people close to you?
- Has your attitude towards PD changed over time?

- What symptoms/problems are affecting you?
- What thoughts/images come to mind when you think about your illness?

In the second round, the partners swap roles.

In the last part of the exercise, everyone takes turns reporting the results of their interviews to the group. Write selected comments on the flip chart to highlight important points.

This exercise will usually take about 30 minutes. If time remains, discuss how information from the interviews is linked to what they will be learning in subsequent sessions, such as how to relax, or ways to think differently about their problems.

An alternative to this exercise is for participants to introduce themselves to the group. However, the "interview" tends to promote better communication among the participants.

Information: PD and stress

Describe stress and stress responses. Say[2]:

> *We all experience stressful situations because stress is part of life. When you encounter a problem or situation that you need to deal with, your body will normally increase its activity to enable you to cope with the challenge. This response is called a "stress response." For example, your heart rate may increase.*
>
> *These changes are usually normal and helpful. Sometimes, however, if you perceive the situation as threatening, or one that you may not be able to handle, you may experience a bigger response that can work against you.*
>
> *A stress response is characterized by three basic features.*
>
> 1. *It has multiple components, which can vary from person to person, and in different situations.*
>
> *Think about the kinds of reactions you have had when you were experiencing a stressful event.*

Ask for comments and/or use examples provided; write categories on flip chart.

> *Some common reactions are:*
>
> - *Unpleasant thoughts and feelings such as worry, restlessness, anger, fear, and sadness*
> - *Physical changes, such as an increase in heart rate, sweating, muscle tension, and blood pressure*
> - *Behavioral changes, such as avoiding doing something, or losing or dropping things. For example, you might be trying to find your keys and look hurriedly in the same places.*

---

[2] Scripts are provided in italics as suggestions for wording of specific content.

2. *These components usually occur in a particular sequence. Your immediate reaction is followed by other responses that can last for different lengths of time, depending on the type of stressor.*
3. *The time course of a stress response is influenced by how you cope with the stressor. The more effective your coping strategies are, the sooner your body will return to normal.*

Describe how stress can affect people with PD. Say:

> *Parkinson's disease (PD) is a physical disorder that can affect how people think, feel, and behave. It is not a "mental illness"—yet stress can be a particular problem for people with PD because:*

1. *The disease symptoms themselves can be difficult to deal with.*
2. *PD can increase a person's susceptibility to stress in everyday life: even small events or tasks may feel more stressful than in the past. For example, you may find yourself feeling stressed by seemingly trivial situations, such as when you are trying to sign your name on a document, or even greeting a person you pass in the street—things that were easy for you before.*
3. *Even slight increases in emotional arousal or excitement, or feelings such as anger, fear or shame, can intensify motor symptoms such as:*
   - *Increase in tremor*
   - *Motor "freezing"*
   - *Clumsiness*
   - *Slowing of movements*
4. *Increased stress for people with PD can also:*
   - *Decrease motivation and drive*
   - *Increase feelings of helplessness or fear*
   - *Increase feelings of insecurity in social interactions*
   - *Create problems in relationships*

> *Psychological effects and ways of coping with the disease vary from person to person, just like the motor symptoms do. These effects can also change over the course of the disease. Identifying the kinds of activities or situations that create stress for you, and the effects of that stress, is our first step in treatment.*

Information: Problems and solutions

Present examples of problems and solutions from Table 5.2. and discuss which issues are of most concern to participants.

Homework assignment: Introductory Questions

Hand out the *Session 1 Summary Sheet*, which includes the homework assignment *Introductory Questions* to work on before the next session. This homework has questions about what participants know about PD, how they are dealing with PD, and their expectations of the training program. Point out the importance of thinking about realistic and unrealistic expectations.

We typically do not ask participants to turn in homework sheets, but instead encourage them to bring the sheets back to the next session for discussion. We offer to look over the homework if a participant would like feedback, and to discuss any issues that participants would like to address.

Feedback round

Ask each participant to comment briefly about their experience of the session, giving their personal impressions. Do not allow discussion, in order to encourage participants to speak honestly and openly, and to prevent the session from running overtime.

Participants can address questions such as the following:

- What did I like the most about the session?
- What didn't I like about the session?
- How do I feel now that the session is over?

Stress Session 2: Stressful Events and Self-Observation

Overview of session
Discussion of homework: • Introductory Questions
Information: • Stressful events • Techniques to manage stress • Self-observation
Group Exercise: • Body Awareness Exercise
Homework assignment: • Body Awareness Exercise • Stress Journal
Handouts: • Stress Session 2 Summary Sheet • Body Awareness Exercise (script or recording) • Stress Journal for People with PD

Discussion of homework

Participants were asked to complete *Introductory Questions*. When discussing the homework:

- Ask participants if they had any questions or difficulties in completing the homework.
- Distinguish realistic from unrealistic expectations. For example, the expectation of being able to cope better with everyday stresses and strains is realistic, whereas the wish to live exactly as they did before the onset of the disease, is not.
- Describe how participants will be able to use these expectations to develop specific goals and target behaviors in later sessions. For example, the expectation of being able to cope better can be realized in part by learning to relax their muscles in stressful situations.

Information: Stressful events

In this session, participants will learn more about stressful events and responses. Say:

> *As we have already discussed, everyone experiences stress. When we are faced with an event that we perceive as threatening or challenging, we react on many levels, with changes in our thoughts, feelings, and behavior, as well as our body. Even "positive" events, such as planning a wedding or moving to a new house, can be stressful, because they demand additional resources. Sometimes you may not even consciously regard an event as stressful, yet if additional resources are required, your PD symptoms can increase.*
>
> *We all experience stress differently: we have different situations that we find stressful, as well as our own ways of reacting to stress. The degree to which we experience an event as stressful depends in part on whether or not we think our abilities to cope match up with those demands.*
>
> *Some stressful events (or "stressors") and responses may be very strong, whereas others are mild. They also differ in how long they last. Most stressors subside after only a few minutes, but some stressors can last for much longer.*
>
> - *Examples of stressors that typically last only short periods include waiting in line when you are in a hurry, traffic jams, or being exposed to a loud noise.*
> - *Stressors that can last for several hours could include attending a crowded event, or being outside in the heat or cold.*
> - *Stressors that can last even longer could include problems with relationships, or difficulties on the job.*
> - *More "permanent" stressors could include the death of a family member, or living with a chronic disease.*
>
> *Even if the stressful event itself is relatively short, your reactions can continue for much longer if the stressor is powerful or if you relive the stressor in your mind.*
>
> *Parkinson's disease can make you more vulnerable to both short- and long-term stressors. For all these reasons, it can be helpful to learn and practice a variety of different methods to deal with stress.*

Information: Techniques to manage stress

Participants will next learn how this training program can help them deal with PD. Say:

> *In order to learn to manage stress, you will practice making small, consistent changes in your daily life. We will be using three main techniques: relaxation, changes in thinking, and activity planning and promotion.*
>
> *Relaxation can help you manage motor symptoms of PD by calming down your body's response to stress. In addition, as your body relaxes, your mind will calm down too.*

> *Changes in thinking can be helpful when particular thoughts increase your stress response. To change these thoughts, which often seem to appear automatically, you must first "observe" them. You can then develop and practice new ways of thinking that increase your ability to cope with situations.*
>
> *Planning activities, and increasing the number of pleasant activities can also help reduce stress. Specifically, we know that it can be stressful if you have too much to do, and try to tackle more than one task at a time. You can reduce that stress by making a plan to reduce the demands on your time. In addition, you can increase feelings of well-being by deliberately increasing how often you engage in pleasant activities.*

Information: Self-observation

Describe the rationale and techniques of self-observation. Say:

> *The first step for changing behaviors is self-observation. Self-observation refers to paying attention to your thoughts, feelings, and behaviors right at this moment, with a non-judgmental attitude.*
>
> *Self-observation can serve two main purposes: to identify problems, and to see a solution to those problems more easily.*
>
> *To practice self-observation, first select a specific thought, feeling, or behavior as the target of your observation. Once you have identified a target, you can learn to become more aware of when it tends to occur: how often and in what situations.*
>
> - *An example of a thought would be that you think you are not capable of doing anything useful. You can then seek to identify when and where you tend to have this or similar thoughts. Of course, you might instead have the thought that you are up to the challenges of the day. Under what circumstances does that thought occur?*
> - *An example of a feeling would be the unpleasant experience you have when you feel that other people are observing you and your motor symptoms. You could identify in which situations these feelings are most likely to occur.*
> - *An example of a behavior would be that you are not getting the things done that you normally do. You could choose to observe what times throughout the day you are more or less productive.*
>
> *We don't normally think consciously about most of what we do, so it can sometimes be difficult to recognize and describe these specific behaviors. However, self-observation is a skill that will improve with regular practice. This kind of careful observation may then lead to a solution.*
>
> *Using self-observation does NOT mean that:*
>
> - *You should constantly question yourself and everything you do, which may just make problems worse. Instead, use self-observation in a targeted way, to identify and solve specific problems, as well as to identify strengths.*

- *You are merely a passive observer. Self-observation helps you deal actively with issues that are important for your quality of life.*

You may also want to talk with others about your self-observations. Through the sharing of observations, you may gain new perspectives on how your experiences are similar or different to those of others, which may in turn help you to understand yourself better.

Group Exercise: Body Awareness Exercise

As a practical introduction to self-observation, participants conduct a *Body Awareness Exercise* (Tausch, 1993; procedure modified from pp. 162-163). In this exercise, participants focus attention on states of tension/relaxation in specific parts of the body. Over the course of the training program, participants will learn to use this exercise in a targeted manner: at the beginning and end of the relaxation exercises, and in connection with everyday stress.

Initially, participants may want to use a recording of the *Body Awareness Exercise*; if desired, you can make a recording for participants to take home (or send a digital recording). Alternatively, hand out the script at the end of the session for participants to make a recording themselves, or allow them to record the session. Eventually they may prefer to practice without external instructions.

Conduct the *Body Awareness Exercise* with participants, using the script in Appendix B.

After the exercise, ask participants to discuss their experiences and any difficulties they had, and invite questions. They may not be accustomed to focusing attention on themselves, or may not understand the intention of the exercise. Point out that self-observation takes practice, and will be needed for interventions later in the program.

Homework assignment: Body Awareness Exercise

Participants continue practicing on their own.

Homework assignment: Stress Journal for People with PD

Hand out copies of the *Stress Journal* (Appendix B) and go through it with the group.

Explain that they will use the journal to record any situations they find stressful and how they reacted to those situations.

To clarify what is meant by a “stressful situation,” ask participants for examples from their daily life. If they find it difficult to identify stressful situations, suggest some of these examples, and ask if they have encountered them:

- Running late for an appointment because it is taking a long time to get ready
- Paying with cash or check at a supermarket checkout

- Signing documents at a bank counter
- Having trouble turning over in bed

Emphasize the importance of writing down this information. As with other homework, we normally do not ask participants to turn in their journals but offer to look at them if participants would like feedback. They will use the journals throughout the training program.

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

Stress Session 3: Coping with Stress in Daily Life

Overview of session
Discussion of homework: • Stress Journal
Information: • Effects of stress in people with PD: Negative and positive stress cycles • Setting goals with a Goal Staircase
Group Exercises: • My reactions in stressful situations • Setting goals with a Goal Staircase
Homework Assignments: • My reactions in stressful situations • Setting goals • Stress Journal
Handouts: • Stress Session 3 Summary Sheet • Homework: My Reactions in Stressful Situations • Homework: Setting Goals

Discussion of homework

Discuss participants' experiences keeping the *Stress Journal*, giving special attention to difficulties and obstacles in knowing how or what to write. For example, many people find it difficult to describe their thoughts and feelings. Emphasize that writing in the journal will get easier with practice and is an integral part of the program. Discuss specific stressful situations that individuals are willing to share with the group. Write the examples on the flip chart.

Information: Effects of stress in people with PD—Negative and positive stress cycles

Now that participants have learned general information about coping with stress, and have identified situations that they feel are stressful, they are prepared to discuss in more detail the specific ways that stress can impact people with PD. Say:

> *Think about the kinds of reactions you have had when you were experiencing a stressful event. What were your thoughts? How did you feel? Did your behavior change?*

Write on flip chart; add common reactions that are not mentioned by participants. Some common reactions are:

- Negative thoughts ("This should not be happening to me!")
- Unpleasant feelings/emotions such as tension, restlessness, anger, fear and sadness
- Physical reactions, such as heart beating faster, sweating, muscles tensing up
- Increased PD symptoms, such as becoming agitated and shaky, or suddenly being unable to move, freezing up "like a deer in the headlights"
- Behaviors, such as leaving a party early, arguing with partner

Stress cycles

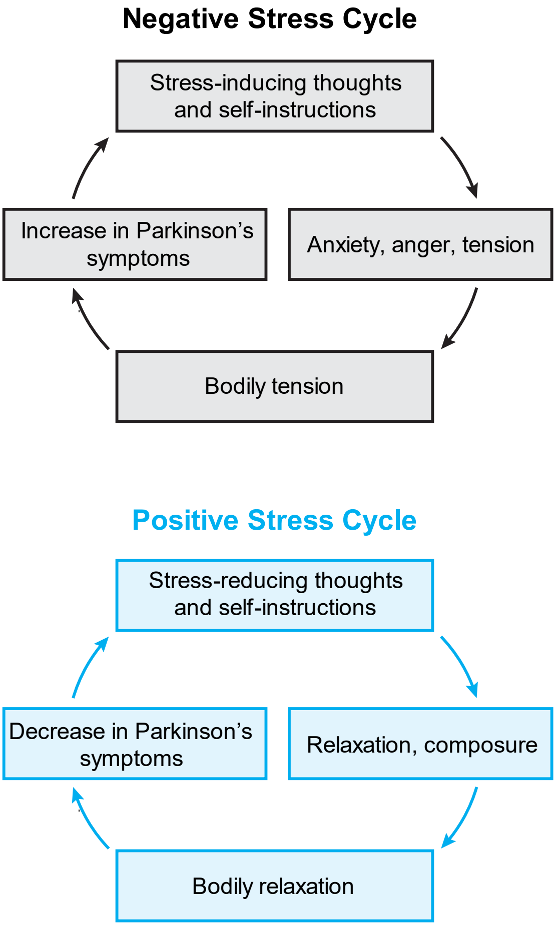
Describe how different components of the stress response can interact with each other to create a negative stress cycle. Say:

> *The motor symptoms of PD, such as tremor, can increase during stressful situations, regardless of whether the events themselves are enjoyable or disagreeable. This increase in motor symptoms during times of high arousal can create a feedback loop, in which the different components of the stress response reinforce each other and increase even more.*
>
> *For example* (draw top part of Figure 6.1 on flip chart), *if you have negative thoughts, you may feel more fearful and tense; your muscles may tighten up, leading to an increase in your PD symptoms. This increase in symptoms makes you feel even worse, resulting in more stress. We call this a "negative stress cycle"—a chain reaction of events that build on each other in an unhelpful way.*
>
> *Describe the case study as an example of a negative stress cycle.*

Case Study: Trying to suppress tremor

Mrs. V is A 59-year-old bank employee who was diagnosed with PD four years ago. Her main motor symptom is tremor in her arms and legs, making daily activities difficult (writing, washing hands, eating with utensils). Mrs. V describes herself as "nervous, anxious and often on the verge of tears." She was brought up to "not make mistakes," and can still hear her mother saying to her: "Don't embarrass me!" Now she fears that other people will see her tremor and react negatively—maybe even think that she is crazy. She avoids public situations whenever possible. When she must go out in public, she tries to suppress the tremor, but these efforts only intensify it. She would like to be able to deal with stress in a more relaxed way, and to gain a greater overall feeling of serenity.

Figure 6.1. Negative and Positive Stress Cycles



On the other hand, a positive stress cycle can occur when thoughts, feelings, physical changes, and behaviors influence each other in a good or useful way. For example (draw bottom part of Figure 6.1 on flip chart), *if you think encouraging thoughts, you are more likely to feel good and allow your muscles to relax, which may then result in fewer motor symptoms.*

One goal of this training program is to identify and break through negative stress cycles and change them into positive stress cycles. The first step is for you to identify your reactions in stressful situations—your thoughts, feelings, and behaviors. These reactions affect each other, so changing one may change the others.

For example, if you are in a stressful situation and realize that you are thinking something negative (such as, "this is hopeless"), you could decide instead to change your *thought to something positive (such as, "I am going to do my best"). Or if you react to a stressful situation with an increase in arousal, you could calm yourself physically by doing a brief relaxation exercise. Either of these changes may interrupt the negative cycle and turn it into a positive cycle. You will be learning specific interventions in later sessions.*

If possible, it is usually more effective to identify signs of stress at an early stage, so that you can apply stress management strategies immediately. For example, relaxation techniques are usually more effective if you use them when the first signs of stress appear, rather than after you are already very tense.

Work through the case study of a man with PD, writing down Mr. B's reactions on a flip chart. Then discuss with the group which areas may be most suitable for intervention, and the benefits of identifying signs of stress early in the cycle.

Case Study: Going to a concert

Mr. B has always enjoyed attending concerts. Now, however, he worries that other people will perceive him negatively because of his tremor. This fear triggers an increase in tremor, which in turn further increases his fear, creating a negative stress cycle.

Stressful situation	**Reaction**
Mr. B noted: I am in the lobby of a concert hall with many people around. They can see the tremor in my right hand.	**Thought**: I look like an old fool. Anyone who sees me is going to want to make fun of me or pity me. ↓ **Feeling**: I feel anxious and embarrassed about the tremor ↓ **Physical reaction** (PD symptom): The tremor gets even worse. ↓ **Behavior**: I hold my right hand with my left hand, but the tremor does not decrease. ↓ **Feeling**: My fear of attracting unwanted attention increases. ↓ [**Long-term behavior**: I stop going to the theater.]

Group exercise: My reactions in stressful situations

In this exercise, participants learn to identify the components of their typical reactions in stressful situations. Ask for a participant to give an example from their own life (e.g., an event from their *Stress Journal*) to share with the group.

As before, write down the different reactions on the flip chart. If desired, role-play can be used to show the importance of individual components of the individual's stress reaction. For example, one participant can play the role of thoughts, another the role of PD symptoms, etc.

Homework assignment: My reactions in stressful situations

Tell the group that they will continue this exercise as homework, and hand out the homework sheet *My Reactions in Stressful Situations*. Describe the format of the handout, by showing that they will write the stressful situations on the left half of the sheet, and the stress reactions on the right side, just as the group did with the flip chart. They can describe any stressful situations they encountered, including situations that they handled well.

Information: Setting goals with a Goal Staircase

In this next component, participants develop individual goals with specific target behaviors. (For more detailed information refer to *Defining Goals and Target Behaviors for Each Participant* in Chapter 5). Say:

> *Making changes is easier, more effective, and more rewarding if you set goals. A goal is not an abstract hope or wish, but instead is an outcome that you want to achieve. To do that, you will identify specific, concrete behaviors to change: your target behaviors. These behaviors can include not only actions, but also thoughts that you observe you are having. To reach a particular goal, you could have one or more target behaviors.*
>
> *For example, suppose you have a general goal of being better able to take care of your responsibilities on time. To achieve that goal, you could set two target behaviors: to find someone to help you at home, and to reduce your number of outside commitments. If you achieve your targets—in this case, you find someone to help you, and you reduce your outside commitments from 3 per week to 2—you may accomplish the goal of taking care of your responsibilities on time.*
>
> *To begin with, it is usually more effective to start with one main goal at a time, and to choose target behaviors that are relatively easy to change.*

The steps to setting goals and target behaviors are:

1. *Decide on a goal. Select an important concern or difficulty that you would like to address. A goal can be short-term or long-term. If you have more than one major concern, pick the one that is most important to you in the immediate future.*
2. *Describe at least one specific, concrete behavior that you could change that will contribute to the goal—this is a target behavior. Choose a behavior that you can work on in the coming week.*
3. *Set a reasonable level of achievement for the target behavior. Take into account your current level of that behavior, and what is realistic for you to achieve in the near future. The type of target may differ depending on the behavior, e.g., frequency per week, intensity of behavior, or time taken to accomplish a task.*
4. *If desired, you can create a Goal Staircase for the target behavior using a 4-point scale, as follows:*

Your current situation with regard to the behavior is 0, and your target is +1. If you improve beyond your target, your rating would be +2. If your situation worsens, you would be -1, like this (write on flip chart)*:*

+2: better than expected
+1: TARGET
0: unchanged
-1: worse

Although you will be aiming for your target level, different levels of improvement are possible—success is not "all or nothing."

Describe the following example of a Goal Staircase (or use your own example).

Example of Goal Staircase

A woman with PD has this goal: “I want to enjoy my life more.”

Comments: This is a very general goal. She chooses a specific target behavior that will contribute to the overall goal. In this case, she chooses to increase the number of enjoyable activities she engages in.

She thinks about the types of enjoyable activities she has done in the past. Her list includes:

- Listening to an opera at home
- Going to the theater
- Taking a hot bath
- Walking in the park
- Sitting in the garden and reading a newspaper
- Drinking tea with her partner

She builds a Goal Staircase by setting an achievable number of enjoyable activities as her target, and then identifies steps above and below the target. For example, if she engaged in three enjoyable activities in the past week (assuming it was a typical week), she could set her target at four activities for the week. Her Goal Staircase could look like this:

Target behavior: Increase number of enjoyable activities

+2: 5 or more per week
(TARGET) +1: 4 per week
(unchanged) 0: 3 per week
-1: < 3 per week

Group exercise: Setting goals with a Goal Staircase

Discuss with the group how each of the following goals could be achieved by identifying target behaviors, and (if desired) by building a *Goal Staircase* for each target behavior. What would be a reasonable target level for each behavior?

- I want to feel less stressed when shopping and using public transportation.
- I don't want my life to be overshadowed so much by my disease.
- I want to have a better relationship with my partner.
- I want to enjoy my life more.
- I want to better manage my fears about my disease progressing.

Homework assignment: Setting goals

Explain to participants that they will practice creating and defining their individual goals and target behaviors as homework. They can choose to use a 4-point *Goal Staircase* or simply describe an overall goal with one or two target behaviors.

Homework assignment: Stress Journal

Participants continue keeping the *Stress Journal.*

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

Relaxation Training: Overview (for Stress Sessions 4 & 5)

The ability to purposefully relax can increase the capacity of people with PD to deal with motor symptoms in stressful situations, and can also enhance general well-being. Not every relaxation method is suitable for everyone, however; the choice of method should take participants' specific symptoms into account. For example, Jacobson's progressive muscle relaxation (Bernstein & Borkovec, 1973) is difficult for people who suffer from a high level of muscle rigidity or frequent muscle cramps. Many people with PD also find it difficult to lie down and get up again. Therefore, relaxation exercises should usually be practiced sitting down, especially in a group setting.

In Sessions 4 and 5, participants learn three different types of relaxation techniques: (1) progressive muscle relaxation, (2) relaxed breathing; and (3) visual imagery. They then learn shorter forms of relaxation, which will later be combined with cognitive therapy. Each technique is practiced first in the group, and then as homework. The goal is to achieve states of relaxation more deeply and quickly so that they can use these methods in stressful situations. Participants may find that they prefer one technique over another, or that certain techniques work better in different situations. By practicing a variety of techniques during the training sessions, they will later be able to choose the ones that are most effective for them. In addition, practicing within the session demonstrates to participants that relaxation can be trained just like other learned skills: using a technique repeatedly and systematically will result in faster and more pronounced relaxation for more effective stress relief. If desired, additional relaxation procedures can be added. The relaxation exercises can also be combined with quiet music (Macht et al., 2000).

Stress Session 4: Relaxation at Rest

Overview of session
Discussion of homework: • My reactions in stressful situations • Setting goals
Information: • Principles of relaxation
Group exercise: • Relaxation at rest
Homework assignments: • Relaxation at rest • Stress Journal
Handouts: • Session 4 Summary Sheet • Tips for Learning to Relax • Relaxation at Rest (script or recording)

Discussion of homework

My Reactions in Stressful Situations: When discussing the homework, ask each participant to describe the most significant or noticeable characteristic of their stress reaction.

Setting Goals: Ask participants to describe the personal goal and target behavior(s) they have chosen. Are the behaviors specific and easy to assess? If they used a *Goal Staircase*, were they able to identify different levels of success? Did they have any difficulties? Remind participants that they will be able to modify and add to their goals and target behaviors in the coming weeks.

Information: Principles of relaxation

In this session, participants will learn basic principles of relaxation, and how to apply them at rest. Say:

Relaxation is the opposite of the state of anxiety: you can't be relaxed and anxious at the same time. Through targeted relaxation practice, your muscles learn to rest, and your entire body can become more relaxed. Why is this important?

- *The most important effect of relaxation is a quieting and calming of your inner thoughts and feelings. This calming will help you recover from stress both physically and mentally.*
- *You can gain some distance from the problems of everyday life, helping you to achieve a feeling of balance and resilience.*
- *Relaxation can help with the motor symptoms of PD. Even though it won't make them disappear forever, they may decrease.*

Relaxation is a skill like any other skill, such as driving a car. When you first learned to drive, you had to learn and think about each thing you needed to do. Later, you were able to drive a car almost automatically. But to get to that point, you needed to practice. It is the same with relaxation. Through practice, you will gradually improve your ability to identify states of relaxation and stress, and to use relaxation techniques. By learning to notice the first signs of stress, you can implement relaxation techniques early on, when they are most effective. That way you can prevent feelings of anxiety from taking hold.

In addition, you can increase the effects of relaxation by making individual adjustments to find out what works best for you.

Group exercise: Relaxation at Rest

First, lead the participants through the *Body Awareness Exercise* (see Session 2; Appendix B).

Next, lead participants through the *Relaxation at Rest* exercise (Appendix B). This exercise has three parts: progressive muscle relaxation, relaxed breathing, and visual imagery. The whole exercise takes about 20 minutes.

Finally, complete the *Body Awareness Exercise* again.

When you are finished, ask participants to describe their experiences, especially any problems they encountered during the exercise.

Homework assignment: Relaxation at Rest

Participants practice the *Relaxation at Rest* exercise at home. If possible, they should practice once a day, but at least 2-3 times per week.

Hand out the sheet *Tips for Learning to Relax* to use as a guide. Review the handout with participants and answer any questions. It may be useful to discuss ideas about when, where, and how often they would like to practice.

As with the *Body Awareness Exercise*, participants may want to use a recording of the relaxation exercises. You can make a recording, hand out a script for them to make their own recording at home, or allow participants to record this part of the session. Eventually they may prefer to practice without external instructions.

Homework assignment: Stress Journal

Participants continue keeping the *Stress Journal*.

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

Stress Session 5: Relaxation in Stressful Situations

Overview of session
Discussion of homework: • Relaxation at rest
Information: • Using relaxation techniques in stressful situations
Group exercise: • Brief relaxation techniques • Using brief relaxation in an imagined stressful situation
Homework assignments: • Relaxation practice • Stress Journal
Handout: • Session 5 Summary Sheet

Discussion of homework

Discuss participants' experiences practicing relaxation techniques. Ask participants to take turns describing the relaxation techniques they tried, and the successes and difficulties they encountered. Address the following issues:

1. What difficulties did they have? Examples of issues participants might share are:
    - I found it difficult to relax, even though I practiced regularly.
    - The relaxation exercise was boring—I prefer to listen to music.
    - I can relax better while watching TV.
    - I was not able to practice daily, because I often had something else on my mind.
2. Which methods were most effective for each of them? Encourage participants to individualize the techniques to find out what increases their feelings of relaxation and well-being.
3. Did they use a recording?
4. Where did participants practice the techniques? Encourage them to try out a wide variety of settings. Provide examples as needed, such as:
    - A living room chair
    - On a park bench
    - In the doctor's office
5. What times of day did they practice, and what times worked best?

Suggest trying the techniques at different times, such as right after waking, after lunch, or before going to bed. Remind participants to integrate relaxation practice into their daily life and habits, as consistent practice is needed to reap full benefits.

Information: Using relaxation techniques in stressful situations

Participants will next learn brief relaxation techniques that can be used in stressful situations. These techniques with eventually be combined with cognitive strategies, which will be introduced later in the program. Say:

> *Teaching your body how to relax will increase your overall ability to handle stress and will build resilience after experiencing challenges. But sometimes you need a quicker way to calm down, for example at the moment when you're confronted with a stressful situation. In that case, you can use shorter versions of the relaxation techniques you have already learned.*
>
> *The key is to modify each technique in a way that is easy for you to use, and effective in particular "emergency" situations. By practicing these techniques in advance, you will be able to use them quickly when you need them.*

Group exercise: Brief relaxation techniques

Introduce brief relaxation techniques. Say:

> *For this exercise, we will discuss how to modify each of the relaxation techniques to make them quicker and easier to use, and then practice using them in an imagined stressful situation.*
>
> *Let's first look at different ways you could modify the techniques.*
>
> *For muscle relaxation, you can combine muscle groups, as follows* (demonstrate and ask participants to try)*:*
>
> - *Hands and arms: Clench both hands into fists and at the same time, bend your arms to tense your biceps.*
> - *Face and neck: Squint your eyes and at the same time, clench your teeth and tense the muscles of your neck.*
> - *Shoulders and abdomen: Pull your shoulders up in a shrug, and at the same time, tense your abdominal muscles by making your stomach hard, like bracing for a punch.*
> - *Legs and feet: Tense the muscles of your thighs and buttocks by pressing your knees together. At the same time, keeping your heels are the floor, pull your feet upward and tense your calves.*
>
> *To relax even more quickly, you can then pick just one of these combinations to tense and relax.*

Ask participants to try; get feedback. Then say:

> *For the breathing technique: You could do just one or two slow breath cycles. Calm your breathing by inhaling slowly, holding your breath for a moment, and then breathing slowly out.*

Ask participants to try; get feedback. Then say:

> *To use visual imagery: link a state of relaxation to a specific peaceful image in your mind. Try to conjure up the image as soon as you feel relaxed. Eventually, the image alone can trigger a state of relaxation. When you are feeling stressed, quickly "recall" this image.*

Ask participants to try; get feedback. Then say:

> *It is usually best to try just one of these strategies at a time, at least to begin with, to be able to judge what works best.*

Group exercise: Brief relaxation in an imagined stressful situation

In this exercise, participants practice using these techniques while imagining a stressful situation.

Ask participants for examples of stressful situations and pick one example to use in the exercise that could be applicable to all participants. If needed or to save time, you can instead provide an example (e.g., paying in a checkout line, with a line of customers behind you).

Ask each participant to choose one of the three brief methods to try, and to describe to the group which one they have picked. Then say:

> *We will now begin the exercise. Close your eyes and imagine that you are now in [the stressful situation chosen by the group]. Try to picture it as clearly as you can. Go ahead and picture it now.*

Pause for everyone to imagine the stressful situation. Then say:

> *While still imagining that you are in [the stressful situation], I would like you to try using the technique you have chosen. Take your time, and when you are finished, open your eyes again.*

Pause for everyone to finish. Ask participants to describe their experience, including any problems they encountered during the exercise.

Homework assignment: Relaxation practice

At home, participants practice relaxation exercises daily, both at rest and while imagining a stressful situation. Emphasize that they should try to identify which techniques are most helpful for them. They can refer to *Tips for Learning to Relax* from the previous session.

Encourage them to find a regular time schedule (e.g., 10 minutes in the afternoon), in a quiet place.

In addition, encourage participants to try brief techniques in real-life stressful situations; this practice can be at different times and places, rather than on a specific schedule. They can ask themselves: were the techniques helpful? Do some techniques work better in some situations than in others?

Homework assignment: Stress Journal

Participants continue keeping the *Stress Journal.*

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

Cognitive Therapy: Overview (for Stress Sessions 6-8)

Changing negative thought patterns through cognitive therapy can enhance stress management in everyday life and improve attitudes towards the disease. Cognitive therapy allows participants to test the reality of their assumptions (especially with regard to negative evaluations by others), to examine how they assign causes to events, to search for alternative explanations, and to de-catastrophize fears (see Beck, 1993, for a review).

We use the method and techniques of "self-instructional training," a form of cognitive therapy that can be used to help gain control in stressful situations (Meichenbaum, 1985).

The starting point in Session 6 is to examine automatic thought processes and evaluations, which are often apparent in participants' stress journals. Specifically, participants learn to identify the role of thoughts in the "stress cycles" that were described in Session 3, and to replace stress-increasing thoughts with stress-reducing thoughts. They then incorporate positive self-talk with relaxation techniques. In Session 7, participants learn how their general attitudes toward PD can affect their stress response. In Session 8, they learn to distinguish between problem-oriented coping and emotion-oriented coping.

Changing maladaptive thoughts can occur at any phase of a potentially stressful event. Meichenbaum (1985) identifies four such phases:

1. Preparing for the stressful situation
2. Confronting the stressful situation
3. Observing and coping with one's reaction to the stressor
4. Self-reflection, including self-reinforcement, even if things do not go well

Cognitive methods are most useful when there is an obvious discrepancy between a person's perspective and reality, resulting in negative consequences such as avoidance of activities that they previously enjoyed (e.g., the person no longer eats in restaurants for fear of what other people might think).

The overall aim of these sessions is to enable participants to break maladaptive chain reactions between thoughts, feelings, physical reactions, and PD symptoms.

Stress Session 6: Self-instruction

Overview of session
Discussion of homework: • Relaxation practice
Information: • Self-talk and self-instructional training • Combining self-instruction with relaxation techniques
Group exercise: • Self-instruction before, during, and after stressful events • Self-instruction and relaxation while re-imagining the past
Homework assignments: • Self-instruction and relaxation in stressful situations • Stress Journal
Handout: • Session 6 Summary Sheet

Discussion of homework

Ask each participant to describe their experiences using brief relaxation techniques. Who tried to use the techniques in a stressful situation, and how did they work?

Information: Self-talk and self-instructional training

In this session, participants will learn the method and technique of self-instructional training (Meichenbaum, 1985): how to identify stress-inducing thoughts and replace them with more adaptive thoughts. Say:

> *Self-talk refers to our "inner dialogue"—we literally talk to ourselves in our thoughts. This running commentary influences our behavior. For example, when you are faced with tackling a difficult task, you might say: "This task is impossible. I have no idea how I'm going to deal with it. I know I'm going to fail." We can consider these thoughts "negative" self-talk because they increase your stress level and don't help you deal with*

the situation at hand. Negative thoughts may have served a purpose in the past, or may even make you feel better momentarily, but they reduce your ability to act now.

You can instead replace those thoughts with "positive" self-talk. This technique of identifying your current thoughts, and then changing negative thoughts into positive self-talk, is called "self-instructional training."

For example, instead of thinking that a task is impossible and you will fail, you could think: "This task is hard, so I'm going to take a moment to calm down and think about the best way to approach it." Positive self-talk is not the same as positive thinking, where you are telling yourself everything will be fine; instead, it is telling yourself that you will be able to do something to deal with the situation.

It can be difficult at first to recognize and change your thoughts because they seem to happen automatically, but you can learn to do it with practice.

Discuss examples of negative and positive self-talk in Table 6.3 (or use your own examples; write on flip chart).

Table 6.3. Negative vs. positive self talk

Negative self-talk	Positive self-talk
Everything I try to do goes wrong.	I will first take a moment to think about my options.
It's not worth it to even try.	Even if I make mistakes or things don't work out, I will have achieved something by trying.
Everyone can see that I'm just a wreck.	I will focus on what I am doing and not worry about what others are doing.
I'm too exhausted to do anything.	I can relax, take a few breaths.
These thoughts and feelings just keep flooding my mind and it's impossible to change that.	It is normal to have some worries and I will move ahead anyway.
If I can't do even this, how can I do anything?	I will take one step at a time.
The future is hopeless.	I will look for the positive and not jump to conclusions.

There are several specific strategies you can use to change your thoughts, which we can examine with a case study.

Go through Case Study.

Case Study: Eating in a restaurant

Mrs. L is a woman with tremor. She is trying to eat in a restaurant. She thinks:

- "If I shake again, all of the other guests will look at me."
- "Those two people over there are already looking at me."
- "They probably think I'm mentally ill."

Say:

Some strategies Mrs. L could use to change her maladaptive thoughts include (write on flip chart):

- *Cognitive reframing. This strategy refers to changing the way you view the situation—you change your perspective. In our example, instead of thinking that all the guests will look at her if she shakes, Mrs. L could tell herself: "Watching me eat is actually not all that interesting."*
- *Possible alternative explanations. With this strategy, you question whether your explanation for what you observe is correct. Instead of thinking that other people are already looking at her, Mrs. L could tell herself: "Those people may be trying to see where their server is."*
- *De-catastrophizing. Ask yourself: What is the worst that could happen in this situation? In the case of Mrs. L, instead of worrying about what other people think of her, she could tell herself: "Even if some people think I'm crazy, so what? I will enjoy my food."*

Using these same kinds of strategies, you can change your self-talk to allow yourself to act more effectively in stressful situations.

In addition, you may have different thoughts depending on when they occur in relation to a stressful event:

- *Preparing for the event*
- *At the moment when you first confront the situation*
- *During the event*
- *Afterwards*

You can change your thoughts during any of these phases.

Group exercise: Self-instruction before, during, and after stressful situations

Work through the following scenario or use one of your own, asking participants for examples of negative and positive thoughts for each phase, and/or using the examples provided.

Scenario: You need to buy stamps at the post office. What negative thoughts might you have during each phase, and how could you replace them with positive thoughts?

1. Preparing for the stressful situation: you are thinking about what will happen when you get to the post office.
    - An example of a negative thought: “I am going to get to the counter and be shaking or unable to move and be so embarrassed!”
    - An example of a positive thought: “I will deal with the situation when it’s time. Right now, I can prepare—I can make sure that I have my money and know what I need to buy.”
2. Confronting the stressful situation: you are in line at the post office, and it’s almost your turn at the counter. You observe that there are many people in line behind you, and that the number is increasing.
    - An example of a negative thought: “I better be fast! These people are all looking at me and are going to be so annoyed with me if I am slow.”
    - An example of a positive thought: “I will focus on one step at a time, and take the time I need. The others are all just waiting in line like I am.”
3. Observing and coping with your reaction to the stressor: As you are paying for the stamps, your hand shakes as you try to take out your money, and you drop some coins on the ground.
    - An example of a negative thought: “What a disaster! I knew this would happen. Why do I even try—I need to just go home and forget about the stamps.”
    - An example of a positive thought: “I am doing my best and will continue to focus on buying the stamps. I can ask for help if I need it—that’s a good thing about having other people here in line with me!”
4. Self-reflection: After you buy or tried to buy stamps, you think about how the episode went. Self-reflection can include self-reinforcement, even if things did not go well.
    - An example of a negative thought: “I was a fool to leave the house. Now everyone knows I can’t even do something as simple as buying stamps.”
    - An example of a positive thought: “I did my best and can learn from it. Next time I will go to the post office when it’s less crowded if I can. But it’s good that I got out of the house and tried—and the post office is there to serve everyone, including me! Most people will be kind if I give them a chance. And for the others, who cares?”

After working through the scenario, say:

> *The key during all phases is to identify which types of thoughts increase your stress reaction, and which thoughts reduce your stress reaction and enable you to function better. Think about what words have the most meaning for you in a particular stressful situation, rather than just using stock phrases.*

If time allows, ask a participant to share a stressful situation. Together with the group, help the person to describe the situation and to identify the different components of their reaction, including thoughts, physical reactions, behaviors, and feelings. Examine when they occur (before, during or after the stressful event). Pay particular attention to their “inner dialogue” in the stressful situation.

Discuss what types of self-instruction might have been helpful in this situation. Solicit ideas and write them down on the flip chart. Ask the participant whose stress reactions are being examined to judge which of the phrases seem most helpful to them.

Information: Combining self-instruction with relaxation techniques

Participants next learn how to combine relaxation techniques with self-talk to improve stress management. Say:

> *In previous sessions, you learned to use relaxation techniques to break out of a negative stress cycle. You can now combine self-talk with brief relaxation techniques to help you deal with stress in the moment.*
>
> *This combination of techniques can be used in different orders and in different situations. For example, you could:*
>
> - *Tell yourself that you are doing your best, and that you will take a deep breath to give you strength, and then breathe deeply.*
> - *Visualize a calming image, and remind yourself that you are in control.*
> - *Contract and relax the muscles of your arms and hands, take a deep breath, and tell yourself that you can focus on one step at a time.*
>
> *The key is to learn which strategies work best for you, and to practice.*

Group exercise: Self-instruction and relaxation while re-imagining the past

In these exercises, participants practice applying self-instruction and relaxation techniques as they imagine themselves in a past stressful situation. Say:

> *Like everything you are learning, it is easier to implement these techniques in stressful situations if you have practiced them in advance. One way to practice is to imagine yourself being back in a situation from your past, and to picture yourself handling the stress. The more you practice—even through imagination—the easier it will be to use the techniques in stressful situations.*
>
> *First, think of a stressful situation, perhaps one from your stress journal. The more vividly you can imagine the situation, the more easily you will be able recognize some of the thoughts and feelings you were having at that time.*

Ask for a volunteer to share this past event with the group, and then proceed by asking the participant:

- *What thoughts were going through your mind as you were dealing with the situation? Which were positive self-talk, and which were negative self-talk?*
- *What feelings did you have? Did you feel stressed out, or energized, or relaxed?*

- *What did you do that was helpful? What could you have done differently?*

  Now imagine yourself changing the situation, as if you are watching yourself on film but handling the situation better, with the help of positive self-talk, brief relaxation techniques, or both.

Ask other group members to provide feedback. As time allows, others can share their examples.

Homework assignment: Self-instruction and relaxation in stressful situations

Participants practice the self-instruction and relaxation exercises at home, by re-imagining past stressful situations. Encourage participants to try these techniques in real-life stressful situations they encounter during the week.

Homework assignment: Stress Journal

Participants continue keeping the *Stress Journal.*

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

Stress Session 7: Changing Attitudes about PD

Overview of session
Discussion of homework: • Self-instruction and relaxation in stressful situations
Information: • Attitudes about disease
Group exercise: • Observing and changing attitudes in stressful situations
Homework assignments: • Observing and changing attitudes • Stress Journal
Handouts: • Session 7 Summary Sheet • Homework sheet: Observing and Changing Attitudes

Discussion of homework

Ask each participant to describe their experience using self-instruction and relaxation techniques both while re-imagining past stressful situations, and in real-life encounters. What types of stressful situations did they experience? Which techniques helped, and which didn't work as well?

Information: Attitudes about disease

Describe how thoughts become attitudes. Say:

> *We have already learned about how thoughts, feelings, and behaviors can influence each other to create a negative or positive stress cycle* (Session 3). *We will now look at how those thoughts can become general assumptions, or "attitudes" that a person might then hold across situations.*

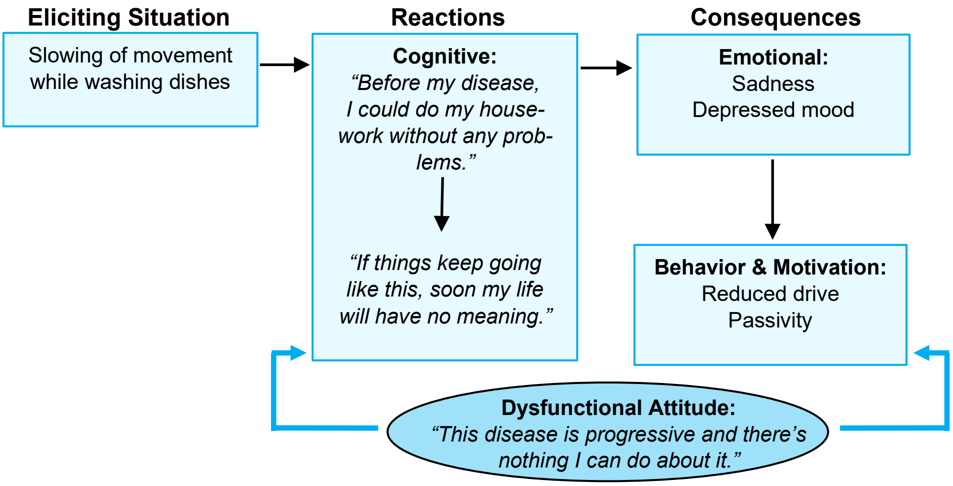
Describe the case of Mrs. R.

Case Study: Household tasks

Mrs. R has taken care of her family and household for many years, and was diagnosed with PD about five years ago. One evening while washing the dishes, she notes that she is feeling weaker, and that her movements are slower.

Mrs. R thinks: “Before I had PD, I could wash the dishes without any problems. I'm just not what I used to be.” She starts feeling sad and hopeless, and thinks, “I can't do anything to keep this disease from getting worse. My life is becoming meaningless.” Her feelings of sadness increase, and she stops washing the dishes. As the days go on, she continues to assume that her situation is hopeless and that there is nothing she can do to make things better. She feels that she will be more and more dependent on others and has lost her motivation.

Figure 6.2. Negative Thoughts and Feelings of a Woman with PD Doing Household Tasks



Draw Figure 6.2 on the flip chart, and say:

> *We can see that Mrs. R's thoughts and feelings as she is washing dishes build on each other, escalating to the point that her attitude is one of hopelessness. While understandable, Mrs. R's attitude is unhelpful to her. Believing that her life is becoming meaningless led her to stop trying to wash the dishes, and has decreased her motivation to do things for herself in the future.*

Some other examples of attitudes towards PD that are unhelpful are:

- *Because of my illness I am nothing more than a burden to others.*
- *I understand why nobody would want me around anymore because of my illness.*
- *My stress is going to make my PD progress even faster.*
- *PD is a punishment I don't deserve.*

However, it is possible to change your attitude about living with PD, by increasing the types of thoughts that enable you to function better.

Some examples of helpful attitudes are:

- *I may need help, but I can also help others.*
- *I am more than my illness.*
- *My life is worth living, despite the illness.*
- *The better I can handle stress, the more comfortable I will feel.*
- *Even if the illness limits what I can do, I will always find things I can enjoy.*

Attitudes can influence your feelings and behaviors across a wide range of situations (write examples on flip chart):

Table 6.4. Examples of helpful and unhelpful attitudes

	Attitude		**Feelings**		**Behaviors**
Example 1	I can no longer lead a life worth living.	→	Sadness	→	Passivity, fewer activities with little enjoyment
Example 2	PD has made me less lovable.	→	Unworthy	→	Social withdrawal
Example 3	I'm still here, I'm still me!	→	Courage, confidence	→	Engaging in activities that are still possible

There is no one "right" attitude, just as there is no one "right" behavior or solution that fits everyone all the time. However, you can observe whether a particular attitude is increasing your stress, and keeping you from pursuing your goals. You can then learn to change your attitude, just as you learned to change your thoughts in specific situations.

Some "warning signals" of unhelpful attitudes are the following:

1. *Self-deprecation:*
    - *"I can't do anything anymore anyway."*
    - *"I'm just a loser."*

2. *All-or-nothing beliefs:*
    - *"I can't even hold my spoon this morning—there goes my ability to ever feed myself again."*
3. *Resignation:*
    - *"These days, you can't expect other people to make time for you."*
    - *"Might as well realize that there's nothing I can do about PD. "*
4. *Unrealistic expectations:*
    - *"I have to be able to do everything perfectly, just like before."*
    - *"Anything is possible if you just try hard enough."*

Group exercise: Observing and changing attitudes in stressful situations

In this exercise, participants learn a procedure for changing unhelpful attitudes, and practice using the sheet *Observing and Changing Attitudes about PD.*

Hand out a copy of the sheet to each participant to go through in the session. They will then continue working on the sheet as homework. Say:

> *As we have seen, unhelpful attitudes about PD can increase your stress and decrease your ability to function. The first step is to identify the attitudes you hold. Just like with more specific thoughts, attitudes can be difficult to recognize, because they often seem to appear automatically.*
>
> *We will do an exercise to identify attitudes that is similar to the one we did before: re-imagining an event from the past.*
>
> *First, think back on a stressful event that you recently experienced, picturing it as vividly as you can, and try to remember the thoughts you were having.*
>
> - *For Mrs. R, the event was washing dishes, and her attitude was that PD was making her life meaningless.*
>
> *Next, think about what happened—did you achieve your desired outcome?*
>
> - *Mrs. R felt sad and stopped washing the dishes.*
>
> *You can then decide whether the attitude was helpful or unhelpful—did it empower you, or bring you down?*
>
> - *In Mrs. R's case, it was unhelpful because she then stopped washing dishes, and felt less motivated to keep trying in the future.*
>
> *Finally, think about alternatives to unhelpful attitudes.*
>
> - *Mrs. R could replace her attitude with a more positive one, such as "PD may have slowed me down, but it won't stop me!"*

Event/Situation	Attitude	Outcome	Helpful or unhelpful?	Alternative helpful attitude
Example: Washing dishes	PD is making my life meaningless and there's nothing I can do about it	I felt sad. I stopped washing the dishes.	Unhelpful	PD may have slowed me down, but it won't stop me!

Ask participants to think about a recent stressful event, and then ask for a volunteer to describe their event or situation. Demonstrate how to complete each column by writing their answers on the flip chart. As time allows, ask other participants to do the same.

If desired, the group can do a role-play to re-enact a participant's stressful situation involving interpersonal interactions. The participant describes the situation, and other group members take the role(s) of other people who were there. The goal is for the participant to relive the experience in a way that will allow them to remember the attitudes or assumptions they had while in that situation.

For this session's homework, participants will write down thoughts and attitudes that occur, using the chart. They can then use these notes as a starting point to change negative thought patterns.

Homework assignment: Observing and changing attitudes

Hand out the assignment sheet *Observing and Changing Attitudes*. Participants continue the exercise at home.

Homework assignment: Stress Journal

Participants continue keeping the *Stress Journal.*

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

Stress Session 8: Coping with Disease

Overview of session
Discussion of homework: • Observing and changing attitudes
Information: • Coping with disease
Group exercise: • Disease management
Homework assignments: • My life with Parkinson's disease • Stress Journal
Handouts: • Session 8 Summary Sheet • Homework sheet: My Life with Parkinson's Disease

Discussion of homework

Discuss participants' homework on observing and changing thoughts and attitudes. Emphasize that negative attitudes do not usually change overnight, but over time. The first step is to be aware of these attitudes, whether positive or negative.

Information: Coping with disease

Describe disease management, different ways of coping, and ways to improve disease management. Say:

> *PD can be physically and emotionally stressful for anyone. Coping with stressors brought on by PD is often called "disease management," and is reflected in your thoughts, attitudes, feelings, and behaviors.*
>
> *People have different ways of coping with the disease. We can distinguish between problem-oriented coping and emotion-oriented coping.*
>
> - *Problem-oriented coping is when you look at a specific problem and try to figure out what needs to be done to change it. For example, when you first noticed symptoms of PD, you might have gone to the doctor and investigated what treatment*

options were available. You might have tried to figure out techniques to deal with new symptoms. Basically, you try to improve the situation.

- *Emotion-oriented coping is when you try to change the feelings you have in reaction to the problem. For example, when you found out you had PD, you might have tried to calm yourself down by relaxing, or learned to accept your illness over time. If emotion-oriented coping is successful, you will have an increase in your feelings of well-being, even if the external situation doesn't improve.*

There is no single way of coping that is best for every person in every situation. The key is to discover different strategies and try them out. You may find that some of the same strategies are effective for you across different situations.

Ask yourself: what thoughts, feelings and behaviors are beneficial, whether that is by improving the situation, or increasing my feelings of well-being? Conversely, what reactions make the situation worse or decrease my sense of well-being?

Group exercise: Disease management

The aim of this exercise is to identify and describe different ways of coping. Start with a specific problem situation from one of the group members, and then examine possible coping strategies. Try to identify whether the primary goal of the coping strategy is more problem-oriented or emotion-oriented. Two alternative ways of doing this exercise are:

Questioning one participant in the group: After the focus participant describes a problem situation, the therapist and/or the entire group asks questions about the situation, the coping strategies the person used, and alternative possible coping strategies, for about 15-20 minutes. Following the discussion, each participant provides feedback about the coping strategies presented, and how they might or might not be useful for their own stressful situations.

Group role-play of a problem situation: The essential characteristics of the problem situation can be simulated by the group in a role-play. The focus participant describes the problem. Other group members each represent specific techniques and make their case for why they should be used. For example, one person could represent an emotion-oriented strategy such as relaxation, and argue that they are best suited to help because they will allow the person to feel better about what is happening. Another person could play a problem-oriented solution and make the case that they would be best at actually changing the problem. A third person could represent a different problem-oriented solution. If desired, unhelpful behaviors and attitudes can also be role-played, to examine what effects they would have compared with more helpful ones.

Homework assignment: My life with Parkinson's disease

Participants' homework is to complete the handout *My Life with Parkinson's Disease* to describe how they think about PD. Emphasize that they should think about what role the disease plays for them in their lives. Ask them to picture moments when they were not thinking about PD. By remembering these moments, they may discover new ways of coping with the disease, and a motto for living with PD.

Homework assignment: Stress Journal

Participants continue keeping the *Stress Journal*.

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

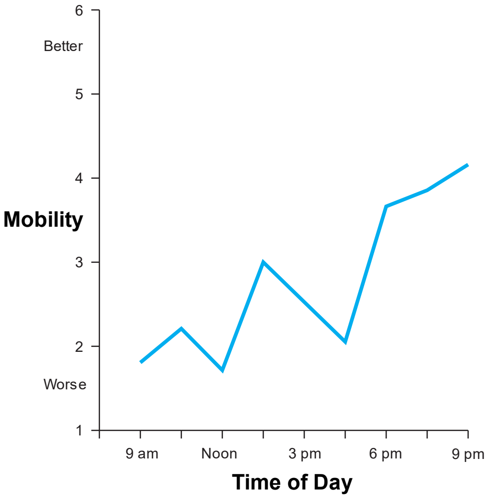
Activity Planning and Pleasant Activities: Overview (for Stress Sessions 9 & 10)

People with PD often have difficulty maintaining an optimal level of activity. In the Stress Program, two interventions target this issue: planning activities to deal with symptom fluctuations, and increasing pleasant activities.

Planning activities can help prevent or reduce stress in daily life, and increase feelings of control. People with PD learn to prioritize and adjust their activities to deal with changes in symptoms over the course of the day, which for many people can include reduced mobility as well as unpredictable on and off phases. These symptom fluctuations can be caused by a variety of factors, including medications wearing off, stress, and fatigue.

Figure 6.3 shows the self-assessment of mobility of a 78-year-old man with PD.

Figure 6.3. Example of Structured Self-Observation of Mobility



Psychological stress can often be reduced considerably if strenuous activities are carried out during periods of the day when the person has better mobility. Periods of less mobility can be used instead for rest, relaxation, or less strenuous activities. Planning more strenuous activities during periods of greater energy or alertness can be helpful even for people who do not have pronounced variability in PD symptoms.

Participants will use structured self-observation sheets to record periodic fluctuations of both mobility and stress, and/or fluctuations in energy levels and alertness.

Increasing activities, particularly pleasant activities, can help prevent or reduce depressive moods. First, participants identify suitable activities that are positively reinforcing, which can be with the aid of lists of pleasant events and activities (e.g., Pleasant Events Schedule; MacPhillamy & Lewinsohn, 1982; or see Smith-Pasqualini & Simons, 2006, p. 85-

86). Second, participants practice the selected activities. The therapist works with each participant to determine the number, duration, and scheduling of pleasant activities to be carried out during the week.

The overall aim of both goals is to increase feelings of self-control and well-being.

Stress Session 9: Activity Planning

Overview of session
Discussion of homework: • My life with Parkinson's disease
Information: • Activity planning
Group exercise: • Activity planning
Homework assignments: • Activity planning • Bring something pleasant • Stress Journal
Handouts: • Session 9 Summary Sheet • Homework sheet: Activity Planning

Discussion of homework

Discuss participants' perceptions about the role PD plays in their lives, including times when they did not think about PD. Have they found a motto for living with PD?

Information: Activity planning

Explain the advantage of changing behaviors directly. Say:

> *As we have already discussed, you can improve how you manage PD by changing thoughts, attitudes, feelings, or behaviors. A change in any of these components can lead to changes in the others. The most direct route, however, is to change behaviors.*
>
> *To use a previous example: you may feel that it is no longer possible for you to have fun because of your PD; this attitude leads to feelings of sadness, and you engage in fewer activities. Changing your attitude may affect your feelings and lead to an increase in your behaviors. An alternative approach is to target your behaviors directly, increasing your activities by actively seeking pleasant experiences. You may then find that your attitude toward living with PD changes, and your mood improves.*

However, PD symptoms can make it more challenging to increase activities. Therefore, our first step will be to develop an activity plan.

Explain the rationale and goals of activity planning. Say:

The main reason for developing an activity plan is to structure the day so that your activities are better aligned with your goals, abilities and energy levels at different times of day—not to try to plan every minute of the day. Specifically:

- *You may be able to prevent situations that are likely to be highly stressful.*
- *You can identify your highest priority items, giving you a greater sense of achievement and control, with less stress.*
- *You will have more time for enjoyable activities.*

The steps for planning activities are:

1. *Make a realistic set of activities, aligned with your goals, which may have changed since your diagnosis. It is important to take into account the variability of your PD symptoms throughout the day.*
2. *Make a list of the things you want or need to do in a certain period of time (e.g., a day or a week).*
3. *Indicate the tasks that are highest priority.*
4. *Examine your plan: is it achievable? Build in flexibility.*

Group exercise: Activity planning

Ask participants about times when they had difficulty completing all the activities they wanted or needed to do, and write examples on the flip chart. Discuss factors that may have contributed to their difficulties (e.g., symptom fluctuations, overestimation of energy levels/strength, trying to do too much, trying to live up to others' expectations).

Next, ask a participant to describe their daily routine. Write it on the flip chart, and discuss questions such as the following:

- Does the type and total number of activities during the day seem appropriate?
- Does the plan take into account the person's typical daily fluctuations in symptoms and/or energy levels?
- Are there sufficient breaks between activities?
- Could the activities be distributed better throughout the day?
- Are pleasant activities included? Is there enough variety in pleasant activities?
- Are there any tasks that could be performed by other people, e.g., partner, other relatives, or professional helpers?

Homework assignment: Activity planning

Go through the homework sheet *Activity Planning*, which includes making a list of priorities and identifying times during the day/week to engage in those activities. Encourage participants to build flexibility into the plan. (Note that if participants do not have a good idea about how their motor symptoms and/or energy levels fluctuate throughout the day, they may first need to track these levels for several days to identify if there is a pattern.)

Homework assignment: Bring something pleasant

Ask each participant to bring to the next group session at least one object that they find pleasant, invigorating, or relaxing (e.g., a photo, a flower, a ring). Participants can instead, or additionally, "bring" and describe pleasant feelings, fantasies, images, or memories that are particularly important to them.

Homework assignment: Stress Journal

Participants continue keeping the *Stress Journal*. If they succeed in incorporating pleasant activities into their daily life, they can note these in the journal.

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

Stress Session 10: Pleasant Activities

Overview of session
Discussion of homework: • Activity planning • Bring something pleasant
Information: • Increasing pleasant activities
Group exercise: • Engaging in pleasant activities
Homework assignments: • Have some fun! • Stress Journal
Handout: • Session 10 Summary Sheet

Discussion of homework

Discuss how well participants were able to prioritize and plan activities, and whether planning helped to reduce stress. Ask whether any participants felt that the activity plans were not useful, and if so, why not. When this occurs, it is often because people feel that they "have nothing to do anyway" or because they cannot do what they would like to do because of their illness.

Note that participants will be asked later in the session to describe the pleasant "object" they brought to the session.

Information: Increasing pleasant activities

Describe pleasant activities (see Csikszentmihalyi, 1990). Say:

> *Pleasant activities are associated with the experience of pleasure, joy, and a good mood—in other words, with positive feelings. These are usually activities that people engage in for their own sake rather than because they are required to.*
>
> *A variety of pleasant activities are often associated with the same types of conditions. Specifically:*

- *Pleasant activities are often linked to goals.*
- *A person experiencing a pleasant activity may feel fully focused, "absorbed" in the activity.*
- *Pleasant activities are often accompanied by a broadening of the senses. We may experience everyday stimuli differently than normal. For example, according to* Csikszentmihayli (1990, p. 213): *"Feeling a breeze on a hot day, seeing a cloud reflected on the glass facade of a high-rise, working on a business deal, watching a child play with a puppy, drinking a glass of water can all be felt as deeply satisfying experiences that enrich one's life."*

Pleasant activities are important because they make our lives more intense, rich, and meaningful. They are part of a happy life. Intentionally engaging in pleasant activities can also help lift feelings of depression.

Pleasant activities are especially important for people with PD because:

- *If you are no longer able to carry out some of your previous activities, it's important to discover new ways of having pleasant experiences.*
- *If you experience negative feelings such as depression, loneliness, or a feeling of loss of control, you could have less interest in engaging in pleasant activities. But intentionally increasing your participation in pleasant activities can improve your quality of life.*

Yet you may feel that you don't have time for pleasant activities because you have so many other things you have to do or because things now take you longer to finish. And even if you do plan something fun, you may feel that you can't really enjoy yourself.

For all these reasons, you may need to deliberately work to increase pleasant activities. Like all behaviors, the ability to plan pleasant activities, and to experience enjoyment, can improve with practice.

Keep the following tips in mind:

- *Take your time.*
- *"Allow" yourself to experience enjoyment; don't let feelings of guilt creep in.*
- *Focus on the activity at hand; concentrate, be absorbed in what you are doing.*
- *Learn what works best for you: get to know what you like best, and what conditions are important for you to experience enjoyment.*
- *Less is more. Too much of a good thing can actually decrease enjoyment.*
- *Enjoyment is not just for special occasions. Pleasant activities are available at almost any time; extraordinary experiences are not necessary.*
- *Practice! Your ability to focus and enjoy activities will increase.*

Discussion of homework/Group exercise: Engaging in pleasant activities

Ask participants to briefly describe the pleasant activity, object, or event they brought with them, and to say why they find it pleasant. Ask questions to clarify and expand the descriptions, and record key features on a flip chart. Then discuss questions such as the following:

- What are ways that people can engage in these activities? For example: Can they be done alone, or in a group? As a one-off activity or as part of a series of activities or training for a larger event? As a challenge or for pure passive enjoyment?
- How can you increase the number of different types of activities you do?
- What pleasant activities can be done often, on a regular basis?

Homework assignment: Have some fun!

Each participant chooses three enjoyable activities that they will engage in during the coming week. The minimum requirement is to carry out one of these activities every day.

Homework assignment: Stress Journal

Participants continue keeping the *Stress Journal*.

Homework assignment: Program review

In preparation for the final session, participants think about their experience of the training program, using the questions on the handout.

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

Stress Session 11: Program Review

In the last group session, review and discuss the main points of the training program.

Overview of session
Discussion of homework: • Have some fun!
Group exercise: • Review of the training program and "pack your bags"
Handout: • Session 11 Summary Sheet

Discussion of homework

Participants discuss their experiences engaging in pleasant activities. What activities did they do? Which could they do regularly? What additional activities could they consider? What obstacles did they face?

Group exercise: Review of the training program and "pack your bags"

For this farewell session, ask each participant to answer the following questions:

- What goals did I achieve?
- How did my achievements compare with my original expectations of the program?
- What are the most important things I learned or experienced during the training program?
- How can I maintain my progress, and apply what I have learned to future situations?
- Which parts of the training, in my view, might be changed or improved in the future?
- What tips and encouragement can I give to others?

The group "packs a suitcase" for each participant's journey through life: each group member "gives" something to every other participant for their journey. Each gift is written onto a suitcase drawn on the flip chart (one participant per page). Say:

> *Each of you will give a gift to every other member, to put in this "suitcase." When deciding on a gift, think about what that person needs for a pleasant and fulfilling journey through life with PD. Take into account:*
>
> - *Difficult, strenuous, and frightening parts of the journey: what would help the person make it through?*

- *Happy, enjoyable, and satisfying parts of the journey: how can the person most fully experience these parts, and increase their frequency?*

One at a time, "pack a suitcase" for each participant. They can each then roll up their sheet to take home to help them on their journey.

As you say farewell, remind participants about individual and/or group booster sessions and assessment (if possible, schedule the booster sessions when participants first enroll in the group).

Stress Program: Booster Session

In a booster session 4 to 8 weeks after training, participants meet again with the therapist and discuss how and in what circumstances they were able to use the skills they acquired during the program. The specific format of the booster session can be modified depending on the needs of the participants.

Discuss questions such as:

- What ideas, techniques, and skills have been helpful?
- What didn't work?
- Are there topics or techniques that it would be helpful to review?
- Are there additional issues that arose? If so, how and where can these needs be addressed?

If desired, you can combine the booster session with repeat assessment.

Chapter 7: Communicating about Parkinson's Disease

The ability to communicate about Parkinson's disease is an important social skill: important not only for people with the disease, but also for their relatives, caregivers, and friends. It enables people with PD to convey to others their own attitude about PD, as well as how they wish others to perceive them and act toward them. Yet in a survey study (Hinrichs, 1992), people with PD reported that they often avoided discussions about the disease. They said that they would "prefer to forget it," lacked the right words, were afraid that others would not understand, and had particular difficulty talking about PD with close relatives. In addition, initiating these conversations requires a form of "social competence" that people with PD may feel they have lost, and can present challenges for which they feel unprepared.

We are often asked by clients: "When should I talk about the disease, and what should I say so that others will understand and support me?" In this training program, people with PD learn to talk to others about the disease across a range of situations. The most important and often most difficult communication is simply to tell another person that they have PD. When people with PD finally do talk about their disease, they are usually glad they did. They may find that their level of stress and emotional burden is reduced, their relationships improve, and they can more easily find external support.

Unlike some conditions, the visible symptoms of PD often provide a starting point for the conversation—for better or worse. Hinrichs (1992) found that the types of physical symptoms the person with PD exhibited affected the reactions of others. Hinrichs' results showed that if stiffness and lack of movement were the predominant symptoms, the conversation partner was more likely to react negatively than if the predominant symptom was tremor—perhaps because many lay people recognize tremor as a symptom of PD, whereas they may not know that akinesia, "freezing," and postural instability are also common. If people with PD are aware of this issue they can be better prepared to deal with potential negative reactions. For example, a client with PD who fell down in public in the morning was accused by a passer-by of being drunk. Learning ways to quickly inform others about the disease may reduce misunderstandings of this sort, and enable others to provide immediate support if needed.

As a first step, people with PD may feel most comfortable talking with others who also have the disease. The vast majority of people with PD benefit from such contacts (Macht & Ellgring, 2003), for several reasons:

- Comparison with others allows a better assessment of their own condition.
- Conversations with other people with PD, unlike contacts with doctors and professional helpers, can yield knowledge based on experience.
- Recognizing that others are dealing with similar problems can help people feel supported.

Case Studies: Talking to other people with PD

Mr. K was not satisfied with his family doctor’s explanation about the disease. Mrs. T, another person with PD who also took part in the training program, could easily relate to his frustration. For her too, many questions had remained unanswered during her doctor's appointments. She had therefore already researched books and patient guides, and was able to recommend resources to Mr. K.

Mrs. S described to other participants her problems while shopping. She became very anxious when trying to pay the cashier, especially when there was a line forming behind her, making it difficult for her to take change from her purse. The other group members were familiar with this problem and proposed solutions:

- Take money out in advance
- Pay by credit card
- Request assistance from others in line
- Shop in stores that are less busy, shop at quieter times, or shop online

Communicating with different types of people and in different settings offers unique opportunities, and can also present specific challenges that require a variety of social skills. Table 7.1 shows examples of problems and solutions that are covered in the program.

Table 7.1. Communicating about Parkinson's disease: Examples of problems and possible solutions

Topic	Problem	Solutions
Communicating with other people who have PD	Gaps in knowledge about PD	Exchanging information and resources
	Difficulty in dealing with the disease	Sharing information about how others cope with disease-related issues
Communicating in public situations	Feeling that others are observing and misinterpreting symptoms	Explaining to others about PD and its symptoms
	Difficulty carrying out everyday activities, e.g., shopping	Asking others for help
	Strangers ask unwanted questions or try to engage in unwanted conversation	Redirecting the topic of conversation, ending the conversation
Communicating with health professionals	Difficulty understanding physicians and other health professionals	Asking questions, asking for technical terms to be explained
	Health professionals misunderstand/ don't ask about important issues	Preparing information prior to appointments, communicating concerns
Communicating with family and friends	Partner/family member misinterprets symptoms or symptom fluctuations	Disclosing PD diagnosis, explaining why symptoms might vary
	Emotional stress on partner	Talking about problems and feelings
	Excessive assistance from family members	Negotiating how to maintain independence

Structure of the Communication Program

The training program consists of 7 group sessions, beginning with an introduction in Session 1, and concluding with a review in Session 7. Sessions 2-6 each include a progress report about the previous session's homework, presentation of new information, group exercises, preparation for new homework, and a feedback round about the session.

Table 7.2 provides an overview of the group sessions. This order is based on level of difficulty. In our experience, participants find it easier to first work on communicating with other people who also have PD, and in public situations. Later, when they know each other better, problems communicating with family and friends can be dealt with more easily. However, the sequence can be adjusted as needed.

Table 7.2. Communicating about PD: Components at a glance

Session	Information	Group Exercises	Homework
1. Introduction	• Overview • Communicating about PD • Problems and solutions	• Getting acquainted	• Introductory questions
2. Talking about PD	• Self-observation • Setting goals with a Goal Staircase	• Self-observation of communication • Setting goals	• Communication Journal[1] • Setting goals
3. Social competence/Talking with a PD colleague	• Social competence • Be an active listener	• Talking about PD/ Listening to a PD colleague	• Conversation with a PD colleague • Communicating in public situations
4. Communicating in public situations	• Confidence and chain reactions • Asking for help in a public situation	• Asking another person for help • Telling someone about your disease • A stranger asks about your symptoms	• Communicating in public situations • Communicating with health professionals
5. Communicating with health professionals	• Communicating with health professionals	• Talking with a health professional	• An appointment with a health professional • Communicating with family and friends
6. Communicating with family and friends	• Effects of PD on close relationships • Improving communication with family and friends	• Talking with a family member or friend about PD	• Talking with a family member or friend about PD • Program review
7. Program review		• Review of training and "pack your bags"	

[1] Participants keep the Communication Journal during the entire training program.

Communication Session 1: Introduction to the Program

Overview of session
Information: • Overview of program • Communicating about Parkinson's disease • Problems and solutions
Group exercise: • Getting acquainted
Homework assignment: • Introductory questions
Handouts: • Overview and Schedule • Communication Session 1 Summary Sheet

Information: Overview of program

Hand out the *Overview and Schedule* sheet (or give to participants during the introductory meeting). Describe the program by carefully going through each point on the sheet and answering questions.

Group exercise: Getting acquainted

In this exercise, participants get to know each other. The participants interview each other in pairs. These interviews work better if participants are paired with someone they don't know well. For odd-numbered groups, you can take on the role of an interview partner. If desired, you can provide paper and pens for participants who would like to take notes about their partner; note, however, that many people with PD have difficulty with handwriting.

In the first round, one member of each pair asks their partner about themselves, which might include questions such as the following:

- Name, age, living situation
- Duration of PD
- How has PD changed your life?
- How has PD changed the lives of people close to you?
- Has PD affected your ability to communicate?
- Who in your life knows that you have been diagnosed with PD?

In the second round, the partners swap roles.

In the last part of the exercise, everyone takes turns reporting the results of their interviews to the group. Write selected comments on the flip chart to highlight important points.

This exercise will usually take about 30 minutes. If time remains, discuss how information from the interviews is linked to what they will be learning in subsequent sessions, such as how they can talk about their disease to different types of people.

An alternative to this exercise is for participants to introduce themselves to the group. However, the "interview" tends to promote better communication among the participants.

Information: Communicating about Parkinson's disease

Provide an overview of issues related to communicating about the disease. Say[*]:

> *Parkinson's disease (PD) is a physical disorder that can affect how people think, feel, and behave. Even though PD is not a "mental illness," it can be difficult to talk about.*
>
> *In research studies, people with PD have reported different reasons for not talking about PD. As I go through a list of some of these reasons, think about which are true for you, and which are not* (or ask participants for comments after each item; modified from a survey of people with PD by Hinrichs, 1992).
>
> - *You feel stressed or embarrassed telling other people that you have PD. Although most people have heard of PD, they may have limited or incorrect knowledge about the disease.*
> - *You have difficulty explaining to others about your specific situation (e.g., different symptoms, severity, progression, problem areas) because PD is a complicated disease and can vary greatly between individuals.*
> - *You feel insecure in social interactions because you are experiencing motor symptoms, or fear that the symptoms will start. This insecurity and fear about motor symptoms keeps you from wanting to start a conversation about PD.*
> - *You feel that you can't communicate as well as before because of disease symptoms, such as vocal changes (talking softer or difficulties enunciating), problems joining conversations, problems finding the right words, and reduced facial expressions.*
> - *You would rather not think about the disease, and not telling others is one way to try to put it out of your mind and live "normally."*
> - *You feel that telling other people places a burden on them; you don't want your family and friends to worry about you.*
>
> *However, research also shows that talking about PD can help you cope with the disease—and that's why we are focusing on this issue. We have found that:*

---

[*] Scripts are provided in italics as suggestions for wording of specific content.

- *Most people with PD have had good experiences when it comes to telling other people about their disease.*
- *People with PD who are willing to talk about their disease tend to be less depressed.*
- *If you explain to someone else about the disease, they are more likely to be understanding instead of having a negative reaction.*

Information: Problems and solutions

Present examples of problems and solutions from Table 7.1 and discuss which issues are of the most concern to participants.

Homework assignment: Introductory questions

Hand out the *Session 1 Summary Sheet*, which includes the homework assignment *Introductory Questions* to work on before the next session. This homework has questions about what participants know about PD, how they are dealing with PD, and their expectations of the training program. Point out the importance of thinking about realistic and unrealistic expectations.

We typically do not ask participants to turn in homework sheets, but instead encourage them to bring the sheets back to the next session for discussion. We offer to look over the homework if a participant would like feedback, and to discuss any issues that participants would like to address.

Feedback round

Ask each participant to comment briefly about their experience of the session, giving their personal impressions. Do not allow discussion, in order to encourage participants to speak honestly and openly, and to prevent the session from running overtime.

Participants can address questions such as the following:

- What did I like the most about the session?
- What didn't I like about the session?
- How do I feel now that the session is over?

Communication Session 2: Talking About PD

Overview of session
Discussion of last session's homework: • Introductory Questions
Information: • Self-Observation • Setting goals with a Goal Staircase
Group Exercises: • Self-observation of communication • Setting goals
Homework assignments: • Communication Journal (Self-observation) • Setting goals
Handouts: • Communication Session 2 Summary Sheet • Communication Journal (Self-observation)

Discussion of homework

Participants were asked to complete *Introductory Questions*. When discussing the homework:

- Ask participants if they had any questions or difficulties in completing the homework.
- Distinguish realistic from unrealistic expectations. For example, the expectation of being able to improve their communication with family members is realistic, whereas the wish for everyone to be patient with them when they are out in public, is not.
- Describe how participants will be able to use these expectations to develop specific goals and target behaviors in later sessions. For example, the expectation of being able to communicate better with family and friends can be realized in part by learning how to describe their symptoms to a loved one.

Information: Self-observation

Describe the rationale and techniques of self-observation. Say:

> *The first step for changing behaviors is self-observation. Self-observation refers to paying attention to your thoughts, feelings, and behaviors right at this moment, with a non-judgmental attitude.*
>
> *Self-observation can serve two main purposes: to identify problems, and to see a solution to those problems more easily.*
>
> *To practice self-observation, first select a specific thought, feeling, or behavior as the target of your observation. Once you have identified a target, you can learn to become more aware of when it tends to occur: how often and in what situations.*
>
> - *An example of a thought would be that nobody understands what PD is like for you. You can then seek to identify when and where you tend to have this or similar thoughts.*
> - *An example of a feeling would be feeling uncomfortable about seeing a friend you haven't seen in a long time. You can ask yourself when else you feel this way.*
> - *An example of a behavior would be that you do not speak to others at a social gathering. You can observe whether you tend to speak in other types of gatherings.*
>
> *We don't normally think consciously about most of what we do, so it can sometimes be difficult to recognize and describe these specific behaviors. However, self-observation is a skill that will improve with regular practice. This kind of careful observation may then lead to a solution.*
>
> *Using self-observation does NOT mean that:*
>
> - *You should constantly question yourself and everything you do, which may just make problems worse. Instead, use self-observation in a targeted way, to identify and solve specific problems, as well as to identify strengths.*
> - *You are merely a passive observer. Self-observation helps you deal actively with issues that are important for your quality of life.*
>
> *You may also want to talk with others about your self-observations. Through the sharing of observations, you may gain new perspectives on how your experiences are similar or different to those of others, which may in turn help you to understand yourself better.*

Group exercise: Self-observation of communication

The goal of this exercise is to examine how participants are currently communicating about PD, in a roundtable discussion. Ask each question and give examples or more detailed explanations as needed. On a flip chart, write down/summarize positive and negative experiences that participants have encountered. In particular, note self-observations of thoughts, feelings, and behaviors. Say:

> *Many of you have probably initiated a conversation about your illness with someone at some point. Perhaps you asked for help, or explained to a friend about PD. Think about some of these specific conversations.*

Then ask participants questions such as the following:

- What was the situation?
  - With whom were you speaking? (E.g., stranger, friend, family member, doctor)
  - Why did you want to speak? What was your motivation or intention?
  - What information did you want to convey? How much detail did you want to give?
  - What was the setting? (E.g., speaking on the phone, via text message, in person at a restaurant, in a quiet room)
- Describe the conversation:
  - What did you say—what words did you use?
  - Did you say what you intended to say? Why or why not?
  - How did the person you were talking to react?
  - How did you feel during the conversation?
- What were the results?
  - What did you think and feel immediately after the conversation?
  - What were the longer-term consequences of the conversation?
  - What would you do the same in the future? What would you do differently?
  - Did it change your opinion about whether you should talk about your illness?

If participants are reluctant or unable to provide examples from their own experience, you can refer back to Table 7.1 and ask about specific situations.

Homework assignment: Communication Journal (Self-observation)

Hand out and go over the *Communication Journal*, which provides a daily record of participants' self-observations of their conversations with others about PD. They will keep this journal throughout the training program (make multiple copies if desired, as participants will complete a separate sheet for each day).

Information: Setting goals with a Goal Staircase

In this next component, participants develop individual goals with specific target behaviors. Say:

> *Making changes is easier, more effective, and more rewarding if you set goals. A goal is not an abstract hope or wish, but instead is an outcome that you want to achieve. To do that, you will identify specific, concrete behaviors to change: your target behaviors. These behaviors can include not only actions, but also thoughts that you observe*

you are having. To reach a particular goal, you could have one or more target behaviors.

For example, suppose you have a general goal of being better able to take care of your responsibilities on time. To achieve that goal, you could set two target behaviors: to find someone to help you at home, and to reduce your number of outside commitments. If you achieve your targets—in this case, you find someone to help you, and you reduce your outside commitments from 3 per week to 2—you may accomplish the goal of taking care of your responsibilities on time.

To begin with, it is usually more effective to start with one main goal at a time, and to choose target behaviors that are relatively easy to change.

The steps to setting goals and target behaviors are:

1. *Decide on a goal. Select an important concern or difficulty that you would like to address. A goal can be short-term or long-term. If you have more than one major concern, pick the one that is most important to you in the immediate future.*
2. *Describe at least one specific, concrete behavior that you could change that will contribute to the goal—this is a target behavior. Choose a behavior that you can work on in the coming week.*
3. *Set a reasonable level of achievement for the target behavior. Take into account your current level of that behavior, and what is realistic for you to achieve in the near future.*
4. *If desired, you can create a Goal Staircase for the target behavior using a 4-point scale, as follows:*

Your current situation with regard to the behavior is 0, and your target is +1. If you improve beyond your target, your rating would be +2. If your situation worsens, you would be -1, like this (write on flip chart):

+2: better than expected
+1: TARGET
0: unchanged
-1: worse

Although you will be aiming for your target level, different levels of improvement are possible—the possibility of success is not "all or nothing."

Describe the following example of a Goal Staircase (or use your own example).

Example of a Goal Staircase

A woman with PD has this goal: "I want a better relationship with my partner."
Comments: This is a very general goal. She needs to choose specific target behaviors that will contribute to the overall goal. In order to do that, she identifies aspects of communication that could be improved, such as:

- When I speak, I want to know if my partner can understand what I've said.
- I would like my partner to know that I am listening to their problems too.
- I would like to be able to tell my partner when I can handle a task myself, rather than having them just do it for me.

For any of these aspects, she can define specific behaviors to change. She decides to focus on making sure her partner understands what she is saying, by tracking and increasing the number of days she asks her partner at least once whether he understands her. She builds a Goal Staircase by setting an achievable number of days to ask her partner, and then identifies steps above and below the target. At present, she only occasionally asks her partner this question (perhaps twice per week). Her Goal Staircase could look like this:

Target Behavior: Increase number of days that I ask my partner at least once whether he understood what I was saying

+2: 4 or more days per week
(TARGET) +1: 3 days per week
(unchanged) 0: 2 days per week
-1: <2 days per week

Group exercise: Setting goals with a Goal Staircase

Discuss with the group how each of the following goals could be achieved by identifying target behaviors, and (if desired) by building a *Goal Staircase* for each target behavior. What would be a reasonable target level for each behavior?

- I want my family to understand my situation.
- I don't want others to think badly of me.
- I want to be treated like others in a restaurant.
- I want to be able to ask for help when I need it.
- I want to be able to tell others about my worries.
- I want others to understand how it feels to live with all these symptoms.

If time remains, discuss ideas for participants' individual goals. The following questions may be helpful:

- In which situations do you have difficulties communicating?
- In which situations do you want to talk about the disease?
- What behaviors would you like to change or learn?

- Are you comfortable explaining your disease to different types of audiences (e.g., friends, family, health professionals)?

Homework assignment: Setting goals

Explain to participants that they will practice creating and defining their individual goals and target behaviors as homework. They can choose to use a 4-point *Goal Staircase* or simply describe an overall goal with one or two target behaviors.

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

Communication Session 3: Social Competence / Communicating with a PD Colleague

Overview of session
Discussion of homework: • Communication Journal • Setting goals
Information: • Social competence • Be an active listener
Group exercise: • Talking about PD/Listening to another person who has PD
Homework assignment: • Conversation with another person who has PD • Questions about communicating in public situations
Handout: • Communication Session 3 Summary Sheet

Discussion of homework

Participants were asked to describe their conversations in the *Communication Journal*. What worked well and what did not? Were they surprised by any of the information they gathered?

Setting goals: Ask participants to describe the personal goal and target behavior(s) they have chosen. Are the behaviors specific and easy to assess? If they used a *Goal Staircase*, were they able to identify different levels of success? Did they have any difficulties? Remind participants that they will be able to modify and add to their goals and target behaviors in the coming weeks.

Information: Social competence

Describe social competence. Say:

> *Social competence involves the ability to interact with other people in ways that promote information exchange and mutual understanding. These positive interactions can help build and maintain relationships. But social competence is not a trait that*

you have to be born with—anyone can increase their social competence by practicing certain behaviors.

"Socially competent" behaviors include (write main categories on flip chart):

- *Actively engaging with other people:*
    - *Initiating and maintaining conversations*
    - *Communicating your feelings in a socially appropriate way*
    - *Complimenting and praising others*
    - *Asking for what you need*
    - *Initiating social events*
- *Effectively handling unpleasant social interactions:*
    - *Saying "no" when you are unable or unwilling to do something*
    - *Standing up for yourself* (e.g., preventing others from interrupting you in conversation, requesting/demanding changes if others behave inappropriately)
    - *Ending unwanted phone calls*
    - *Responding effectively to criticism*
    - *Apologizing when appropriate*
- *Responding positively to other people's behaviors:*
    - *Accepting compliments and praise*
    - *Accepting offers to socialize*

Socially competent behavior is different from insecure, unassertive, or aggressive behavior. Examples of insecure/unassertive behavior are:

- *Unclear, vague responses (as opposed to stating clearly what you want or need)*
- *Superfluous, unnecessary explanations and excuses*
- *Apologizing when it is not warranted*
- *Immediately giving in on something even if you are not yet sure you agree*
- *Going along with others when you don't want to*
- *Talking too much*
- *Speaking in a low, timid voice*
- *Avoiding eye contact*

Socially competent behavior is also different from aggressive behavior. Examples of aggressive behavior are:

- *Using threatening or offensive language*
- *Using a loud, aggressive voice, or acting in an uncontrolled manner*
- *Refusing to answer when someone asks a reasonable question*
- *Refusing to make a reasonable compromise*
- *Infringing on others' rights*

(modified from Pfingsten & Hinsch, 1991)

Information: Be an active listener

Describe active listening. Say:

> *When you think about being a socially competent communicator or conversationalist, you may think mostly about being a good speaker. In later sessions we will discuss keys to communication when speaking. But it is equally important to be a good listener when another person is talking. It is not always easy, especially if you are worried about what you will say next.*
>
> *Being a good listener means being an active listener, and there are specific techniques you can use to improve your active listening skills* (write notes on flip chart, and provide examples or ask participants for examples):

- *Maintain appropriate eye contact, and show nonverbally that you are listening* (e.g., head nods).
- *Withhold your own opinion while the other person is speaking.*
- *To make sure you understand the other person correctly, paraphrase: report back to the speaker what they said, in your own words, and ask if that is what they meant.* ("So you're saying that your boss doesn't think you can do your job anymore?")
- *Ask clarifying questions.* ("Did your boss tell you that you must reduce your hours?")
- *Ask open questions: If you are not sure what the person is thinking or feeling, ask them directly what they mean or how they feel.* ("How did you feel about that?")
- *Ask follow-up questions to show interest and to understand the speaker better.* ("What happened after you talked to your boss?")
- *Give positive feedback* (e.g., when they explain something openly and clearly, tell them so).
- *Provide feedback about how the interaction makes you feel.* ("It makes me sad to hear that you were treated that way.")
- *Be honest: If you are unable to engage in a conversation at a particular time, acknowledge those feelings directly.*

Group exercise: Talking about PD/Listening to a PD colleague

Two participants have a short conversation about a disease-related problem, while the other group members observe and give feedback. Choose one participant to be the "Speaker" and the other to be the "Listener." Say:

> *Throughout this program, we will be talking about and practicing specific social competence skills that will help you interact with different people in a variety of settings. The first one will be how to discuss your disease with another person who has PD: a "PD Colleague."*

When you are in the role of the Speaker, talk about an experience you've had, describing your thoughts, feelings, and behaviors as specifically as possible. The more honest and open you are, the better the exercise will be. You can describe any disease-related problem, such as:

- *Problems with handwriting*
- *Worries about being dependent on medication*
- *Stress-induced increases in symptoms*
- *Problems buying clothes*
- *Dealing with unhelpful or unwanted assistance from others*

When you are in the role of the Listener, practice listening actively, keeping in mind the techniques we discussed.

Following the conversation, the Speaker and Listener switch roles. If time allows, each member of the group takes part in a conversation, as both a Speaker and a Listener.

Homework assignment: Conversation with a PD colleague

Participants conduct an interview either with another member of the group (if they are able to) or with a partner/friend. The general topic is "What do you know about PD?" In preparation for the interview, participants think about and write down specific issues they would like to talk about.

Homework assignment: Communicating in public situations

Participants complete the homework sheet *Communicating in Public Situations* to prepare for the next session.

Homework assignment: Communication Journal

Participants continue keeping the *Communication Journal.*

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

Communication Session 4: Communicating in Public Situations

The visibility of physical symptoms can be one of the most difficult aspects of PD to deal with psychologically. People with PD may worry that other people will notice changes such as slowness, shuffling gait, bent posture, trembling hands, quiet speech, and reduced facial expressions and gestures. They may also worry that others will assume that their symptoms are a sign of alcoholism or mental illness. These worries about the visibility of symptoms are typically most pronounced in public settings, such as getting on a bus or buying groceries. Many people with PD feel helpless in such situations, avoiding public settings and thus becoming socially isolated.

Case Studies: Dealing with PD in public

Mrs. E (age 53) has always liked privacy. She feels shy, and finds social events difficult. Ever since she was diagnosed with PD, she has been bothered by the thought that others are noticing the stiffness in her right arm, which is worse when she is in public. In the group, she asks the other participants how noticeable the stiffness in her arm is, and asks for strategies on how to deal with public situations.

Mr. B (age 45) regularly picks up his young daughter from kindergarten. The children must put on their shoes when they get picked up. One day, when his tremor is particularly bad, he has difficulty tying his daughter's shoelaces. He overhears a conversation between his daughter's friend and her mother: "Mom, what's wrong with that man? He's shaking!" The mother replies: "He must not have had a beer yet today—that's what makes him shake." Mr. B decides he needs to talk more about his illness in public. In the group, he describes and reenacts the situation.

Overview of session

Discussion of homework:
- Conversation with a PD colleague
- Communicating in public situations
- Communication Journal

Information:
- Communicating in public situations: Confident behaviors and chain reactions
- Asking another person for help

Group exercise
- Asking another person for help
- Telling someone about your disease
- A stranger asks about your symptoms

Homework assignments:
- Self-observation in public situations
- Communicating with family and friends
- Communication Journal

Handout:
- Communication Session 4 Summary Sheet

Discussion of homework

Conversation with a PD colleague: Participants report back on their discussion with another person with PD. What topics did they discuss? What similarities and differences did they find between themselves and the other person? Which role was easier, Speaker or Listener?

Communicating in public situations: When do participants think it is helpful to talk about PD in public? When is it not helpful?

Information: Confidence and chain reactions

In this session, participants learn to communicate about PD in public situations. They learn about the importance of looking and feeling confident. Say:

> *We will now focus on how best to communicate in public situations. When you are around people in public, you will do better if you look and feel confident, rather than insecure or aggressive.*

Imagine that you are riding in a crowded bus and don't have a seat. You are exhausted and need to sit down. You consider whether to ask someone for a seat.

First, imagine that you do not feel confident in this situation. What thoughts, feelings, and reactions might you have? (Write participant comments on flip chart and/or go through examples from Table 7.3.)

Each component affects the next, creating a chain reaction.

Now imagine instead that you do feel confident in this situation. How are your thoughts, feelings, and reactions different? What does that chain reaction look like? (Write comments and/or examples from Table 7.3 on flip chart.)

Table 7.3. Confidence and chain reactions

	Not Confident	**Confident**
Thoughts	• Nobody is going to want to help me. • I shouldn't have even come out in public; I am a burden.	• I'll ask someone to give me a seat. • The woman behind me looks kind; I'll ask her.
Feelings	• Fear • Sadness • Anger	• Confidence • Determination
Physical reactions	• Tension, heart racing, sweating, increase in PD symptoms	• Energized

Changing how you think about yourself in the situation—such as telling yourself that you are deserving of respect—can change your feelings and reactions, and ultimately how successful you are in communicating to others.

Information: Asking for help in a public situation

Describe issues related to asking for help. Say:

One of the main situations where you may need to communicate in public about PD is when you need help of some sort. There are a variety of factors to think about, such as:

- *What help do I need?*
- *What specifically would I like the helper to do* (e.g., pull me up by the hand)*?*
- *Who is most likely to be able to help me?*
- *What do I need to say or do in order to get help quickly?*

- *Do I need to say that I am sick?*
- *Do I need to give information about my disease?*

When you are asking for help, you will be more likely to be successful if you:

- *Get the attention of the person you want to talk to and look at them directly.*
- *Present your request in a friendly and straightforward manner, using the word "I" to describe your thoughts and feelings* (e.g., "I am feeling ill; would you be willing to give me your seat?").
- *If someone asks you a question, answer directly and openly. If you don't want to answer the question, say that instead.*
- *Give praise or say "thank you" when someone reacts in a positive, helpful way towards you.*

After the encounter:

- *Reward yourself for behaving confidently, even if things don't turn out the way you want. A reward can be as simple as telling yourself "well done!"*
- *Don't be too hard on yourself if you behaved in an insecure or aggressive way. Instead, reflect on what you were thinking and feeling at the time, and how you might behave differently in this type of situation in the future.*
- *Remember that you deserve respect, just as you respect others.*

Group exercise: Asking another person for help (role-play)

In a role-play, participants learn to ask for help in public situations that may elicit different kinds of reactions from the person being asked. One participant plays the person asking for help (Requester), and another participant plays the person being asked (Target). Several participants can each role-play different reactions.

Present the following situation (or use your own or a participant's example if you prefer): "You ask a stranger on the bus to give you their seat."

Reaction 1: They willingly give you their seat.
Reaction 2: They politely but hesitantly give you their seat.
Reaction 3: They reluctantly give you their seat.
Reaction 4: They do not give you their seat.

As the role-play progresses, ask the Requester and Target what they are thinking and feeling. Does the Requester feel confident? Would they like to try a different approach? Does the Target think they have enough information to know what to do? Ask other group members give feedback about the interaction. Change roles as time allows.

Alternative/additional group exercise: Telling someone about your disease (role-play)

In this role-play, participants practice speaking about PD to someone who is not familiar with the disease. One participant plays the role of the person with PD (Speaker), and another participant plays the Listener. The role-play continues until everyone has had a chance to take both roles. The Speaker can practice not only what words to use, but also how to effectively use gestures, eye contact, facial expressions, and posture.

The role-play can be varied, such as changing the level of interest/motivation of the Listener. The Speaker then learns to judge whether to provide a shorter or more detailed explanation.

If desired, you can first ask the Speaker what information they want to convey, and write it on the flip chart.

Following each role-play, ask questions such as the ones provided below.

For the Speaker:

- How do you think it went, for you and for the Listener?
- What was most difficult?
- What would you do differently in the future?

For the Listener:

- Did you get the answers you wanted?
- Do you feel that you now better understand the situation of the person with PD?
- What other questions do you still have?
- How did it feel to be in the role of the Listener?

For other participants who viewed the role-play:

- What aspects do you think went well?
- What aspects could have been better? What could the Speaker have done differently?
- How do you think you would have felt if you were the Speaker?
- How do you think you would have felt if you were the Listener?

Alternative/additional group exercise: A stranger asks about your symptoms (role-play)

People with PD may be asked by other people about their visible symptoms while out in public. The goal of this role-play is to practice speaking to a stranger about PD, using a variety of scenarios representing different behaviors of the stranger.

Ask participants to share examples of situations where strangers made a comment or asked a question about their symptoms. For each example, ask the group to analyze the situation, and then to role-play possible ways to deal with it.

You can also provide the following scenarios as examples:

1. You are in a waiting room filling out forms for a doctor's visit. Your PD symptoms are evident as you try to sign the forms, although you manage to complete the task.
   - A stranger sitting near you asks about your symptoms, kindly and with interest. Practice responding to the person.
   - A stranger sitting near you asks you rudely about a symptom. Practice stating that you do not want to talk about your illness.
2. You are in the grocery checkout line and are having trouble getting out your credit card because of your symptoms.
   - As the checkout person is finishing the transaction, the next person in line speaks to you kindly, asking about your illness. Practice responding to the person.
   - The next person in line appears to be impatient and angry because of your slowness. As the checkout person is finishing the transaction, they ask you rudely about your symptoms. Practice stating that you do not want to talk about your illness.

Homework assignment: Communication Journal/Communicating in public situations

Participants continue keeping the *Communication Journal*, including examples of situations in which they needed to communicate in a public situation.

Homework assignment: Communicating with health professionals

Participants complete the homework *Communicating with Health Professionals* to prepare for the next session.

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

Communication Session 5: Communicating with Health Professionals

Communication problems can occur in meetings with physicians and other health professionals. For example, people with PD may worry that their doctors don't understand them or don't give them time to explain their situation. Conversely, people with PD may not fully understand the information provided by health professionals, and they may not know how best to ask for clarification. The following case study shows how a health professional can unintentionally impact a person with PD in a negative way.

Case Study: Problems communicating with health professionals

When going to doctors' appointments, Mr. R is normally accompanied by his wife. Mr. R is concerned that he might miss important information or advice from the doctor, and appreciates that his wife is able to come with him. However, he is irritated by the doctor's way of communicating, which follows a typical pattern: The doctor asks Mr. R briefly how things are going, but then turns to his wife and continues the interview with her ("Does he take his medication regularly? How is his digestion?" etc.). In this way, the doctor and the caregiver talk about Mr. R, but not with him. The doctor does not mean to insult Mr. R, and this pattern is most likely due to Mr. R's slowness in responding, combined with the doctor's time pressure. Nevertheless, Mr. R and his wife find the interaction humiliating.

Overview of session
Discussion of homework: • Communicating in public situations • Communicating with health professionals: Questions
Information: • Communicating with health professionals
Group exercise: • Speaking with a health professional
Homework assignments: • Self-observation with health professionals • Communicating with family and friends • Communication Journal
Handout: • Communication Session 5 Summary Sheet

Discussion of homework

Participants report back on experiences communicating in public.

Information: Communicating with health professionals

In this session, participants learn to develop self-confident behaviors when communicating with health professionals. Say:

> *Visits to health professionals can be challenging for a variety of reasons. Depending on the nature of your visit, the person may or may not be familiar with your medical and personal history, or may not even be knowledgeable about the effects of PD in general. They may be dealing with their own time constraints and lack of resources. However, there are actions you can take to improve your experience. In addition to the skills we have already talked about, the following tips may be helpful:*
>
> - *Be prepared for your visit by writing down your questions. This preparation will give you confidence. You can even type out your questions to hand to the health professional if that is easier than saying them.*
> - *If your health professional has an option for you to provide information through an online patient portal about insurance, medical history, and current questions, you may prefer to take care of these items in advance of your visit, at your own pace. You can then simply remind the health professional of your questions from the portal if needed, and add any additional questions that come up.*
> - *Think about how your behavior and speech may come across to the health professional, particularly if they are not familiar with PD, and explain your situation. For example, if you respond slowly, they may think that you are reluctant to answer, or are cognitively impaired. You could explain that your slowness is part of the disease. You could say "You may notice that I am a bit slow in responding. This is due to motor symptoms of my PD, not because I am uninterested or because I am unable to understand what you are saying."*
> - *If needed, use words to compensate for reduced facial expressions and gestures, for example by saying "I understand" instead of nodding your head, or saying "thank you" instead of smiling.*
> - *Reinforce the health professional's efforts to understand. You could say, "Thank you for listening and answering so patiently."*
> - *If the health professional does not listen to or address your concerns, speak up in an assertive, direct manner. Avoid sounding accusatory or aggressive.*
> - *If desired, ask the health professional to write down sources that you can access for additional information or training.*

All of these strategies will help you to build a good relationship, which is particularly important when you may be dealing with the same health professionals for many years.

Group exercise: Talking with a health professional (role-play)

In a role-play, participants learn to communicate with health professionals under different conditions. One participant plays the person with PD (Patient), another participant plays the health professional (e.g., Doctor), and a third plays the Partner (if desired). Several participants can each role-play different reactions.

Present the following situation (or use your own or a participant's example if you prefer): "You and your partner arrive at your visit to the doctor with a list of questions, including whether or not your medication schedule could be changed."

Reaction 1: The Doctor listens attentively and patiently to your concerns.
Reaction 2: The Doctor listens at first but then directs the conversation to your partner.
Reaction 3: The Doctor listens and answers your question, but uses a lot of medical jargon that you do not understand.
Reaction 4: The Doctor stops you because you are taking so long to ask your question, and says that it should be fine to just keep things as they are, as they start to escort you out of the room.

Following each role-play, ask the Patient questions such as the following:

- How do you think it went?
- Did you get the answers you wanted?
- What was most difficult?
- What would you do differently in the future?

You can also get feedback from the Doctor, Partner, and other group members about how the session went, and what suggestions they might have.

Homework assignment: An appointment with a health professional

Participants complete the homework *An Appointment with a Health Professional*, rehearsing for an upcoming appointment.

Homework assignment: Communicating with family and friends

Participants complete the homework *Communicating with Family and Friends* to prepare for the next session.

Homework assignment: Communication Journal

Participants continue keeping the *Communication Journal.*

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

Communication Session 6: Communicating with Family and Friends

Parkinson's disease can change relationships with partners, family members, and close friends. Problems such as changes in symptom severity during the day or in different situations may be misunderstood. For example, slowness may be exacerbated by demanding situations, leading others to believe that the person with PD is intentionally slowing down. This session can help people with PD to deal with these types of issues by improving communication.

Overview of session
Discussion of homework: • Communicating with health professionals • Communicating with family and friends
Information: • Effects of PD on close relationships • Improving communication with family and friends
Group exercise: • Role-play: Talk with a family member or friend about PD
Homework assignment: • Talk with a family member or friend about PD • Program Review • Communication Journal
Handout: • Communication Session 5 Summary Sheet

Discussion of homework

Participants discuss their experiences dealing with health professionals.

Information/Discussion of homework: Effects of PD on close relationships

Describe how PD can affect relationships with others, asking for comments and feedback as you go along. Say:

> *PD can be a challenge not only for you, as the person diagnosed with the disease, but also for your family and friends. Because of these challenges, relationships can be tested.*
>
> *You may feel misunderstood or think that it is difficult for your family members to empathize with your feelings, needs and difficulties.*
>
> *In addition, a partner can have their own difficulties dealing with changes brought on by PD. Partners may say things like:*
>
> - *"My spouse (person with PD) is more anxious and sensitive than before."*
> - *"It requires a lot of patience for me to deal with my partner's needs."*
> - *"Sometimes I just don't know what to do: on one hand, I want to encourage their independence; on the other hand, it would be easier if I did it myself."*
> - *"We can't do the activities together that we used to do."*
>
> *PD can also create specific burdens for family members such as:*
>
> - *Needing to restrict their own activities due to the person's illness*
> - *Needing to take over duties and decision-making responsibilities*
> - *Fear that they may get sick themselves*
> - *Fear that the person's illness will get worse*
> - *Concern that their own difficulties are not understood by others*

Ask participants to describe some of the difficulties and stressors that they and their family members and friends have experienced in dealing with PD (from homework).

Information: Improving communication with family and friends

Describe issues related to communication with family/friends. Say:

> *You might feel reluctant to talk about your problems to family members and friends. But if you do, you may feel relief, and may uncover new ways to cope with your problems.*
>
> - *Has this been true for you—have you felt reluctant to talk about problems related to PD?*
> - *What has happened when you did talk about them?*
>
> (Participants describe these experiences.)
>
> *The way you communicate can affect how willing the person will be to talk about it with you, as well as how they will respond* (make notes on flipchart).
>
> *When you are the one who is speaking, you can improve conversations by using the same direct communication techniques you learned in previous sessions, such as:*

- *Getting the person's attention before speaking*
- *Using the word "I" to describe your own thoughts and feelings* ("I think this; I feel that")
- *Expressing what you want to say openly and honestly*

In addition, however, the way you communicate can affect your ongoing, personal relationships. In order to maintain and improve these relationships, keep these tips in mind:

- *Deal with specific situations, and avoid generalizations like "always" or "never." Instead of saying, "It's always horrible when the whole family gets together," you could say: "I felt overwhelmed when we had the whole family come over and everyone was talking at once."*
- *When bringing up something related to how the other person is behaving, refer to the behavior, not the person. For example, you could say, "I feel like you're annoyed with me when I take a long time to finish my dinner" rather than "You're always such a grouch."*
- *Stay in the present: Talk about what's happening right now, rather than digging up past problems that are no longer as important.*
- *If the person makes a request that seems unreasonable to you, you can ask about the purpose of the request. Perhaps with more information, you will realize it is something you are willing and able to do.*
- *If you are unwilling or unable to comply with a request, say "no" clearly. Depending on the situation, you may want to explain your reasons for saying no, but do not apologize excessively.*

When you are listening, remember the techniques for active listening (see Session 3). *In addition, if you are emotionally unable to engage in a conversation at that time, acknowledge those feelings directly.*

Group exercise: Talk with a family member or friend about PD (role-play)

For this exercise, participants role-play talking to a family member or friend about a disease-related problem or issue. Ask participants for examples or use examples based on the problems listed in Table 7.1.

Homework assignment: Talk with a family member or friend about PD

Participants think about disease-related topics that they would like to discuss with someone close to them. A brief conversation can be a good first step as it may be easier than a longer discussion.

Homework assignment: Communication Journal

Participants continue keeping the *Communication Journal.*

Homework assignment: Program review

In preparation for the final session, participants think about their experience of the training program, using the questions on the handout.

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

Communication Session 7: Program Review

Overview of session
Discussion of homework: • Talk with a family member or friend about PD
Group exercise: • Review of the training program and "pack your bags"
Handout: • Communication Session 6 Summary Sheet

Discussion of homework

Participants report back on their conversations with a family member or friend about PD.

Group exercise: Review of the training program and "pack your bags"

For this farewell session, ask each participant to answer the following questions:

- What goals did I achieve?
- How did my achievements compare with my original expectations of the program?
- What are the most important things I learned or experienced during the training program?
- How can I maintain my progress, and apply what I have learned to future situations?
- Which parts of the training, in my view, might be changed or improved in the future?
- What tips and encouragement can I give to others?

The group "packs a suitcase" for each participant's journey through life: each group member "gives" something to every other participant for their journey. Each gift is written onto a suitcase drawn on the flip chart (one participant per page). Say:

> *Each of you will give a gift to every other member, to put in this "suitcase." When deciding on a gift, think about what that person needs for a pleasant and fulfilling journey through life with PD. Take into account:*
>
> - *Difficult, strenuous, and frightening parts of the journey: what would help the person make it through?*
> - *Happy, enjoyable, and satisfying parts of the journey: how can the person most fully experience these parts, and increase their frequency?*

One at a time, "pack a suitcase" for each participant. They can each then roll up their sheet to take home to help them on their journey.

As you say farewell, remind participants about individual and/or group booster sessions and assessment (if possible, schedule the booster sessions when participants first enroll in the group).

Communication Program: Booster Session

In a booster session 4 to 8 weeks after training, participants meet again with the therapist and discuss how and in what circumstances they were able to use the skills they acquired during the program. The specific format of the booster session can be modified depending on the needs of the participants.

Discuss questions such as:

- What ideas, techniques, and skills have been helpful?
- What didn't work?
- Are there topics or techniques that it would be helpful to review?
- Are there additional issues that arose? If so, how and where can these needs be addressed?

If desired, you can combine the booster session with repeat assessment.

Chapter 8: Emotional Expression in Parkinson’s Disease

The ability to express emotions, moods, personality, and intentions can be affected by PD due to effects of the disease on facial movements, gestures, and the voice. Facial expressions may be reduced, and the voice may lack melody (“prosody”) and become softer. Changes in expressive behaviors may be barely noticeable at the beginning of the disease but can become increasingly problematic over time. Yet people with PD still experience a range of emotions, even if they are no longer expressing them as they used to. Thus, emotional experience and emotional expression can become decoupled from each other. This dissociation is characteristic of PD.

As reviewed in Chapter 3, when expressions are reduced by PD, communication can be affected. Just as PD can cause slowness in thinking that can be mistaken for dementia, PD can cause a reduction in expression that can be mistaken for a lack of feeling. The person with PD can give the impression that they are apathetic, disinterested, depressed, and uninvolved. They may feel that they can no longer express their true personality and feelings.

Family members may complain that they no longer really know where they stand with the person with PD. They can’t tell if the person is happy or angry, whether they like something or not. Some relatives may think that the person with PD is no longer being honest with them. Thus, people with PD may correctly believe that others are evaluating them negatively. These difficulties can lead to increased social withdrawal and emotional stress: problems that can be particularly difficult in long-term partnerships, where partners implicitly assume that they should already know what each other is thinking and feeling. Family and friends are often relieved when they learn that the disease can cause a dissociation between expressions and feelings, even if it remains difficult to keep from “automatically” assuming the person with PD is unhappy or uninterested.

These issues can affect interactions and impressions not only with family and friends, but also with health professionals. For example, a person’s lack of expression can affect a physician’s behavior during an intake interview. The doctor may address most of their questions to a family member, rather than to the person with PD. The person with PD may be “talked about” rather than “talked with.”

The overall goal of the Emotions Program is to improve communication of feelings during interactions in daily life. The first strategy we use is to help people with PD to be aware of and to increase facial and gestural expressions of emotion, as illustrated in the case of Mr. W.

Case Study: Expressions of joy

Mr. W, a 60-year-old man with PD, noted that his wife complained that he never looked happy. As part of the training program, he practiced making facial expressions in front of a mirror, paying attention to how his face and gestures appeared both while talking and while imagining that he was listening. After the training, his friends said that he was moving his hands in conversation the way he used to. He was also not interrupted as much while speaking. His wife observed that he laughed more intensely, and that their conversations were more pleasant.

The second strategy we use is to help people with PD to be aware of and to increase vocal expressions of emotion. People with PD may be unaware that their voice has become softer and monotone. Thus, we work with people with PD to speak with greater volume and prosody.

However, the amount of improvement using these two strategies alone is potentially limited for some people with PD for several reasons:

- Most nonverbal communication takes place automatically, without conscious awareness. For example, a speaker may raise their eyebrows for a fraction of a second without even realizing it. The listener may not consciously perceive this movement, yet it still contributes to their impression of the interaction. Although nonverbal signals are part of normal conversations, they may require too much attention to routinely perform in a deliberate, intentional way.
- There are limits to the degree to which conscious control of expressive behavior can be effective. For example, a spontaneous smile can differ from a consciously "posed" smile by tiny, fleeting characteristics that create a different impression.
- Intentionally moving the facial muscles can be painful for some people with PD.
- Increasing voice volume may be tiring.

Because of these limitations, our training program includes a third strategy: using words to explicitly communicate emotions. We work with people with PD to state clearly what they are feeling, including telling others that their words reflect their feelings even when their face, gestures, and voice may not.

Table 8.1 shows typical problem areas and solutions.

Table 8.1. Emotional expression: Examples of problems and possible solutions

Topic	Problem	Solutions
Facial/gestural expression of emotion	Person is unaware of how their facial expressions are coming across to others	• Self-observation of facial expressions • Video feedback • Group feedback
	Reduced facial expression and gestures	• Posing facial expressions • Practice conveying emotions nonverbally to others • Practice using words to describe feelings
Verbal and vocal expression of emotion	Person is unaware of how their vocal expressions of emotion are coming across to others	• Self-observation of vocal communication • Video feedback • Group feedback
	Soft voice, speaking in a monotone	• Practice speaking with emotion • Practice using words to describe feelings

After completing the training program, participants typically report comments such as these:

- I enjoy talking about my feelings.
- My hands are expressive again.
- My facial expressions have increased.
- I can laugh again!
- I'm using my skills to reconnect with others.
- I'm more facially expressive than I thought I was.
- I‘ve gained confidence.

Structure of the Emotions Program

This training program consists of 6 group sessions, beginning with an introduction in Session 1, and concluding with a review in Session 6. Sessions 2-5 each include a progress report about the previous session's homework, presentation of new information, group exercises, preparation for new homework, and a feedback round about the session.

Table 8.2 provides an overview of the group sessions.

Table 8.2. Training emotional expression: Components at a glance

Session	Information	Group exercises	Homework
1. Introduction	• Overview of program • Emotions in PD • Problems and solutions	• Getting acquainted	• Introductory questions
2. Self-awareness of emotional expressions	• Self-observation • Emotional feelings and expressions • Setting goals with a Goal Staircase	• Eliciting and observing emotions • Setting goals	• Setting goals • Emotions & Reactions Log[1]
3. Facial expressions and gestures	• Nonverbal emotional expression	• Facial expressions	• Practicing facial expressions
4. Vocal expression of emotion	• Expressing feelings through the voice	• Expressing feelings nonverbally	• Expressing feelings nonverbally
5. Emotional expression: Putting it all together	• Learning what works for you	• Asking for feedback • Telling stories	• Telling stories • Program review
6. Program review		• Review of the program and "pack your bags"	

[1] Participants keep the Emotions & Reactions Log during the entire program.

Emotions Session 1: Introduction to the Program

Overview of session
Information: • Overview of program • Emotions in PD • Problems and solutions
Group Exercise: • Getting acquainted
Homework Assignment: • Introductory questions
Handouts: • Overview and Schedule • Emotion Session 1 Summary Sheet

Information: Overview of program

Hand out the *Overview and Schedule* sheet (or give to participants during the introductory meeting). Describe the program by carefully going through each point on the sheet and answering questions.

Group exercise: Getting acquainted

In this exercise, participants get to know each other. The participants interview each other in pairs. These interviews work better if participants are paired with someone they don't know well. For odd-numbered groups, you can take on the role of an interview partner. If desired, provide paper and pens for participants who would like to take notes about their partner; note, however that many people with PD have difficulty with handwriting.

In the first round, one member of each pair asks their partner about themselves, which might include questions such as the following (write the questions on the flip chart):

- Name, age, living situation
- Duration of PD
- How has PD changed your life?
- How has PD changed the lives of people close to you?
- Has PD affected your ability to express your feelings or personality to others?

In the second round, the partners swap roles.

In the last part of the exercise, everyone takes turns reporting the results of their interviews to the group. Write selected comments on the flip chart to highlight important points.

This exercise will usually take about 30 minutes. If time remains, discuss how information from the interviews is linked to what they will be learning in subsequent sessions, such as how they express their emotions, and whether they think that other people understand how they are feeling.

An alternative to this exercise is for participants to introduce themselves to the group. However, the "interview" tends to promote better communication among the participants.

Information: Emotions in PD

Describe how PD affects emotions. Say[*]:

> *When we think about emotions, we normally think about feelings, and the way we may express those feelings to other people. Emotional expressions normally occur automatically—you don't have to think about them.*
>
> *However, PD can reduce your expressions of emotions, including your automatic facial movements, gestures, the melody in your voice, and how loud you speak.*
>
> *At the same time, you probably still experience emotions in the same way that you always have. Because you feel the same as before, you may naturally assume that your emotions are still being expressed to other people. But if your expressions are reduced, your feelings and expressions no longer automatically go together—they become decoupled from each other.*
>
> *The problem is that most people you talk to probably don't understand that PD is affecting your expressions in this way. For example, if you are having a conversation with someone, they might notice that you are not nodding or smiling, and think that that you are uninterested in what they are saying. This can lead to misunderstandings and stress in relationships—particularly for friends or family who feel that they should know how you are feeling.*

Information: Problems and solutions

Present examples of problems and solutions from Table 7.1, and discuss situations that participants have experienced when they felt they were not expressing their emotions or showing their personality.

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[*] Scripts are provided in italics as suggestions for wording of specific content.

Homework assignment: Introductory questions

Hand out the *Session 1 Summary Sheet*, which includes the homework assignment *Introductory Questions* to work on before the next session. This homework has questions about what participants know about PD, how they are dealing with PD, and their expectations of the training program. Point out the importance of thinking about realistic and unrealistic expectations.

We typically do not ask participants to turn in homework sheets, but instead encourage them to bring the sheets back to the next session for discussion. We offer to look over the homework if a participant would like feedback, and to discuss any issues that participants would like to address.

Feedback round

Ask each participant to comment briefly about their experience of the session, giving their personal impressions. Do not allow discussion, in order to encourage participants to speak honestly and openly, and to prevent the session from running overtime.

Participants can address questions such as the following:

- What did I like the most about the session?
- What didn’t I like about the session?
- How do I feel now that the session is over?

Emotions Session 2: Self-awareness of Emotional Expressions

Overview of Session
Information: • Self-observation • Emotional feelings and expressions • Setting goals with a Goal Staircase
Group Exercise: • Eliciting and observing emotions • Setting goals
Homework Assignments: • Emotions & Reactions Log • Setting goals
Handout: • Emotion Session 2 Summary Sheet

Discussion of homework

Participants were asked to complete *Introductory Questions*. When discussing the homework:

- Ask participants if they had any questions or difficulties in completing the homework.
- Distinguish realistic from unrealistic expectations. For example, the expectation of being able to improve their ability to show when they are happy is realistic, whereas the wish for their partner to always know how they are feeling is not.
- Describe how participants will be able to use these expectations to develop specific goals and target behaviors in later sessions. For example, the expectation of being able to show they are happy can be realized in part by increasing self-awareness of facial expressions and saying in words what their faces cannot.

Information: Self-observation

Describe the rationale and techniques of self-observation. Say:

> *The first step for changing behaviors is self-observation. Self-observation refers to paying attention to your thoughts, feelings, and behaviors right at this moment, with a non-judgmental attitude.*

> *Self-observation can serve two main purposes: to identify problems, and to see a solution to those problems more easily.*
>
> *To practice self-observation, first select a specific thought, feeling, or behavior as the target of your observation. Once you have identified a target, you can learn to become more aware of when it tends to occur: how often and in what situations.*
>
> - *An example of a thought is that you think other people no longer smile back when you smile at them. You could choose to observe how often you smile and whether the reaction of others is similar across situations.*
> - *An example of a feeling would be the unpleasant experience you have when someone is observing your tremor or difficulties moving. You could ask yourself in what types of situations this feeling tends to occur.*
> - *An example of a behavior would be gesturing when you speak. You could choose to observe whether there are times when you gesture more or less than other times.*
>
> *We don't normally think consciously about most of what we do, so it can sometimes be difficult to recognize and describe these specific behaviors. However, self-observation is a skill that will improve with regular practice. This kind of careful observation may then lead to a solution.*
>
> *Using self-observation does NOT mean that:*
>
> - *You should constantly question yourself and everything you do, which may just make problems worse. Instead, use self-observation in a targeted way, to identify and solve specific problems, as well as to identify strengths.*
> - *You are merely a passive observer. Self-observation helps you deal actively with issues that are important for your quality of life.*
>
> *You may also want to talk with others about your self-observations. Through the sharing of observations, you may gain new perspectives on how your experiences are similar or different to those of others, which may in turn help you to understand yourself better.*

Information: Emotional feelings and expressions

Describe what emotions are, and the functions they serve. Say:

> *Emotional feelings are internal, something we experience. They are hard to describe in words, yet we all know what it means to feel emotions. There are many different emotions, such as fear, anger, sadness, joy, disgust, pride, shame, and sorrow. In addition to brief feelings of emotion, we also have feelings that last longer, which we usually call "moods."*
>
> *Emotional feelings signal that something important is happening. They help us to cope with our environment in a variety of ways, such as* (write notes on flip chart):

- *Guiding behavior. Emotions can help us to act quickly in critical situations, and to make decisions. For example, fear can help you cope with potential dangers. Joy can increase your desire to engage with the world, and to make social connections. Sadness may be unpleasant but can be useful: this feeling tells you that something is wrong and might motivate you to make changes.*
- *Shaping our relationships with others. For example, feelings of mutual joy can strengthen friendships.*
- *Enriching daily life. It's hard to imagine what life would be like if we didn't feel emotions! Experiencing the ups and downs of normal life can make you feel alive.*

However, feelings can also hold us back. For example, although fear is useful for helping to identify threatening situations, fear can be maladaptive if you are constantly worrying about things in the future that may not even happen.

Describe emotional expression. Say:

In addition to experiencing these internal feelings, we normally communicate our emotions in a variety of ways—in other words, we "express" our emotions.

Emotional expression is important in its own right because it allows other people to understand our feelings and intentions. Knowing that other people understand us may make us feel less alone and less stressed. In addition, expressing emotions can strengthen our social relationships. For example, when you show others that you are sad, they may be more likely to help—just as you may be more likely to help them when they look sad.

Of course, we may also need to control the expression of intense emotional feelings from time to time to fit the situation. For example, if you are very angry, you may need to control your anger in order to maintain good relationships or to avoid escalating a tense situation.

Describe how feelings are communicated. Say:

There are many ways to express feelings. The main categories of expression are verbal and nonverbal.

- *We express feelings verbally by using words—we talk or write about our feelings. For example, you could say to someone, "I feel happy."*
- *We express feelings nonverbally through physical behaviors that other people can see. Nonverbal expressions include facial expressions, gestures, posture, and tone of voice. For example, when you feel happy, you are more likely to smile, be more active, and speak in a cheerful way. When you feel sad, you may be more likely to sit with your head down and be quiet.*

Describe how PD can affect emotional expression. Say:

As we discussed in the last session, while PD does not affect emotional feelings—you most likely feel emotions as strongly as you ever did—it can affect your expression of emotion. For example:

- *You may show less facial expression of emotion.*
- *In conversation, you may make fewer small movements that indicate that you are interested, such as head nodding and gestures.*
- *Your voice may become quieter, with less melody.*

Normally, expressions of emotion occur automatically—you don't have to think about them. When those expressions are missing because of PD, other people may think that you are not interested, even when you are. They may not recognize what you are feeling because your expressions no longer match up.

The challenge is to express your feelings and intentions, despite the effects of PD.

You can start by being more aware of your own expressions, using the techniques of self-observation. As part of this training program you will practice observing yourself in a mirror, and will ask for feedback about your emotional expression from group members in the sessions, as well as from family members and friends.

Group exercise: Eliciting and observing emotions

In this exercise, participants are presented with a variety of stimuli to elicit emotional reactions. Stimuli could include:

- Different types of odors, such as vanilla, vinegar, and lemon, presented in small bottles that participants can sniff
- Photographs or videos of laughing and crying babies
- Small gifts, such as bags of candy

Describe the exercise. Say:

> *I will be presenting a variety of stimuli* (or say more specifically what you are presenting) *to each of you. When it's your turn, I would like you to pay attention to your emotional reaction—how do you feel? Here are some possible reactions you might have* (write on flip chart):
>
> - *Anxious*
> - *Disgusted*
> - *Sad*
> - *Annoyed*
> - *Relaxed*
> - *Cheerful*
> - *Pleasantly surprised*

> *In addition, as I present each stimulus to a member of the group, the rest of the group can observe the person's reactions, including their facial expressions, gestures, and comments. Be sure to look carefully at their facial expressions for information about how they are feeling.*

Proceed with presenting the stimuli.

Information: Setting goals with a Goal Staircase

In this next component, participants develop individual goals with specific target behaviors. Say:

> *Making changes is easier, more effective, and more rewarding if you set goals. A goal is not an abstract hope or wish, but instead is an outcome that you want to achieve. To do that, you will identify specific, concrete behaviors to change: your target behaviors. These behaviors can include not only actions, but also thoughts that you observe you are having. To reach a particular goal, you could have one or more target behaviors.*
>
> *For example, suppose you have a general goal of being better able to take care of your responsibilities on time. To achieve that goal, you could set two target behaviors: to find someone to help you at home, and to reduce your number of outside commitments. If you achieve your targets—in this case, you find someone to help you, and you reduce your outside commitments from 3 per week to 2—you may accomplish the goal of taking care of your responsibilities on time.*
>
> *To begin with, it is usually more effective to start with one main goal at a time, and to choose target behaviors that are relatively easy to change.*
>
> *The steps to setting goals and target behaviors are:*
>
> 1. *Decide on a goal. Select an important concern or difficulty that you would like to address. A goal can be short-term or long-term. If you have more than one major concern, pick the one that is most important to you in the immediate future.*
> 2. *Describe at least one specific, concrete behavior that you could change that will contribute to the goal—this is a target behavior. Choose a behavior that you can work on in the coming week.*
> 3. *Set a reasonable level of achievement for the target behavior. Take into account your current level of that behavior, and what is realistic for you to achieve in the near future.*
> 4. *If desired, you can create a Goal Staircase for the target behavior using a 4-point scale, as follows:*

> *Your current situation with regard to the behavior is 0, and your target is +1. If you improve beyond your target, your rating would be +2. If your situation worsens, you would be -1, like this* (write on flip chart)*:*
>
> *+2: better than expected*
> *+1: TARGET*
> *0: unchanged*
> *-1: worse*
>
> *Although you will be aiming for your target level, different levels of improvement are possible—the possibility of success is not "all or nothing."*

Describe the following example of a Goal Staircase (or use your own example).

Example of a Goal Staircase

A man with PD has this goal: "I want others to understand how I feel."

Comments: This is a very general goal. He chooses a specific target behavior that will contribute to the overall goal. For example, he could specify as a target behavior: "I want to intentionally express to my wife how I am feeling." He thinks about the times when he would want to express his feelings to her, such as:

- Feeling grateful for a kind act that she has performed for him.
- Feeling annoyed when she interrupts and talks over him in a conversation.
- Feeling frustrated because she thinks he doesn't care.

He decides to track how many days he tells his wife at least once about his feelings. He builds a *Goal Staircase* by setting a target, and then identifying steps above and below the target. At present, he only occasionally expresses his feelings (perhaps twice per week).

His *Goal Staircase* could look like this:

Goal: Increase number of days that I intentionally express my feelings to my wife at least once

+2: 4 or more days per week
(TARGET) +1: 3 days per week
(unchanged) 0: 2 days per week

Group exercise: Setting goals with a Goal Staircase

Discuss with the group how each of the following goals could be achieved by identifying target behaviors, and (if desired) by building a *Goal Staircase* for each target behavior. What would be a reasonable target level for each behavior?

- I want to be able to have fun conversations with other people like I used to.
- I want to be able to express my personality.
- I want my friends to help me when I am upset.

If time remains, discuss ideas for participants' individual goals. The following questions may be helpful:

- In which situations do you have difficulties discussing your feelings?
- In which situations do you feel misunderstood?
- Have others mentioned that you are lacking in emotional expression? In what ways?
- How did you express your personality in the past?

Homework assignment: Setting goals

Explain to participants that they will practice creating and defining their individual goals and target behaviors as homework. They can choose to use a 4-point *Goal Staircase* or simply describe an overall goal with one or two target behaviors.

Homework assignment: Emotions & Reactions Log

Participants identify emotional situations and reactions in daily life that they experience, as well as the reactions of others, in the *Emotions & Reactions Log*.

Note: Ask participants to bring a hand-held mirror to the next session if they have one (unless you can provide one for each participant).

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

Emotions Session 3: Facial Expressions and Gestures

Overview of session
Information: • Nonverbal emotional expression
Group exercises: • Facial expressions
Homework: • Practicing facial expressions • Emotions & Reactions Log
Handout: • Emotion Session 3 Summary Sheet

Discussion of homework

Emotions & Reactions Log: What emotions and expressions did participants observe in themselves? What emotional expressions did other people show?

Setting goals: Ask participants to describe the personal goal and objective(s) they have chosen. Are the targeted behaviors specific and easy to assess? If they used a *Goal Staircase*, were they able to identify different levels of success? Did they have any difficulties? Remind participants that they will be able to modify and add to their goals and objectives in the coming weeks.

Information: Nonverbal emotional expression

Describe different forms of nonverbal emotional expression. Say:

> *For healthy relationships as well as our own well-being, it is important to be able to communicate our feelings in ways that other people will understand. Nonverbal emotional expression refers to any of the ways we can show emotion beyond the use of words. Nonverbal expression includes expression in the face, body, and voice.*
>
> *Most nonverbal expressions occur automatically, with no conscious awareness. People differ in how expressive they are: some people are naturally very expressive, and others are more restrained. This is true for people with and without PD.*

However, PD can reduce nonverbal emotional expression, and you may not even be aware that it is happening. You may feel that you are making the same "effort" as always, yet the expressions may be less apparent to others. Therefore, it's important to learn to recognize what nonverbal behaviors you are expressing and which you are not. Today we will be focusing on the face and body.

Go through Table 8.3, writing behaviors on the flip chart.

Table 8.3. Nonverbal behaviors

Category of nonverbal behavior	Examples of behaviors
Gestures	• Gesturing with arms and hands while talking • Clapping hands • Clenching fist • Raising index finger • Waving
Facial Movements	• Blinking • Smiling • Clenching teeth • Looking down at the ground • Frowning • Crying • Opening mouth wide • Opening eyes wide
Posture	• Leaning in toward another person • Upright • Bent over • Slouched, casual • Rigid, tense
Actions/Behavior patterns	• Giving someone a present • Hugging • Kissing • Holding hands • Running away • Throwing things

Group exercise: Facial expressions

In this exercise, participants intentionally pose a variety of facial movements. Say:

> *You will next practice making facial movements that can be used to communicate your feelings to other people. As we go through each one, try to pose a natural-looking expression. Think about which movements are easier or harder to make, and what types of feelings you associate with each expression. Trying to express or "act out" the feelings may help you intensify the movement.*

Write each facial movement on the flip chart, asking what feelings they associate with the movement.

- Pull your eyebrows tightly together
- Raise your eyebrows all the way up
- Open your eyes wide
- Pull the corners of the mouth upwards, pushing your cheeks upwards
- Pull the corners of your mouth down
- Push your chin forward
- Press your lips together
- Pull in the corners of your mouth and make dimples
- Raise your upper lip
- Scrunch up your nose
- Open your mouth wide

> *Next, try making some of these same expressions while looking at yourself in the mirror, and observe the different movements in your face. As you look at your facial expressions, continue to think about what feelings are typically associated with each expression. Have fun, and don't worry if you can't get all the expressions just right!*

Allow time for participants to practice.

For the second part of the exercise, choose one participant to select an expression and pose it for the group. The other participants describe what they see, and report what emotion they would expect a person with that expression to be feeling.

For the third part of the exercise, ask participants to think again about the emotional situations they identified during the homework exercises. Did they make any of the same expressions from the exercise they just completed? Ask participants to describe the emotions they were feeling, and make the facial movements that would express that emotion (e.g., smiling when happy).

Encourage participants to give each other feedback about the facial expressions they are making as they interact with each other throughout the training program.

Homework assignment: Practicing facial expressions

Participants continue the facial expression exercises at home in front of a mirror. They can practice making the individual facial movements, and then try to show specific feelings. The aim of the homework is for participants to discover the nuances of their own emotional expressions.

Homework assignment: Emotions & Reactions Log

Participants continue tracking their emotional expressions in the *Emotions & Reactions Log*.

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

Emotions Session 4: Vocal Expression of Emotion

Overview of session
Information: • Expressing feelings through the voice
Group exercise: • Expressing feelings nonverbally
Homework assignment: • Expressing feelings nonverbally • Emotions & Reactions Log
Handout: • Emotion Session 4 Summary Sheet

Discussion of homework

Ask participants to report on their experiences posing movements and emotional expressions at home in front of the mirror. Which expressions were easy, and which were difficult?

Information: Expressing feelings through the voice

Describe vocal expression of emotions. Say:

> *One of the most important ways to communicate your feelings is by talking. When you talk to others, you convey your feelings through your voice in two main ways: by using specific words that reflect your feelings, and by the way you speak—your tone of voice. We will first look at words that can be used to express feelings.*

Go through the basic emotions and ask participants for words they would use, and/or hand out the sheet *Words and Phrases that Express Feelings* and ask participants for additional suggestions.

Next, go through the phrases on the handout. Say:

> *In the left-most column are feelings that you may have. In the middle column are phrases that convey a message about the feelings directly and assertively. In the right-most column are phrases meant to convey the same message indirectly, or with sarcasm or aggression. Because of changes due to PD, it is particularly important to use words to express your message directly to be most effective and to avoid being misunderstood.*

Ask participants for feedback on phrases, and then discuss expressing feelings nonverbally. Say:

> *The second way that the voice is used to convey feelings is by how you speak—your tone of voice, the melody of your speech, the words you emphasize.*
>
> *When you feel a specific emotion, your voice normally reflects that emotion, regardless of the specific words you use. You can whisper or shout, sound excited or bored: the way you speak will change the message you communicate to another person.*
>
> *In addition, as we have already learned, the gestures that normally accompany speaking will also reflect your feelings. How you say something can sometimes be more important than the words you use.*

Group exercise: Expressing feelings nonverbally

The exercise sheet *Expressing Feelings Nonverbally* contains seven statements, each with descriptions of three situations that differ with regard to the emotion a person might be feeling. Go through the sentences and descriptions with the participants to make sure everyone understands them. Then in the first round, each participant chooses a sentence and says it in a neutral tone of voice. In the second round, the participant says the same sentence, but this time with feeling—either a “happy” or “annoyed” tone of voice. Ask the other participants to try to identify which emotion was chosen, and what about the expression led to their guess. In the third round, the participant says the same sentence expressing the remaining emotion.

Encourage participants to have fun with this exercise. They can stand up, use gestures, and do whatever else they would like to add to their performance.

Homework assignment: Expressing feelings nonverbally

As homework, participants continue practicing saying the sentences in front of a mirror, intentionally using different facial, gestural and vocal expressions to communicate different emotions. If desired, they can videotape their expressions for feedback.

Note that this kind of “self-confrontation” can potentially be upsetting to some participants, if the image they see contrasts with their own self-image. Before assigning this homework, consider whether you may need to undertake a more thorough discussion about this issue, either with the group as a whole or with individual participants (cf. McRae et al., 2018).

Homework assignment: Emotions & Reactions Log

Participants continue tracking their emotional expressions in the *Emotions & Reactions Log*, paying particular attention to whether or not they were able to convey their feelings clearly.

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

Emotions Session 5: Emotional Expression—Putting it All Together

Overview of session
Information: • Learning what works for you
Group exercise: • Asking for feedback • Telling stories
Homework assignment: • Telling stories • Program review • Emotions & Reactions Log
Handout: • Emotion Session 5 Summary Sheet

Discussion of homework

Ask participants to report on their experiences expressing emotions in front of a mirror or on video. Take care to note if any participants found that practicing with feedback was difficult or upsetting.

Information: Learning what works for you

Describe the importance of learning which ways of communicating feelings are most effective for each individual, by practicing and asking for feedback. Say:

> *Communicating your emotions to others in an appropriate way can improve your social relationships and reduce stress, but it takes continued practice, feedback, and experimentation to figure out what works best for you. Think about which forms of expression you feel most comfortable with—which are easiest for you to do?*
>
> *In addition to practicing on your own to increase your emotional expressions, you can ask friends and colleagues directly which cues from your face, gestures, voice, and words they normally use or could use to understand how you feel. The cues they have used in the past may no longer be useful. For example, if you are feeling happy and say so, but your face is less expressive than in the past, does your friend understand that your words reflect your feelings more than your face does?*

Talking directly about these cues with specific people can help prevent future misunderstandings. In addition, you can ask for feedback during a conversation—in the moment—to learn if you are coming across in the way you intend. It's easy to feel frustrated if you are not understanding each other, so it is important to ask for clarification in a calm and non-judgmental way.

Group exercise: Asking for feedback (role-play)

Ask participants for examples from their *Emotions & Reactions Log* of times when other people did not appear to understand what they were feeling. Then ask for a volunteer to re-enact one of the situations, with another participant playing the conversation partner.

The volunteer describes the setting, the topic, and the other person's original response, and then together with the second participant role-playing the conversation partner, re-enacts what happened. They then repeat the role-play, but this time the volunteer includes questions designed to elicit feedback about how their emotions are coming across to the partner.

Examples of questions could be:

- Can you tell that I'm happy to go with you? I know that sometimes my face may not show it.
- I'm feeling frustrated but I'm not sure if you can tell that. Do you understand what I'm saying?

Group exercise: Telling stories

The aim of the exercise is to practice verbal and nonverbal emotional expressions while describing what is happening in a cartoon or reading a fairy tale—and to have fun!

The cartoon "Father and the Lost Son" and the fairy tale "The Fox and the Geese" are provided with session materials in Appendix B. Alternatively, you can choose your own cartoon (as long as it can be easily summarized as a short story) or fairy tale.

Divide the group into pairs, and ask each pair to decide who will be the Speaker and who will be the Listener.

If using a cartoon, hand a copy of the cartoon to the Speaker in each pair and say:

In a moment, I would like for each Speaker to tell their partner what's happening in the cartoon. Tell the story in your own words. Before beginning, think about what feelings the characters in the cartoon may be experiencing. Then when you tell the story, try to show these feelings. Pay attention to your choice of words, vocal expression, facial expression and gestures. When you are finished, your partner will give you brief feedback about what they saw and heard.

Say to the listener in each pair:

> *While you are listening, think about what is going well. What helped you to understand the story, what made it interesting? Did the Speaker express feelings? If so, what feelings, and how were they expressed? After you give feedback, you will switch roles and become the Speaker.*

Each Speaker describes the cartoon to their partner, receives feedback, and then switches roles so that everyone has a chance to perform both parts.

Alternatively, you can show everyone the cartoon, and ask volunteers to take turns being the Speaker, describing the cartoon to the group. After each speaker, the group provides feedback.

If using the fairy tale, proceed using the same format as for the cartoon, emphasizing that the main goal is to read with feeling, trying to really reflect the emotions in the story.

Homework assignment: Telling stories

Participants look for stories and cartoons to practice speaking using emotional expression.

Homework assignment: Emotions & Reactions Log

Participants continue tracking their emotional expressions in the *Emotions & Reactions Log*, and practice asking for feedback whenever the other person does not appear to understand them.

Homework assignment: Program review

In preparation for the final session, participants think about their experience of the training program, using the questions on the handout.

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

Emotions Session 6: Program Review

Overview of session
Discussion of homework: • Telling Stories
Group exercise: • Review of the program and "pack your bags"
Handout: • Emotion Session 6 Summary Sheet

Discussion of homework

Telling Stories: Were participants able to show emotion in their voices and gestures?

Emotions & Reactions Log: Did participants ask for and receive feedback about what is working and what is not?

Group exercise: Review of the training program and "pack your bags"

For this farewell session, ask each participant to answer the following questions:

- What goals did I achieve?
- How did my achievements compare with my original expectations of the program?
- What are the most important things I learned or experienced during the training program?
- How can I maintain my progress, and apply what I have learned to future situations?
- Which parts of the training, in my view, might be changed or improved in the future?
- What tips and encouragement can I give to others?

The group "packs a suitcase" for each participant's journey through life: each group member "gives" something to every other participant for their journey. Each gift is written onto a suitcase drawn on the flip chart (one participant per page). Say:

> *Each of you will give a gift to every other member, to put in this "suitcase." When deciding on a gift, think about what that person needs for a pleasant and fulfilling journey through life with PD. Take into account:*
>
> - *Difficult, strenuous, and frightening parts of the journey: what would help the person make it through?*
> - *Happy, enjoyable, and satisfying parts of the journey: how can the person most fully experience these parts, and increase their frequency?*

One at a time, "pack a suitcase" for each participant. They can each then roll up their sheet to take home to help them on their journey.

As you say farewell, remind participants about individual and/or group booster sessions and assessment (if possible, schedule the booster sessions when participants first enroll in the group).

Emotions Program: Booster Session

In a booster session 4 to 8 weeks after training, participants meet again with the therapist and discuss how and in what circumstances they were able to use the skills they acquired during the program. The specific format of the booster session can be modified depending on the needs of the participants.

Discuss questions such as:

- What ideas, techniques, and skills have been helpful?
- What didn't work?
- Are there topics or techniques that it would be helpful to review?
- Are there additional issues that arose? If so, how and where can these needs be addressed?

If desired, you can combine the booster session with repeat assessment.

Chapter 9: Interventions for Caregivers

Parkinson's disease changes not only the life of the person with the disease, but also the lives of their family members and friends. In this chapter we will focus primarily on family members/friends who also serve as the primary support for the person with PD. We will refer to the "caregiver," while recognizing that the level of care required may range from the normal level of care given by partners to each other, to much higher levels of care required for a person with severe disease. The program may be useful, however, for any family member or friend of a person with PD, whether or not they are the primary support.

Using empirically-supported techniques for the treatment of partnership issues (Schindler et al., 2007), the training program is intended for caregivers who want to learn more about the disease, better understand what their partner is experiencing, manage psychological stress, and improve communication with their partner.

Caregiver Concerns

Caregivers can experience depressed mood, strains on the relationship with their partner, and psychological and physical stress due to the partner's PD (see Chapter 3). Psychological stressors can include:

- Feelings of burden from constant care
- Fear about the partner's disease progressing, and the consequences that could occur
- Difficulties dealing with the partner's specific behavioral, emotional, and physical problems, such as agitation, apathy, anxiety, disinhibition, and nighttime waking
- Worries about becoming ill themselves, and what would happen to the person with PD if that happened
- Financial concerns
- Lack of time for social contacts and pleasant activities, resulting in feelings of isolation

For example, the wife of one man with PD reported: "I can only leave my husband alone for one or two hours at a time, and have hardly any time left for my friends. Plus, I'm so worn out from caretaking that my own health has suffered."

Effects of PD on Relationships

As a person with PD faces increasing disability, a change in roles within the relationship often occurs. The caregiver takes over tasks that were previously performed by the person with PD. Opportunities to do things together become less frequent, as evidenced by this comment from a caregiver: "Things we used to be able to do, and our plans for old age, are no longer possible." As the patterns of daily life change, the quality of the relationship often changes as well.

In addition, caregivers often report that their partner's behavior has been changed for the worse by the disease, as described by another client: "My husband's personality has changed. He has become slower, less spontaneous, less adventurous, and more anxious. He's not the man I married." Impaired speech and reduced facial expressions may contribute to these types of concerns, particularly if they affect communication between the partners. For example, the caregiver may feel that their partner is just less interested than before in having conversations.

Case Study: Problems in the relationship

Mrs. D (74 years) has cared for her children, husband and household since her marriage forty years ago. Now the children are out of the house and she would like to have more time for other activities. But her daily routine is filled with household chores and caring for her husband (74 years), who has PD. She feels physically and emotionally burdened and demoralized. Her husband is slowing down and his increasing forgetfulness makes her impatient, sometimes even angry. Mr. D needs the support of his wife when getting up and going to bed, and for personal hygiene, dressing and eating. Mrs. D must accompany him on his daily walks and frequent visits to the doctor, because he is always in danger of falling. As this activity log from a typical day shows, she has little time for her own interests: theater, concerts, swimming, reading and watercolor painting.

8:00	Get up, wash, dress, make breakfast
8:45	Wake up husband and help him wash, shave and dress
9:30	Eat breakfast together (help husband eat)
10:00	Do household chores, shop, fix lunch
1:00	Eat lunch together (help husband eat)
1:30	Help husband get in bed for a nap; clean up kitchen, short break, more housework
3:00	Take a walk together
4:00	Drive husband to the doctor; go in with husband to see the doctor
6:30	Fix dinner
7:00	Eat dinner together (help husband eat)
7:30	Clean up kitchen, additional housework
8:30	Rest period: possibly read or watch television
10:00	Help husband get ready for bed and get into bed
10:30	Get ready for bed

Mr. D, on the other hand, misses the tenderness that he and his wife used to share. He is having difficulty coming to terms with the disease; even though it's been ten years since his diagnosis, he still hopes the disease will just go away. He feels depressed and suffers from insomnia. Recently he has been experiencing visual hallucinations. He feels insecure and worries that he is going crazy. He doesn't talk about the hallucinations with his wife because he's afraid that will worry her even more.

Emotional stress and the quality of the relationship have a reciprocal influence: people with PD who have a stable relationship tend to experience less depression than those living alone. However, the highest rates of depression in people with PD are those with poor quality relationships (Seiler et al., 1992), highlighting the importance of positive social connections.

Thus, to be most effective, psychological interventions for PD should include not only the person with the illness, but also those people who are most important to them, to achieve the best outcomes for everyone affected by the disease.

Table 9.1 presents examples of problems and solutions addressed in the training program.

Table 9.1. Training program for caregivers: Examples of problems and possible solutions

Topic	Problem	Solutions
Psychological stress	Anxiety about disease progression	• Information • Discussion • Coping strategies
	Physical and psychological demands of caregiving	• How to find external support • Stress management through relaxation and cognitive therapy techniques • Activity planning
Communication with the partner	Difficulties due to changes in the partner's ability to communicate	• Information about how PD can affect communication • Conversation training

Assessment of Caregiver Participants

We administer the following instruments to caregivers (see Chapter 5 and Appendix A):

- Caregiver Information Form
- Self-Rating Depression Scale
- Stress Questionnaire for PD Caregivers (short form)

Structure of the Caregiver Program

We typically lead caregiver groups with 4-12 participants, to allow for active participation by all members. One exception would be for a group that is focused only on providing information. The caregiver program should normally be conducted separately from the programs for people with PD. In all cases, we encourage caregivers to be open with their partners about what they are doing in the group, in order to avoid misunderstandings.

This program consists of 9 group sessions, beginning with an introduction in Session 1, and concluding with a review in Session 9. Sessions 2-8 each include a progress report about the previous session's homework, presentation of new information, group exercises, preparation for new homework, and a feedback round about the session.

Table 9.2 provides an overview of the group sessions and individual components, which can be adjusted as needed.

Table 9.2. Training for caregivers: Components at a glance

Session	Information	Group Exercises	Homework
1. Introduction	• Overview of program • Psychological stress of caregivers • Problems and solutions	• Getting acquainted	• Introductory questions
2. Stressful events and self-observation	• Stressful events • Techniques to manage stress • Self-observation	• Body Awareness Exercise	• Body Awareness Exercise • Stress Journal[1]
3. Stress Management I: Relaxation	• Principles of relaxation	• Relaxation at rest • Examples of stressful situations	• Relaxation at rest
4. Stress Management II: Self-instruction	• Self-talk and self-instructional training • Combining self-instruction with relaxation techniques	• Self-instruction before, during, and after a stressful situation • Self-instruction and relaxation while re-imagining the past	• Self-talk and relaxation in stressful situations
5. Activity planning	• Setting goals with a Goal Staircase • Activity planning	• Setting goals with a Goal Staircase • Activity planning	• Setting goals • Activity planning • Bring something pleasant
6. Pleasant activities	• Increasing pleasant activities	• Engaging in pleasant activities	• Have some fun!
7. Communication I: Listening	• How PD can affect close relationships • Be an active listener	• Active listening	• Active listening
8. Communication II: Speaking	• Speaking directly	• Speaking directly	• Conversation practice • Program review
9. Program review		• Review of the program and "pack your bags"	

[1] Participants keep the Stress Journal during the entire program.

Caregiver Session 1: Introduction to the Program

Overview of session
Information: • Overview of program • Psychological stress of caregivers • Problems and solutions
Group exercise: • Getting acquainted
Homework assignment: • Introductory questions
Handouts: • Overview and Schedule • Caregiver Session 1 Summary Sheet

Information: Overview of program

Hand out the *Overview and Schedule* sheet (or give to participants during the introductory meeting). Describe the program by carefully going through each point on the sheet and answering questions.

Group exercise: Getting acquainted

In this exercise, participants get to know each other. The participants interview each other in pairs. These interviews work better if participants are paired with someone they don't know well. For odd-numbered groups, you can take on the role of an interview partner. If desired, you can provide paper and pens for participants who would like to take notes about their partner.

In the first round, one member of each pair asks their partner about themselves, which might include questions such as the following:

- Name, age, living situation
- Duration of partner's PD
- How has your partner's PD changed your partner's life?
- How has your partner's PD changed your own life, and the lives of other people close to you?

In the second round, the partners swap roles.

In the last part of the exercise, everyone takes turns reporting the results of their interviews to the group.

An alternative to this exercise is for participants to introduce themselves to the group. However, the "interview" tends to promote better communication among the participants.

If time allows, discuss how information from the interviews is linked to what they will be learning in subsequent sessions, such as how to handle stress, and how to communicate better with their partner.

Information: Psychological stress of caregivers

Describe stress and stress responses. Say[*]:

> *We all experience stressful situations because stress is part of life. When you encounter a problem or situation that you need to deal with, your body will normally increase its activity to enable you to cope with the challenge. This response is called a "stress response." For example, your heart rate may increase.*
>
> *These changes are usually normal and helpful. Sometimes, however, if you perceive the situation as threatening, or one that you may not be able to handle, you may experience a bigger response that can work against you.*
>
> *A stress response is characterized by three basic features.*
>
> 1. *It has multiple components, which can vary from person to person, and in different situations.*
>
> *Think about the kinds of reactions you have had when you were experiencing a stressful event.*

Ask for comments and/or use examples provided; write categories on flip chart.

> *Some common reactions are:*
>
> - *Unpleasant thoughts and feelings such as worry, restlessness, anger, fear, and sadness*
> - *Physical changes, such as an increase in heart rate, sweating, muscle tension, and blood pressure*
> - *Behavioral changes, such as avoiding doing something, or losing or dropping things. For example, you might be trying to find your keys and look hurriedly in the same places.*
>
> 2. *These components usually occur in a particular sequence. Your immediate reaction is followed by other responses that can last for different lengths of time, depending on the type of stressor.*

---

[*] Scripts are provided in italics as suggestions for wording of specific content.

3. *The time course of a stress response is influenced by how you cope with the stressor. The more effective your coping strategies are, the sooner your body will return to normal.*

Describe the significance of stress for people with PD and caregivers. Say:

> *Parkinson's disease (PD) is a physical disorder that can affect how people think, feel, and behave. It is not a "mental illness"—yet stress can be a particular problem for people with PD because:*

- *The disease symptoms themselves can be difficult to deal with.*
- *PD can increase a person's susceptibility to stress in everyday life: even small events or tasks may feel more stressful than in the past. For example, when people with PD are stressed, they may become agitated and shaky, or suddenly unable to move, freezing up "like a deer in the headlights."*
- *Even slight increases in emotional arousal or excitement can intensify motor symptoms.*
- *The motor problems can then increase the person's feelings of fear or insecurity, and decrease motivation and drive, creating a vicious cycle.*
- *Living with a chronic and progressive physical illness can feel like a permanent stressor.*
- *When you are close to a person with PD, you too can be more vulnerable to stress because:*
- *You may feel emotionally stressed from seeing a person you care about deal with this disease.*
- *You may experience physical stressors and time constraints from helping them.*
- *These stressors can contribute to difficulties in the relationship.*

> *For all these reasons, it is helpful to learn and practice a variety of different methods to deal with stress.*
>
> *Psychological effects and ways of coping with the disease vary from person to person. Identifying the kinds of situations that create stress for you, and the effects of that stress, is our first step in treatment.*

Information: Problems and solutions

Present examples of problems and solutions from Table 9.2, and discuss which issues are of most concern to participants.

Homework assignment: Introductory questions

Hand out the *Session 1 Summary Sheet*, which includes the homework assignment *Introductory Questions* to work on before the next session. This homework has questions about what participants know about PD, how they are dealing with their partner's PD, and their expectations of the training program. Point out the importance of thinking about realistic and unrealistic expectations.

We typically do not ask participants to turn in homework sheets, but instead encourage them to bring the sheets back to the next session for discussion. We offer to look over the homework if a participant would like feedback, and to discuss any issues that participants would like to address.

Feedback round

Ask each participant to comment briefly about their experience of the session, giving their personal impressions. Do not allow discussion, in order to encourage participants to speak honestly and openly, and to prevent the session from running overtime.

Participants can address questions such as the following:

- What did I like the most about the session?
- What didn't I like about the session?
- How do I feel now that the session is over?

Caregiver Session 2: Stressful Events and Self-Observation

Overview of session
Discussion of homework: • Introductory Questions
Information: • Stressful events • Techniques to manage stress • Self-observation
Group exercise: • Body Awareness Exercise
Homework assignment: • Body Awareness Exercise • Stress Journal
Handouts: • Caregiver Session 2 Summary Sheet • Body Awareness Exercise (script or recording) • Stress Journal for Caregivers

Discussion of homework

Participants were asked to complete *Introductory Questions*. When discussing the homework:

- Ask participants if they had any questions or difficulties in completing the homework.
- Distinguish realistic from unrealistic expectations. For example, the expectation of being able to cope better with everyday stresses and strains is realistic, whereas the wish to live exactly as they did before the onset of their partner's disease, is not.
- Describe how participants will be able to use these expectations to develop specific goals and target behaviors in later sessions. For example, the expectation of being able to cope better can be realized in part by learning to relax their muscles in stressful situations.

Information: Stressful events

In this session, participants will learn more about stressful events and responses. Say:

> *The first part of this training program is about how to manage stress. As we discussed in the first session, we all experience stressful situations. When we are faced with an event that we perceive as threatening or challenging, we react on many levels, with changes in our thoughts, feelings, and behavior, as well as our body. Even "positive" events, such as planning a wedding or moving to a new house, can be stressful, because they demand additional resources.*
>
> *We all experience stress differently: we have different situations that we find stressful, as well as our own ways of reacting to stress. The degree to which we experience a particular event as stressful depends in part on whether or not we think our abilities to cope match up with those demands.*
>
> *Some stressful events (or "stressors") and reactions may be very strong, whereas others are mild. They also differ in how long they last. Most stressors subside after only a few minutes, but some stressors can last for much longer.*
>
> - *Examples of stressors that typically last only short periods include waiting in line when you are in a hurry, traffic jams, or being exposed to a loud noise.*
> - *Stressors that can last for several hours could include attending a crowded event, or being outside in the heat or cold.*
> - *Stressors that can last even longer could include problems with relationships, or difficulties on the job.*
> - *More "permanent" stressors could include the death of a family member, or living with a chronic disease.*
>
> *Even if the stressful event itself is relatively short, your reactions can continue for much longer if the stressor is powerful or if you relive the stressor in your mind.*

Information: Techniques to manage stress

Participants will next learn how this training program can help them manage stress. Say:

> *In order to learn to manage stress, you will practice making small, consistent changes in your daily life. We will be using three main techniques: relaxation, changes in thinking, and activity planning and promotion.*
>
> *Relaxation can help you to calm down your body's reaction to stress. In addition, as your body relaxes, your mind will calm down too.*
>
> *Changes in thinking can be helpful when particular thoughts increase your stress response. To change these thoughts, which often seem to appear automatically, you must first "observe" them. You can then develop and practice new ways of thinking that increase your ability to cope with situations.*

> *Planning activities, and increasing the number of pleasant activities can also help reduce stress. Specifically, we know that it can be stressful if you have too much to do, and try to tackle more than one task at a time. You can reduce that stress by making a plan to reduce the demands on your time. In addition, you can increase feelings of well-being by deliberately increasing how often you engage in pleasant activities.*

Information: Self-observation

Describe the rationale and techniques of self-observation. Say:

> *The first step for using any of these techniques is self-observation. Self-observation refers to paying attention to your thoughts, feelings, and behaviors right at this moment, with a non-judgmental attitude.*
>
> *Self-observation can serve two main purposes: to identify problems, and to see a solution to those problems more easily.*
>
> *To practice self-observation, first select a specific thought, feeling, or behavior as the target of your observation. Once you have identified a target, you can learn to become more aware of when it tends to occur: how often and in what situations.*
>
> - *An example of a thought would be that you think you are unable to do anything to improve your current situation. You can then seek to identify when and where you tend to have this or similar thoughts. Of course, you might instead have the thought that you are up to the challenges of the day. Under what circumstances does that thought occur?*
> - *An example of a feeling would be the unpleasant experience you have when your partner is unable to complete a task and you feel helpless, anxious, or embarrassed. You could ask yourself in what types of situations these unpleasant feelings are more likely to occur.*
> - *An example of a behavior would be that you cancel activities that you have planned. You could choose to observe when and for what reasons that is most likely to happen.*
>
> *We don't normally think consciously about most of what we do, so it can sometimes be difficult to recognize and describe these specific behaviors. However, self-observation is a skill that will improve with regular practice. This kind of careful observation may then lead to a solution.*
>
> *Using self-observation does NOT mean that:*
>
> - *you should constantly question yourself and everything you do, which may just make problems worse. Instead, use self-observation in a targeted way, to identify and solve specific problems, and to identify strengths.*
> - *you are merely a passive observer. Self-observation helps you deal actively with issues that are important for your quality of life.*

> *You may also want to talk with others about your self-observations. Through the sharing of observations, you may gain new perspectives on how your experiences are similar or different to those of others, which may in turn help you to understand yourself better.*

Group exercise: Body Awareness Exercise

As a practical introduction to self-observation, participants conduct a *Body Awareness Exercise* (Tausch, 1993; procedure modified from pp. 162-163). In this exercise, participants focus attention on states of tension/relaxation in specific parts of the body. Over the course of the training program, participants will learn to use this exercise in a targeted manner: at the beginning and end of the relaxation exercises, and in connection with everyday stress.

Initially, participants may want to use a recording of the *Body Awareness Exercise*; if desired, you can make a recording for participants to take home (or send a digital recording). Alternatively, hand out the script at the end of the session for participants to make a recording themselves, or allow them to record the session. Eventually they may prefer to practice without external instructions.

Conduct the *Body Awareness Exercise* with participants, using the script in Appendix B.

After the exercise, ask participants to discuss their experiences and any difficulties they had, and invite questions. They may not be accustomed to focusing attention on themselves, or may not understand the intention of the exercise. Point out that self-observation takes practice, and will be needed for interventions later in the program.

Homework assignment: Body Awareness Exercise

Participants continue practicing on their own.

Homework assignment: Stress Journal for Caregivers

Hand out copies of the *Stress Journal for Caregivers* (Appendix B) and go through it with the group.

Explain that they will use the journal to identify situations that they find stressful and how they reacted to those situations.

To clarify what is meant by a “stressful situation,” ask participants for examples from their daily life. If they find it difficult to identify stressful situations, suggest some of these examples, and ask if they have encountered them:

- Running late for an appointment because your partner is taking a long time to get ready
- Being awakened in the middle of the night because your partner needs help getting up to use the bathroom

- Feeling like you are being observed in public due to your partner's tremor
- Feeling helpless because your partner is unhappy, and you don't know how to help
- Worrying that your partner's PD will progress
- Going out to run an errand or visit a friend, but worrying that your partner could be having problems at home alone

Emphasize the importance of writing down this information. We normally do not ask participants to turn in their journals but offer to look at them if participants would like feedback. They will use the journals throughout the training program.

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

Caregiver Session 3: Stress Management I—Relaxation

Overview of session
Discussion of homework: • Stress Journal
Information: • Principles of relaxation
Group exercise: • Relaxation at rest • Examples of stressful situations
Homework assignment: • Relaxation at rest • Stress Journal
Handouts: • Caregiver Session 3 Summary Sheet • Tips for learning to relax • Relaxation at rest script (or recording)

Discussion of homework

Discuss participants' experiences keeping the *Stress Journal*, giving special attention to difficulties and obstacles in knowing how or what to write. For example, many people find it difficult to describe their thoughts and feelings. Emphasize that writing in the journal will get easier with practice, and is an integral part of the program. Discuss specific stressful situations that individuals are willing to share with the group. Write the examples on the flip chart.

Information: Principles of relaxation

In today's session, participants learn basic principles of relaxation, and how to apply them at rest. Say:

> *Relaxation is the opposite of the state of anxiety: you can't be relaxed and anxious at the same time. Through targeted relaxation practice, your muscles learn to rest, and your entire body can become more relaxed. Why is this important?*

- *The most important effect of relaxation is a quieting and calming of your inner thoughts and feelings. This calming will help you recover from stress both physically and mentally.*
- *You can gain some distance from the problems of everyday life, helping you to achieve a feeling of balance and resilience.*

Relaxation is a skill like any other skill, such as driving a car. When you first learned to drive, you had to learn and think about each thing you needed to do. Later, you were able to drive a car almost automatically. But to get to that point, you needed to practice. It is the same with relaxation. Through practice you will gradually improve your ability to identify states of relaxation and stress, and to use relaxation techniques.

By learning to notice the first signs of stress, you can implement relaxation techniques early on, when they are most effective. That way you can prevent feelings of anxiety from taking hold.

In addition, you can increase the effects of relaxation by making individual adjustments to find out what works best for you.

Group exercise: Relaxation at Rest

First, lead the participants through the *Body Awareness Exercise* (see Session 2; Appendix B).

Next, lead participants through the *Relaxation at Rest* exercise (Appendix B). This exercise has three parts: progressive muscle relaxation, relaxed breathing, and visual imagery. The whole exercise takes about 20 minutes.

Finally, complete the *Body Awareness Exercise* again.

When you are finished, ask participants to describe their experiences, especially any problems they encountered during the exercise.

Group exercise: Examples of stressful situations

Participants describe and discuss typical stressful situations. They identify how they reacted in the situations, including physical, mental, and emotional reactions. What increased or decreased the stress? What other ideas do participants have for reducing stress?

Homework assignment: Relaxation at Rest

Participants practice the *Relaxation at Rest* exercise at home. If possible, they should practice once a day, but at least 2-3 times per week.

Hand out the sheet *Tips for Learning to Relax: Caregivers* to use as a guide. Review the handout with participants and answer any questions. It may be useful to discuss ideas about when, where, and how often they would like to practice.

As with the *Body Awareness Exercise*, participants may want to use a recording of the relaxation exercises. You can make a recording, hand out a script for them to make their own recording at home, or allow participants to record this part of the session. Eventually they may prefer to practice without external instructions.

Homework assignment: Stress Journal

Participants continue keeping the *Stress Journal.*

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

Caregiver Session 4: Stress Management II—Self-Instruction

Overview of session
Discussion of homework: • Relaxation at rest
Information: • Brief muscle relaxation • Self-talk and self-instructional training • Combining self-instruction with relaxation techniques
Group exercise: • Self-instruction before, during, and after a stressful situation • Self-instruction and relaxation while re-imagining the past
Homework assignment: • Self-instruction and relaxation in stressful situations • Stress Journal
Handout: • Caregiver Session 4 Summary Sheet

Discussion of homework

Discuss participants' experiences practicing relaxation techniques. Ask participants to take turns describing the relaxation techniques they tried, and the successes and difficulties they encountered. Address the following issues:

1. What difficulties did they have? Examples of issues participants might share are:
    - I found it difficult to relax, even though I practiced regularly.
    - The relaxation exercise was boring—I prefer to listen to music.
    - I can relax better while watching TV.
    - I was not able to practice daily, because I often had something else on my mind.
2. Which methods were most effective for each of them? Encourage participants to individualize the techniques to find out what increases their feelings of relaxation and well-being.
3. Did they use a recording?
4. Where did participants practice the techniques? Encourage them to try out a wide variety of settings. Provide examples as needed, such as:

- A living room chair
- On a park bench
- In the doctor's office

5. What times of day did they practice, and what times worked best?

Suggest trying the techniques at different times, such as right after waking, after lunch, or before going to bed. Remind participants to integrate relaxation practice into their daily life and habits, as consistent practice is needed to reap full benefits.

Information: Brief muscle relaxation

Describe brief muscle relaxation. Say:

> *In order to relax your muscles more quickly, you can combine muscle groups. For example, you can combine* (demonstrate and ask participants to try):
>
> - *Hands and arms: Clench both hands into fists and at the same time, bend your arms to tense your biceps.*
> - *Face and neck: Squint your eyes and at the same time, clench your teeth and tense the muscles of your neck.*
> - *Shoulders and abdomen: Pull your shoulders up in a shrug, and at the same time, tense your abdominal muscles by making your stomach hard, like bracing for a punch.*
> - *Legs and feet: Tense the muscles of your thighs and buttocks by pressing your knees together. At the same time, keeping your heels are the floor, pull your feet upward and tense your calves.*
>
> *We will be discussing later how this brief relaxation can then be combined with self-talk.*

Information: Self-talk and self-instructional training

In this session, participants will learn the method and technique of self-instructional training (Meichenbaum, 1985): how to identify stress-inducing thoughts and replace them with more adaptive thoughts. Say:

> *Self-talk refers to our "inner dialogue"—we literally talk to ourselves in our thoughts. This running commentary influences our behavior. For example, when you are faced with tackling a difficult task, you might say: "This task is impossible. I have no idea how I'm going to deal with it. I know I'm going to fail." We can consider these thoughts "negative" self-talk because they increase your stress level and don't help you deal with the situation at hand. Negative thoughts may have served a purpose in the past, or may even make you feel better momentarily, but they reduce your ability to act now.*

You can instead replace those thoughts with "positive" self-talk. This technique of identifying your current thoughts, and then changing negative thoughts into positive self-talk, is called "self-instructional training."

For example, instead of thinking that a task is impossible and you will fail, you could think: "This task is hard, so I'm going to take a moment to calm down and think about the best way to approach it." Positive self-talk is not the same as positive thinking, where you are telling yourself everything will be fine; instead, it is telling yourself that you can deal with the situation.

It can be difficult at first to recognize and change your thoughts because they seem to happen automatically, but you can learn to do it with practice.

Discuss examples of negative and positive self-talk from Table 9.3 (or use your own examples; write on flip chart).

Table 9.3. Negative vs. positive self-talk

Negative self-talk	Positive self-talk
I am just not a good partner; I make things worse, not better.	Even if I don't do everything perfectly, I can help.
Everything I try to do goes wrong.	I will first take a moment to think about my options.
It is wrong for me to feel stressed about myself; my partner is the one with the disease.	It is important for me to take care of myself, as well as my partner.
These worries just keep flooding my mind and it's impossible to change that.	I am worried about my partner: that's normal.
I'm exhausted and can't possibly do everything I need to do.	Nobody can do everything, but I can prioritize the things I need to do.
I'm useless as a helper.	I can learn the best way to help, or to find help.
I get too stressed out so why even bother?	My feelings of stress are a useful signal. I can relax, take a few breaths.
Our relationship will never be good again.	Our relationship has endured changes before, and we will work through the new challenges together.
My social life is over.	I can make some time to see friends.
The future is hopeless.	I will look for the positive and not jump to conclusions.

Describe how the first step is recognizing self-talk. Say:

> *Changing your self-talk can help you deal with stressful situations. The key is to identify which types of thoughts increase your stress reaction, and which reduce it.*
>
> *You may have different thoughts depending on when they occur in relation to a stressful event:*
>
> - *Preparing for the event*
> - *At the moment when you first confront the situation*
> - *During the event*
> - *Afterwards*
>
> *You can change your thoughts during any of these phases.*

Group exercise: Self-instruction before, during, and after a stressful situation

Demonstrate the technique of self-instruction with a specific example. Say:

> *Imagine that your partner has a doctor's appointment and it's time for you to leave, but neither one of you is ready yet. You are feeling more and more stressed out as you worry that you will be late.*
>
> *You can use positive self-talk to help you feel calm and in control. Your self-talk should be specific to the immediate situation, such as:*
>
> - *I can take a moment to think about what is essential right now and what can wait.*
> - *I am breathing calmly.*
> - *We are ok and doing the best we can.*
> - *It's not that important if we arrive late; people will understand.*
>
> *You can apply this same kind of self-talk at different times before, during and after the event. For example:*
>
> - *On the morning of the doctor's appointment, you can think about what is likely to happen. What thoughts might you have?*

Ask participants for examples of positive and negative self-talk, and give examples as needed, e.g., "This is going to be another big hassle and we will be late again"; "I know what we need to do to get ready in time. In any event, we will deal with whatever happens." Then ask for examples of self-talk for subsequent time periods:

> - *Once it is time to get ready, you see that your partner is moving slowly and having trouble getting dressed. What thoughts might you have?*
> - *You are both about ready to leave, but your partner has an unexpected problem. Even though you had allowed extra time to get ready, it appears that you might be late. What thoughts might you have?*

> - *After you are back home, as you think back on the event, what thoughts might you have?*
>
> *The key during all phases is to identify which types of thoughts increase your stress reaction, and which thoughts reduce your stress reaction and enable you to function better. Think about what words have the most meaning for you in a particular stressful situation, rather than just using stock phrases.*

Information: Combining self-instruction with relaxation techniques

Participants next learn how to combine relaxation techniques with self-talk to improve stress management. Say:

> *Next, we will talk about how you can deliberately integrate self-instruction with the relaxation techniques you have already learned: muscle relaxation, relaxed breathing, and relaxing visual images. This combination of techniques can be used in different orders and in different situations—whatever works for you.*
>
> *For example, you could:*
>
> - *Tell yourself that you are doing your best, and that you will take a deep breath to give you strength, and then breathe deeply.*
> - *Visualize a calming image, and remind yourself that you are in control.*
> - *Contract and relax the muscles of your arms and hands, take a deep breath, and tell yourself that you can focus on one step at a time.*
>
> *The key is to learn which strategies work best for you, and to practice.*

Group exercise: Self-instruction and relaxation while re-imagining the past

Describe how stress techniques can be practiced by imagining situations from the past. Say:

> *Like everything you are learning, it is easier to implement these techniques in stressful situations if you have practiced them in advance. One way to practice is to imagine yourself being back in a situation from your past, and to picture yourself handling the stress. The more you practice—even through imagination—the easier it will be to use the techniques in stressful situations.*
>
> *First, think of a stressful situation, perhaps one from your stress journal. The more vividly you can imagine the situation, the more easily you will be able recognize some of the thoughts and feelings you were having at that time.*

Ask for a volunteer to share this past event with the group, and then proceed by asking the participant:

- *What thoughts were going through your mind as you were dealing with the situation? Which were positive self-talk, and which were negative self-talk?*
- *What feelings did you have? Did you feel stressed out, or energized, or relaxed?*
- *What did you do that was helpful? What could you have done differently?*

Now imagine yourself changing the situation, as if you are watching yourself on film but handling the situation better, with the help of positive self-talk, relaxation techniques, or both.

- *What techniques are you using?*
- *What are your thoughts and feelings?*

Ask other group members to provide feedback. As time allows, others can share their examples.

Homework assignment: Relaxation at Rest

Participants continue practicing *Relaxation at Rest* exercises, adding brief relaxation techniques.

Homework assignment: Self-instruction and relaxation in stressful situations

Participants practice the self-instruction and relaxation exercises by re-imagining past stressful situations. Encourage participants to try these techniques in real-life stressful situations they encounter during the week.

Homework assignment: Stress Journal

Participants continue keeping the *Stress Journal.*

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

Caregiver Session 5: Activity Planning

Overview of session
Discussion of homework: • Self-instruction and relaxation in stressful situations
Information: • Setting goals with a Goal Staircase • Activity planning
Group exercise: • Activity planning
Homework assignments: • Setting goals • Activity planning • Bring something pleasant • Stress Journal
Handout: • Caregiver Session 5 Summary Sheet

Discussion of homework

Ask each participant to describe their experiences using self-talk and relaxation in stressful situations. What stressful situations did they use for practice? Who used relaxation techniques, self-talk, or both, in imaginary or real stressful situations? What difficulties did they experience?

Information: Setting goals with a Goal Staircase

In this next component, participants develop individual goals with specific target behaviors. (For more detailed information refer to “Defining goals and target behaviors for each participant” in Chapter 5). Say:

> *Making changes is easier, more effective, and more rewarding if you set goals. A goal is not an abstract hope or wish, but instead is an outcome that you want to achieve. To do that, you will identify specific, concrete behaviors to change: your target behaviors. These behaviors can include not only actions, but also thoughts that you observe*

you are having. To reach a particular goal, you could have one or more target behaviors.

For example, suppose you have a general goal of being better able to take care of your responsibilities on time. To achieve that goal, you could set two target behaviors: to find someone to help you at home, and to reduce your number of outside commitments. If you achieve your targets—in this case, you find someone to help you, and you reduce your outside commitments from 3 per week to 2—you may accomplish the goal of taking care of your responsibilities on time.

To begin with, it is usually more effective to start with one main goal at a time, and to choose target behaviors that are relatively easy to change.

The steps to setting goals and target behaviors are:

1. *Decide on a goal. Select an important concern or difficulty that you would like to address. A goal can be short-term or long-term. If you have more than one major concern, pick the one that is most important to you in the immediate future.*
2. *Describe at least one specific, concrete behavior that you could change that will contribute to the goal—this is a target behavior. Choose a behavior that you can work on in the coming week.*
3. *Set a reasonable level of achievement for the target behavior. Take into account your current level of that behavior, and what is realistic for you to achieve in the near future. The type of target may differ depending on the behavior, e.g., frequency per week, intensity of behavior, or time taken to accomplish a task.*
4. *If desired, you can create a Goal Staircase for the target behavior using a 4-point scale, as follows:*

Your current situation with regard to the behavior is 0, and your target is +1. If you improve beyond your target, your rating would be +2. If your situation worsens, you would be -1, like this (write on flip chart):

+2: better than expected
+1: TARGET
0: unchanged
-1: worse

Although you will be aiming for your target level, different levels of improvement are possible—success is not "all or nothing."

Describe the following example of a Goal Staircase (or use your own example).

Example of a Goal Staircase

A woman who cares for her husband with PD has this goal: “I want to enjoy my life more.”

Comments: This is a very general goal. She chooses a specific target behavior that will contribute to the overall goal. In this case, she chooses to increase the number of enjoyable activities she engages in.

She thinks about the types of enjoyable activities she has done in the past. Her list includes:

- Listening to an opera at home
- Going to the theater
- Taking a hot bath
- Walking in the park
- Sitting in the garden and reading a newspaper
- Drinking tea with her partner

She builds a *Goal Staircase* by setting an achievable number of enjoyable activities as her target, and then identifies steps above and below the target. For example, if she engaged in three enjoyable activities in the past week (assuming it was a typical week), she could set her target at four activities for the week. Her *Goal Staircase* could look like this:

Target behavior: Increase number of enjoyable activities

+2:	5 or more per week
(TARGET) +1:	4 per week
(unchanged) 0:	3 per week
-1:	< 3 per week

Group exercise: Setting goals with a Goal Staircase

Discuss with the group how each of the following goals could be achieved by identifying target behaviors, and (if desired) by building a *Goal Staircase* for each target behavior. What would be a reasonable target level for each behavior?

- I want to feel less stressed when I go out in public with my partner.
- I don’t want my life to be overshadowed so much by my partner’s disease.
- I want to have a better relationship with my partner.
- I want to enjoy my life more.
- I want to better manage my fears about my partner’s disease progressing.

Homework assignment: Setting goals

Explain to participants that they will practice creating and defining their individual goals and target behaviors as homework. They can choose to use a 4-point *Goal Staircase* or simply describe an overall goal with one or two target behaviors.

Information: Activity planning

Explain the purpose of activity planning. Say:

> *The main reason for developing an activity plan is to structure the day so that your activities are better aligned with your goals, needs and abilities, and those of your partner's—not to try to plan every minute of the day. Specifically:*
>
> - *You may be able to prevent situations that are likely to be highly stressful.*
> - *You can identify your highest priority items, giving you a greater sense of achievement and control, with less stress.*
> - *You will have more time for enjoyable activities.*
>
> *The steps for planning activities are:*
>
> 1. *Make a realistic set of activities, aligned with your goals, which may have changed with your partner's PD. It is important to take into account the variability of your partner's PD symptoms throughout the day, as well as your own energy levels.*
> 2. *Make a list of the things you want or need to do in a certain period of time (a day or a week).*
> 3. *Indicate the tasks that are highest priority.*
> 4. *Examine your plan: is it achievable? Build in flexibility.*

Group exercise: Activity planning

Ask participants about times when they had difficulty completing all the activities they wanted or needed to do, and write examples on the flip chart. Discuss factors that may have contributed to their difficulties (e.g., their partner's symptom fluctuations, overestimation of their partner's or their own energy levels/strength, trying to do too much, trying to live up to others' expectations).

Next, ask a participant to describe their daily routine. Write it on the flip chart, and discuss questions such as the following:

- Does the type and total number of activities during the day seem appropriate?
- Does the plan take into account the partner's typical daily fluctuations in symptoms and/or energy levels, as well as their own energy levels?
- Are there sufficient breaks between activities?
- Could the activities be distributed better throughout the day?

- Are pleasant activities included? Is there enough variety in pleasant activities?
- Are there any tasks that could be performed by other people, e.g., other relatives, or professional helpers?

Homework assignment: Activity planning

Go through the homework sheet *Activity Planning for Caregivers*, which involves making a list of priorities and identifying times during the day/week to engage in those activities. Encourage participants to build flexibility into the plan. (Note that if participants do not have a good idea about how their partner's motor symptoms and energy levels fluctuate throughout the day, they may first need to track those levels for several days to identify if there is a pattern.)

Homework assignment: Bring something pleasant

Ask each participant to bring to the next group session at least one object that they find pleasant, invigorating, or relaxing (e.g., a photo, a flower, a ring). Participants can instead (or additionally) "bring" and describe pleasant feelings, fantasies, images, or memories that are particularly important to them.

Homework assignment: Stress Journal

Participants continue keeping the *Stress Journal.* If they succeed in incorporating pleasant activities into their daily life, they can note these in the journal.

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

Caregiver Session 6: Pleasant Activities

Overview of session
Discussion of homework: • Setting goals • Activity planning • Bring something pleasant
Information: • Pleasant activities
Group exercise: • Engaging in pleasant activities
Homework assignment: • Have some fun! • Stress Journal
Handout: • Caregiver Session 6 Summary Sheet

Discussion of homework

Setting goals: Ask participants to describe the personal goal and target behavior(s) they have chosen. Are the behaviors specific and easy to assess? If they used a *Goal Staircase*, were they able to identify different levels of success? Did they have any difficulties? Remind participants that they will be able to modify and add to their goals and target behaviors in the coming weeks.

Activity planning: Discuss how well participants were able to prioritize and plan activities, and whether planning helped to reduce stress. Ask whether any participants felt that the activity plans were not useful, and if so, why not. When this occurs, it is often because caregivers feel that they cannot do what they would like to do because of changes brought about by their partner's illness.

Note that participants will be asked later in the session to describe the pleasant "object" they brought to the session.

Information: Increasing pleasant activities

Describe pleasant activities (see Csikszentmihyalyi, 1990). Say:

Pleasant activities are associated with the experience of pleasure, joy, and a good mood—in other words, with positive feelings. These are usually activities that people engage in for their own sake rather than because they are required to.

A variety of pleasant activities are often associated with the same types of conditions. Specifically:

- *Pleasant activities are often linked to goals.*
- *A person experiencing a pleasant activity may feel fully focused, or "absorbed" in the activity.*
- *Pleasant activities are often accompanied by a broadening of the senses. We may experience everyday stimuli differently than normal. For example, according to psychologist Csikszentmihayli* (1990, p. 213): *"Feeling a breeze on a hot day, seeing a cloud reflected on the glass I of a high-rise, working on a business deal, watching a child play with a puppy, drinking a glass of water can all be felt as deeply satisfying experiences that enrich one's life."*

Pleasant activities are important because they make our lives more intense, rich, and meaningful. They are part of a happy life. Intentionally engaging in pleasant activities can also help lift feelings of depression.

Pleasant activities are especially important for caregivers of people with PD because:

- *If you are no longer able to do all the things you used to do because of your partner's PD, it's important to discover new ways of having pleasant experiences.*
- *If you experience negative feelings such as depression, loneliness, or a feeling of loss of control, you could have less interest in engaging in pleasant activities, which can create a vicious cycle.*

Yet you may feel that you don't have time for them because you have so many other things you have to do or because things take you longer to finish now because of your partner's PD. And even if you do plan to do something fun, you may feel that you can't really enjoy yourself.

For all these reasons, you may need to deliberately work to increase pleasant activities. Like all behaviors, the ability to plan pleasant activities, and to experience enjoyment, can improve with practice.

Keep the following tips in mind:

1. *Take your time.*
2. *"Allow" yourself to experience enjoyment; don't let feelings of guilt creep in.*
3. *Focus on the activity at hand; concentrate, be absorbed in what you are doing.*
4. *Learn what works best for you: get to know what you like best, and what conditions are important for you to experience enjoyment.*

5. *Less is more. Too much of a good thing can actually decrease enjoyment.*
6. *Enjoyment is not just for special occasions. Pleasant activities are available at almost any time; extraordinary experiences are not necessary.*
7. *Practice! Your ability to focus and enjoy activities will increase.*

Discussion of homework/group exercise: Engaging in pleasant activities

Ask participants to briefly describe the pleasant activity, object, or event they brought with them, and to say why they find them pleasant. Ask questions to clarify and expand the descriptions, and record key features on a flip chart. Then discuss questions such as the following:

- What are ways that people can engage in these activities? For example: can they be done alone, or in a group? As a one-off activity or as part of a series of activities or training for a larger event? As a challenge or for pure passive enjoyment?
- How can you increase the number of different types of activities you do?
- What pleasant activities can you do often, on a regular basis?

Homework assignment: Have some fun!

Each participant chooses three enjoyable activities that they will engage in during the coming week. The minimum requirement is to carry out one of these activities every day.

Homework assignment: Stress Journal

Participants continue keeping the *Stress Journal.*

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

Caregiver Session 7: Communication I—Active Listening

Overview of session
Discussion of homework: • Have some fun!
Information: • How PD can affect close relationships • Be an active listener
Group exercises: • Active listening
Homework assignment: • Problems in communication • Stress Journal
Handout: • Caregiver Session 7 Summary Sheet

Discussion of homework

Participants discuss their experiences engaging in pleasant activities. What activities did they do? Which could they do regularly? What additional activities could they consider? What obstacles did they face?

Information: How PD can affect close relationships

Describe how PD can affect close relationships with others. Say:

> *You may have discovered that PD has affected your relationship with your partner. One reason this can happen is that PD can affect the ability to communicate.*
>
> *Some of the symptoms of PD can affect the person's communication abilities directly, such as not speaking loud enough, not responding quickly enough, or having trouble finding the right words. Other symptoms can affect communication indirectly, such as when the person lacks motivation to do things, which can include having conversations with other people. For these reasons, it can be difficult for a person with PD to bring up their problems with people who are close to them.*

> *These challenges can test relationships. You may both feel that the other person doesn't really understand what you are going through, and that other family members and friends don't understand what either of you are experiencing.*

Ask participants for examples of problems in the relationship; write on the flip chart. As needed, you can provide quotes from previous participants that reflect issues of concern, such as:

- "My spouse (person with PD) is more anxious and sensitive than before." You might wonder how and when to talk to them about their worries.
- "Sometimes I just don't know what to do: on one hand, I want to encourage their independence; on the other hand, it would be easier if I did it all myself." You might want or need to take over duties and decision-making responsibilities, but don't know where to draw the line.
- "Dealing with them requires all my patience." You might find yourself getting irritated or annoyed, even though you know that it is not their fault.
- "Dealing with them requires all my time." You might find that you are restricting your own activities due to your partner's illness.
- "We can't do the activities together that we used to do." You might feel sad or annoyed that your life has changed because of your partner's PD.
- "I worry all the time about what will happen next." You might fear that your partner's illness will get worse, or that you will get sick yourself and be unable to care for them.

Information: Be an active listener

Describe active listening. Say:

> *We will next discuss and then practice strategies to make conversations with your partner go better. Today we will focus on the role of the Listener, and in the next session we will focus on the role of the Speaker.*
>
> *Being a good listener means being an active listener, and there are specific techniques you can use to improve your active listening skills* (write notes on flip chart, and provide examples or ask participants for examples):
>
> - *Maintain appropriate eye contact, and show nonverbally that you are listening* (e.g., head nods).
> - *Withhold your own opinion while your partner is speaking.*
> - *Have patience: give them as much time as they need to express themselves.*
> - *To make sure you understand your partner correctly, paraphrase: report back to them what they said, in your own words, and ask if that is what they meant.*
> - *Ask clarifying questions.*
> - *Ask open questions: If you are not sure what they are thinking or feeling, ask them directly what they mean or how they feel.*
> - *Ask follow-up questions to show interest and to understand them better.*

- *Give positive feedback* (e.g., when they explain something openly and clearly, tell them so).
- *Provide feedback about how the interaction makes you feel.*
- *Be honest: If you are unable to engage in a conversation at a particular time, acknowledge those feelings directly.*

Group exercise: Active listening

For this exercise, two participants have a conversation. Designate one person to be the "Speaker," and one to be the "Listener." Ask the Speaker to choose a non-controversial topic such as where they would like to go on vacation, describing their thoughts, feelings, and behaviors as specifically as possible. Ask the Listener to listen actively, keeping in mind the techniques discussed. The other group members observe and give feedback to the Listener.

The Speaker and Listener then switch roles. If time allows, each member of the group takes part in a conversation, as both a Speaker and a Listener.

Homework assignment: Active listening

Participants "observe" conversations with their partner with the goal of being an active listener, following the *Key Points* of active listening.

Homework assignment: Stress Journal

Participants continue keeping the *Stress Journal.*

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

Caregiver Session 8: Communication II—Speaking

Overview of session
Discussion of homework: • Active listening
Information: • Speaking directly
Group exercise: • Speaking directly
Homework assignment: • Conversation practice • Stress Journal
Handout: • Caregiver Session 8 Summary Sheet

Discussion of homework

Participants describe their conversations with their partner. Were they able to use active listening skills? What problems and successes did they observe?

Information: Speaking directly

Describe ways to speak directly. Say:

> *In the last session, we focused on how to be a good listener. In this session we will discuss how to improve communication when you are the Speaker. The way you communicate with your partner affects how willing and motivated they will be to discuss a topic, and how they will respond.*
>
> *You can improve conversations by using direct communication techniques* (modified from Schindler et al., 2007; write notes on flip chart):
>
> - *Before beginning, be sure you have your partner's attention and look at them directly.*
> - *Use the word "I": Describe your own thoughts and feelings. "I think this, I feel that…"*
> - *Open up: Try to be honest about what you are thinking and feeling. Express your needs directly.*

- *Deal with specific situations, and avoid generalizations like "always" or "never." For example, you could say: "I felt frustrated when we were late for an appointment again today" rather than "You always make us late."*
- *When bringing up something related to how your partner is behaving, deal with specific behaviors, and avoid attributing negative characteristics to them. For example, you could say: "When I was trying to help you get ready, I felt like you were annoyed with me because you wouldn't look at me" rather than "You've become such a mean person."*
- *Stay in the present: Talk about what's happening right now, rather than digging up past problems that are no longer as important.*
- *If your partner makes a request that seems unreasonable to you, you can ask about the purpose of the request. Perhaps with more information, you will realize it is something you are willing and able to do.*
- *If you are unwilling or unable to comply with a request, say "no" clearly. Depending on the situation, you may want to explain your reasons for saying no, but do not apologize excessively.*

Group exercise: Speaking directly

Practice these skills in a role-play. Two participants have a conversation. Designate one person to be the Speaker, who will practice direct communication, and one to be the Listener, who will practice active listening and provide positive feedback. Participants can use examples from previous conversations they have had.

Homework assignment: Conversation practice

Participants practice conversation skills from the role-play, with a partner, friend, or another participant, focusing on speaking directly as well as active listening. Encourage participants to use a *Goal Staircase* to set one or more achievable target behaviors that will lead to more effective speaking and listening. For example, they could identify and prepare for conversations with specific people and/or specific topics, or pick specific behaviors to focus on (e.g., eye contact, staying in the present).

Homework assignment: Stress Journal

Participants continue keeping the *Stress Journal*.

Homework assignment: Program review

In preparation for the final session, participants think about their experience of the training program, using the questions on the handout.

Feedback round

Each participant briefly comments about their experience of the session, giving their personal impressions, without discussion.

Caregiver Session 9: Program Review

Overview of session
Discussion of homework: • Conversation practice
Group exercise: • Review of the program and "pack your bags"
Handout: • Caregiver Session 9 Summary Sheet

Discussion of homework

Participants report back on their conversations with a partner, friend, or another participant. Were they able to speak directly? Did they have any difficulties?

Group exercise: Review of the training program and "pack your bags"

For this farewell session, ask each participant to answer the following questions:

- What goals did I achieve?
- How did my achievements compare with my original expectations of the program?
- What are the most important things I learned or experienced during the training program?
- How can I maintain my progress, and apply what I have learned to future situations?
- Which parts of the training, in my view, might be changed or improved in the future?
- What tips and encouragement can I give to others?

The group "packs a suitcase" for each participant's journey through life: each group member "gives" something to every other participant for their journey. Each gift is written onto a suitcase drawn on the flip chart (one participant per page). Say:

> *Each of you will give a gift to every other member, to put in this "suitcase." When deciding on a gift, think about what that person needs for a pleasant and fulfilling journey through life. Take into account:*
>
> - *Difficult, strenuous, and frightening parts of the journey: what would help the person make it through?*
> - *Happy, enjoyable, and satisfying parts of the journey: how can the person most fully experience these parts, and increase their frequency?*

One at a time, “pack a suitcase” for each participant. They can each then roll up their sheet to take home to help them on their journey.

As you say farewell, remind participants about individual and/or group booster sessions and assessment (if possible, schedule the booster sessions when participants first enroll in the group).

Caregiver Program: Booster Session

In a booster session 4 to 8 weeks after training, participants meet again with the therapist and discuss how and in what circumstances they were able to use the skills they acquired during the program. The specific format of the booster session can be modified depending on the needs of the participants.

Discuss questions such as:

- What ideas, techniques, and skills have been helpful?
- What didn't work?
- Are there topics or techniques that it would be helpful to review?
- Are there additional issues that arose? If so, how and where can these needs be addressed?

If desired, you can combine the booster session with repeat assessment.

Chapter 10: Dealing with Specific Problems

In this chapter, we discuss three problem areas that can affect people with PD: freezing of gait, impulse control problems, and hallucinations/delusions. We present a brief outline of how psychological interventions can be used to help manage these issues, whether in individual therapy, couples therapy, or therapy with caregivers.

Freezing of Gait

"Freezing" has been defined as a "brief, episodic absence or marked reduction of forward progression of the feet despite the intention to walk" (Nutt et al., 2011, p. 735). Considerable variability in symptoms among people with PD has made defining and studying this phenomenon difficult. Freezing of gait is relatively common in PD and is more likely to occur as the disease progresses (Fahn, 1995; Giladi, McDermott, et al., 2001; Giladi, McMahon, et al., 1992). Five years after diagnosis, half of people with PD experience freezing; in advanced stages of the disease the percentage increases to 80% (Amarell et al., 2014; Macht et al., 2007). Freezing is associated with falls and restricted mobility, and can cause a great deal of stress and reduced quality of life.

Most freezing episodes last from a couple of seconds up to a minute, but they can sometimes last longer. The episodes often occur during transitions from one type of movement to another, such as when starting to walk, when turning, just before reaching a goal, or upon reaching the top or bottom of a staircase. Episodes are also more likely when there is limited space. In some cases, the person is able to move forward during a freezing episode with very small steps. In other cases, however, there is a complete blockage of movement; the person does not move no matter how hard they try, and the knees and ankles may visibly shake. The affected person may report that they feel as if their feet are glued to the floor, or that an Invisible magnet is holding them down.

Similar types of motor blocks can occur in other areas of the body, including difficulties with finger movements or when trying to speak. An ongoing research question is how these other types of motor blocks are related to freezing of gait (Nutt, 2011). In contrast, cycling movements are rarely affected by freezing (Nonnekes et al., 2015). Thus, cycling may provide an alternative means of exercise, whether outside or on a stationary bicycle.

Many researchers believe that freezing results from degeneration in brain structures that control automatic movements, attention, and visual processing (see Nutt et al., 2011). However, the mechanism underlying freezing is still largely unexplained. Freezing is more likely if the person with PD is distracted, feeling stressed, or under time pressure. For example, freezing may be worse when the person is trying to board a bus or enter an elevator with other people present. These findings demonstrate the importance of psychological factors in understanding and treating freezing.

Assessing and treating freezing

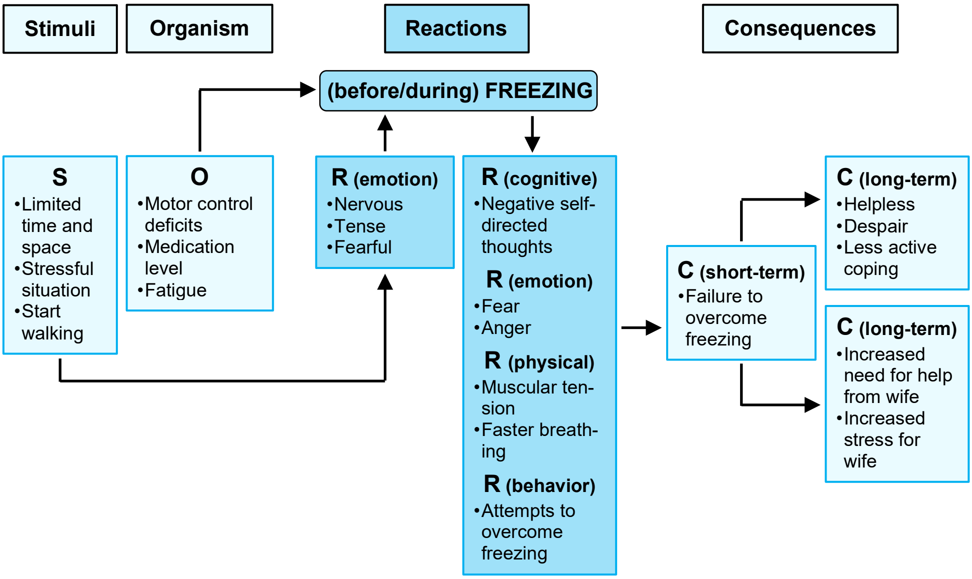
Medical approaches

Because freezing is more likely to occur when the person is in an "off" condition (i.e., when effects of dopamine medication have worn off), the first step for physicians is usually to optimize the medication dosage and schedule. In advanced stages of the disease, when PD medication is no longer as effective, deep brain stimulation (DBS) may be considered, although studies of the effectiveness of DBS have yielded mixed results (Amarell et al., 2014). Less commonly, people with PD may show greater freezing with increased dopamine, or no effects of dopamine levels; thus, a thorough assessment of medication effects is important (Nonnekes et al., 2015).

Non-medical approaches: Using the "SORC" model

Therapists can perform a "situational behavioral analysis" using the SORC model (Stimulus-Organism-Response-Consequences: see Goldfried, 2003) to identify triggers of freezing, and potential targets for change. Just as with stress cycles, one component in the sequence can increase or decrease the likelihood of the next step. A SORC model can be viewed as a way to describe the dynamic flow of behavior in functional terms, disentangling a complex situation in order to faciliate change. Macht & Ellgring (1999) presented a SORC analysis of freezing in a 77-year-old man with PD, as shown in Figure 10.1.

Figure 10.1. Behavioral Analysis of Freezing Behavior (from Macht & Ellgring, 1999)



The components can be further described and illustrated, as follows:

S = Stimulus: the triggering conditions, which can be external and/or internal.

- An example of an external condition is limited space in the environment or a change in the floor pattern. Adapting the home environment by moving obstacles and eliminating tripping hazards such as carpets may be helpful (Amarell et al., 2014). Occupational therapists can provide a more thorough assessment and recommendations for physical adaptation of the environment.
- An example of an internal condition is a person realizing that they have an upcoming doctor's appointment, or simply the person's intention to start walking.

O = Organism: the characteristics of the person, which may be long-term traits, disease effects, or temporary changes. These are modifying factors that can affect how the person reacts to the stimulus.

- An example of a long-term trait is a personality characteristic, such as being someone who worries a lot.
- An example of a disease effect is the person's disease stage of PD, and PD subtype.
- An example of a temporary change is medication effects or fatigue.

R = Reaction: what the person does when the Stimulus occurs. The reaction can include thoughts, feelings, and behaviors.

The freezing episode itself can be considered an example of a reaction to the Stimulus (triggering condition). In addition, feeling nervous when the Stimulus occurs might increase the likelihood of freezing, and increased negative thoughts, fear, and muscular tension could exacerbate the episode as the person tries to overcome the freezing.

C = Consequences: the results, which can be short-term or long-term. In this case, the immediate consequence may be failure to overcome freezing, with longer-term feelings of helplessness and increased dependency.

Applying the SORC model with clients

To conduct a SORC analysis for freezing of gait, ask the participant (or caregiver) to record each time freezing occurs, and to try to identify any triggering conditions (S), modifying factors (O) of the person with PD (e.g., were they tired or having an off-period?), reactions (R; e.g., were they feeling anxious?), and consequences I. You can work through how to do a SORC analysis within the session, which the participant/caregiver then continues at home.

Based on the SORC analysis, we use three main approaches to improve the management of freezing: behavioral cueing, enlisting the help of others, and reducing negative emotions. Although these interventions do not eliminate freezing, they can decrease it substantially, as well as improve the ability to cope (Macht & Ellgring, 1999).

Behavioral cueing

People with PD often develop strategies on their own, such as using visual stimuli or sounds as cues to "release" from freezing (Stern et al., 1980). Examples include:

- Rhythmic sounds (e.g., a metronome, music, loud counting)
- Rhythmic movements with the hands and arms (e.g., clapping hands, slapping legs)
- Visual stimuli (e.g., regular patterns on the floor, small objects to step over)
- Visual imagery (e.g., imagining that they are rising above something).

We help people with PD to develop and practice these types of strategies within the framework of cognitive behavioral therapy (CBT). They can also be used in conjunction with physical therapy. Researchers are developing more technologically-advanced external aids to provide auditory, visual and somatosensory cueing, which may further increase the effectiveness of these techniques (see Sweeney et al., 2019, for a review).

Enlisting the help of others

A person with PD can be best helped by others if they can describe the specific difficulties they are having with freezing. For the therapist, therefore, the first step in this process is often to help the person with PD to communicate what is most helpful to them. For example, they could ask friends and family to help them to identify places and situations where freezing is more likely to occur, to remind them to actively use strategies such as loud counting or clapping hands, or to touch their shoulder if they are experiencing an episode while trying to walk through a door.

Reducing negative emotions

Negative emotions, such as fear of falling, or worry about creating problems for others by moving too slowly, can increase the likelihood and severity of freezing, and can also reduce a person's ability to use strategies to overcome freezing. Therefore, psychological methods to regulate emotions can help in these situations.

Case Study: Hurrying to get ready

Mr. J is in a hurry to get ready to go to work, and is trying to button his coat.

Mrs. J sees that he is having difficulty. She tries to help him and take over the buttoning.

Mr. J, however, feels that his wife is "infantilizing" or humiliating him, and he gets angry and tense. These feelings of anger elicit freezing.

Mrs. J feels that Mr. J is becoming angry and difficult for no good reason.

Comments: For Mr. J, the knowledge that he is in a hurry to get to work and needs to button his coat elicits stress. Together with his PD condition (O), this stimulus situation (S) results in futile efforts to do the buttoning, and a freezing episode I. In addition, his lack of success, together with his wife's attempts to help him (S), elicit anger and the perception of feeling infantilized I and general negative feelings about the relationship (long-term C).

From Mrs. J's perspective, Mr. J's attempts to button his coat (S) elicit her efforts to help him I. She views his refusal to accept help as evidence that he is getting annoyed for no reason, creating a strain in their relationship I.

Note how more than one SORC can be applied in this situation, with each representing one aspect of the dynamic flow of behavior.

The therapist could work with Mr. and Mrs. J to change any of the steps in the sequence. For example:

SORC analysis

S: Mr. and Mrs. J could both agree that Mrs. J will only help when asked.

O: Mr. J could plan his day to include more time to get ready for work.

R: Mr. J could learn to re-interpret his wife's help as support.

C: Mrs. J could learn to recognize how her actions may be perceived, and could explicitly tell Mr. J that she respects his desire for independence and would like to see them working as a team when necessary.

Case Study: Entering elevators

Miss D has problems with freezing when entering elevators in public buildings. Lately, whenever she approaches an elevator and the door opens, she starts to worry that she will have a freezing episode. One day she goes to visit a friend from out of town who is staying at a hotel. As she is trying to enter an elevator, she freezes, and her anxiety increases, which in turn makes her freezing worse. She goes home instead of visiting her friend.

Comments: Entering an elevator (S), together with Miss D's PD medication state and anxiety related to elevators (O), can be viewed as the triggering situation, with Miss D's freezing as a reaction I. Avoiding elevators in the future would then be a consequence I. The therapist could work with Miss D as follows:

SORC analysis

S: Miss D could prepare in advance for this type of situation. For example, she could rehearse saying to another person, "Please, when the elevator comes, could you just tell me 'go!' so I can start walking in? I have Parkinson's disease and this helps me to overcome motor blocks."

O: Miss D could make sure to plan her visits for times when her medication is working optimally.

R: Miss D could practice quick relaxation exercises as she is entering the elevator.

C: Miss D could call her friend to explain the situation, relax herself, and try again to go in the elevator.

Impulse Control Problems

PD can be associated with a variety of impulse control difficulties, including excessive gambling, strong or unusual sexual impulses or actions (hypersexuality), and compulsive thoughts and behaviors, including "punding" (purposeless, stereotyped behaviors). An increase in impulse strength and a decrease in impulse control are believed to be caused by dopaminergic medication, particularly dopamine agonists (Garcia-Ruiz et al., 2014; Voon et al., 2011), although psychosocial factors may contribute (Delaney et al., 2012).

Caregivers often note that the person's personality has changed in a disturbing way. In fact, family members may notice or report changes before the person with PD does. In a study by Baumann-Vogel et al. (2015), 55% of relatives reported that the person with PD showed signs of hypersexuality, compared with only 17% of people with PD who self-reported these signs. Similarly, 22% of relatives vs. 9% of people with PD reported punding.

Assessing and treating impulse control problems

Medical approaches

Evaluation and adjustment of medication should always be the first step in dealing with impulse control problems, as a change in the medication regimen may be the only treatment needed. During medical consultations, it is important for the person with PD and their family members to clearly describe and provide examples of the impulsive behaviors, and to ask how specific medications may be associated with these behavioral changes. If the person with PD does not consider a behavior to be problematic even though family members do, the physician may need to provide additional encouragement for the person to consider a change in medication.

Non-medical approaches

Assessment

When medication changes alone are not effective, psychological assessment and intervention may be needed. A difficulty when assessing impulse control issues is that the person with PD and their family members may consider the behaviors embarrassing or shameful, and may be reluctant to bring them to the attention of the physician or therapist. Therefore, we find it useful to ask directly about increases in impulsive thoughts or behaviors, such as a desire to gamble or unusual sexual thoughts, as part of our routine assessment procedure.

We use a questionnaire entitled *Questionnaire for Impulsive-Compulsive Disorders in Parkinson's Disease* (QUIP; Weintraub et al., 2009), or a revision of the scale that also measures severity (QUIP-RS; Weintraub et al., 2012; reviewed in Evans et al., 2019); see Chapter 5 and Appendix A.

In addition, as with freezing, we use the "SORC" model of behavioral analysis to help identify stimuli (S: thoughts, actions, or situations) that precede and can "trigger" reactions I. For impulse control problems, organism (O) factors can include level of dopamine and effects of medication, as well as other disease or personality characteristics. The problematic reactions I are impulsive thoughts/urges and behaviors. These reactions result in consequences I, which can be short-term or long-term.

To conduct a SORC analysis for impulse control problems, ask the client (or caregiver) to record each time a potentially triggering stimulus occurs, together with reactions (whether positive or negative), and consequences, both short and long-term. We normally work through how to do a SORC analysis within the session, which the client/caregiver then continues at home. For example, seeing or thinking about a casino could serve as a stimulus (S); reactions I could include the impulse to engage in internet gambling or to go to a casino, and actually gambling. Consequences I could be feeling excited (positive short-term consequence), or financial and relationship problems (negative long-term consequences).

Another example is hypersexuality (heightened libido), which can be disturbing for family members and friends, especially when the person with PD exhibits inappropriate behaviors. First, clarify whether the person with PD sees it as a problem, and whether they have already tried to control it. People with PD often report that the sensations associated with sexual impulses are stressful. Second, using a SORC analysis, identify trigger stimuli, reactions, and consequences (which could range from increased use of pornography to sexual assaults).

Interventions

Cognitive Behavioral Therapy (CBT) techniques

When dealing with impulse control problems, we adapt CBT techniques that have been shown to be effective for treatment of obsessive-compulsive disorders, addictions, and other similar disorders. Although conclusive research on the effectiveness of psychotherapeutic treatments for impulse control disorders in PD is not yet available, Okai et al. (2013) showed promising results for the use of CBT in a pilot study.

When designing an intervention, we follow our SORC analysis by identifying the triggering situations; thoughts, feelings and behaviors that occur in reaction to the situations; and the consequences. The goal is to prevent the unwanted consequences by focusing on alternative thoughts or actions earlier in the behavioral chain.

Intervention techniques can include modifying the environment, changing attentional focus on triggers or signs, thought stopping, skills training, conscious use of incompatible alternative behaviors, mindfulness exercises, and changing cognitions about feelings (for a review of behavioral techniques, see Martin & Pear, 2019). Different intervention measures may be appropriate depending on whether the focus is on unwanted thoughts or unwanted behaviors.

For example, mindfulness techniques can be used to weaken the link between an impulse and behavior by enabling the person to identify and “observe” the impulse, and then allow it to subside without acting on it. As another example, alternative behaviors can substitute for unwanted behaviors; one spouse of a man with PD reported that she was able to substitute board games for her husband’s gambling behaviors.

Although an in-depth discussion of behavioral techniques is beyond the scope of this book, an understanding of the symptoms of PD, and in particular, the influence of dopaminergic medication on impulse control, will enable therapists to use psychological principles to treat these issues more effectively.

Couples counseling

For some types of impulse control problems, psychotherapy with the individual may not be sufficient. For example, hypersexuality may threaten a couple’s relationship in ways that the partners are unable or unwilling to discuss with each other. These kinds of issues can be longstanding and may benefit from targeted couples counseling to create open communication.

Hallucinations/Delusions

Psychotic symptoms, such as hallucinations (the experience of perceiving something that is not there) and delusions (false beliefs) can develop as undesirable long-term effects of PD medication. We therefore first recommend consultation with a physician, who may suggest a change in PD medication or the use of atypical neuroleptic medication. In addition, we discuss the symptoms with the person and their family members, and help them to develop ways of managing the symptoms.

One of the earliest symptoms is often vivid nightmares, with confusion, delusions, and/or hallucinations appearing as the disease progresses. Hallucinations in people with PD are typically different from those experienced by people with psychiatric disorders, such as schizophrenia. In PD, hallucinations are usually visual (e.g., seeing a bouquet of flowers on the table as a face, or reporting that unknown people appear unexpectedly), whereas in psychiatric disorders they are more likely to be auditory (e.g., hearing voices).

Psychological techniques for managing hallucinations

Hallucinations are far less stressful for the person with PD if they can recognize the objects as sensory illusions, or "pseudo-hallucinations." Ludin (1995, p. 113, translated from German) reported that a client with PD said "if someone sits down next to me on the train, I don't even look at them anymore, because I know that nobody is there." The illusions can sometimes even be comforting: one doctor reported that a patient asked him to "not take the Japanese woman away" by making him take neuroleptics (Ceballos-Baumann, personal communication, 2017). Reclassifying hallucinations in this way—potentially even viewing them with humor—reduces their threatening quality.

Other possible strategies include adopting a detached attitude toward the hallucinations, distraction, looking closely at or touching the "object," checking the reality of the perceptual illusion, and talking about it. The goal is to put the hallucination into a safe context.

Communication with caregivers

The situation is more difficult when people with PD are unable to "reclassify" these perceptions, and are haunted by fears or think they are losing their minds. They may not tell anyone about their perceptions because they fear a negative reaction. Indeed, caregivers will likely be concerned and feel increased stress if their loved one reports these symptoms. Yet if the person with PD remains silent, the caregiver may nevertheless sense a change in behavior and wonder why they are acting differently. Encouraging and supporting honest reports of symptoms is critical in order for treatment to be initiated.

How caregivers communicate with the person with PD when addressing these concerns is very important. It is usually not helpful for the caregiver to try to convince the person that their perceptions are not based in reality; this approach may lead them to feel that they are not being taken seriously. Instead, caregivers can acknowledge that the perception is real for the other person, but that they themselves do not see it. When dealing with hallucinations, it may be helpful to suggest a change in location, such as going into another room, away from the hallucinated object.

Caregivers can also remind the person with PD that the hallucinations and delusions are caused by medication. In any case, we recommend alerting a physician at the first stages, such as when unusually vivid or threatening nightmares are reported.

Final Words

People with PD and their caregivers face challenges that can be difficult to understand and navigate. Although PD is a progressive disease with no cure at this time, medication and other medical treatments give people with PD the potential to maintain a high quality of life for years after diagnosis. One of our primary goals is to support clients in making the most of these treatments. By expanding our perspective of PD from a purely medical condition towards one that views the disease as part of a larger biopsychosocial system, the extent of potential needs becomes apparent—as do the possibilities for a wider range of effective treatments.

Although the first attempts to use psychological interventions to help people with PD can be traced back to 1955 (Chafetz et al.), only a few case reports and pilot studies were published in the decades that followed. Controlled studies of treatment efficacy did not appear until the turn of the millennium. These studies showed that psychotherapeutic methods can help coping efforts significantly: to manage problems with movement, to deal with anxiety and depression, to improve communication. Unfortunately, such approaches are too rarely used. Many people with PD, caregivers, and medical professionals simply do not know about the benefits of psychotherapy and some may not believe in its power. But psychotherapy can help, in particular when life seems hopeless, and this is too often the case with PD.

The interventions presented here provide practical information and structure for mental health professionals to enhance their delivery of services to those in need. Individuals living with PD–whether they have the disease themselves or are caring for someone who does—may also benefit from reading this book, with support from a professional.

We believe that these interventions, in conjunction with medical treatment, can empower clients to try new ways of thinking and behaving, and increase their flexibility to cope with challenges as they arise. Our programs are supported by empirical evidence, where available, as well as by clinical experience. By providing a structured format, we hope that the interventions in this book will be used as a basis for research to further evaluate and expand their effectiveness.

We would appreciate feedback from anyone reading this book or using these programs. Please contact any of the authors at the addresses listed in the Preface.

References

Aarsland, D., Beyer, M. K., & Kurz, M. W. (2008). Dementia in Parkinson's disease. *Current Opinion in Neurology, 21,* 676-682.

Aarsland, D., Pahlhagen, S., Ballard, C. G., Ehrt, U., & Svenningson, P. (2012). Depression in Parkinson disease—epidemiology, mechanisms and management. *Nature Reviews Neurology, 8,* 35-47.

A'Campo, L. E. I., Spliethoff-Kamminga, N. G. A., Macht, M., EduPark Consortium, & Roos, R. A. C. (2010). Caregiver education in Parkinson's disease: Formative evaluation of a standardized program in seven European countries. *Quality of Life Research, 19*(1)*,* 55-64.

A'Campo, L. E. I., Wekking, E. M., Spliethoff-Kamminga, N. G. A., Le Cessie, S., & Roos, R. A. C. (2010). The benefits of a standardized patient education program for patients with Parkinson's disease and their caregivers. *Parkinsonism and Related Disorders, 16,* 89-95.

A'Campo, L. E. I., Wekking, E. M., Spliethoff-Kamminga, N. G. A., Stijnen, T., & Roos, R. A. C. (2012). Treatment effect modifiers for the patient education programme for Parkinson's disease. *International Journal of Clinical Practice, 66*(1), 77-83.

Advocat, J., Enticott, J., Vandenberg, B., Hassed, C., Hester, J., & Russell, G. (2016). The effects of a mindfulness-based lifestyle program for adults with Parkinson's disease: A mixed methods, wait list controlled randomised control study. *BMC Neurology, 16*(1), 166. https://doi.org/10.1186/s12883-016-0685-1

Amarell, M., Cepuran, F., Timmermann, L., Allert, N., & Barbe, M. T. (2014). Diagnostik und Therapie von "Freezing of Gait" bei Patienten mit Morbus Parkinson [Diagnostics and therapy for "freezing of gait" in Parkinson's disease patients]. *Fortschritte der Neurologie und Psychiatrie, 82*, 593–605.

Argaud, S., Verin, M., Sauleau, P., & Grandjean, D. (2018). Facial emotion recognition in Parkinson's disease: A review and new hypotheses. *Movement Disorders, 33*(4), 554-567.

Armento, M. E. A., Stanley, M. A., Marsh, L., Kunik, M. E., York, M. K., Bush, A. L., & Calleo, J. S. (2012). Cognitive behavioral therapy for depression and anxiety in Parkinson's disease: A clinical review. *Journal of Parkinson's Disease, 2*, 135-151.

Armstrong, M. J., & Okun, M. S. (2020). Diagnosis and treatment of Parkinson Disease: A review. *Journal of the American Medical Association*, 323(6), 548-560.

Antonini, A., Odin, P., Pahwa, R., Aldred, J., Alobaidi, A., Jalundhwala, Y. J., Kukreja, P., Bergmann, L., Inguva, S., Bao, Y., & Chaudhuri, K. R. (2021). The long-term impact of levodopa/carbidopa intestinal gel on “off”-time in patients with advanced Parkinson’s disease: A systematic review. *Advances in Therapy, 38*, 2854-2890.

Arroyo, A., Periáñez, J. A., Ríos-Lago, M., Lubrini, G., Andreo, J., Benito-León, J., Louis, E. D., & Romero, J. P. (2021). Components determining the slowness of information processing in Parkinson’s disease. *Brain and Behavior*, 11(3), Article e02031. https://doi.org/10.1002/brb3.2031

Barichella, M., Cereda, E., & Pezzoli, G. (2009). Major nutritional issues in the management of Parkinson’s disease. *Movement Disorders, 24*(13), 1881-1892.

Barnish, M. S., Horton, S. M., Butterfint, Z. R., Clark, A. B., Atkinson, R. A., & Deane, K. H. O. (2017). Speech and communication in Parkinson’s disease: A cross-sectional exploratory study in the UK. *British Medical Journal Open*, *7*(5), Article e014642. https://doi.org/10.1136/bmjopen-2016-014642

Baumann-Vogel, H., Valko, P. O., Eisele, G., & Baumann, C. R. (2015). Impulse control disorders in Parkinson’s disease: Don’t set your mind at rest by self-assessment. *European Journal of Neurology, 22*(4), 603-609.

Beck, A. T. (1993). Cognitive therapy: Past, present, and future. *Journal of Consulting and Clinical Psychology, 61*(2), 194-198.

Behrman, A., Cody, J., Elandary, S., Flom, P., & Chitnis, S. (2020). The effect of SPEAK OUT! And The LOUD Crowd on dysarthria due to Parkinson’s disease. *American Journal of Speech-Language Pathology, 29*, 1448-1465.

Beier, K. M., Lüders, M., & Boxdorfer, S. A. (2000). Sexualität und Partnerschaft bei Morbus Parkinson [Sexuality and partnership in Parkinson’s disease]. *Fortschritte der Neurologie-Psychiatrie (Thieme), 68*(12), 564-575. https://doi.org/10.1055/s-2000-10040

Berardelli, I., Bloise, M. C., Bologna, M., Conte, A., Pompili, M., Lamis, D. A., Pasquini, M., & Fabbrini, G. (2018). Cognitive behavioral group therapy versus psychoeducational intervention in Parkinson’s disease. *Neuropsychiatric Disease and Treatment, 14*, 399-405.

Bernstein, D. A., & Borkovec, T. D. (1973). *Progressive relaxation training: A manual for the helping professions*. Research Press.

Biundo, R., Weis, L., & Antonini, A. (2016). Cognitive decline in Parkinson’s disease: The complex picture. *NPJ Parkinson’s Disease*, *2*(1), 1-7. https://doi.org/10.1038/npjparkd.2016.18

Boersma, I., Jones, J., Carter, J., Bekelman, D., Miyasaki, J., Kutner, J., & Kluger, B. (2016). Parkinson disease patients’ perspectives on palliative care needs: What are they telling us? *Neurology Clinical Practice, 6*(3), 209-219.

Bologna, M., Fabbrini, G., Marsili, L., Defazio, G., Thompson, P. D., & Berardelli, A. (2013). Facial bradykinesia. *Journal of Neurology, Neurosurgery & Psychiatry, 84*(6), 681-685.

Bowers, D., Miller, K., Mikos, A., Kirsch-Darrow, L., Springer, U., Fernandez, H., Foote, K., & Okun, M. (2006). Startling facts about emotion in Parkinson's disease: Blunted reactivity to aversive stimuli. *Brain, 129*(12), 3356-3365.

Braak, H., Del Tredici, K., Rub, U., de Vos, R.A.I., Steur, E., & Braak, E. (2003). Staging of brain pathology related to sporadic Parkinson's disease. *Neurobiology and Aging*, 24, 197–211. https://doi.org/10.1016/S0197-4580(02)00065-9

Broen, M. P. G., Narayen, N. E., Kuijf, M. L., Dissanayaka, N. N. W., & Leentjens, A. F. G. (2016). Prevalence of anxiety in Parkinson's disease: A systematic review and meta-analysis. *Movement Disorders, 31*(8), 1125–1133. https://doi.org/10.1002/mds.26643

Bronner, G., Royter, V., Korczyn, A., & Giladi, N. (2004). Sexual dysfunction in Parkinson's disease. *Journal of Sex and Marital Therapy, 30*(2), 95-105.

Brown, R., & Jahanshahi, M. (1995). Depression in Parkinson's disease: A psychosocial viewpoint. In W. J. Weiner & A. E. Lang (Eds.), *Advances in Neurology. Behavioral Neurology of Movement Disorders* (pp. 61-84). Raven Press.

Buck, R. (1984). *The communication of emotion*. Guilford Press.

Buhmann, C., Dogac, S., Vettorazza, E., Hidding, U., Gerloff, C., & Jurgens, T. P. (2017). The impact of Parkinson disease on patients' sexuality and relationship. *Journal of Neural Transmission, 124*, 983-996.

Buxton, S. L., MacDonald, L., & Tippett, L. J. (2013). Impaired recognition of prosody and subtle emotional facial expressions in Parkinson's disease. *Behavioral Neuroscience, 127*(2), 193-203.

Calleo, J. S., Amspoker, A. B., Sarwar, A. I., Kunik, M. E., Jankovic, J., Marsh, L., York, M., & Stanley, M. A. (2015). A pilot study of a cognitive–behavioral treatment for anxiety and depression in patients with Parkinson disease. *Journal of Geriatric Psychiatry and Neurology*, *28*(3), 210-217.

Canivet, C., Costa, N., Ory-Magne, F., Arcari, C., Mohara, C., Pourcel, L., Derumeaux, H., Berard, E., Bourrel, R., Molinier, L., & Brefel-Courbon, C. (2016). Clinical impact and cost-effectiveness of an education program for PD patients: A randomized controlled trial. *PloS ONE, 11*(9). https://doi.org/10.1371/journal.pone.0162646

Chafetz, M. E., Bernstein, N., Sharpe, W., & Schwag, R. (1955). Short-term group therapy of patients with Parkinson´s disease. *New England Journal of Medicine, 253*, 961-964.

Chahine, L. M., Edison, B., Daeschler, M., Mantri, S., Kahl, S., Rapoport, R., Goyle, A., Precht, C., Kopil, C., & Marras, C. (2020). The most bothersome aspects of off periods reported by individuals with Parkinson's disease. *Movement Disorders, 7*(3), 284-292.

Chahine, L. M., Feldman, R., Althouse, A., Torsney, B., Alzyoud, L., Mantri, S., Edison, B., Albert, S., Daeschler, M., Kopil, C., & Marras, C. (2021). Contribution of neuropsychiatric symptoms in Parkinson's disease to different domains of caregiver burden. *Journal of Neurology, 268*, 2961-2972.

Chlond, M., Bergmann, F., Güthlin, C., Schnoor, H., Larisch, A., & Eggert, K. (2016). Patient education for patients with Parkinson's disease: A randomised controlled trial. *Basal Ganglia*, *6*(1), 25-30.

Chung, W., Poppen, R., & Lundervold, D. A. (1995). Behavioral relaxation training for tremor disorders in older adults. *Biofeedback and Self-Regulation, 20*(2), 123-135.

Corti, O., Lesage, S., & Brice, A. (2011). What genetics tells us about the causes and mechanisms of Parkinson's disease. *Physiological Reviews, 91*(4), 1161–1218.

Csikszentmihalyi, M. (1990). *Flow: The psychology of optimal experience*. Harper & Row.

Dakof, G. A., & Mendelsohn, G. A. (1989). Patterns of adaptation to Parkinson's disease. *Health Psychology, 8(3),* 355–372.

Dara, C., Monetta, L., & Pell. M. D. (2008). Vocal emotion processing in Parkinson's disease: Reduced sensitivity to negative emotions. *Brain Research, 1188*, 100-111.

Davie, C. A. (2008). A review of Parkinson's disease. *British Medical Bulletin, 86,* 109-127.

Delaney, M., Leroi, I., Simpson, J., & Overton, P. G. (2012). Impulse control disorders in Parkinson's disease: a psychosocial perspective. *Journal of Clinical Psychology in Medical Settings*, *19*(3), 338-346.

Den Brok, M. G., van Dalen, J. W., van Gool, W. A., Moll van Charante, E. P., de Bie, R. M., & Richard, E. (2015). Apathy in Parkinson's disease: A systematic review and meta-analysis. *Movement Disorders*, *30*(6), 759-769.

Dissanayaka, N. N. W., Pye, D., Mitchell, L. K., Byrne, G. J., O'Sullivan, J. D., Marsh, R., & Pachana, N. A. (2016). Cognitive behavior therapy for anxiety in Parkinson's disease: Outcomes for patients and caregivers. *Clinical Gerontologist, 40*(3), 159-171. https://doi.org/10.1080/07317115.2016.1240131

Dobkin, R. D., Mann, S. L., Interian, A., Gara, M. A., & Menza, M. (2019). Cognitive behavioral therapy improves diverse profiles of depressive symptoms in Parkinson's disease. *International Journal of Geriatric Psychiatry, 34*(5), 722-729. https://doi.org/10.1002/gps.5077

Dobkin, R. D., Menza, M., Allen, L. A., Gara, M. H., Tiu, J., Bienfait, K. L., & Friedman, J. (2011). Cognitive-behavioral therapy for depression in Parkinson's disease: A randomized, controlled trial. *The American Journal of Psychiatry, 168,* 1066-1074. https://doi.org/10.1176/appi.ajp.2011.10111669

Dobkin, R. D., Menza, M., & Bienfait, K. L. (2008). CBT for the treatment of depression in Parkinson's disease: A promising non-pharmacological approach. *Expert Review of Neurotherapeutics, 8*(1), 27-35.

Dobkin, R. D., Rubino, J. T., Allen, L. A., Friedman, J., Gara, M. A., Mark, M. H., & Menza, M. (2012). Predictors of treatment response to cognitive-behavioral therapy for depression in Parkinson's disease. *Journal of Consulting and Clinical Psychology, 80*(4), 694–699. https://doi.org/10.1037/a0027695

Doty, R. L. (2012). Olfactory dysfunction in Parkinson disease. *Nature Reviews Neurology*, *8*(6), 329-339.

Dunstan, D., & Scott, N. (2018). Assessing clinical significance and symptom severity using the Zung Scales: Levels of misclassification arising from confusion between index and raw scores. *Depression Research and Treatment.* https://doi.org/10.1155/2018/9250972

Ekker, M. S., Janssen, S., Nonnekes, J., Bloem, B. R., & De Vries, N. M. (2015). Neurorehabilitation for Parkinson's disease: Future perspectives for behavioural adaptation. *Parkinsonism & Related Disorders, 22*, S73-S77. https://doi.org/10.1016/j.parkreldis.2015.08.031

Elfil, M., Kamel, S., Kandil, M., Koo, B. B., & Schaefer, S. M. (2020). Implications of the gut microbiome in Parkinson's disease. *Movement Disorders, 35*(6), 921-933. https://doi.org/10.1002/mds.28004

Ellgring, H., Gerlich, C., Macht, M., Schradi, M., & EduPark-Konsortium (Eds.). (2006). *Psychosoziales Training bei Neurologischen Erkrankungen–Schwerpunkt Parkinson. Ein Programm für die Schulung von Patienten und Angehörigen* [*Psychosocial training in neurological diseases—focus on Parkinson's disease. An education program for patients and families*]. Kohlhammer.

Ellgring, H., Oertel, W., Ploog, D., & Struppler, A. (1989). Verbesserung der Psychosozialen Anpassung bei Parkinson Patienten [Improving psychosocial adjustment in Parkinson's disease patients]. Unpublished interim report for Robert Bosch Foundation, Max Planck Institute for Psychiatry, Munich.

Ellgring, H., Seiler, S., Perleth, B., Frings, W., Gasser, T., & Oertel, W. (1993). Psychosocial aspects of Parkinson's disease. *Neurology, 43*(6, Suppl), S41-S44.

Enrici, I., Adenzato, M., Ardito, R. B., Mitkova, A., Cavallo, M., Zibetti, M., Lopiano, L., & Castelli, L. (2015). Emotion processing in Parkinson's disease: A three-level study on recognition, representation, and regulation. *PloS ONE*, *10*(6), Article e0131470. https://doi.org/10.1371/journal.pone.0131470

Evans, A., Okai, D., Weintraub, D., Lim, S. -Y., O'Sullivan, S. S., Voon, V., Krack, P., Sampaio, C., Post, B., Leentjens, A. F. G., Martinez-Martin, P., Stebbins, G. T., Goetz, C. G., Schrag, A., & members of the International Parkinson and Movement Disorder Society (IPMDS) Rating Scales Review Committee. (2019). Scales to assess impulsive and compulsive behaviors in Parkinson's disease: Critique and recommendations. *Movement Disorders, 34*(6), 791-798. https://doi.org/10.1002/mds.27689

Even, C., & Weintraub, D. (2012). Is depression in Parkinson's Disease (PD) a specific entity? *Journal of Affective Disorders*, *139*(2), 103-112.

Fahn, S. (1995). The freezing phenomenon in Parkinsonism. In S. Fahn, M. Hallet, H. O. Lüders, & C. D. Marsden (Eds.), *Negative motor phenomena* (pp. 53-63). Lippincott-Raven-Publishers.

Fredericks, D., Norton, J. C., Atchinson, C., Schoenhaus, R., & Pill, M. W. (2017). Parkinson's disease and Parkinson's disease psychosis: A perspective on the challenges, treatments, and economic burden. *American Journal of Managed Care, 23*(5, Suppl.), S83-S92.

Fričová, D., Korchak, J. A. & Zubair, A. C. (2020). Challenges and translational considerations of mesenchymal stem/stromal cell therapy for Parkinson's disease. *NPJ Regenerative Medicine,* 5(20). https://doi.org/10.1038/s41536-020-00106-y

Fullard, M. E., Morley, J. F., & Duda, J. E. (2017). Olfactory dysfunction as an early biomarker in Parkinson's disease. *Neuroscience, 33*(5), 515-525. https://doi.org/10.1007/s12264-017-0170-x

Garcia-Ruiz, P. J., Martinez Castrillo, J. C., Alonso-Canovas, A., Barcenas, A. H., Vela, L., Alonso, P. S., Mata, M., Gonzalez, N. O., & Fernandez, I. M. (2014). Impulse control disorder in patients with Parkinson's disease under dopamine agonist therapy: A multicentre study. *Journal of Neurology, Neurosurgery & Psychiatry, 85*(8), 840-844.

Gibb, W. R. G., & Lees, A. J. (1988). The relevance of the Lewy body to the pathogenesis of idiopathic Parkinson's disease. *Journal of Neurology, 51*, 745-752.

Giladi, N., McDermott, M. P., Przedborski, S., Jankovic, J., Stern, M., Tanner, C., & The Parkinson Study Group (2001). Freezing of gait in PD: Prospective assessment in the DATATOP cohort. *Neurology, 56*, 1712-1721.

Giladi, N., McMahon, D., Przedborski, S., Flaster, Guillory, S., Kostic, V., & Fahn, S. (1992). Motor blocks in Parkinson's disease. *Neurology, 42,* 333-339.

Gillivan-Murphy, P., Miller, N., & Carding, P. (2019). Voice treatment in Parkinson's disease: Patient perspectives. *Research and Reviews in Parkinsonism, 9*, 29-42. https://doi.org/10.2147/JPRLS.S180183

Goldfried, M. R. (2003). Cognitive-behavior therapy: Reflections on the evolution of a therapeutic orientation. *Cognitive Therapy and Research, 27*(1), 53-69.

Gray, H. M., & Tickle-Degnen, L. (2010). A meta-analysis of performance on emotion recognition tasks in Parkinson's disease. *Neuropsychology, 24*(2), 176.

Griffin, W. A., & Greene, S. M. (1994). Social interaction and symptom sequences: A case study of orofacial bradykinesia exacerbation in Parkinson's disease during negative marital interaction. *Psychiatry*, *57*(3), 269-274.

Grimm, J., & Grimm, W. (1884). The fox and the geese. In M. Hunt (Trans.) *Household Tales*. George Bell.

Grun, D., Pieri, V., Vaillant, M., & Diederich, N. J. (2016). Contributory factors to caregiver burden in Parkinson disease. *Journal of the American Medical Directors Association, 17*, 626-632. https://doi.org/10.1016/j.jamda.2016.03.004

Guo, L., Jiang, Y., Yatsuya, H., Yoshida, Y., & Sakamoto, J. (2009). Group education with personal rehabilitation for idiopathic Parkinson's disease. *The Canadian Journal of Neurological Sciences, 36*, 51-59.

Hand, A., Oates, L. L., Gray, W. K., Dismore, L. L., Baker, K., Naisby, J., & Walker, R. W. (2021). Understanding caregiver strain in Parkinsonism—A mixed methods approach. *Journal of Geriatric Psychiatry and Neurology, 35*(3), 363-373. https://doi.org/10.1177/0891988721996819

Hauptmann, A. (1922). Der "Mangel an Antrieb"—von innen gesehen [A "lack of motivation"—seen from the inside]. *Archiv für Psychiatrie und Nervenkrankheiten, 66,* 615–686.

Hellqvist, C., Berterö, C., Dizdar, N., Sund-Levander, M., & Hagell, P. (2020). Self-management education for persons with Parkinson's disease and their care partners: A quasi-experimental case-control study in clinical practice. *Parkinson's Disease,* Article 6920943. https://doi.org/10.1155/2020/6920943

Hellqvist, C., Berterö, C., Hagell, P., Dizdar, N., & Sund-Levander, M. (2020). Effects of self-management education for persons with Parkinson's disease and their care partners: A qualitative observational study in clinical care. *Nursing & Health Sciences*, *22*(3), 741-748. https://doi.org/10.1111/nhs.12721

Hinrichs, M. (1992). Sprechen über die Parkinson-Erkrankung: Einfluß demographischer und krankheitsbezogener Merkmale und Zusammenhänge zur emotionalen Krankheitsbewältigung [Talking about Parkinson's disease: Influence of demographic and disease-related characteristics on emotional coping with the disease]. [Unpublished master's thesis]. Free University Berlin.

Hipp, G., Diederich, N. J., Pieria, V., & Vaillant, M. (2014). Primary vision and facial emotion recognition in early Parkinson's disease. *Journal of the Neurological Sciences, 338*(1-2), 178-182.

Hirsch, L., Jette, N., Frolkis, A., Steeves, T., & Pringsheim, T. (2016). The incidence of Parkinson's disease: A systematic review and meta-analysis. *Neuroepidemiology, 46*, 292-300.

Hoehn, M., & Yahr, M. (1967). Parkinsonism: Onset, progression, and morality. *Neurology, 17,* 427-442.

Hopkinson, M. D., Reavell, J., Lane, D. A., & Mallikarjun, P. (2019). Cognitive behavioral therapy for depression, anxiety, and stress in caregivers of dementia patients: A systematic review and meta-analysis. *The Gerontologist, 59*(4), e343-e362. https://doi.org/10.1093/geront/gnx217

Horsager, J., Knudsen, K., & Sommerauer, M. (2022). Clinical and imaging evidence of brain-first and body-first Parkinson's disease. *Neurobiology of Disease*, *164*, 105626. https://doi.org/10.1016/j.nbd.2022.105626

Ille, R., Wabnegger, A., Schwingenschuh, P., Katschnig-Winter, P., Kögl-Wallner, M., Wenzel, K., & Schienle, A. (2016). Intact emotion recognition and experience but dysfunctional emotion regulation in idiopathic Parkinson's disease. *Journal of the Neurological Sciences, 361*, 72-78. https://doi.org/10.1016/j.jns.2015.12.007

Jahanshahi, M., & Marsden, C. D. (2000). *Parkinson's disease: A self-help guide*. Demos Medical Publishing.

Katsikitis, M., & Pilowsky, I. (1996). A controlled study of facial mobility treatment in Parkinson's disease. *Journal of Psychosomatic Research, 40*(4), 387-396.

Kehagia, A. A., Barker, R. A., & Robbins, T. W. (2010). Neuropsychological and clinical heterogeneity of cognitive impairment and dementia in patients with Parkinson's disease. *Neurology, 9*, 1200-1213.

Kowal, S. L., Dall, T. M., Chakrabarti, R., Storm, M. V., & Jain, A. (2013). The current and projected economic burden of Parkinson's disease in the United States. *Movement Disorders, 28*(3), 311-318.

Koychev, I., & Okai, D. (2017). Cognitive–behavioural therapy for non-motor symptoms of Parkinson's disease: A clinical review. *BMJ Mental Health*, *20*(1), 15-20.

Kwan, L. C., & Whitehill, T. L. (2011). Perception of speech by individuals with Parkinson's disease: A review. *Parkinson's Disease.* https://doi.org/10.4061/2011/389767

Langston, J. W. (1985). MPTP and Parkinson's disease. *Trends in Neurosciences*, *8*, 79-83.

Lawrence, A. D., Goerendt, I. K., & Brooks, D. J. (2011). Apathy blunts neural response to money in Parkinson's disease. *Social Neuroscience, 6*(5-6), 653-662.

Levy, E. S., Moya-Gale, G., Change, Y. H. M., Freeman, K., Forrest, K., Brin, M. F., & Ramig, L. A. (2020). The effects of intensive speech treatment on intelligibility in Parkinson's disease: A randomised controlled trial. *EclincicalMedicine, 24.* https://doi.org/10.1016/j.eclinm.2020.100429

Lhommée, E., Klinger, H., Thobois, S., Schmitt, E., Ardouin, C., Bichon, A., Kistner, A., Fraix, V., Xie, J., Kombo, M. A., Chabardes, S., Seigneuret, E., Benabid, A. -L., Mertens, P., Polo, G., Carnicella, S., Quesada, J. -L., Bosson, J. -L., Broussolle, E., Pollak, P., & Krack, P. (2012). Subthalamic stimulation in Parkinson's disease: Restoring the balance of motivated behaviours. *Brain, 135*, 1463-1477. https://doi.org/10.1093/brain/aws078

Livingstone, S. R., Vezer, E., McGarry, L. M., Lang, A. E., & Russo, F. A. (2016). Deficits in the mimicry of facial expressions in Parkinson's disease. *Frontiers in Psychology, 7.* https://doi.org/10.3389/fpsyg.2016.00780

Ludin, H.-P. (1995). Das Parkinsonsyndrom (2. Aufl.) [Parkinson's syndrome (2nd ed.)]. Kohlhammer.

Lundervold, D. A., Belwood, M. F., Craney, J. L., & Poppen, R. (1999). Reduction of tremor severity and disability following behavioral relaxation training. *Journal of Behavior Therapy and Experimental Psychiatry, 30*, 119–135.

Macht, M., & Ellgring, H. (1999). Behavioral analysis of the freezing phenomenon in Parkinson's disease: A case study. *Journal of Behavior Therapy & Experimental Psychiatry, 30*, 241–249.

Macht, M., & Ellgring, H. (2003). Belastungsfragebogen für Parkinson-Patienten (BELA) [Stress Questionnaire for Parkinson's Disease Patients (SQPD-P)]. In *Psychologische Interventionen bei der Parkinson-Erkrankung. Ein Behandlungsmanual* (pp. 208–217). Kohlhammer.

Macht, M., Gerlich C., Ellgring, H., Schradi, M., Bayés Rusiñol, M., Crespo, M., Prats, A., Viemero, V., Lankinen, A., Ricci Bitti, P. E., Candini, L., Spliethoff-Kamminga, N., de Vreugd, J., Simons, G., Smith Pasqualini, M., Thompson, S. B. N., Taba, P., Krikmann, U., & Kanarik, E. (2007). Patient education in Parkinson's disease: Formative evaluation of a standardized programme in seven European countries. *Patient Education and Counselling, 65*, 245-252.

Macht, M., Kaussner, Y., Möller, J. C., Karin Stiasny-Kolster, K. , Karla Maria Eggert, K. M., Krüger, H.-P., & Ellgring, H. (2007). Predictors of freezing in Parkinson's disease: A survey of 6,620 patients. *Movement Disorders, 22*, 953-956.

Macht, M., Klecker, J., Pfeiffer, B., Annecke, R., Ulm, G., & Ellgring, H. (2000). Wirkungen von Entspannung und Musik auf Befinden und Motorik von Parkinson-Patienten [Effects of relaxation and music on well-being and motor function in Parkinson's disease patients]. *Verhaltenstherapie, 10*, 25-30.

Macht, M., Schwarz, R., & Ellgring, H. (1999a). Psychosoziale Belastungen bei Parkinson-Patienten: Ausgewählte Ergebnisse einer bundesweiten Befragung [Psychosocial stress in Parkinson's disease patients: Results from a nationwide survey]. *Sexualmedizin für den Arzt, 2,* 18-21.

Macht, M., Schwarz, R., & Ellgring, H. (1999b). Wirkungen eines Trainings der krankheitsbezogenen Kommunikation bei jüngeren und älteren Parkinson-Patienten [Effects of training in disease-related communicaton in younger and older Parkinson's disease patients]. *Verhaltenstherapie und Verhaltensmedizin, 20(3)*, 343-357.

Macht, M., Schwarz, R., & Ellgring, H. (2005). Patterns of psychological problems in Parkinson's disease. *Acta Neurologica Scandinavica, 111*, 95–101.

Macht, M., Smith Pasqualini, M., & Taba, P. (2007). Cognitive-behavioral strategies for Parkinson's disease: A report of three cases. *Journal of Clinical Psychology in Medical Settings, 14*, 165–176.

MacPhillamy, D. J., & Lewinsohn, P. M. (1982). The Pleasant Events Schedule: Studies on reliability, validity, and scale intercorrelation. *Journal of Consulting and Clinical Psychology*, *50*(3), 363-380.

Mantri, S., Klawson, E., Albert, S., Nabieva, K., Lepore, M., Kahl, S., Daeschler, M., Mamikonyan, E., Kopil, C., Marras, C., & Chahine, L. M. (2020). Understanding the lexicon of fatigue in Parkinson's disease. *Journal of Parkinson's Disease, 10*, 1185-1193.

Margolesky, J., & Singer, C. (2018). Extended-release oral capsule of carbidopa–levodopa in Parkinson disease. *Therapeutic Advances in Neurological Disorders*, *11*, 1-12.

Marras, C., Beck, J. C., Bower, J. H., Roberts, E., Ritz, B., Ross, G. W., Abbott, R. D., Savica, R., Van Den Eeden, S. K., Willis, A. W., & Tanner, C. M. (2018). Prevalence of Parkinson's disease across North America. *NPJ Parkinson's Disease, 21*. https://doi.org/10.1038/s41531-018-0058-0

Martin, G. P., McDonald, K. R., Allsop, D., Diggle, P. J., & Leroi, I. (2020). Apathy as a behavioural marker of cognitive impairment in Parkinson's disease: A longitudinal analysis. *Journal of Neurology*, *267*(1), 214-227.

Martin, G., & Pear, J. (2019). *Behavior modification: What it is and how to do it.* Routledge.

Martinez-Martin, P., Rodriguez-Blazquez, C., & Joao Forjaz, M. (2012). Quality of life and burden in caregivers for patients with Parkinson's disease: Concepts, assessment and related factors. *Expert Review of Pharmacoeconomics & Outcomes Research, 12*(2), 221-230.

McRae, C., Cherin, E., Yamazaki, G., Diem, G., Vo, A. H., Russell, D., Ellgring, J. H., Fahn, S., Greene, P., Dillon, S., Winfield, H., Bjugstad, K. B., & Freed, C. R. (2004). Effects of perceived treatment on quality of life and medical outcomes in a double-blind placebo surgery trial. *Archives of General Psychiatry, 61*, 412-627.

McRae, C., Fazio, E., Hartsock, G., Kelley, L., Urbanski, S., & Russell, D. (2009). Predictors of loneliness in caregivers of persons with Parkinson's disease. *Parkinsonism & Related Disorders, 15* (8), 554-557.

McRae, C., Caspari, J., Russell, D., Ellgring, H., Bezzant, C., Greene, P., & Fahn, S. (2018). Video review of baseline performance on global ratings in a double-blind placebo surgery trial. *Movement Disorders in Clinical Practice, 5*(6), 597-602.

Meichenbaum, D. (1985) *Coping with stress*. Facts on File.

Mosley, P. E., Robinson, K., Dissanayaka, N. N., Coyne, T., Silburn, P., Marsh, R., & Pye, D. (2021). A pilot trial of cognitive behavioral therapy for caregivers after deep brain stimulation for Parkinson's disease. *Journal of Geriatric Psychiatry and Neurology, 34*(5), 454-465.

Moustafa, A. A., Chakravarthy, S., Phillips, J. R., Gupta, A., Keri, S., Polner, B., Frank, M. J., & Jahanshahi, M. (2016). Motor symptoms in Parkinson's disease: A unified framework. *Neuroscience & Biobehavioral Reviews*, *68*, 727-740.

Moya-Gale, G., & Levy, E. S. (2019). Parkinson's disease-associated dysarthria: Prevalence, impact and management strategies. *Research and Reviews in Parkinsonism, 9*, 9-16.

Müller, V., Mohr, B., Rosin, R., Pulvermuller, F., Muller, F., & Birbaumer, N. (1997). Short-term effects of behavioral treatment on movement initiation and postural control in Parkinson's disease: A controlled clinical study. *Movement Disorders, 12*, 306–314.

Mulvaney, C. A., Duarte, G. S., Handley, J., Evans, D. J. W., Menon, S., Wyse, R., & Emsley, H. C. A. (2020). GLP-1 receptor agonists for Parkinson's disease. *Cochrane Database of Systematic Reviews*. https://doi.org/10.1002/14651858.CD012990.pub2

Nalls, M. A., Blauwendraat, C., Vallerga, C. L., Heilbron, K., Bandres-Ciga, S., Chang, D., Tan, M., Kia, D. A., Noyce, A. J., Xue, A., Bras, J., Young, E., von Coelln, R., Simón-Sánchez, J., Schulte, C., Sharma, M., Krohn, L., Pihlstrøm, L., Siitonen, A., ... The International Parkinson's Disease Genomics Consortium. (2019). Identification of novel risk loci, causal insights, and heritable risk for Parkinson's disease: A meta-analysis of genome-wide association studies. *The Lancet Neurology*, *18*(12), 1091-1102.

Narme, P., Mouras, H., Roussel, M., Duru, C., Krystkowiak, P., & Godefroy, O. (2013). Emotional and cognitive social processes are impaired in Parkinson's disease and are related to behavioral disorders. *Neuropsychology, 27*(2), 182-192.

Navarta-Sanchez, M. V., Ambrosio, L., Portillo, M. C., Ursua, M. E., Senosiain, J. M., & Riverol, M. (2020). Evaluation of a psychoeducational intervention compared with education in people with Parkinson's disease and their informal caregivers: A quasi-experimental study. *Journal of Advanced Nursing, 76*(10), 2719-2732.

Nonnekes, J., Snijders, A. H., Nutt, J. G., Deuschl, G., Giladi, N., & Bloem, B. R. (2015). Freezing of gait: A practical approach to management. *The Lancet Neurology*, *14*(7), 768-778.

Novotny, M., Tykalova, T., Ruzickova, H., Ruzicka, E., Dusek, P., & Rusz, J. (2022). Automated video-based assessment of facial bradykinesia in de-novo Parkinson's disease. *NPJ Digital Medicine*, *5*(1), 1-8.

Nusselt, L., & Legewie, H. (1975). Biofeedback und systematische Desensibilisierung bei Parkinson-Tremor. Eine Fallstudie [Biofeedback and systematic desensitization for Parkinson's tremor. A case study]. *Zeitschrift für Klinische Psychologie, 4*, 112–123.

Nutt, J. G., Bloem, B. R., Giladi, N., Hallett, M., Horak, F. B., & Nieuwboer, A. (2011). Freezing of gait: Moving forward on a mysterious clinical phenomenon. *The Lancet Neurology, 10*(8), 734-744.

Obeso, J. A., Rodriguez-Oroz, M. C., Goetz, C. G., Marin, C., Kordower, J. H., Rodriguez, M., Hirsch, E. C., Farrer, M., Schapira, A. H. V., & Halliday, G. (2010). Missing pieces in the Parkinson's disease puzzle. *Nature Medicine, 16*, 653–661.

Okai, D., Askey-Jones, S., Samuel, M., O'Sullivan, S. S., Chaudhuri, K. R., Martin, A., Mack, J., Brown, R. G., & David, A. S. (2013). Trial of CBT for impulse control behaviors affecting Parkinson patients and their caregivers. *American Academy of Neurology*, *80*(9), 792-799.

Olanow, C. W., Stern, M. B., & Sethi, K. (2009). The scientific and clinical basis for the treatment of Parkinson disease. *Neurology, 72*(4, Suppl.), S1-S136. https://doi.org/10.1212/WNL.0b013e3181a1d44c

Pagonabarraga, J., Kulisevsky, J., Strafella, A. P., & Krack, P. (2015). Apathy in Parkinson's disease: Clinical features, neural substrates, diagnosis, and treatment. *The Lancet Neurology, 14*(5), 518-531. https://doi.org/10.1016/S1474-4422(15)00019-8

Palakurthi, B., & Preetham Burugupally, S. P. (2019). Postural instability in Parkinson's disease: A review. *Brain Sciences, 9*(9), 239. https://doi.org/10.3390/brainsci9090239

Palmeri, R., Lo Buono, V., Bonanno, L., Allone, C., Drago, N., Sorbera, C., Cimini, V., di Lorenzo, G., Bramanti, A., & Marino, S. (2020). Impaired recognition of facial emotion in patients with Parkinson disease under dopamine therapy. *Journal of Geriatric Psychiatry*, *33*(5), 265-271. https://doi.org/10.1177/0891988719882094

Pappa, K., Doty, T., Taff, S. D., Kniepmann, K., & Foster, E. (2017). Self-management program participation and social support in Parkinson's disease: Mixed methods evaluation. *Physical & Occupational Therapy in Geriatrics, 35*(2), 81-98. https://doi.org/10.1080/02703181.2017.1288673

Parkinson, J. (1817). *An essay on the shaking palsy*. Sherwood, Neely, and Jones.

Pearson, C., Hartzman, A., Munevar, D., Feeney, M., Dolhun, R., Todaro, V., Rosenfeld, S., Willis, A., & Beck, J. C. (2023). Care access and utilization among Medicare beneficiaries living with Parkinson's disease. *Npj Parkinson's Disease, 9*(1), 108. https://doi.org/10.1038/s41531-023-00523-y

Pfingsten, U., & Hinsch, R. (1991). *Gruppentraining Sozialer Kompetenzen* [Group Social Skills Training]. Psychologie Verlagsunion.

Phokaewvarangkul, O., Boonpang, K., & Bhidayasiri, R. (2019). Subthalamic deep brain stimulation aggravates speech problems in Parkinson's disease: Objective and subjective analysis of the influence of stimulation frequency and electrode contact location. *Parkinsonism & Related Disorders*, *66*, 110-116. https://doi.org/10.1016/j.parkreldis.2019.07.020

Picillo, M., Nicoletti, A., Fetoni, V., Garavaglia, B., Barone, P., & Pellecchia, M. T. (2017). The relevance of gender in Parkinson's disease: A review. *Journal of Neurology, 264*(8), 1583–1607. https://doi.org/10.1007/s00415-016-8384-9

Pigott, J. S., Kane, E. J., Ambler, G., Walters, K., & Schrag, A. (2022). Systematic review and meta-analysis of clinical effectiveness of self-management interventions in Parkinson's disease, *BMC Geriatrics, 22*(45). https://doi.org/10.1186/s12877-021-02656-2

Pitcairn, T. K., Clemie, S., Gray, J. M., & Pentland, B. (1990a). Impressions of Parkinsonian patients from their recorded voices. *British Journal of Disorders of Communication, 25*, 85–92.

Pitcairn, T. K., Clemie, S., Gray, J. M., & Pentland, B. (1990b). Non-verbal cues in the self-presentation of Parkinsonian patients. *British Journal of Clinical Psychology, 29*, 177–184.

Potashkin, J., & Seidl, S. E. (2011). The promise of neuroprotective agents in Parkinson's disease. *Frontiers in Neurology, 2*, 68. https://doi.org/10.3389/fneur.2011.00068

Prenger, M. T. M., Madray, R., Van Hedger, K., Anello, M. & MacDonald, P. A. (2020). Social symptoms of Parkinson's disease. *Parkinson's Disease,* Article 8846544. https://doi.org/10.1155/2020/8846544

Ramig, L., Halpern, A., Spielman, J., Fox, C., & Freeman, K. (2018). Speech treatment in Parkinson's disease: Randomized controlled trial (RCT). *Movement Disorders, 33*(11), 1777-1791. https://doi.org/10.1002/mds.27460

Reijnders, J. S., Ehrt, U., Weber, W. E., Aarsland, D., & Leentjens, A. F. (2008). A systematic review of prevalence studies of depression in Parkinson's disease. *Movement Disorders*, *23*(2), 183-189.

Ricciardi, L., Visco-Comandini, F., Erro, R., Morgante, F., Bologna, M., Fasano, A., Ricciardi, D., Edwards, M. J., & Kilner, J. (2017). Facial emotion recognition and expression in Parkinson's disease: An emotional mirror mechanism? *PloS ONE, 12*(1). https://doi.org/10.1371/journal.pone.0169110

Reynolds, G. O., Saint-Hilaire, M., Thomas, C. A., Barlow, D. H., & Cronin-Golomb, A. (2020). Cognitive-behavioral therapy for anxiety in Parkinson's disease. *Behavior Modification*, *44*(4), 552–579. https://doi.org/10.1177/0145445519838828

Richard, I. H. (2005). Anxiety disorders in Parkinson's disease. *Advances in Neurology, 96*, 42-55.

Ringendahl, H., Werheid, K., Leplow, B., Ellgring, H., Annecke, R., & Emmans, D. (2000). Vorschläge für eine standardisierte Diagnostik bei Parkinsonpatienten [Proposals for standardized diagnostic procedures in Parkinson's disease patients]. *Nervenarzt, 71*, 946–954.

Rinn, W. E. (1984). The neuropsychology of facial expression: A review of the neurological and psychological mechanisms for producing facial expressions. *Psychological Bulletin, 95*, 52–77.

Roger, K., & Medved, M. (2010). Living with Parkinson's disease—managing identity together. *International Journal of Qualitative Studies on Health and Well-being, 5*(2), 5129. https://doi.org/10.3402/qhw.v5i2.5129

Russ, M. O., & Seger, L. (1995). The effect of task complexity on reaction times in memory scanning and visual discrimination in Parkinson's disease. *Neuropsychologia, 33*(5), 561– 575.

Saku, M., & Ellgring, H. (1992). Emotional reactions to odours in Parkinson's disease: A clinical application of ethological methods. *Journal of Ethology, 10*, 47–52.

Salamon, A., Zádori, D., Szpisjak, L., Klivényi, P., & Vécsei, L. (2020). Neuroprotection in Parkinson's disease: Facts and hopes. *Journal of Neural Transmission*, *127*, 821-829. https://doi.org/10.1007/s00702-019-02115-8

Santangelo, G., D'lorio, A., Maggi, G., Cuoco, S., Pellecchia, M. T., Amboni, M., Barone, P., & Vitale, C. (2018). Cognitive correlates of "pure apathy" in Parkinson's disease. *Parkinsonism & Related Disorders, 53,* 101-104. https://doi.org/10.1016/j.parkreldis.2018.04.023.

Santangelo, G., Trojano, L., Barone, P., Errico, D., Grossi, D., & Vitale, C. (2013). Apathy in Parkinson's disease: Diagnosis, neuropsychological correlates, pathophysiology and treatment. *Behavioural Neurology*, *27*(4), 501-513.

Santos-Garcia, D., de Deus Fonticoba, T., Cores Bartolome, C., Iniguez Alvarado, M. C., Feal Panceiras, M. J., Suarez Castro, E., Canfield, H., Martinez Miro, C., Jesus, S., Aguilar, M., Pastor, P., Planellas, L., Cosgaya, M., Garcia Caldentey, J., Caballol, N., Legarda, I., Hernandez Vara, J., Cabo, I., Lopez Manzanares, L., …COPPADIS Study Group. (2022). Predictors of the change in burden, strain, mood, and quality of life among caregivers of Parkinson's disease patients. *International Journal of Geriatric Psychiatry*. https://doi.org/10.1002/gps.5761

Schalling, E., Gustafsson, J., Ternstrom, S., Bulukin Wilen, F., & Sodersten, M. (2013). Effects of tactile biofeedback by a portable voice accumulator on voice sound level in speakers with Parkinson's disease. *Journal of Voice, 27*(6), 729-737.

Schalling, E., Johansson, K., & Hartelius, L. (2017). Speech and communication changes reported by people with Parkinson's disease. *Folia Phoniatrica et Logopaedica*, *69*(3), 131-141. https://doi.org/10.1159/000479927

Schienle, A., Ille, R., & Wabnegger, A. (2015). Experience of negative emotions in Parkinson's disease: An fMRI investigation. *Neuroscience Letters, 609*, 142-146.

Schindler, L., Hahlweg, K., & Revenstorf, D. (2007). *Partnerschaftsprobleme: Möglichkeiten zur Bewältigung* [Methods for dealing with relationship problems]. Springer.

Schulte, W. (1964). Zum Selbsterleben des Parkinsonkranken [Personal experiences of Parkinson's disease patients]. *Acta Neurovegetativa, 26*, 537–543.

Schwab, P. S., & England, A. C. (1969). Projection technique for evaluation surgery in Parkinson's disease. In F. H. Gillingham & M. C. Donaldson (Eds.), *Third Symposium on Parkinson's Disease* (pp. 152-157). Livingstone & Livingstone.

Scott, S., Caird, F. I., & Williams, B. O. (1984). Evidence for an apparent sensory speech disorder in Parkinson's disease. *Journal of Neurology, Neurosurgery & Psychiatry, 47*(8), 840-843.

Secker, D. L., & Brown, R. G. (2005). Cognitive behavioural therapy (CBT) for carers of patients with Parkinson's disease: A preliminary randomized controlled trial. *Journal of Neurology, Neurosurgery, & Psychiatry, 76*, 491-497. http://doi.org/10.1136/jnnp.2004.042291

Seidl, S. E., Santiago, J. A., Bilyk, H., & Potashkin, J. A. (2014). The emerging role of nutrition in Parkinson's disease. *Frontiers in Aging Neuroscience, 6*. https://doi.org/10.3389/fnagi.2014.00036

Seiler, S., Perleth, B., Gasser, T., Ulm, G., Oertel, W. H., & Ellgring, H. (1992). Partnership and depression in Parkinson's disease. *Behavioural Neurology, 5*, 75–81.

Seppi, K., Ray Chaudhuru, K., Coelho, M., Fox, S. H., Katzenschlager, R., Perez Lloret, S., Weintraub, D., Sampaio, C., & the collaborators of the Parkinson's Disease Update on Non-Motor Symptoms Study Group on behalf of the Movement Disorders Society Evidence-Based Medicine Committee. (2019). Update on treatments for nonmotor symptoms of Parkinson's disease—an evidence-based medicine review. *Movement Disorders, 34*(2), 180-198. https://doi.org/10.1002/mds.27602

Shumaker, R. G. (1980). The response of manual motor functioning in Parkinsonians to frontal EMG biofeedback and progressive relaxation. *Biofeedback and Self-regulation, 5,* 229–234.

Siciliano, M., Trojano, L., Santangelo, G., De Micco, R., Tedeschi, G., & Tessitore, A. (2018). Fatigue in Parkinson's disease: A systematic review and meta-analysis. *Movement Disorders, 33*, 1712-1723. https://doi.org/10.1002/mds.27461

Siderowf, A., Concha-Marambio, L., Lafontant, D.-E., Farris, C. M., Ma, Y., Urenia, P. A., Nguyen, H., Alcalay, R. N., Chahine, L. M., Foroud, T., Galasko, D., Kieburtz, K., Merchant, K., Mollenhauer, B., Poston, K. L., Seibyl, J., Simuni, T., Tanner, C. M., Weintraub, D., ... Soto, C. (2023). Assessment of heterogeneity among participants in the Parkinson's Progression Markers Initiative cohort using α-synuclein seed amplification: A cross-sectional study. *The Lancet Neurology*, *22*(5), 407-417.

Simons, G., Ellgring, H., & Smith Pasqualini, M. C. (2003). Disturbance of spontaneous and posed facial expressions in Parkinson's disease. *Cognition and Emotion, 17*, 759–778.

Simons, G., Smith Pasqualini, M., Reddy, V., & Wood, J. H. (2004). Emotional and nonemotional facial expressions in people with Parkinson's disease. *Journal of the International Neuropsychological Society, 10*(4), 521-535.

Simons, G., Thompson, S. B. N., Smith Pasqualini, M. C., & members of the EduPark consortium. (2006). An innovative education programme for people with Parkinson's disease and their carers. *Parkinsonism & Related Disorders, 12*, 478-485.

Smith Pasqualini, M. C., & Simons, G. (Eds.). (2006). *Patient education for people with Parkinson's disease and their carers*. John Wiley & Sons.

Smith, M. C., Ellgring, H., & Oertel, W. (1997). Sleep disturbance in PD patients and caregivers. *Journal of the American Geriatric Society, 45*, 194-199.

Smith, M. C., Goldman, W. P., Janer, K. W., Baty, J. D., & Morris, J. C. (1998). Cognitive speed in nondemented Parkinson's disease. *Journal of the International Neuropsychological Society*, *4*(6), 584-592.

Smith, M. C., Smith, M. K., & Ellgring, H. (1996). Spontaneous and posed facial expression in Parkinson's disease. *Journal of the International Neuropsychological Society, 2*, 383-391.

Spliethoff-Kamminga, N. G. A., Zwinderman, A. H., Springer, M. P., & Roos, R. A. C. (2003a). A disease-specific psychosocial questionnaire for Parkinson's disease caregivers. *Journal of Neurology, 250*(10), 1162–1168.

Spliethoff-Kamminga, N. G. A., Zwinderman, A. H., Springer, M. P., & Roos, R. A. C. (2003b). Psychosocial problems in Parkinson's disease: Evaluation of a disease-specific questionnaire. *Movement Disorders, 18*(5), 503–509.

Stallibrass, C. (1997). An evaluation of the Alexander Technique for the management of disability in Parkinson's disease—a preliminary study. *Clinical Rehabilitation, 11*, 8–12.

Steinke, A., Lange, F., Seer, C., Hendel, M. K., & Kopp, B. (2020). Computational modeling for neuropsychological assessment of bradyphrenia in Parkinson's disease. *Journal of Clinical Medicine, 9*(4), 1158. https://doi.org/10.3390/jcm9041158

Stern, G. M., Lander, C. M., & Lees, A. J. (1980). Akinetic freezing and trick movements in Parkinson's disease. *Journal of Neural Transmission, 16*, 137–141.

Sweeney, D., Quinlan, L., Browne, P., Richardson, M., Meskell, P., & Ólaighin, G. (2019). A technological review of wearable cueing devices addressing freezing of gait in Parkinson's disease. *Sensors, 19*(6), 1277. https://doi.org/10.3390/s19061277

Szekely, B. C., Turner, S. M., & Jacob, R. G. (1982). Behavioral control of L-Dopa induced dyskinesia in Parkinsonism. *Biofeedback and Self-Regulation, 7*, 443–447.

Takahashi, K., Tickle-Degnen, L., Coster, W. J., & Latham, N. K. (2010). Expressive behavior in Parkinson's disease as a function of interview context. *American Journal of Occupational Therapy, 64*(3), 484-495.

Tamplin, J., Morris, M. E., Marigliani, C., Baker, F. A., & Vogel, A. P. (2019). ParkinSong: A controlled trial of singing-based theory for Parkinson's disease. *Neurorehabilitation and Neural Repair, 33*(6), 453-463.

Tanji, H., Anderson, K. E., Gruber-Baldini, A. L., Fishman, P. S., Reich, S. G., Weiner, W. J., & Shulman, L. M. (2008). Mutuality of the marital relationship in Parkinson's disease. *Movement Disorders, 23*(13), 1843-1849.

Tausch, R. (1993). *Hilfen bei Streß und Belastung* [Help for dealing with stress and burden]. Rowohlt Verlag.

Tennigkeit, J., Feige, T., Haak, M., Hellqvist, C., Seven, U. S., Kalbe, E., Schwarz, J., Warnecke, T., Tonges, L., Eggers, C., & Loewenbruck, K. E. (2020). Structured care and self-management education for persons with Parkinson's disease: Why the first does not go without the second—systematic review, experiences and implementation concepts from Sweden and Germany. *Journal of Clinical Medicine, 9*, 2787. https://doi.org/10.3390/jcm9092787

Thompson, M., & Thompson, L. (2002). Biofeedback for movement disorders (dystonia with Parkinson's disease): Theory and preliminary results. *Journal of Neurotherapy, 6*(4), 51-70.

Troeung, L., Egan, S. J., & Gasson, N. (2014). A waitlist-controlled trial of group cognitive behavioural therapy for depression and anxiety in Parkinson's disease. *BMC Psychology, 14*(19). https://doi.org/10.1186/1471-244X-14-19

Turner-Stokes, L. (2009). Goal attainment scaling (GAS) in rehabilitation: A practical guide. *Clinical Rehabilitation, 23*(4), 362-370.

Vandenberg, B. E., Advocat, J., Hassed, C. S., Hester, J., Enticott, J., & Russell, G. M. (2018). Mindfulness-based lifestyle programs for the self-management of Parkinson's disease in Australia. *Health Promotion International, 34*(4), 668-676. https://doi.org/10.1093/heapro/day021

van der Eijk, M., Nijhuis, F. A., Faber, M. J., & Bloem, B. R. (2013). Moving from physician-centered care towards patient-centered care for Parkinson's disease patients. *Parkinsonism & Related Disorders*, *19*(11), 923-927. https://doi.org/10.1016/j.parkreldis.2013.04.022

van Uem, J., Marinus, J., Canning, C. G., Van Lummel, R., Dodel, R., Lipelt-Scarfone, I., Berg, D., Morris, M. E., & Maetzler, W. (2015). Health-related quality of life in patients with Parkinson's disease—a systematic review based on the ICF model. *Neuroscience & Biobehavioral Reviews, 61*, 26-34. https://doi.org/10.1016/j.neubiorev.2015.11.014

Veazey, C., Cook, K. F., Stanley, M., Lai, E. C., & Kunik, M. E. (2009). Telephone-administered cognitive behavioral therapy: A case study of anxiety and depression in Parkinson's disease. *Journal of Clinical Psychology in Medical Settings*, *16,* 243–253.

Vicente, S., Péron, J., Biseul, I., Ory, S., Philippot, P., Drapier, S., Drapier, D., & Vérin, M. (2011). Subjective emotional experience at different stages of Parkinson's disease. *Journal of the Neurological Sciences, 310*(1-2), 241-247.

Viwattanakulvanid, P., Kaewwilai, L., Jitkritsadakul, O., Brenden, N. R., Setthawatcharawanich, S., Boonrod, N., Mekawichai, P., & Bhidayasiri, R. (2014). The impact of the nocturnal disabilities of Parkinson's disease on caregivers' burden: Implications for interventions. *Journal of Neural Transmission, 121*(1, Suppl.), S15–S24. https://doi.org/10.1007/s00702-014-1200-8

Viwattanakulvanid, P., & Kittisopee, T. (2017). Influence of disease-related knowledge and personality traits on Parkinson's patient empowerment. *Thai Journal of Pharmaceutical Sciences, 41*(2), 76-83.

Vlagsma, T. T., Koerts, J., Tucha, O., Dijkstra, H. T., Duits, A. A., van Laar, T., & Spikman, J. M. (2016). Mental slowness in patients with Parkinson's disease: Associations with cognitive functions? *Journal of Clinical and Experimental Neuropsychology, 38*(8), 844-852. https://doi.org/10.1080/13803395.2016.1167840

von Coelln, R., & Shulman, L. M. (2016). Clinical subtypes and genetic heterogeneity: Of lumping and splitting in Parkinson disease. *Current Opinion in Neurology*, *29*(6), 727-734. https://doi.org/10.1097/WCO.0000000000000384

von Linstow, C. U., DeLano-Taylor, M., Kordower, J. H., & Brundin, P. (2020). Does developmental variability in the number of midbrain dopamine neurons affect individual risk for sporadic Parkinson's disease? *Journal of Parkinson's Disease, 10*(2), 405-411. https://doi.org/10.3233/JPD-191877

Voon, V., Mehta, A. R., & Hallett, M. (2011). Impulse control disorders in Parkinson's disease: Recent advances. *Current Opinion in Neurology: August, 24*(4), 324–330.

Walter, A. (2000). *Nonverbaler Ausdruck von Emotionen bei Morbus Parkinson* [Nonverbal expression of emotions in Parkinson's disease]. [Unpublished master's thesis]. Würzburg: Psychologisches Institut der Universität.

Weil, R. S., Schrag, A. E., Warren, J. D., Crutch, S. J., Lees, A. J., & Morris, H. R. (2016). Visual dysfunction in Parkinson's disease. *Brain, 139*, 2827-2843. https://doi.org/10.1093/brain/aww175

Weiner, W. J., Shulman, L. M., & Lang, A. E. (2013). *Parkinson's disease: A complete guide for patients and families* (3rd ed.). Johns Hopkins Press.

Weintraub, D., Hoops, S., Shea, J. A., Lyons, K. E., Pahwa, R., Driver-Dunckley, E. D., & Voon, V. (2009). Validation of the questionnaire for impulsive-compulsive disorders in Parkinson's disease. *Movement Disorders, 24*(10), 1461–1467.

Weintraub, D., Mamikonyan, E., Papay, K., Shea, J. A., Xie, S. X., & Siderowf, A. (2012). Questionnaire for impulsive-compulsive disorders in Parkinson's Disease-Rating Scale. *Movement Disorders*, *27*(2), 242-247.

Wieser, M. J., Mühlberger, A., Alpers, G. W., Macht, M., Ellgring, H., & Pauli, P. (2006). Emotion processing in Parkinson's disease: Dissociation between early neuronal processing and explicit ratings. *Clinical Neurophysiology, 117*(1), 94-102.

Zach, H., Walter, U., Liepelt-Scarfone, I., & Maetzler, W. (2017). Diagnostik des klinischen und prodromalen idiopathischen Parkinson-Syndroms [Diagnostics of clinical and prodromal idiopathic Parkinson‘s disease: New criteria]. *Nervenarzt, 88*(4), 356-364. https://doi.org/10.1007/s00115-017- 0290-6

Zarotti, N., Eccles, F. J. R., Foley, J. A., Paget, A., Gunn, S., Leroi, I., & Simpson, J. (2020). Psychological interventions for people with Parkinson's disease in the early 2020s: Where do we stand? *Psychology and Psychotherapy: Theory, Research and Practice, 94*(3), 760-797. https://doi.org/10.1111/papt.12321

Zung, W. W. K. (1965). A self-rating depression scale. *Archives of General Psychiatry, 12*, 63–70.

Zung, W. W. K. (1973). From art to science: The diagnosis and treatment of depression. *Archives of General Psychiatry*, *29*(3), 328-337.

List of Appendices

Appendix A: Assessment Instruments

Assessment of People with PD

The results of the individual questionnaires can be summarized using the Participant Assessment Summary sheet.

Participant Assessment Summary (PD)

Participant Name				
Scale	**Subscale**	**Score**	**% of max.**	**Notes**
Hoehn & Yahr				
Daily Living (ADL)				
Depression (SDS)	Somatic			
	Emotional			
	Total			
Stress (SQPD-P)	Motor			
	Emotional stress			
	Social relationships			
	Partnership/ Family			
	Total			
Communicating (CPD-20)				
Impulsive-Compulsive (QUIP-RS)	Gambling			
	Sex			
	Buying			
	Eating			

	Hobbyism			
	Punding			
	Medication			

Participant Information (PD)

Instructions: Please answer the following questions by checking the box that applies to you.

1. Gender	☐ Male ☐ Female ☐ Nonbinary/Other
2. Age	_________years
3. Living arrangement (check all that apply)	☐ Alone ☐ With spouse/partner ☐ With adult family members (not spouse/partner) ☐ With children under 18 years old ☐ With others (not family) ☐ Additional support by other persons (e.g., part-time health care aide)
4. Employment status	☐ Employed full-time ☐ Employed part-time ☐ Job title(s): ________________ ☐ Stay-at-home provider or caregiver ☐ Retired ☐ Not employed (include disabled and early retirement)
5. When were you diagnosed with PD?	Month/year
6. Were your PD symptoms preceded by any precipitating event?	☐ No ☐ Yes (explain):
7. Which motor symptom is prominent?	☐ Tremor ☐ Stiffness/rigidity/immobility ☐ Both equally prominent

The items listed below refer to physical abilities that can be affected by Parkinson's disease. For each item, check the box that applies to you.	
Facial expression	☐ Normal ☐ Slightly reduced ☐ Moderately reduced ☐ Very little or no expression
Walking	☐ Normal ☐ Mild difficulty (e. g., mild instability) ☐ Moderate difficulty (e.g., unstable, small steps) ☐ Severe difficulty or unable to walk
Balance (when standing and walking)	☐ Normal ☐ Mild difficulty ☐ Moderate difficulty ☐ Severe difficulty or unable to stand/walk unaided
Speech: Melody and/or volume	☐ Normal ☐ Mild changes (slightly flat/monotonous and/or quieter) ☐ Moderate changes ☐ Severe changes (can hardly be heard)
Speech: Articulation	☐ Normal ☐ Mild difficulty ☐ Moderate difficulty/difficult to comprehend ☐ Severe difficulty/not understandable
Handwriting (Size and/or readability)	☐ Normal ☐ Mild changes ☐ Moderate changes ☐ Severe changes (unreadable)
Standing from seated position	☐ Normal ☐ Mild difficulties ☐ Moderate difficulties ☐ Severe difficulties (cannot stand without assistance)
Speed of movements	☐ Normal ☐ Slightly slower ☐ Moderately slower ☐ Much slower

Posture	☐ Normal ☐ Slightly stooped ☐ Moderately stooped ☐ Severely stooped (or unable to stand)
Tremor: Right hand/arm	☐ None ☐ Mild ☐ Moderate ☐ Severe
Tremor: Left arm/hand	☐ None ☐ Mild ☐ Moderate ☐ Severe
Tremor: Right leg	☐ None ☐ Mild ☐ Moderate ☐ Severe
Tremor: Left leg	☐ None ☐ Mild ☐ Moderate ☐ Severe
Tremor: Body	☐ None ☐ Mild ☐ Moderate ☐ Severe
Stiffness: Right hand/arm	☐ None ☐ Mild ☐ Moderate ☐ Severe
Stiffness: Left hand/arm	☐ None ☐ Mild ☐ Moderate ☐ Severe

Stiffness: Right leg	☐ None ☐ Mild ☐ Moderate ☐ Severe
Stiffness: Left leg	☐ None ☐ Mild ☐ Moderate ☐ Severe
Stiffness: Body	☐ None ☐ Mild ☐ Moderate ☐ Severe

Disease Stage Classification

Instructions: Please check the **one** statement that best describes you.

☐ I: I have no significant motor disability. My motor symptoms (tremor and/or stiffness) are only on one side of my body.
☐ II: I have slight to mild motor disability. My motor symptoms are on both sides of my body. I have no problems with my balance.
☐ III: I have mild to moderate motor disability. My motor symptoms are on both sides of my body. I have difficulties with my balance. I am still physically independent.
☐ IV: I have severe motor disability. I am still able to walk and stand by myself.
☐ V: I have very severe motor disability. I am bedridden or confined to a wheelchair unless I have help.

(adapted from Hoehn & Yahr, 1967)

Depression: Zung Self-Rating Depression Scale (SDS)

The questionnaire contains ten items related to emotions/feelings (labeled "E") and ten items related to somatic/physical symptoms (labeled "S"). Somatic items that are most likely to occur in PD are additionally labeled "P" (items 4, 8, 12, 13).

Name (Number):		Date:			
Instructions: For each item below, please place a check mark in the column that best describes how often you felt or behaved this way during the past several days.					
Code	Item	A little of the time	Some of the time	Good part of the time	Most of the time
E	1. I feel down-hearted and blue.	1	2	3	4
E	2. Morning is when I feel the best.	4	3	2	1
E	3. I have crying spells or feel like it.	1	2	3	4
S-P	4. I have trouble sleeping at night.	1	2	3	4
S	5. I eat as much as I used to.	4	3	2	1
S	6. I still enjoy sex.	4	3	2	1
S	7. I notice that I am losing weight.	1	2	3	4
S-P	8. I have trouble with constipation.	1	2	3	4
S	9. My heart beats faster than usual.	1	2	3	4
S	10. I get tired for no reason.	1	2	3	4
S	11. My mind is as clear as it used to be.	4	3	2	1
S-P	12. I find it easy to do the things I used to.	4	3	2	1
S-P	13. I am restless and can't keep still.	1	2	3	4
E	14. I feel hopeful about the future.	4	3	2	1
E	15. I am more irritable than usual.	1	2	3	4
E	16. I find it easy to make decisions.	4	3	2	1

E	17. I feel that I am useful and needed.	4	3	2	1
E	18. My life is pretty full.	4	3	2	1
E	19. I feel that others would be better off if I were dead.	1	2	3	4
E	20. I still enjoy the things I used to do.	4	3	2	1

(Zung, 1965)

Quantitative Assessment for Zung Self-Rating Depression Scale (SDS)

We recommend computing separate subscales for Emotion items (SDS-Emotional; items 1-3 and 14-20) and for Somatic items (SDS-Somatic; items 4-13), due to the overlap of somatic items with core symptoms of PD. This overlap can otherwise lead to an overestimation of depressive symptoms.

The range for the total scale score is 20-80, and the range for each subscale is 10-40. To convert the raw score to an index score, divide the raw score by 80 and either express as a decimal or multiply by 100 to express as a percentage. The range for index scores is thus 25-100% (Zung, 1973). Alternatively, you can simply use the raw scores (see Dunstan & Scott, 2018).

Depression severity can be estimated using the following guidelines (Zung, 1973):

Level of depression	**SDS Index Score %**	**SDS: Total raw scores**	**SDS: Emotion/Somatic raw scores**
Normal range	25-49	20-39	10-19
Mild to moderate depression	50-59	40-47	20-23
Moderate to severe depression	60-69	48-55	24-27
Severe depression	70-100	56-80	28-40

Activities of Daily Living Scale

Instructions: Please read each statement. Check the number on the scale that best describes you.

100%		I am completely independent. I am able to do all chores without slowness, difficulty, or impairment. I am unaware of any difficulty.
90%		I am completely independent. I am able to do all chores with some degree of slowness, difficulty and impairment. Chores may take twice as long. I am beginning to be aware of difficulty.
80%		I am completely independent in most chores. Chores take twice as long. I am conscious of difficulty and slowness.
70%		I am not completely independent. I have more difficulty with some chores, and may take three to four times as long in some. I must spend a large part of the day with chores.
60%		I am partly dependent on others. I can do most chores, but exceedingly slowly and with much effort. I make errors and some chores are impossible.
50%		I am more dependent on others. I need help with half of my chores. I have difficulty with everything.
40%		I am very dependent on others. I can assist with all chores, but can do few of them alone.
30%		I need much help. With effort, I can sometimes do a few chores alone or begin chores alone.
20%		I am unable to do anything alone, but can be of slight help with some chores. I am very disabled.
10%		I am totally helpless and dependent on others.
0%		My vegetative functions such as swallowing, bladder and bowel functions are not functioning. I am bedridden.

(modified from Schwab & England, 1969).

Stress Questionnaire for People with Parkinson's Disease (SQPD-P)

This questionnaire has 19 items, each rated on a 4-point scale. Specific item topics can be used in the training sessions, as a basis for discussion or role plays.

Instructions: Please read the following statements and rate how much the problem affects and stresses you by checking the box that corresponds to your answer.

Item	Problem	1 Not at all	2 Slightly	3 Moderately	4 A great deal
1	I am no longer able to do things as well as I used to.				
2	My body can no longer meet the physical demands that I place on it.				
3	I have stopped doing things I used to enjoy.				
4	My desire to go and do things has decreased.				
5	I depend on others for daily tasks.				
6	Physical limitations control my thoughts and my view on life.				
7	I am more often bothered by mood swings than I used to be.				
8	My symptoms get worse with the least bit of stress or excitement.				
9	I am afraid of the future.				
10	I feel more insecure in my interactions with other people than I used to.				

11	I have difficulty explaining to others when help is appropriate and when it is unnecessary/superfluous.				
12	My circle of friends is decreasing.				
13	My physical condition prevents me from expressing my personality.				
14	I have to delegate my personal obligations and responsibilities.				
15	I can no longer do as much with my family or partner.				
16	My partner does things for me that I can do for myself, more than in the past (e.g., speaks for me, takes over simple activities)				
17	Other family members seem to find it hard to empathize with the difficulties of a person with PD.				
18	My relationship with my partner has gotten worse since I developed Parkinson's disease.				
19	PD has caused sexual difficulties.				
	Other problems not mentioned above				

(modified from Ellgring et al., 1989)

Quantitative Assessment for SQPD-P

For ease of use, total scores can be converted into percentages: Stress % = (Total score - Min)/(Max - Min) x 100, so that the lowest possible stress percentage = 0%. The following table can be used as a guide to severity; however, the focus for therapy should always be the specific areas of functioning that are affected.

Conversion of raw scores to % of maximum

Stress Level	SQPD-P % of maximum	SQPD-P Raw Score
Low	0	19
	10	26
	20	31
	30	36
Moderate	40	42
	50	48
	60	53
High	70	59
	80	65
	90	70
	100	76

Communicating about Parkinson’s Disease (CPD-20)

The scale includes 20 statements that are rated for frequency from 1 (never) to 4 (most or all of the time). The items are then summed for a total score, ranging from 20-80, with higher scores representing greater difficulty.

Instructions: Please read each statement and rate how often it applies to you.

Item	**Issue**	**This statement is true for me…**			
		Never	Some-times	Often	Most or all of the time
1	I am able to talk about my illness to other people.	4	3	2	1
2	I feel comfortable asking for help when I need it (e.g., asking for a seat on the bus, or for help getting seated in a restaurant).	4	3	2	1
3	I have difficulty knowing how to describe my illness to others.	1	2	3	4
4	People reject me when I tell them that I have Parkinson’s disease (or I fear they could reject me if I told them).	1	2	3	4
5	When someone asks me about my tremor or other symptoms, I feel uncomfortable.	1	2	3	4
6	People react better than I think they will when I tell them that I have Parkinson’s disease. Note: if you never tell anyone, choose 4 (“never”).	4	3	2	1
7	I am ashamed that I have Parkinson’s disease.	1	2	3	4
8	If I have a negative thought, such as “everyone looks out only for themselves,” I am able to replace it with an encouraging thought, such as “other people will help me if I need it.”	4	3	2	1

9	If need be, I am able to tell other people about my symptoms (e.g., that I have slower movements or difficulty walking).	4	3	2	1
10	When I am in public I have the feeling that I am being watched, and wonder what the others are thinking.	1	2	3	4
11	If need be, I am able to explain to others what help is appropriate and what help is unnecessary.	4	3	2	1
12	I am concerned that other people aren't really interested in me or in hearing about my illness.	1	2	3	4
13	Because of changes in my appearance and/or the way I speak, I have difficulty expressing my opinions to others.	1	2	3	4
14	I can't really talk to anyone about my feelings, such as sadness.	1	2	3	4
15	When I talk about my illness, I get nervous, and my symptoms, such as trembling, increase. Note: if you never talk to other people about PD, choose "most or all of the time."	1	2	3	4
16	If other people ask me to do things that I am reluctant or unwilling to do, I am able to say no.	4	3	2	1
17	If I tell others that I have Parkinson's disease they will think I have a mental illness.	1	2	3	4
18	Talking to other people with Parkinson's disease makes it easier for me to accept my illness. Note: if you never talk to other people about PD, choose "never."	4	3	2	1
19	I am aware of whether and how much Parkinson's disease affects my emotional expression (e.g., speech, gestures, facial	4	3	2	1

	expressions) and the way I come across to others.				
20	If I don't feel like talking about my illness to others, I am able to tell them that.	4	3	2	1

(modified from Hinrichs, 1992)

Quantitative Assessment for Communicating about Parkinson's Disease (CPD-20)

The following categories of raw scores can be used as a guide:

- 20-40: no difficulty or mild difficulty
- 40-60: moderate difficulty
- 60 and above: severe difficulty

For ease of use, total scores can be converted into percentages of the maximum: CPD-20 % = (Total score - min)/(max - min) x 100, with the minimum % set at 0

Level of difficulty	Difficulty as % of maximum	CPD-20 Raw Scores
No difficulty to mild difficulty	0	20
	10	26
	20	32
	30	38
Moderate difficulty	40	44
	50	50
	60	56
Severe difficulty	70	62
	80	68
	90	74
	100	80

Questionnaire for Impulsive-Compulsive Disorders in Parkinson's Disease: Rating Scale (QUIP-RS)

Instruction Sheet

TIME FRAME: Either past 4 weeks OR any 4-week period in a designated time frame.

Description of behaviors:

A. Gambling (casinos, internet gambling, lotteries, scratch tickets, betting, or slot or poker machines)
B. Sex (making sexual demands on others, promiscuity, prostitution, change in sexual orientation, masturbation, internet or telephone sexual activities, or pornography)
C. Buying (too much of the same thing or things that you don't need or use)
D. Eating (eating larger amounts or different types of food than in the past, more rapidly than normal, until feeling uncomfortably full, or when not hungry)
E. Hobbyism (specific tasks, hobbies or organized activities, such as writing, painting, gardening, repairing or dismantling things, collecting, computer use, working on projects, etc.)
F. Punding (repeating certain simple motor activities, such as cleaning, tidying, handling, examining, sorting, ordering, collecting, hoarding, or arranging objects, etc.)
G. Medication Use (consistently taking too much of your Parkinson's medications, or increasing on your own, without medical advice, your overall intake of Parkinson's medications)

Frequency of behaviors:
Never (0) = not at all
Rarely (1) = infrequently or 1 day/week
Sometimes (2) = at times or 2-3 days/week
Often (3) = most of the time or 4-5 days/week
Very often (4) = nearly always or 6-7 days/week

To score: Compute a total for each behavior (range 0-16). Total ICD score is the sum of A-D. Total QUIP-RS score is the sum of A-F.

(Weintraub et al., 2012)

Name:	Date:

Reported by:
☐ Patient
☐ Informant
☐ Patient and Informant

1. How much do you think about the following behaviors? (such as having trouble keeping thoughts out of your mind or feeling guilty)?

	0 Never	1 Rarely	2 Sometimes	3 Often	4 Very often
Gambling					
Sex					
Buying					
Eating					
Performing tasks or hobbies					
Repeating simple activities					
Taking your PD medications					

2. Do you have urges or desires for the following behaviors that you feel are excessive or cause you distress (including becoming restless or irritable when unable to participate in them)?

Gambling					
Sex					
Buying					
Eating					
Performing tasks or hobbies					

Repeating simple activities					
Taking your PD medications					
3. Do you have difficulty controlling the following behaviors (such as increasing them over time, or having trouble cutting down or stopping them)?					
Gambling					
Sex					
Buying					
Eating					
Performing tasks or hobbies					
Repeating simple activities					
Taking your PD medications					
4. Do you engage in activities specifically to continue the following behaviors (such as hiding what you are doing, lying, hoarding things, borrowing from others, accumulating debt, stealing, or being involved in illegal acts)?					
Gambling					
Sex					
Buying					
Eating					
Performing tasks or hobbies					
Repeating simple activities					
Taking your PD medications					

Training Program Evaluation (PD)

Instructions: Please read each statement and circle the number corresponding to the option that best describes your opinion of the training program.

Name/Number		Date		
Item	Statement	Do not agree	Partly agree	Agree
1	I received helpful information about Parkinson's disease and the psychological and social effects of the disease.	1	2	3
2	I am more aware of my thoughts, feelings and attitudes about living with PD.	1	2	3
3	The exchange of ideas and experiences in the group was helpful.	1	2	3
4	The program has helped me to see that I am not alone with my problems.	1	2	3
5	It is easier now for me to talk about my illness to other people with PD.	1	2	3
6	The information presented was confusing.	3	2	1
7	I would have liked more information than was presented.	3	2	1
8	Too much time was spent discussing theories about the disease.	3	2	1
9	My understanding of the psychological effects of the disease has increased.	1	2	3
10	I think I can handle my problems better now.	1	2	3
11	Much of the information was new to me.	1	2	3
12	The participants were not involved enough in the training process.	3	2	1
13	The atmosphere was pleasant.	1	2	3
14	Some of the activities were boring or uninteresting.	3	2	1

15	Overall, the training program met my expectations.	1	2	3
16	The training program was not useful for me.	3	2	1
17	I would like to participate in additional training programs.	1	2	3

Additional comments:

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Assessment of Caregivers

The results of the individual questionnaires can be summarized using the Participant Assessment Summary sheet.

Participant Assessment Summary (Caregiver)

Participant Name:				
Scale	**Subscale**	**Score**	**% of maximum**	**Notes**
Depression (SDS)	Somatic			
	Emotional			
	Total			
Stress (SQPD-C)	Motor			
	Emotional stress			
	Social relationships			
	Partnership/Family			
	Total			

Participant Information (Caregiver)

Instructions: Please answer the following questions by checking the box that applies to you.

1. Gender	☐ Male ☐ Female ☐ Non-binary/Other
2. Age	_________years
3. Living arrangement (check all that apply)	☐ Alone ☐ With spouse/partner ☐ With adult family members (not spouse/partner) ☐ With children under 18 years old ☐ Additional support by other persons (e.g., part-time health care aide)
4. Employment status	☐ Employed full-time ☐ Employed part-time ☐ Job title(s): _______________ ☐ Stay-at-home provider or caregiver ☐ Retired ☐ Not employed (include disabled and early retirement)
5. When was your partner/family member diagnosed with PD?	Month/year

Depression: Zung Self-Rating Depression Scale (SDS)

The questionnaire contains ten items related to emotions/feelings (labeled "E") and ten items related to somatic/physical symptoms (labeled "S").

Name:		Date:			
Instructions: For each item below, please place a check mark in the column that best describes how often you felt or behaved this way during the past several days.					
Code	Item	A little of the time	Some of the time	Good part of the time	Most of the time
E	1. I feel down-hearted and blue.	1	2	3	4
E	2. Morning is when I feel the best.	4	3	2	1
E	3. I have crying spells or feel like it.	1	2	3	4
S-P	4. I have trouble sleeping at night.	1	2	3	4
S	5. I eat as much as I used to.	4	3	2	1
S	6. I still enjoy sex.	4	3	2	1
S	7. I notice that I am losing weight.	1	2	3	4
S-P	8. I have trouble with constipation.	1	2	3	4
S	9. My heart beats faster than usual.	1	2	3	4
S	10. I get tired for no reason.	1	2	3	4
S	11. My mind is as clear as it used to be.	4	3	2	1
S-P	12. I find it easy to do the things I used to.	4	3	2	1
S-P	13. I am restless and can't keep still.	1	2	3	4
E	14. I feel hopeful about the future.	4	3	2	1
E	15. I am more irritable than usual.	1	2	3	4
E	16. I find it easy to make decisions.	4	3	2	1
E	17. I feel that I am useful and needed.	4	3	2	1

E	18. My life is pretty full.	4	3	2	1
E	19. I feel that others would be better off if I were dead.	1	2	3	4
E	20. I still enjoy the things I used to do.	4	3	2	1

(Zung, 1965)

Quantitative Assessment of Zung Self-Rating Depression Scale (SDS) - Caregivers

The range for the total scale score is 20-80, and the range for each subscale is 10-40. To convert the raw score to an index score, divide the raw score by 80 and either express as a decimal or multiply by 100 to express as a percentage. The range for index scores is thus 25-100% (Zung, 1973). Alternatively, you can simply use the raw scores (see Dunstan & Scott, 2018).

Depression severity can be estimated using the following guidelines (Zung, 1973):

Level of depression	**SDS Index Score %**	**SDS: Total raw values**
Normal range	25-49	20-39
Mild to moderate depression	50-59	40-47
Moderate to severe depression	60-69	48-55
Severe depression	70-100	56-80

Stress Questionnaire for Parkinson's Disease Caregivers (SQPD-C)

The questionnaire has 15 items, each rated on a 4-point scale. Specific item topics can be used in the training sessions, as a basis for discussion or role plays.

Instructions: Please read the following statements and rate how much the problem affects you by checking the box that corresponds to your answer.

Item	**Problem**	**1** **Not at all**	**2** **Somewhat**	**3** **Moderately**	**4** **A great deal**
1	Taking care of my partner is physically demanding.				
2	My partner depends on me for daily chores.				
3	I have too little spare time because of my partner's PD.				
4	I don't know whether or not I am adequately helping my partner.				
5	My partner's motivation has decreased.				
6	I feel psychologically stressed by interactions with my partner.				
7	Parkinson's disease overshadows my thoughts and my view on life.				
8	I am bothered by my partner's mood swings.				
9	I am afraid of the future.				
10	Because of my partner's PD symptoms, other people address me rather than talking to my partner directly.				
11	My circle of friends is decreasing.				
12	The relationship with my partner has gotten worse since the onset of their PD.				
13	My partner's PD has caused sexual difficulties.				
14	PD has made our financial situation worse.				

15	My health has suffered due to the extra burdens from my partner's PD.				
	Other problems not mentioned above				

(modified from Ellgring et al., 1989)

Quantitative Assessment of SQPD-C (Caregivers)

Conversion of raw scores to % of maximum
For ease of use, overall scores can be converted into percentages: Stress % = (Total score - Min)/(Max - Min) x 100, so that the lowest possible stress percentage 0 %. The following table can be used as a guide to severity; however, the focus for therapy should always be the specific areas of functioning that are affected.

Stress Level	SQPD-C % of maximum	SQPD-C raw value
Low	0	15
	10	20
	20	24
	30	29
Moderate	40	33
	50	38
	60	42
High	70	47
	80	51
	90	56
	100	60

Training Program Evaluation (Caregiver)

Instructions: Please read each statement and circle the number corresponding to the option that best describes your opinion of the training program.

Name		Date		
Item	Statement	Do not agree	Partly agree	Agree
1	I received helpful information about Parkinson's disease and the psychological and social effects of the disease.	1	2	3
2	I am more aware of my thoughts, feelings, and attitudes about PD.	1	2	3
3	The exchange of ideas and experiences in the group was helpful.	1	2	3
4	The program has helped me to see that I am not alone with my problems.	1	2	3
5	It is easier now for me to talk to other people about my partner's PD.	1	2	3
6	The information presented was confusing.	3	2	1
7	I would have liked more information than was presented.	3	2	1
8	Too much time was spent discussing theories about the disease.	3	2	1
9	My understanding of the psychological effects of the disease has increased.	1	2	3
10	I think I can handle my problems better now.	1	2	3
11	Much of the information was new to me.	1	2	3
12	The participants were not involved enough in the training process.	3	2	1
13	The atmosphere was pleasant.	1	2	3

14	Some of the activities were boring or uninteresting.	3	2	1
15	Overall, the training program met my expectations.	1	2	3
16	The training program was not useful for me.	3	2	1
17	I would like to participate in additional training programs.	1	2	3

Additional comments:

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Appendix B: Program Handouts

Stress Program Handouts

Stress Program: Overview and Schedule

Therapist Name: ________________

Contact information: ______________________

Location of sessions: ______________________

Key points: Training Program

Goals:

- The goal of this training program is for you to be better able to cope with stress and difficulties associated with PD, and to increase life satisfaction.
- This program was developed to augment medical treatment, in order to improve your ability to manage stress and deal with challenges in daily life.
- You will learn about the nature and importance of stress and stress responses.
- You will learn a variety of skills, including self-observation, relaxation, changing maladaptive thoughts, and activity planning.
- By working toward these goals, you can increase life satisfaction.

Format:

- The Stress Program has 11 group sessions, plus a booster session (see *Schedule*).
- In each session, you will receive new information, practice skills in the group, and provide feedback about the session.
- Between sessions, you will work on homework that will enable you to apply what you have learned to daily life.
- To get the most out of this program: participate actively in the session, practice regularly at home, and be prepared to change your behaviors and ways of thinking.
- You may also meet individually with the therapist as needed.

Follow-up:

- After the program has finished, you will meet again individually with the therapist, and complete post-treatment questionnaires.
- A group booster session will take place 4-8 weeks after the end of the program (see *Schedule*).

SCHEDULE

Session	Date	Topic
1		Introduction; Learning about stress
2		Principles about coping with stress; Self-observation
3		Coping with stress in everyday life
4		Relaxation I: Relaxation at rest
5		Relaxation II: Brief relaxation techniques
6		Cognitive Therapy I: Self-instruction
7		Cognitive Therapy II: Attitudes about disease
8		Cognitive Therapy III: Disease management
9		Activity Planning I
10		Activity Planning II: Activity Promotion
11		Review
		Booster Session

Stress Session 1: Introduction to the Program

Summary Sheet

Key Points: Parkinson's Disease (PD) and Stress

- PD is a physical disorder, not a mental illness.
- Psychological and motor symptoms of PD can vary greatly from person to person, and over the course of the disease.
- Stressful events and our reactions to those events ("stress response") are a normal part of life. We experience changes in feelings, thoughts, physical reactions, and behavior, all lasting for different periods of time.
- What feels stressful, and how we react to stress, varies from person to person, and in different situations.
- Normally, these reactions can help us cope with challenges. Sometimes, however, the stress response can itself become maladaptive.
- PD can increase sensitivity towards stressors (stressful events) and the stress response. Stress can make motor and psychological symptoms worse.
- Learning better ways to cope with stressful events can decrease an unhelpful, dysfunctional stress response.
- Identifying stressors, and how we typically react, is the first step in treatment.

Homework: Introductory Questions

Ask yourself the following questions about PD. If desired, you can mark which questions are most important to you, and/or make notes about issues to bring up in the sessions.

- What do I know already about PD?
- How has PD changed my life?
- What effects does PD have on my relationships with other people?
- What would I like to change about how I live with PD?
- How could I bring about these changes?
- What have I tried so far to improve my ability to live with PD?
- What will I do to cope if my condition gets worse?
- Should I tell other people that I have PD? If so, who and in what situations?
- Who can I talk to about my PD?

Ask yourself the following questions about your expectations for this program:

- What are my expectations for the training program?
- What can the training program help me with?
- What can the training program *not* help me with?

What other questions do you think are important?

Stress Session 2: Stressful Events & Self-Observation

Summary Sheet

Key Points: Stressful Events

What are stressful events?

- A stressful event, or “stressor,” is any event that we perceive as threatening or challenging, or that requires additional resources.
- “Negative” events (that make us angry or afraid) as well as “positive” events (that make us happy) can be stressful if they require greater mental resources such as increased attention or increased physical effort.
- Sometimes you may not consciously regard an event as stressful (e.g., saying “hello” when you pass by an acquaintance in the street), yet if additional resources are required, your PD symptoms can increase.
- Whether or not something feels stressful to you depends in part on whether you think you can cope with the stressor.
- Stressors can be weak or strong, and can be short or long. Even if the stressful event itself is relatively short, your reactions can continue for much longer if the stressor is powerful or if you relive the stressor in your mind.
- Identifying the conditions and situations that tend to create stress is the first step in training. For example, other people’s behaviors, your own thoughts and physical symptoms, and environmental factors might all elicit or increase stress.

Key Points: Techniques to Manage Stress

You will be more likely to reach the goal of managing stress by making small, consistent changes in your daily life. We will use three main approaches:

- *Relaxation* can calm your body and mind.
- *Changes in thinking* are possible by first “observing” your thoughts, and then practicing new ways of thinking.
- *Activity planning* can help in two ways:
  - By scheduling and limiting demanding activities, you can tackle one thing at a time.
  - By engaging in more pleasant activities, you can increase feelings of well-being.

Key Points: Self-Observation

- Self-observation refers to paying attention to your thoughts, feelings, and behaviors right at this moment, with a non-judgmental attitude. You can use it to identify behaviors to change, and to find solutions.
- To practice self-observation, select a specific thought, feeling, or behavior as the target of your observation. Identify when and where it tends to occur. Practice often and talk with others for additional feedback.

Homework:

- Practice the Body Awareness Exercise.
- Start writing in the *Stress Journal.*

Stress Journal for People with PD

Directions: Complete one form for each day, each evening before going to bed. In the top half of the form, briefly describe stressful situations that occurred that day. In the lower half, describe your reactions and thoughts about the most important stressful situation using the categories provided.

Date:		
Stressful situations today:		
The most important stressful situation today (from list above):		
My reactions in this situation (circle/write in all that apply):		
Feelings	Physical reactions	PD symptoms
Distress	Sweating	Tremor
Fear/Anxiety	Heart pounding/racing	Stiffness
Sadness	Muscular tension	Slowness
Restlessness	Other reactions (write in)	Other symptoms (write in)
Excitement		
Other feelings (write in)		
Thoughts:		

Stress Session 3: Coping with Stress in Daily Life

Summary Sheet

Key Points: Negative and Positive Stress Cycles

Physical changes, negative thoughts, emotional reactions, and behaviors can interact with each other to create a *negative stress cycle*. The different components of the stress response reinforce each other and increase even more, in a feedback loop.

A *positive stress cycle* can occur when these reactions influence each other in a good or useful way. For example, if you tell yourself that you can take your time and do your best, your body may relax and enable you to perform better.

You can interrupt negative stress cycles and change them into positive stress cycles by doing the following:

1. Recognize the components of the sequence:
   - the stressful situation
   - the ways that you react to the situation (thoughts, feelings, physical changes, behaviors)
2. Change any part of the sequence, ideally at an early stage, to change the cycle.

Key Points: Setting Goals

Making changes is easier, more effective, and more rewarding if you set goals. A goal is an outcome that you want to achieve. It can be short-term or long-term.

To achieve a goal, identify specific, concrete "target behaviors" that you can change. A goal may have more than one target behavior that contributes to the outcome.

To set goals and target behaviors:

1. Decide on a goal. Select an important concern or difficulty that you would like to address. If you have more than one major concern, pick the one that is most important to you in the immediate future.
2. Describe at least one target behavior that you can work on in the coming week, which will contribute to the goal.
3. Set a reasonable level of achievement for the target behavior. Take into account your current level of that behavior, and what is realistic for you to achieve in the near future.
4. If desired, you can create a *Goal Staircase* using a 4-point scale, for one or more of the target behaviors. A *Goal Staircase* enables you to visualize your desired behavior change. Although you will be aiming for your target, different levels of improvement are possible—success is not "all or nothing."

Creating a Goal Staircase

Your current situation with regard to the behavior is 0, and your target is +1. If you improve beyond your target, your rating would be +2. If your situation worsens, you would be -1, like this:

+2: better than expected
+1: TARGET
0: unchanged
-1: worse

Homework: My Reactions in Stressful Situations

In this exercise, you will describe stressful situations that occurred in the past few days or weeks, and your reactions in those situations. Be as specific as you can, and try to identify the sequence of your reactions.

- The stressful situation. Describe the conditions under which you experienced stress, including:
  - the situation you were in
  - if you were alone or with other people
  - what was particularly stressful about this situation
- Your reactions to the stressor. Describe how you reacted in this situation, including:
  - thoughts: what was going through your mind
  - feelings
  - physical reactions
  - behaviors

Describe the stressful situation on the left half of a sheet of paper and the sequence of your reactions on the right half. Write the first reaction at the top, with arrows between each reaction to show the sequence, as in the example.

Stressful situation	Reactions
Going to a concert: I am in the lobby of a concert hall with many people around. They can see the tremor in my right hand.	**Thought**: I look like an old fool. Anyone who sees me is going to want to make fun of me or pity me. ↓ **Feeling**: I feel anxious and embarrassed about the tremor ↓ **Physical reaction (PD symptom):** The tremor gets even worse. ↓ **Behavior**: I hold my right hand with my left hand, but the tremor does not decrease. ↓ **Feeling**: My fear of attracting unwanted attention increases.

Stressful situation	**Reactions**
Stressful situation	**Reactions**

Homework: Setting Goals

For this homework, you will identify a goal (outcome) that you would like to achieve, and one or more target behaviors that will help you meet the goal. Follow the guidelines under *Key Points*.

Homework: Stress Journal

Continue writing in the *Stress Journal.*

Stress Session 4: Relaxation at Rest

Summary Sheet

Key Points: Principles of Relaxation

Relaxation is the opposite of the state of anxiety. Through targeted relaxation practice, your muscles learn to rest, and your entire body can become more relaxed. This is important because:

- You can calm your thoughts and feelings, allowing you to recover from stress mentally and physically.
- You can gain distance from problems of everyday life.
- Relaxation can help reduce motor symptoms.

Relaxation is a skill you can learn: By relaxing at the first signs of stress, you can prevent anxiety. You can increase the effects of relaxation by making adjustments to find out what works best for you.

Homework: Relaxation at Rest

Practice the *Relaxation at Rest* exercise every day (see *Tips* to make the exercise more effective).

Homework: Stress Journal

Continue writing in the *Stress Journal.*

Tips for Learning How to Relax: People with PD

1. Practice regularly, preferably daily.
    - Learning to relax takes regular practice. Don't expect miracles: the healing effects of relaxation usually appear over time, with repeated practice.
2. Make relaxation a habit by practicing at specific times of day.
    - With practice, you will find your personal rhythm. Make the relaxation exercises an integral part of your daily routine by choosing specific times of day to practice. Some people prefer to practice when they have finished with their work and chores, because it is easier for them to "switch off" at that time. Others prefer to practice in the morning in order to focus and feel stronger throughout the day. Pick the times that are best for you: you may need to experiment to find out what those times are.
3. First learn how to relax under restful conditions.
    - In the beginning, practice in a quiet, stress-free environment. Find a pleasant place where you like to spend time. Ask family members not to disturb you and put your phone away. The time for relaxation is all yours!
4. Assume a comfortable posture.
    - Sit in a comfortable chair. Do not cross your legs, as this will inhibit blood flow.

5. Close your eyes if you wish.
   - Many people prefer to close their eyes during the relaxation exercise; do what is comfortable for you.
6. Deal calmly with interruptions.
   - During practice, your feelings of relaxation may be interrupted by hearing outside noises, by unrelated thoughts and worries, or other disturbances. Don't fight it. Let the sounds and thoughts come and go. Then turn back to the exercise.
7. Relax using the methods that work best for you.
   - Experiment until you find the methods that work best for you, whether that is muscle relaxation, relaxed breathing, visual imagery, other techniques, or a combination.
8. Deal with PD symptoms calmly.
   - Although relaxation is generally helpful for dealing with symptoms of PD, it is possible for symptoms to increase during a relaxation exercise. Continue with the exercise, and if desired, make adjustments to increase your comfort. For example, if you are bothered by tremor in your hand, place your arm on a pillow or other supportive surface.
9. Enjoy the relaxation!

Stress Session 5: Relaxation in Stressful Situations

Summary Sheet

Key Points: Using Relaxation for Stress Management

- Learning to relax will increase your overall ability to handle stress and to build resilience after experiencing challenges.
- To deal with stressful situations in the moment, you can use brief relaxation techniques that are quicker and easier to implement.

Brief Relaxation Techniques: Guide

Each of the three relaxation techniques can be modified for quicker use.

Muscle relaxation: Combine muscle groups as follows:

- Hands and arms: Clench both hands into fists and at the same time, bend your arms to tense your biceps.
- Face and neck: Squint your eyes and at the same time, clench your teeth and tense the muscles of your neck.
- Shoulders and abdomen: Pull your shoulders up in a shrug, and at the same time, tense your abdominal muscles by making your stomach hard, like bracing for a punch.
- Legs and feet: Keeping your heels on the floor, pull your feet upward as far as possible and tense your calves.

To relax even more quickly, you can then pick just one of these combinations to tense and relax.

Breathing: complete one or two slow breath cycles. Inhale slowly, hold your breath for a moment, and then breathing slowly out.

Visual imagery: Relax your body (e.g., using muscle relaxation and/or breathing). Then link a state of relaxation to a specific picture in your mind as soon as you feel relaxed. Eventually, the image alone can trigger a state of relaxation.

Homework: Relaxation Practice

- Practice *Relaxation at Rest* (from Session 4) as well as brief relaxation techniques.
- Practice using brief relaxation techniques if you encounter a stressful situation.
- Develop/continue to use a *Goal Staircase* to monitor practice or another target behavior, if desired.

Homework: Stress Journal

Continue writing in the *Stress Journal.*

Stress Session 6: Self-Instruction

Summary Sheet

Key Points: Self-Talk and Self-Instruction

What is self-talk?

- Self-talk refers to our “inner dialogue,” which can influence our behavior.
- Some thoughts increase stress (“negative self-talk”) and some thoughts decrease stress (“positive self-talk”).
- These thoughts may be hard to identify because they seem to occur automatically.

How and why might you change your self-talk?

- One way to control stress is to replace stress-increasing thoughts with stress-reducing thoughts.
- Deliberately changing thoughts is called “self-instructional training,” and takes practice.
- These thoughts can occur before, during, or after a stressful event; we can change them during any of these phases.
- By replacing negative self-talk with positive self-talk, you can stop a negative stress cycle and potentially avoid an increase in PD symptoms.
- Self-instructional training techniques include cognitive reframing (changing the way you view a situation), possible alternative explanations (questioning whether your explanation is correct), and de-catastrophizing (asking yourself the worst that could happen in this specific situation).
- Use words that have the most meaning for you, not just stock phrases.

Integrating self-talk with relaxation techniques

- You can combine positive self-instructions with brief relaxation techniques, such as muscle relaxation, controlled breathing, and visualizing relaxing images.
- You can practice by re-imagining a stressful situation in your past; then imagine changing how you handled it.

Homework: Self-Instruction and Relaxation in Stressful Situations

- Practice using self-instruction and relaxation techniques by re-imagining past stressful situations. What did you do that worked well? Imagine yourself using the techniques you have learned to change how you dealt with the situation.
- As you encounter stressful situations this week, try using these techniques to see what works best for you.

Homework: Stress Journal

Continue writing in the *Stress Journal.*

Stress Session 7: Changing Attitudes about PD

Summary Sheet

Key Points: Attitudes About Disease

How do attitudes affect us?

- Thoughts in specific situations can become general assumptions, or “attitudes” that you make across a wide range of situations.
- Attitudes about PD can influence your feelings and behaviors, even if you are not consciously thinking about them.
- Attitudes about PD can be helpful or unhelpful with regard to your ability to deal with stressful situations.

Warning signs of maladaptive attitudes:

- Self-deprecation
- “All-or-nothing” beliefs
- Resignation
- Unrealistic expectations

How can you change your attitudes about PD?

1. Identify the attitudes or assumptions you hold, especially unhelpful attitudes that may increase your stress reaction.
2. Identify and examine the outcome of the situation, such as unpleasant feelings or changes in behavior. Was the attitude more helpful or unhelpful?
3. For every unhelpful attitude, develop a more useful alternative.
4. Practice! Write down thoughts as they occur throughout the day, using the homework chart.

Homework: Observing and Changing Attitudes About PD

Continue working to observe attitudes using the sheet.

Homework: Stress Journal

Continue writing in the *Stress Journal.*

Observing and Changing Attitudes About PD

Event/ Situation	Attitude	Outcome	Helpful or unhelpful?	Alternative helpful attitude
(Example): Washing dishes	PD is making my life meaningless and there's nothing I can do about it	I felt sad. I stopped washing the dishes.	Unhelpful	PD may have slowed me down, but it won't stop me!

Stress Session 8: Coping with Disease

Summary Sheet

Key Points: Disease Management & Coping

“Disease management” refers to how you can cope with stressors brought on by Parkinson’s disease. Thoughts, attitudes, feelings, and behaviors can all reflect reactions to disease as well as ways of coping.

There are two main categories of coping:

- Problem-focused coping: you look at a specific problem and try to figure out what needs to be done to change it.
- Emotion-focused coping: you try to change the feelings you have in reaction to the problem. You feel better about the situation, even if the situation itself doesn’t change.

No single way of coping is best for every person in every situation; try out different strategies to see what works best for you!

Homework: My Life with Parkinson’s Disease

Complete the handout *My Life with Parkinson’s Disease* to describe how you think about PD. Think about what role the disease plays for you in your life. Picture moments when you forgot that you were ill.

Homework: Stress Journal

Continue writing in the *Stress Journal.*

My Life with Parkinson's Disease

As you strive to live a better life with PD, the first step is to take stock of your condition. The following questions are designed to help you think about the role that PD plays in your life.

1. What goes through my mind when I think about PD?
    - Thoughts (what I say to myself about PD)
    - Feelings
    - Images
    - Words/phrases that other people use to describe PD
2. Which areas of my life are affected by PD, and which are not?
    - Dealing with other people
    - Daily activities
    - Noticing and enjoying pleasant things, such as nature and music
    - Memories
3. Think about when the disease is most on your mind and when it is not. Ask yourself: Under what circumstances do I think about it the most? Are there moments when I forget that I have PD?
4. Picture an image of yourself together with PD. Some people might see PD as an unruly companion they can talk to, and they may even give it a nickname. Others might see PD as a heavy backpack they must carry. Ask yourself: What image might be useful for me?
5. Find a motto for your life with the PD, such as the following:
    - I'm learning to live with PD
    - I'm taking it one step at a time
    - I'm making my best life with PD
    - PD or not, there is always something I can do
    - I'm moving forward, even if I must drag PD along too!

Stress Session 9: Activity Planning

Summary Sheet

Key Points: Activity Planning

- The most direct route to changing how you manage living with PD is through changing behaviors.
- PD symptoms can make it more challenging to increase activities.
- Developing an activity plan to structure the day will enable you to better align your activities with your goals, abilities and energy levels.
- An activity plan will make it more likely that you will accomplish your highest priority activities, and will allow time for enjoyable activities.

Homework Assignment: Activity Planning

Complete the homework sheet *Activity Planning*.

Homework: Stress Journal

Continue writing in the *Stress Journal.*

Homework Sheet: Activity Planning

Create an activity plan with the following objectives:

- Avoid situations with excessive demands.
- Ensure time for high priority activities.
- Create more time for pleasant activities.

You will first identify priority activities, and then make a schedule of activities. Consider how your goals and abilities may have changed with PD, and how your PD symptoms may vary throughout the day. If your symptoms vary, identify "good periods" and plan more demanding activities for those periods.

Step 1: Identify priority activities (see examples):

- Make a list of the things you want or need to do, and the target frequency (e.g., number of times per day or week). You do not need to include as targets any required activities that you must always do (e.g., go to work).
- Rate the priority level of each activity.

Target activity	**Target frequency**	**Priority level (1 = highest; 5 = lowest)**
Long walk in the park	3 times a week	2
Talk to my daughter on the phone	2 times a week	1
Stretching exercises	2 times per day	2
Read a book	Once per day	4

Step 2: Create an activity plan

- Create a template schedule for a typical week. You can adjust the time intervals to fit your normal wake-up and bedtimes, and make the time intervals smaller (e.g., hourly) or larger—whatever is most useful to you.
- Block out time periods that include required, unchangeable activities (e.g., time at work). Note the times that you normally feel your best, and schedule the most mentally or physically strenuous activities for those periods. Build flexibility into the plan. Ask yourself:

- Does the total number of activities during the day seem appropriate?
- Could the activities be distributed better throughout the day?
- Are there sufficient breaks between activities?
- Is the plan achievable?
- Does the plan take into account my typical daily fluctuations in symptoms and energy levels?
- Are pleasant activities included? Is there enough variety in pleasant activities?

Note: If you are not sure what the "best" times for you or your partner are, you may first want to track your energy/functional levels throughout the day for several days, to discover if there is a pattern to the fluctuations.

TIME	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
6-9 am							
9-12 am							
12-3 pm							
3-6 pm							
6-9 pm							
9-12 pm							

Stress Session 10: Pleasant Activities

Summary Sheet

Key points: Increasing Pleasant Activities

Pleasant activities are associated with positive feelings, make our lives more meaningful, and are part of a happy life. Intentionally engaging in pleasant activities can also help lift feelings of depression.

Pleasant activities typically:

- are linked to goals
- enable a person to feel fully focused, “absorbed” in the activity
- are accompanied by a broadening of the senses

Pleasant activities are especially important for people with PD because:

- If you are no longer able to carry out some of your previous activities, it's important to discover new ways of having pleasant experiences.
- If you experience negative feelings such as depression, loneliness, or a feeling of loss of control, you could have less interest in activities. Intentionally increasing your participation in pleasant activities can improve your quality of life.

Like all behaviors, the ability to plan pleasant activities, and to experience enjoyment, can improve with practice.

Tips for Enjoying Pleasant Activities (Lutz, 1996):

1. Take your time.
2. “Allow” yourself to experience enjoyment; don’t let feelings of guilt creep in.
3. Focus on the activity at hand; concentrate, be absorbed in what you are doing.
4. Learn what works best for you: get to know what you like best, and what conditions are important for you to experience enjoyment.
5. Less is more. Too much of a good thing can actually decrease enjoyment.
6. Enjoyment is not just for special occasions. Pleasant activities are basically available at any time; extraordinary experiences are not necessary.
7. Practice! Your ability to focus and enjoy activities will increase.

Homework: Have Some Fun!

Choose three enjoyable activities to do this week. Carry out at least one of these activities every day. If desired, create a *Goal Ladder* to track your progress.

Homework: Stress Journal

Continue writing in the *Stress Journal.*

Homework: Program Review

Think about the following questions:

- What goals did I achieve? (Reviewing your *Stress Journal* may help you to assess your progress.)
- How did my achievements compare with my original expectations of the program?
- What are the most important things I learned or experienced during the training program?
- How can I maintain my progress, and apply what I have learned to future situations?
- Which parts of the training, in my view, might be changed or improved in the future?
- What tips and encouragement can I give to others?

Stress Session 11: Program Review

Summary Sheet

Check Your Suitcase

After you leave the session, you can review the “suitcase” you have received for your journey through life with Parkinson’s disease at any time: both for the difficult parts of the journey, and the happy parts. In addition, think about your goals prior to the booster session. Ask yourself:

- How will I maintain or expand upon my achievements?
- What new goals will I set?

Follow-up

My individual session will be on DATE/TIME.

The group booster session will be on DATE/TIME.

Communication Program: Overview and Schedule

Therapist Name: ________________

Contact information: ______________________

Location of sessions: ______________________

Key Points: Training Program

Goals:

- The goal of this training program is for you to learn to communicate with others about PD.
- You will learn skills to improve communication with other people with PD, in public, with health professionals, and with family and friends. Thus, this program is particularly suitable for people who experience challenges in their social interactions due to PD.
- By working toward these goals, you can increase life satisfaction.

Format:

- The Communication Program has 7 sessions, plus a booster session (see *Schedule*).
- In each session, you will learn new information, practice skills in the group, and provide feedback about the session.
- Between sessions, you will work on homework that will enable you to apply what you have learned to daily life.
- To get the most out of this program: participate actively in the session, practice regularly at home, and be prepared to change your behaviors and ways of thinking.
- You may also meet individually with the therapist as needed.

Follow-up:

- After the program has finished, you will meet again individually with the therapist, and complete post-treatment questionnaires.
- The booster session will take place 4-8 weeks after the end of the program (see *Schedule*).

SCHEDULE

Session	Date	Topic
1		Introduction
2		Talking about PD
3		Social competence/ Talking with a PD colleague
4		Communicating in public situations
5		Communicating with health professionals
6		Communicating with family and friends
7		Review
		Booster Session

Communication Session 1: Introduction to the Program

Summary Sheet

Key Points: Communicating About Parkinson's Disease (PD)

Parkinson's disease (PD) is a physical disorder that can affect how people think, feel, and behave. Even though PD is not a "mental illness," it can be difficult to talk about. You may have different reasons for not talking about PD, such as:

- Feeling stressed or embarrassed
- Difficulty explaining about your specific situation
- Feeling insecure in social interactions because of motor symptoms, or fear of motor symptoms
- Difficulties communicating due to disease symptoms
- Not wanting to think about the disease
- Not wanting to burden or worry others

Talking about PD can help you cope with the disease. For example:

- Most people with PD have had good experiences when they have told other people about their disease.
- People with PD who are willing to talk about their disease tend to be less depressed.
- Explaining about the disease to other people can increase the likelihood that they will be understanding.

Homework: Introductory Questions

Ask yourself the following questions about PD. If desired, you can mark which questions are most important to you, and/or make notes about issues to bring up in the sessions.

- What do I know already about PD?
- How has PD changed my life?
- What effects does PD have on my relationships with other people?
- What would I like to change about how I live with PD?
- How could I bring about these changes?
- What have I tried so far to improve my ability to live with PD?
- What will I do to cope if my condition gets worse?
- Should I tell other people that I have PD? If so, who and in what situations?
- Who can I talk to about my PD?

Ask yourself the following questions about your expectations for this program:

- What are my expectations for the training program?
- What can the training program help me with?
- What can the training program *not* help me with?

What other questions do you think are important?

Communication Session 2: Talking about Parkinson's Disease

Summary Sheet

Key Points: Self-Observation

- Self-observation refers to paying attention to your thoughts, feelings, and behaviors right at this moment, with a non-judgmental attitude. You can use it to identify behaviors to change, and to find solutions.
- To practice self-observation, select a specific thought, feeling, or behavior as the target of your observation. Identify the circumstances and situations in which it occurs to help solve specific problems. Practice often and talk with others for additional feedback.

Key Points: Setting Goals

Making changes is easier, more effective, and more rewarding if you set goals. A goal is an outcome that you want to achieve. It can be short-term or long-term.

To achieve a goal, identify specific, concrete "target behaviors" that you can change. A goal may have more than one target behavior that contributes to the outcome.

To set goals and target behaviors:

1. Decide on a goal. Select an important concern or difficulty that you would like to address. If you have more than one major concern, pick the one that is most important to you in the immediate future.
2. Describe at least one target behavior that you can work on in the coming week, which will contribute to the goal.
3. Set a reasonable level of achievement for the target behavior. Take into account your current level of that behavior, and what is realistic for you to achieve in the near future.
4. If desired, you can create a *Goal Staircase* using a 4-point scale, for one or more of the target behaviors. A *Goal Staircase* enables you to visualize your desired behavior change. Although you will be aiming for your target, different levels of improvement are possible—the possibility of success is not "all or nothing."

Creating a Goal Staircase

Your current situation with regard to the behavior is 0, and your target is +1. If you improve beyond your target, your rating would be +2. If your situation worsens, you would be -1, like this:

+2: better than expected
+1: TARGET
0: unchanged
-1: worse

Homework: Setting Goals

For this homework, you will identify a goal (outcome) that you would like to achieve, and one or more target behaviors that will help you meet the goal. Follow the guidelines under *Key Points*.

Homework: Communication Journal

Keep a daily record of your self-observations of conversations. Use a separate sheet for each day.

Communication Journal (Self-Observation)

Date: ________

Today I had:

☐ no conversations
☐ one conversation
☐ more than one conversation

My conversation partner(s) were: (check all that apply)

☐ partner
☐ relative, friend or acquaintance
☐ another person with PD
☐ stranger
☐ health professional
☐ other (specify): ___________________________________

The conversation(s) took place (check all that apply):

☐ in public
☐ at home
☐ in another person's home
☐ on the phone (call)
☐ via text message
☐ via video call (e.g., Zoom, Skype, Facetime)
☐ other (specify): ___________________________________

Of the conversations noted above, how many included PD as a topic?

☐ no conversations
☐ one conversation
☐ more than one conversation

Comments:

Complete the following scales by rating your feelings from 1 to 5, if you had at least one conversation about PD. If you had more than one such conversation, pick the one that was most important for you.

I found it difficult to talk about the disease.
Extremely difficult (1) to not at all difficult (5). My rating: ___

It was helpful for me to talk about the disease.
Not at all helpful (1) to extremely helpful (5). My rating: ___

The reactions of my conversation partner were
Very negative (1) to very positive (5). My rating: ___

Communication Session 3: Social Competence / Communicating with a PD Colleague

Summary Sheet

Key Points: Social Competence

Social competence involves the ability to interact with other people in ways that promote information exchange and mutual understanding. These positive interactions can help build and maintain relationships. Social competence is associated with certain behaviors, which you can learn and practice. These behaviors include:

1. Actively engaging with other people:
    - Initiating and maintaining conversations
    - Communicating your feelings in a socially appropriate way
    - Complimenting and praising others
    - Asking for what you need
    - Initiating social events
2. Effectively handling unpleasant social interactions
    - Saying “no” when you are unable or unwilling to do something
    - Standing up for yourself
    - Ending unwanted phone calls
    - Responding appropriately to criticism
    - Apologizing when appropriate
3. Responding positively to other people’s behaviors:
    - Accepting compliments and praise
    - Accepting offers to socialize

Socially competent behavior is different from insecure, unassertive, or aggressive behavior.

Key Points: Be an Active Listener

It is not always easy to be a good listener, especially if you are worried about what you will say next. These guidelines may be helpful:

- Maintain appropriate eye contact, and show nonverbally that you are listening.
- Withhold your own opinion while the other person is speaking.
- To make sure you understand the other person correctly, repeat it back to them, in your own words.
- Ask clarifying questions.
- Ask open questions about what they are thinking or feeling.
- Ask follow-up questions.
- Give positive feedback when the speaker’s message is clear.
- Provide feedback about how the interaction makes you feel.
- Be honest if you are unable to engage in a conversation at a particular time.

Homework: Conversation with a PD Colleague

Contact information for your conversation partner: ________________________

For this assignment, you will have a conversation with another person with PD. Take your time, and focus on being an active listener. It is often helpful to write out a list of questions/topics in advance. You could discuss questions such as:

- Do we have similar symptoms?
- Do we have similar worries?
- What do we each know about the disease? Is there helpful information I can learn, and information I can give?

Homework: Communicating in Public Situations

Think about where and when it is likely to be helpful to talk about PD in public situations, and when it is not likely to be helpful. Ask yourself the following questions, and make notes to bring back to the group.

- In which types of public situations do I feel uneasy around other people?
- When I've been out in public, have people looked at me and misinterpreted my symptoms?
- Are there public situations where it would help if I told people I have PD? Have I done so? If not, what has stopped me from telling them?
- Are there situations where it is better *not* to discuss my PD?

Homework: Communication Journal

Continue keeping the *Communication Journal*.

Communication Session 4: Communicating in Public Situations

Summary Sheet

Key Points: Confidence and Chain Reactions

- How you think about yourself—for example, as a confident person deserving of respect, or as a person with no confidence who is a burden to others—affects your ability to communicate with others.
- Thoughts, feelings, and physical reactions all affect each other.
- Your likelihood of success will improve if you appear confident, rather than insecure or aggressive.

Key Points: Asking for Help in a Public Situation

Factors to consider when asking for help:

- What help do I need?
- What specifically would I like the helper to do (e.g., pull me up by the hand)?
- Who is most likely to be able to help me?
- What do I need to say or do in order to get help quickly?
- Do I need to say that I am sick?
- Do I need to give information about my disease?

Tips when asking for help:

- Get the attention of the person you want to talk to and look at them directly.
- Present your request in a friendly and straightforward manner, using the word “I” to describe your thoughts and feelings.
- If someone asks you a question, answer directly and openly. If you don’t want to answer the question, say that instead.
- Give praise or say “thank you” when someone reacts in a positive, helpful way towards you.

After the encounter:

- Reward yourself for behaving confidently, even if things don’t turn out the way you want.
- Don’t be too hard on yourself if you behaved in an insecure or aggressive way. Instead, reflect on what you were thinking and feeling at the time, and how you might behave differently in this type of situation in the future.
- Remember that you deserve respect, just as you respect others.

Homework: Communication Journal/Communicating in Public Situations

Continue keeping the *Communication Journal.* Include examples of situations in which you needed to communicate in a public situation. Ask yourself: How did I cope? Did I speak? What would I do differently in the future?

Homework: Communicating with Health Professionals

The following questions are designed to help you think about how you discuss Parkinson's disease with health professionals.

- Am I able to tell my doctor (nurse, therapist) how I am doing and what I need?
- Do I sometimes feel that the health professionals who are treating me don’t understand me and my needs?
- If I haven't understood something the doctor said, am I able to ask for clarification?
- When I am at appointments with health professionals, do family members speak for me? If so, is that my preference, and do they communicate what I would like to say?
- At the end of the appointment, can I summarize the points the doctor explained?

Communication Session 5: Communicating with Health Professionals

Summary Sheet

Key Points: Dealing with Health Professionals:

Developing and maintaining good relationships with health professionals is important for receiving optimal care. When you have an appointment with health professionals, the following tips may help:

- Be prepared for your visit by writing down your questions for your own use, and/or to give to the health professional.
- If your health professional has an option for you to provide information through an online patient portal, you may prefer to take care of these things in advance of your visit.
- Think about how your behavior and speech may come across to the health professional, particularly if they are not familiar with PD, and explain your situation (e.g., why you are responding slowly).
- If needed, use words to compensate for reduced facial expressions and gestures.
- Reinforce the health professional's efforts to understand.
- If the health professional does not listen to or address your concerns, speak up in an assertive, direct manner. Avoid sounding accusatory or aggressive.

Homework: An Appointment with a Health Professional

- Think about an upcoming appointment with a health professional. Ask yourself:
  - What information do I need to give and receive in the session?
  - What else do I hope to achieve from the appointment?
- Practice what you will need to tell and ask, either as a role-play with a partner/friend, or on your own. Consider your thoughts, feelings, and behaviors as you practice (e.g., are my thoughts focused, is my breathing calm?). Make notes to bring to the next session.
- If you interact with a health professional before the next session, observe your own behavior. Ask yourself:
  - What were my thoughts, feelings, and behaviors?
  - Did I achieve my goals?
  - Did I feel that the health professional respected and listened to me?
  - What went well, and what would I do differently in the future?

Homework: Communicating with Family and Friends

The following questions are designed to help you think about how you communicate with people close to you.

- Do I talk less to my family/friends, now that I have PD?
- Do I sometimes feel that my family/friends don't understand me as well as they used to?
- Is it sometimes difficult for me to explain to family/friends how they could best help me?
- Do my family/friends sometimes misunderstand the symptoms of my disease?
- Am I aware of the difficulties and stressors that my family/friends are dealing with because of the disease?

Homework: Communication Journal

Continue keeping the *Communication Journal.*

Communication Session 6: Communicating with Family and Friends

Summary Sheet

Key Points: Effects of PD on Close Relationships

Effects of PD on relationships:

- People with PD, as well as family members, often feel misunderstood.
- PD can create specific burdens for caregivers, such as a need to restrict activities and take over duties.
- People with PD are often reluctant to talk about their problems to family members and friends, yet this communication can be beneficial.

Key Points: Improving Communication with Family and Friends

When you are speaking to others, continue to use the direct communication techniques described in Sessions 3 and 4. In addition:

- Deal with specific situations, and avoid generalizations.
- When bringing up something related to how the other person is behaving, refer to the behavior, not the person.
- Stay in the present: Talk about what's happening right now, rather than digging up past problems that are no longer as important.
- If someone makes a request that seems unreasonable to you, you can ask about the purpose of the request. Perhaps with more information, you will realize it is something you are willing and able to do.
- If you are unwilling or unable to comply with a request, say "no" clearly. Depending on the situation, you may want to explain your reasons for saying no, but do not apologize excessively.

When you are listening to others:

- Use techniques for active listening (see Session 3).
- If you are emotionally unable to engage in a conversation at that time, acknowledge those feelings directly.

Homework: Talk with a Family Member or Friend About PD

Look for disease-related topics to talk about with someone close to you. You can start small, with a brief conversation.

Homework: Communication Journal

Continue keeping the *Communication Journal*.

Homework: Program Review

Think about the following questions:

- What goals did I achieve? (Reviewing your *Communication Journal* can help you to assess your progress.)
- How did my achievements compare with my original expectations of the program?
- What are the most important things I learned or experienced during the training program?
- How can I maintain my progress, and apply what I have learned to future situations?
- Which parts of the training, in my view, might be changed or improved in the future?
- What tips and encouragement can I give to others?

Communication Session 7: Program Review

Summary Sheet

Check Your Suitcase

After you leave the session, you can review the “suitcase” you have received for your journey through life with Parkinson’s disease at any time: both for the difficult parts of the journey, and the happy parts. In addition, think about your goals prior to the booster session. Ask yourself:

- How will I maintain or expand upon my achievements?
- What new goals will I set?

Follow-up

My individual session will be on DATE/TIME.

The group booster session will be on DATE/TIME.

Emotions Program Handouts

Emotions Program: Overview and Schedule

Therapist Name: ________________
Contact information: ______________________
Location of sessions: ______________________

Key Points: Training Program

Goals:

- The goal of this training program is for you to improve your ability to express your emotions.
- We all experience feelings and need to share them with others. This program is particularly suitable for people whose emotional expression has been affected by PD.
- You will learn strategies to increase your ability to observe emotions in other people, become more aware of your own emotional expressions, and to convey emotion through your face, voice, gestures, and by describing how you feel. You will learn new skills, and will learn how to use existing skills in new ways.
- By working toward these goals, you can increase life satisfaction.

Format:

- The Emotions Program has 6 sessions, plus a booster session (see *Schedule*).
- In each session, you will learn new information, practice skills in the group, and provide feedback about the session.
- Between sessions, you will work on homework that will enable you to apply what you have learned to daily life.
- To get the most out of this program: participate actively in the session, practice regularly at home, and be prepared to change your behaviors and ways of thinking.
- You may also meet individually with the therapist as needed.

Follow-up:

- After the program has finished, you will meet again individually with the therapist, and complete post-treatment questionnaires.
- The booster session will take place 4-8 weeks after the end of the program (see *Schedule*).

SCHEDULE

Session	Date	Topic
1		Introduction
2		Self-awareness of emotional expressions
3		Facial expressions and gestures
4		Vocal expression of emotion
5		Emotional expression: Putting it all together
6		Review
		Booster Session

Emotions Session 1: Introduction to the Program

Summary Sheet

Key Points: Emotions in Parkinson's Disease (PD)

- When we have emotions, we typically have feelings as well as expressions that reflect those feelings.
- PD may affect emotional expressions, with no change in feelings. Thus, expressions can become "decoupled" from feelings in PD.
- People with PD may appear to be lacking in feeling due to this reduction in expression.
- This decoupling of expressions from feelings can cause misunderstandings.
- There are strategies you can learn that will improve your expression of emotion.

Homework: Introductory Questions

Ask yourself the following questions about PD. If desired, you can mark which questions are most important to you, and/or make notes about issues to bring up in the sessions.

- What do I know already about PD?
- How has PD changed my life?
- What effects does PD have on my relationships with other people?
- What would I like to change about how I live with PD?
- How could I bring about these changes?
- What have I tried so far to improve my ability to live with PD?
- What will I do to cope if my condition gets worse?
- Should I tell other people that I have PD? If so, who and in what situations?
- Who can I talk to about my PD?

Ask yourself the following questions about your expectations for this program:

- What are my expectations for the training program?
- What can the training program help me with?
- What can the training program *not* help me with?

What other questions do you think are important?

Emotions Session 2: Self-Awareness of Emotional Expressions

Summary Sheet

Key Points: Self-Observation

- Self-observation refers to paying attention to your thoughts, feelings, and behaviors right at this moment, with a non-judgmental attitude. You can use it to identify behaviors to change, and to find solutions.
- To practice self-observation, select a specific thought, feeling, or behavior as the target of your observation. Identify the circumstances and situations in which it occurs. Practice often and talk with others for additional feedback.

Key Points: Emotional Feelings and Expressions

- Emotional feelings (experience)
  - Emotional feelings are hard to describe, but we all know what it means to experience different emotions.
  - We can experience brief emotions as well as longer-lasting feelings (moods).
  - Emotional feelings help us to cope with our environment, by signaling what is important, guiding our behavior, and shaping our relationships with others.
  - Emotions enrich our lives but can also be maladaptive.
- Emotional expressions
  - Expressions refer to the ways we communicate our emotions to others, and can be verbal or nonverbal. They normally occur automatically.
  - PD can affect your expression of emotion, and thus can also affect whether or not your emotions can be perceived by other people. Changes can include less emotion in the voice, less facial expression, and fewer movements in conversation.

The first step in improving your emotional expressions is to understand how you are coming across to others, through self-observation and by asking others for feedback.

Key Points: Setting Goals

Making changes is easier, more effective, and more rewarding if you set goals. A goal is an outcome that you want to achieve. It can be short-term or long-term.

To achieve a goal, identify specific, concrete “target behaviors” that you can change. A goal may have more than one target behavior that contributes to the outcome.

To set goals and target behaviors:

1. Decide on a goal. Select an important concern or difficulty that you would like to address. If you have more than one major concern, pick the one that is most important to you in the immediate future.
2. Describe at least one target behavior that you can work on in the coming week, which will contribute to the goal.

3. Set a reasonable level of achievement for the target behavior. Take into account your current level of that behavior, and what is realistic for you to achieve in the near future.
4. If desired, you can create a *Goal Staircase* using a 4-point scale, for one or more of the target behaviors. A *Goal Staircase* enables you to visualize your desired behavior change. Although you will be aiming for your target, different levels of improvement are possible—the possibility of success is not "all or nothing."

Creating a Goal Staircase

Your current situation with regard to the behavior is 0, and your target is +1. If you improve beyond your target, your rating would be +2. If your situation worsens, you would be -1, like this:

+2: better than expected
+1: TARGET
0: unchanged
-1: worse

Homework: Setting Goals

For this homework, you will identify a goal (outcome) that you would like to achieve, and one or more target behaviors that will help you meet the goal. Follow the guidelines under *Key Points*.

Homework: Start the Emotions & Reactions Log

At least once per day, write down notes about emotional situations and reactions you experience.

Emotions & Reactions Log

Date	Event/Situation	My feelings	My expressions of emotion	Emotions/reactions expressed by others
	(Example) Talking with my partner about our plans for the day	I am excited about getting out of the house.	I am smiling and nodding and saying ok.	Partner appears annoyed—seems to think that I do not really want to go out.

Emotions Session 3: Facial Expressions and Gestures

Summary Sheet

Key Points: Nonverbal Emotional Expression

- Nonverbal emotional expression refers to any of the ways you show emotion beyond the use of words.
- Most expressions occur automatically, with no conscious awareness.
- People with and without PD differ in how expressive they tend to be, but PD can reduce expression.
- Because expressions usually occur automatically, you may not notice that your expressions are reduced.

Homework Assignment: Practicing Facial Expressions

1. Practice making facial movements in front of a mirror.
   - Pull your eyebrows tightly together
   - Raise your eyebrows all the way up
   - Open your eyes wide
   - Pull the corners of the mouth upwards, pushing your cheeks upwards
   - Pull the corners of your mouth down
   - Push your chin forward
   - Press your lips together
   - Pull in the corners of your mouth and make dimples
   - Raise your upper lip
   - Scrunch up your nose
   - Open your mouth wide
2. Practice making natural-looking emotional expressions, such as looking:
   - Happy
   - Annoyed
   - Puzzled
   - Disgusted
   - Angry
   - Sad

Homework Assignment: Emotions & Reactions Log

Continue recording in the *Emotions & Reactions Log*.

Emotions Session 4: Vocal Expression of Emotion

Summary Sheet

Key Points: Expressing Feelings Through the Voice

In addition to conveying feelings through facial expressions and gestures, we convey feelings through the *voice* by:

1. Using specific words to express how we feel (see handout *Words and Phrases that Express Feelings*)
2. Our tone of voice, including volume, rhythm, which words are emphasized.

Homework Assignment: Expressing Feelings Nonverbally

Continue practicing expressing feelings nonverbally using the handout from class. If desired, you can videotape your expressions for feedback.

Homework Assignment: Emotions & Reactions Log

Continue recording in the *Emotions & Reactions Log*. Ask yourself: Does it appear that the people I am communicating with understand what I am feeling?

In-Class/Homework Activity: Words and Phrases that Express Feelings

We choose certain words to express our feelings. The following is a list of words and phrases that can be used to express feelings, but there are many others. Which words or phrases would YOU choose? I am/I feel…

Happiness	Love	Anger	Fear	Hate	Grief
thrilled	connected	irritated	uncertain	loathing	defeated
having fun	content	insulted	worried	resentful	depressed
satisfied	enamored	furious	anxious	disgusted	heartache
proud	moved	annoyed	frightened	contempt	lonely
in a good mood	appreciative	livid	terrified	revulsion	desperate

Phrases/Sentences

Feeling	Type of speech	
	Direct/Assertive	**Indirect/Sarcastic/Aggressive**
Anger	I'm angry because you didn't show up for our date today.	Hmm, I wondered if you were dead.
	I'm disappointed because you keep saying things to other people that I told you in confidence.	How nice of you to tell everyone my personal information!
Disgust	I hope you don't mind me mentioning this, but you often smell sweaty. I'm very sensitive to different smells.	Oh my goodness, we really must open some windows!
Joy	I'm thrilled with this gift—it's perfect!	You really shouldn't have done that.
	I'm so glad you thought of me!	And here I thought you'd forgotten me.

Annoyance	As I mentioned before, I must study for my exam, so I hope you understand that I can't go out with you tonight.	Leave me alone! Can't you see that I must study now?
	I would really like for us to leave now—I'm worn out trying to make conversation with so many people.	So you are suddenly the life of the party? Do you plan for us to stay all night?
Love	I like you very much/I love you.	You're a pleasant person to work with.
	I like it when you smile at me that way.	Do people tell you that you have a nice smile?
Sadness	I'm very sad that you don't want to be with me anymore.	That's just like you! You have never cared what happens to me.
	I get lonely when we see each other only on weekends.	You must care a lot if you want to see me only on weekends!

In-Class activity/Homework: Expressing Feelings Nonverbally

The same statement can send different signals depending on the speaker's tone of voice and the situation. For this exercise, practice saying each sentence in three different ways, by changing your emotional expression: happy, neutral, and annoyed. The description of the situation provides the rationale for the emotion.

Happy	Neutral/Objective	Angry/Annoyed
You met up with a good friend at a café. You had a fun afternoon. You later say *happily* to your neighbor:	You met up with a good friend at a café. Your neighbor later asks you what you did this afternoon. You tell her in a *matter-of-fact* way:	You were supposed to meet a good friend at a café. You waited an hour, but your friend didn't show up. You later say *angrily* to your neighbor:
"I had a coffee date this afternoon."		
You went to the doctor, who prescribed a new medication. It is supposed to have fewer side effects than your previous medication. You say *happily* to a good friend:	You went to the doctor, who prescribed a new medication. The doctor said it will work in the same way as your current medication. You make a *matter-of-fact* comment to a good friend:	You went to the doctor, who prescribed a new medication. It is said to have more side effects than your previous medication. *Annoyed*, you say to a good friend:
"This is the new medicine the doctor prescribed for me."		

You are invited to dinner at a friend’s house. The coffee tastes very good and you would like to have another cup. You say *pleasantly* say to your friend:	You are invited to dinner at a friend’s house. You would like to have a second cup of coffee. You ask your friend in a *matter-of-fact* way:	You are invited to dinner at a friend’s house. You have spilled your coffee and would like to have another cup. *Annoyed at yourself*, you ask your friend:
“Could I please have another cup of coffee?”		
You’re in a department store. A salesperson is very friendly to you and asks if you have decided yet what to buy. You say *pleasantly* to them:	You’re in a department store. A salesperson asks if you have decided yet what to buy. You tell her in a *matter-of-fact* way:	You’re in a department store. The salesperson appears to be impatient with you and asks for the third time if you have decided yet what to buy. *Annoyed*, you say to her:
“I’m afraid you’ll have to wait a bit; I need some more time.”		
Your phone is ringing. You are expecting a call from a good friend you are excited to talk with. You answer the phone by *happily* saying:	Your phone is ringing. You answer the phone by saying in a *matter-of-fact* way:	Your phone is ringing. It's after 11:00 pm, and the ringing wakes you up from your sleep. *Annoyed*, you answer the phone by saying:
“Hello, who is this?”		
You want to go for a walk with a good friend. Outside the sky is blue and the sun is shining. You say *happily* to your friend:	You want to go for a walk with a good friend. You’re looking out the window. You tell your friend in a *matter-of-fact* way:	You want to go for a walk with a good friend. It’s pouring down rain outside. *Annoyed*, you say to your friend:
“Come to the window and look at this weather.”		
You would like to know the name of a town that you see when looking through photos with a friend. You *happily* ask your friend:	You would like to know the name of a town that is an answer in a crossword puzzle. You ask a friend in a *matter-of-fact* way:	You can’t remember the name of a town even though you know the town very well. You’re upset that you can’t remember. *Annoyed with yourself*, you ask a friend:
“What is the name of that town with 15 churches?”		

Emotions Session 5: Emotional Expression—Putting it All Together

Summary Sheet

Key Points: Learning What Works for You

- Communicating your emotions to others takes practice, feedback, and experimentation to figure out what works best for you.
- Consider which forms of expression are easiest for you to do.
- Ask friends and colleagues directly what cues they use to understand your feelings.
- Ask for feedback in the moment—calmly and nonjudgmentally—about whether you are coming across in the ways you intend.

Telling Stories

Fairy Tale: The fox and the geese (Grimm & Grimm 1884)

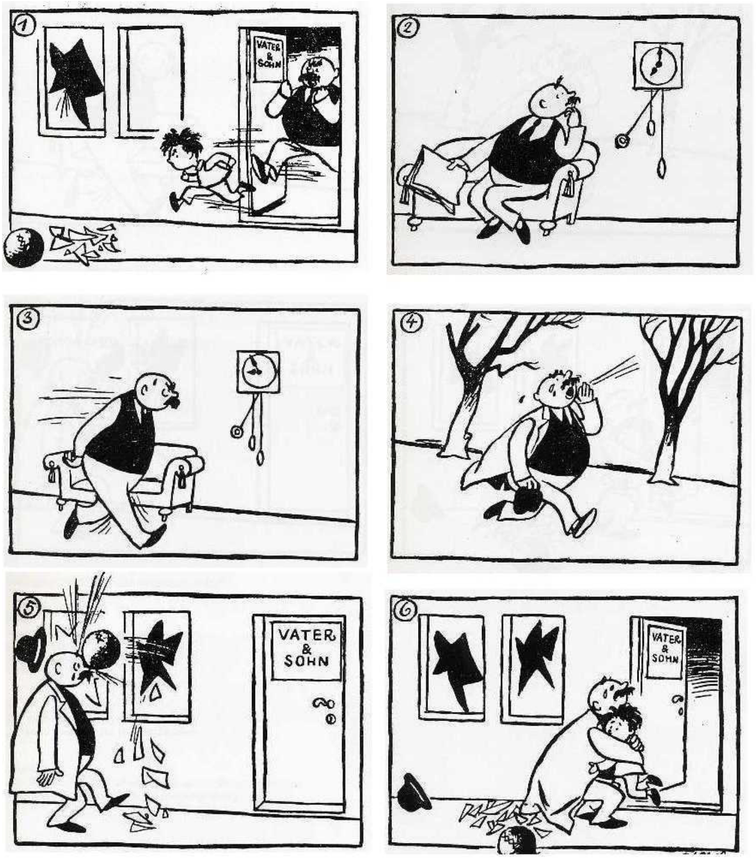
The fox once came to a meadow in which was a flock of fine fat geese, on which he smiled and said, "I come at the nick of time, you are sitting together quite beautifully, so that I can eat you up one after the other." The geese cackled with terror, sprang up, and began to wail and beg piteously for their lives. But the fox would listen to nothing, and said, "There is no mercy to be had! You must die."

At length one of them took heart and said, "If we poor geese are to yield up our vigorous young lives, show us the only possible favor and allow us one more prayer, that we may not die in our sins, and then we will place ourselves in a row, so that you can always pick yourself out the fattest."

"Yes," said the fox, "that is reasonable, and a pious request. Pray away, I will wait till you are done." Then the first began a good long prayer, forever saying, "Ga! Ga!" and as she would make no end, the second did not wait until her turn came, but began also, "Ga! Ga!" The third and fourth followed her, and soon they were all cackling together.

When they have done praying, the story shall be continued further, but at present they are still praying without stopping.

Figure B1: Cartoon from the Father and Son series of E. O. Plauen (1903-1944)



Homework Assignment: Emotions & Reactions Log

Continue recording in the *Emotions & Reactions Log.*

Homework: Program Review

Think about the following questions:

- What goals did I achieve?
- How did my achievements compare with my original expectations of the program?
- What are the most important things I learned or experienced during the training program?
- How can I maintain my progress, and apply what I have learned to future situations?
- Which parts of the training, in my view, might be changed or improved in the future?
- What tips and encouragement can I give to others?

Emotions Session 6: Program Review

Summary Sheet

Check your Suitcase

After you leave the session, you can review the "suitcase" you have received for your journey through life with Parkinson's disease at any time: both for the difficult parts of the journey, and the happy parts. In addition, think about your goals prior to the booster session. Ask yourself:

- How will I maintain or expand upon my achievements?
- What new goals will I set?

Follow-up

My individual session will be on DATE/TIME.

The group booster session will be on DATE/TIME.

Caregiver Program Handouts

Caregiver Program: Overview and Schedule

Therapist Name: ________________
Contact information: ______________________
Location of sessions: ______________________

Key Points: Training Program

Goals:

- The goals of this training program are for you to learn to cope with everyday stress and difficulties associated with your partner's PD, and to improve communication.
- Any relative, friend, or caregiver of a person with PD can participate.
- This program is particularly suitable for people who often experience emotional and physical stress in everyday life and find it difficult to deal with problems brought on by their partner's PD.
- You will learn a variety of skills, including self-observation, relaxation, changing maladaptive thoughts, and activity planning. You will also learn techniques to improve communication with your partner.
- By working toward these goals, you can increase life satisfaction.

Format:

- The Caregiver Program has 9 sessions, plus a booster session (see *Schedule*).
- In each session, you will learn new information, practice skills in the group, and provide feedback about the session.
- Between sessions, you will work on homework that will enable you to apply what you have learned to daily life.
- To get the most out of this program: participate actively in the session, practice regularly at home, and be prepared to change your behaviors and ways of thinking.
- You may also meet individually with the therapist as needed.

Follow-up:

- After the program has finished, you will meet again individually with the therapist, and complete post-treatment questionnaires.
- The booster session will take place 4-8 weeks after the end of the program (see *Schedule*).

SCHEDULE

Session	Date	Topic
1		Introduction
2		Stressful Events; Self-Observation
3		Stress Management I: Relaxation
4		Stress Management II: Self-instruction
5		Activity Planning I: Relief
6		Activity Planning II: Pleasant Activities
7		Communication I: Listening
8		Communication II: Speaking
9		Review
		Booster Session

Caregiver Session 1: Introduction to the Program

Summary Sheet

Key Points: Psychological Stress of Caregivers

Stress is normal: When you encounter a problem or situation that you need to deal with, your body will normally increase its activity to enable you to cope with the challenge. This response is called a "stress response." A stress response is characterized by three basic features.

1. It has multiple components, which can vary from person to person, and in different situations:
    - Unpleasant thoughts and feelings (e.g., worry, restlessness, anger, fear, and sadness)
    - Physical changes (e.g., increase in heart rate, sweating, muscle tension, and blood pressure)
    - Behavioral changes (e.g., avoidance, forgetfulness)
2. These components usually occur in a particular sequence.
3. The time course of a stress response is influenced by how you cope with the stressor.

For people with PD, stress can increase motor symptoms, which can in turn increase feelings of insecurity, creating a vicious cycle. For caregivers of people with PD, stress can be a particular problem because:

- Observing and helping a partner with PD can be emotionally stressful.
- Helping a partner with PD can be physically stressful and take a great deal of time.
- Continual stressors can contribute to problems in the relationship.

Homework: Introductory Questions

Ask yourself the following questions about PD (if desired, you can mark which questions are most important to you, and/or make notes about issues to bring up in the sessions):

- What do I know already about PD?
- How has PD changed my life, and my partner's life?
- What effects does PD have on my contacts with other people?
- What would I like to change about how I live with my partner's PD?
- How could I bring about these changes?
- What have I tried so far to improve my ability to live with my partner's PD?
- What will I do to cope if my partner's condition gets worse?
- Should I tell other people about my partner's PD? If so, who and in what situations?
- Who can I talk to about my partner's PD, and my own concerns?

Ask yourself the following questions about your expectations for this program:

- What are my expectations for the training program?
- What can the training program help me with?
- What can the training program not help me with?
- What other questions do you think are important?

Caregiver Session 2: Stressful Events and Self-Observation

Summary Sheet

Key Points: Stressful Events

- A stressful event, or "stressor," is any event that we perceive as threatening or challenging, or that requires additional resources. Even "positive" events can be stressful if they require resources.
- Whether or not something feels stressful to you depends in part on whether you think you can cope with the stressor.
- Stressors can be weak or strong, and can be short or long. Even if the stressful event itself is relatively short, your reactions can continue for much longer if the stressor is powerful or if you relive the stressor in your mind.
- Identifying the conditions and situations that tend to create stress is the first step in training.

Key Points: Techniques to Manage Stress

You will be more likely to reach the goal of managing stress by making small, consistent changes in your daily life. We will use three main approaches:

1. *Relaxation* can calm your body and mind.
2. *Changes in thinking* are possible by first "observing" your thoughts, and then practicing new ways of thinking.
3. *Activity planning* can help in two ways:
   - By scheduling and limiting demanding activities, you can tackle one thing at a time.
   - By engaging in more pleasant activities, you can increase feelings of well-being.

Key Points: Self-Observation

- Self-observation refers to paying attention to your thoughts, feelings, and behaviors right at this moment, with a non-judgmental attitude. You can use it to identify behaviors to change, and to find solutions.
- To practice self-observation, select a specific thought, feeling, or behavior as the target of your observation. Identify when and where it tends to occur. Practice often, and talk with others for additional feedback.

Homework Assignment: Body Awareness

Practice the *Body Awareness Exercise.*

Homework Assignment: Stress Journal

Write in the *Stress Journal for Caregivers.*

Stress Journal for Caregivers

Directions: Complete one form for each day, each evening before going to bed. In the top half of the form, briefly describe stressful situations that occurred that day. In the lower half, describe your reactions and thoughts about the most important stressful situation using the categories provided.

Date:	
Stressful situations today:	
The most important stressful situation today (from list above):	
My reactions in this situation (circle/write in all that apply):	
Feelings	Physical Reactions
Distress	Sweating
Fear/Anxiety	Heart pounding/racing
Sadness	Muscular tension
Restlessness	Other reactions (write in):
Excitement	
Other feelings (write in):	

Thoughts:

Caregiver Session 3: Stress Management I—Relaxation

Summary Sheet

Key Points: Relaxation for Stress Management

Relaxation is the opposite of the state of anxiety. Through targeted relaxation practice, your muscles learn to rest, and your entire body can become more relaxed. This is important because:

- You can calm your thoughts and feelings, allowing you to recover from stress mentally and physically.
- You can gain distance from problems of everyday life.

Relaxation is a skill you can learn: By relaxing at the first signs of stress, you can prevent anxiety. You can increase the effects of relaxation by making adjustments to find out what works best for you.

Homework: Relaxation Practice

- Practice *Relaxation at Rest* exercise every day (see *Tips* to make the exercise more effective).

Homework: Stress Journal

Continue writing in the *Stress Journal*.

Tips for Learning how to Relax: Caregivers

1. Practice regularly, preferably daily.
    - Learning to relax takes regular practice. Don’t expect miracles: the healing effects of relaxation usually appear over time, with repeated practice.
2. Make relaxation a habit by practicing at specific times of day.
    - With practice, you will find your personal rhythm. Make the relaxation exercises an integral part of your daily routine by choosing specific times of day to practice. Some people prefer to practice when they have finished with their work and chores, because it is easier for them to “switch off” at that time. Others prefer to practice in the morning in order to focus and feel stronger throughout the day. Pick the times that are best for you: you may need to experiment to find out what those times are.
3. First learn how to relax under restful conditions.
    - In the beginning, practice in a quiet, stress-free environment. Find a pleasant place where you like to spend time. Ask family members not to disturb you and put your phone away. The time for relaxation is all yours!
4. Assume a comfortable posture.
    - Sit in a comfortable chair. Do not cross your legs, as this will inhibit blood flow.
5. Close your eyes if you wish.
    - Many people prefer to close their eyes during the relaxation exercise; do what is comfortable for you.
6. Deal calmly with interruptions.
    - During practice, your feelings of relaxation may be interrupted by hearing outside noises, by unrelated thoughts and worries, or other disturbances. Don't fight it. Let the sounds and thoughts come and go. Then turn back to the exercise.
7. Relax using the methods that work best for you.
    - Experiment until you find the methods that work best for you, whether that is muscle relaxation, relaxed breathing, visual imagery, other techniques, or a combination.
8. Enjoy the relaxation!

Caregiver Session 4: Stress Management II—Self-Instruction

Summary Sheet

Key Points: Brief Muscle Relaxation

To relax more quickly, muscle groups can be combined:

- Hands and arms: Clench both hands into fists and at the same time, bend your arms to tense your biceps.
- Face and neck: Squint your eyes and at the same time, clench your teeth and tense the muscles of your neck.
- Shoulders and abdomen: Pull your shoulders up in a shrug, and at the same time, tense your abdominal muscles by making your stomach hard, like bracing for a punch.
- Legs and feet: Keeping your heels on the floor, pull your feet upward as far as possible and tense your calves.

Key Points: Self-Instructional Training

What is self-talk?

- Self-talk refers to our "inner dialogue," which can influence our behavior.
- Some thoughts increase stress ("negative self-talk") and some thoughts decrease stress ("positive self-talk").
- These thoughts may be hard to identify because they seem to occur automatically.

How and why might you change your self-talk?

- One way to control stress is to replace stress-increasing thoughts with stress-reducing thoughts.
- Deliberately changing thoughts is called "self-instructional training," and takes practice.
- These thoughts can occur before, during, or after a stressful event; we can change them during any of these phases.
- Using words that have the most individual meaning for you in a particular stressful situation will increase the effectiveness of this technique.

Integrating self-talk with relaxation techniques

- You can combine positive self-instructions with brief relaxation techniques, such as muscle relaxation, controlled breathing, and visualizing relaxing images.
- You can practice by re-imagining a stressful situation in your past; then imagine changing how you handled it.

Homework Assignment: Self-Instruction and Relaxation in Stressful Situations

- Practice the self-talk and relaxation exercises at home, by re-imagining the past and handling the situation with positive self-talk and relaxation.
- Use self-talk and relaxation techniques in stressful situations you encounter.

Homework: Stress Journal

Continue writing in the *Stress Journal*.

Caregiver Session 5: Activity Planning

Summary Sheet

Key Points: Setting Goals

Making changes is easier, more effective, and more rewarding if you set goals. A goal is an outcome that you want to achieve. It can be short-term or long-term.

To achieve a goal, identify specific, concrete “target behaviors” that you can change. A goal may have more than one target behavior that contributes to the outcome.

To set goals and target behaviors:

1. Decide on a goal. Select an important concern or difficulty that you would like to address. If you have more than one major concern, pick the one that is most important to you in the immediate future.
2. Describe at least one target behavior that you can work on in the coming week, which will contribute to the goal.
3. Set a reasonable level of achievement for the target behavior. Take into account your current level of that behavior, and what is realistic for you to achieve in the near future.
4. If desired, you can create a *Goal Staircase* using a 4-point scale, for one or more of the target behaviors. A *Goal Staircase* enables you to visualize your desired behavior change. Although you will be aiming for your target, different levels of improvement are possible—success is not “all or nothing.”

Creating a Goal Staircase

Your current situation with regard to the behavior is 0, and your target is +1. If you improve beyond your target, your rating would be +2. If your situation worsens, you would be -1, like this:

+2: better than expected
+1: TARGET
0: unchanged
-1: worse

Key Points: Activity Planning

Keeping an activity plan will help you structure your day to align with the goals, needs and abilities of both you and your partner. Activity planning can help you:

- Prevent stressful situations
- Identify highest-priority activities
- Have more time for enjoyable activities

Homework: Setting Goals

For this homework, you will identify a goal (outcome) that you would like to achieve, and one or more target behaviors that will help you meet the goal. Follow the guidelines under *Key Points*.

Homework Assignment: Activity Planning

Complete the homework sheet Activity Planning for Caregivers.

Homework Assignment: Bring Something Pleasant

Bring at least one object that you find pleasant, invigorating or relaxing to the next group session. If you prefer, you can instead (or additionally) "bring" and describe pleasant feelings, fantasies, images, or memories that are particularly important to you.

Homework: Stress Journal

Continue writing in the *Stress Journal*.

Homework Sheet: Activity Planning for Caregivers

Create an activity plan with the following objectives:

- Avoid situations with excessive demands.
- Ensure time for high priority activities.
- Create more time for pleasant activities.

You will first identify priority activities, and then make a schedule of activities. Consider how your goals and abilities may have changed with your partner's PD, and how their PD symptoms may vary throughout the day. If their symptoms vary, identify "good periods" and plan more demanding activities for those periods.

Step 1: Identify priority activities (see examples):

- Make a list of the things you want or need to do, and the target frequency (e.g., number of times per day or week). You do not need to include as targets any required activities that you must always do (e.g., go into work).
- Rate the priority level of each activity.

Target activity	**Target frequency**	**Priority level** **(1 = highest; 5 = lowest)**
Long walk in the park	3 times a week	2
Talk to my daughter on the phone	2 times a week	1
Stretching exercises	2 times per day	2
Read a book	Once per day	4

Step 2: Create an activity plan

- Create a template schedule for a typical week. You can adjust the time intervals to fit your normal wake-up and bedtimes, and make the time intervals smaller (e.g., hourly) or larger—whatever is most useful to you.
- Block out time periods that include required, unchangeable activities (e.g., time at work). Note the times that you normally feel your best, and schedule the most mentally or physically strenuous activities for those periods. Build flexibility into the plan. Ask yourself:
  - Does the total number of activities during the day seem appropriate?
  - Could the activities be distributed better throughout the day?

- Are there sufficient breaks between activities?
- Are the goals achievable?
- Does the plan take into account my partner's typical daily fluctuations in symptoms and energy levels?
- Are pleasant activities included? Is there enough variety in pleasant activities?

Note: If you are not sure what the "best" times for you or your partner are, you may first want to track your energy/functional levels throughout the day for several days, to discover if there is a pattern to the fluctuations.

TIME	**Monday**	**Tuesday**	**Wednesday**	**Thursday**	**Friday**	**Saturday**	**Sunday**
6-9 am							
9-12							
12-3 pm							
3-6							
6-9							
9-12							

Caregiver Session 6: Pleasant Activities

Summary Sheet

Key Points: Pleasant Activities

Pleasant activities are activities that you want to do, and are associated with positive feelings. They are important because they make our lives more intense, rich, and meaningful, and can reduce feelings of depression. Typically:

- Pleasant activities are often linked to goals.
- A person experiencing a pleasant activity feels “absorbed” in the activity.
- Pleasant activities are accompanied by a broadening of the senses.

Your ability to plan and enjoy pleasant activities can improve with practice. Pleasant activities are especially important for caregivers of people with PD because:

- You may need to discover new ways to engage in pleasant experiences.
- If you experience negative feelings you could have less interest in engaging in pleasant activities, creating a vicious cycle.

Obstacles to increasing pleasant activities include:

- Not having enough time
- Lack of motivation
- Guilt about having fun

Tips for increasing pleasant activities:

1. Take your time.
2. “Allow” yourself to experience enjoyment.
3. Focus on the activity at hand.
4. Learn what works best for you.
5. Less is more. Too much of a good thing can actually decrease enjoyment.
6. Enjoyment is not just for special occasions.
7. Practice!

Homework Assignment: Have Some Fun!

Choose three enjoyable activities to engage in during the coming week. Carry out at least one of these activities every day.

Homework: Stress Journal

Continue writing in the *Stress Journal*.

Caregiver Session 7: Communication I—Active Listening

Summary Sheet

Key Points: How PD can Affect Close Relationships

A person with PD may have difficulties that affect their ability to communicate, either directly (e.g., not speaking loud enough, not responding quickly enough, or trouble finding the right words) or indirectly (e.g., reduced motivation to communicate). Communication difficulties can test a relationship.

Key Points: Active Listening

- Maintain appropriate eye contact, and show nonverbally that you are listening (e.g., head nods).
- Withhold your own opinion while your partner is speaking.
- Have patience: give them as much time as they need to express themselves.
- To make sure you understand your partner correctly, paraphrase: report back to them what they said, in your own words, and ask if that is what they meant.
- Ask clarifying questions.
- Ask open questions: If you are not sure what they are thinking or feeling, ask them directly what they mean or how they feel.
- Ask follow-up questions to show interest and to understand them better.
- Give positive feedback: after your partner has explained something openly and clearly, tell them so.
- Provide feedback about how the interaction makes you feel.
- Be honest: If you are unable to engage in a conversation at a particular time, acknowledge those feelings directly.

Homework Assignment: Active Listening

“Observe” conversations with your partner, with the goal of being an active listener. Make note of any problems or successes that you observe.

Homework: Stress Journal

Continue writing in the *Stress Journal.*

Caregiver Session 8: Communication II—Speaking

Summary Sheet

Key Points: Speaking Directly

The way you communicate with your partner affects how willing and motivated they will be to discuss a topic, and how they will respond.

- Get the person's attention before speaking and look at them directly.
- Use the word "I" to describe your own thoughts and feelings ("I think this; I feel that").
- Open up: Be honest and express your needs directly.
- Deal with specific situations, and avoid generalizations.
- When bringing up something related to how the other person is behaving, refer to the behavior, not the person.
- Stay in the present: Talk about what's happening right now, rather than digging up past problems that are no longer as important.
- If your partner makes a request that seems unreasonable to you, ask about the purpose of the request. Perhaps with more information, you will realize it is something you are willing and able to do.
- If you are unwilling or unable to comply with a request, say "no" clearly. Depending on the situation, you may want to explain your reasons for saying no, but do not apologize excessively.

Homework Assignment: Conversation Practice

Practice conversation skills from the role-play with a partner, friend, or another participant, with a focus on speaking directly as well as active listening. If desired, use a *Goal Staircase* to identify target behaviors to work on during the conversations.

Homework: Stress Journal

Continue writing in the *Stress Journal.*

Homework Assignment: Program Review

Think about the following questions:

- What goals did I achieve?
- How did my achievements compare with my original expectations of the program?
- What are the most important things I learned or experienced during the training program?
- How can I maintain my progress, and apply what I have learned to future situations?
- Which parts of the training, in my view, might be changed or improved in the future?
- What tips and encouragement can I give to others?

Caregiver Session 9: Program Review

Summary Sheet

Check Your Suitcase

After you leave the session, you can review the “suitcase” you have received for your journey through life at any time: both for the difficult parts of the journey, and the happy parts. In addition, think about your goals prior to the booster session. Ask yourself:

- How will I maintain or expand upon my achievements?
- What new goals will I set?

Follow-up

My individual session will be on DATE/TIME.

The group booster session will be on DATE/TIME.

Relaxation Scripts

Body Awareness Exercise (Script)

- Please sit in a comfortable position, and close your eyes... (pause).
- The aim of this exercise is to become aware of tension in your body.
- Just concentrate on different areas of your body as I go through the exercise with you, one area at a time. Notice how the different parts of your body feel - whether they are relaxed or tense, or whatever else you notice about them. Please do not rate or judge how you are doing; simply become aware.
- We will start with the feet.
- First, move your attention to your left foot. How does your left foot feel? How do your toes feel? The sole of your foot?
- Move your attention up your left leg to your calf. How does your calf feel? Your knee? Your upper leg? Your hip?
- Now bring your attention to your right foot. To your toes ... to the sole of your foot ...
- Take note of what is happening in the body. Go on to your right calf... knee... your upper leg... and the hip...
- Now bring your attention to your belly... to your bottom... Simply observe. With each part of your body, ask yourself how it feels.
- Now focus on your chest. How does it feel?
- Move your attention to your back, your spine, your shoulder blades. How does it feel?
- Now focus on your left hand ... your fingers ... palm ... forearm ... upper arm and shoulder
- Go next to your right hand... your fingers... palm... forearm... upper arm and shoulder
- Now move your attention to your shoulders... to your neck... and up to your jaw... Observe if your jaw is tense or relaxed. Leave the lips slightly open. Now bring your attention to your cheeks...
- And now, for a brief moment, move your attention to your thoughts. Observe the thoughts as they go through your mind without evaluating them.
- And now observe how you are feeling.
- Take some deep breaths... and slowly open your eyes.

(modified from Tausch, 1993, pp. 162-163).

Relaxation at Rest (Script)

The following relaxation exercise consists of three parts: progressive muscle relaxation, relaxed breathing, and visual imagery. The whole exercise takes about 20 minutes. Read the script in a calm and soothing voice, following the instructions in parentheses about speed of delivery and volume.

Before the progressive muscle relaxation exercise is presented, demonstrate each muscle group to make sure that the participants know how to perform each contraction, and answer any questions. If possible, perform each contraction/relaxation along with the participants.

Introduction

Sit down comfortably. Lean back so that your back is firmly supported. Place your feet on the floor at a comfortable distance next to each other. Let your arms rest on the chair or on your lap. Keep your muscles as loose and relaxed as possible. Close your eyes and take a deep breath.

Prepare to switch off: from the environment (*pause*), from sounds you hear (*pause*), from thoughts that may run through your mind. Let these thoughts come and go.

Muscle relaxation

We will start with muscle relaxation. An essential part of learning to relax is to pay close attention to feelings of tension and relaxation in your muscles, to recognize the difference between these feelings.

You will practice tensing and then releasing specific muscle groups throughout your body. When I ask you to tense the muscles, do so as strongly as you can and still feel comfortable. I will then ask you to relax the muscles. Be sure to release the tension all at once, rather than gradually, to feel the full effects of relaxation. Allow yourself to let go, to reach a greater state of relaxation than before.

We will focus first on the muscles of the right hand.

- (*Faster and more forcefully*): Clench your right hand into a fist. Notice the feeling of tension in your forearm... in your hand...
- (*Slower, softer*): And let it go. Let the arm rest comfortably and loosely. Pay attention to the change from the tension before to the pleasant relaxation now. Take your time, and let your muscles relax.
- (*Faster*): Now clench your left hand into a fist. Pay attention to the feeling of tension in your forearm... in your hand...
- (*Slower, softer*): And let it go. Allow your arm to be very loose and relaxed. Let both forearms sink down, concentrate on each finger: your thumbs, your index fingers, middle fingers, ring fingers, little fingers.

We will move next to the upper arms.

- (*Faster*): Bend both arms and tense your biceps. Keep your hands relaxed at first, and then tense your hands into fists while keeping your biceps tensed. Pay attention to the tension in the upper arms.
- (*Slower*): And let it go. Let your arms rest comfortably on your thighs or on the chair. Let the muscles in your arms and hands become loose and relaxed. Concentrate on the feeling of relaxation. It can be a feeling of warmth, (*short pause*) a feeling of heaviness, (*short pause*) a tingling sensation (*short pause*). Just let it happen and relax even further.

Now concentrate on the forehead.

- (*Faster*): Lift your eyebrows as high as possible. Hold the tension for a moment.
- (*Slower*): And let it go. Let your forehead become smooth and relaxed. Pay attention to the pleasant feeling of relaxation in your muscles. Allow your forehead to become more and more relaxed.

We will next focus on the eyes.

- (*Faster*): Squint your eyes tightly as if you were looking into bright light. Tense the muscles but not to the point that you feel uncomfortable. Tense...
- (*Slower*): And release the tension. Keep your eyes slightly closed, let your eyelids get heavy, and pay attention to the pleasant feeling of relaxation as your muscles relax more and more.

We will next focus on the jaw.

- (*Faster*): Bite down, showing your teeth and clenching them, and pulling the corners of your mouth outward. Pay attention to the tension in the entire jaw area.
- (*Slower*): And let it go. Allow the muscles of the jaw area to relax. Allow the lips and all of your facial muscles to relax. Let go more and more and relax more and more deeply. Let your forehead relax. Your eyelids are heavy and relaxed, the jaw area loose. Pay attention to the feeling of calmness that spreads across your face as you continue to relax.

Now we will move to the neck muscles.

- (*Faster*): Pull your chin down toward your chest. Keeping your muscles tight, turn your head slowly to the right side. Now slowly turn your head to the left side.
- (*Slower*): And let it go. Bring your head back up into a comfortable position. Enjoy the pleasant feeling of relaxation in your neck as you relax more and more deeply.

Next, we come to the shoulders.

- (*Faster*): Pull your shoulders up, in a shrug—notice the tension this creates, hold that tension.
- (*Slower*): And let it go. Let your shoulders sink down. Pay attention to the pleasant feeling of relaxation. Just let your muscles loosen, let the relaxation deepen even more, from your shoulders into your arms and hands, down to your fingertips. Relax more and more deeply.

We will next focus on the abdomen.

- (*Faster*): Tense your abdominal muscles by making your stomach hard, as if you were bracing for a punch.
- (*Slower*): And let it go. Relax your abdomen, feel the difference between the tension before, and the pleasant relaxation now. Keep relaxing...

Now we move to the muscles of the back.

- (*Faster*): Tense your back muscles by pulling your shoulder blades back and together. Feel the tension in your back.
- (*Slower*): And let it go. Allow your back and shoulders to relax completely. Pay attention to the pleasant feeling of relaxation in your back... to your neck and shoulders... your arms... down to your fingertips.

We will next move to the upper legs.

- (*Faster*): Tense the muscles of your thighs and buttocks by pressing your knees together. Pay attention to the feeling of tension all across your upper legs and buttocks.
- (*Slower*): And let it go. Let your legs feel comfortable and relaxed. Feel the pleasant feelings of relaxation in your legs. Let go completely and relax even more.

We will next move to the lower legs.

- (*Faster*): Flex your feet, pulling your toes towards you and feeling the tension in your calves.
- (*Slower*): And let it go, feeling the weight of your legs sinking down. Just relax, let it go.

We will now move to your toes.

- (*Faster*): Point your toes and curl them under, without cramping. Feel the tension in your feet.
- (*Slower*): And let it go. Allow the muscles of your feet to relax completely. Pay attention to the pleasant feeling of relaxation, as it spreads further and further.

Relaxed breathing (1-3 minutes)

For this next part, I would like for you to concentrate on your breathing. Pay attention to how the air flows in and out.

- Inhale slowly, holding your breath for a moment, paying attention to the tension that builds in your chest.
- Slowly breathe out, and feel how your chest becomes relaxed.
- Now feel the calm, steady rhythm of your breathing as you breathe in and out. (*pause)* Just follow your breath as you inhale, exhale.
- If you want to, you can say to yourself "in—out"—as you breathe at your own rhythm.
- Do not try to influence your breathing at all, just let it flow. Pay attention to the feeling of calm spreading throughout your body with every breath.

- Let your body rest on the chair with its full weight. Pay attention to your breathing, do not try to influence it, just let your breath flow in and out and relax a little more with each breath.

Visual Imagery

Close your eyes and imagine that you are in a place where you feel completely at ease: by the sea, in the forest, in a flowery meadow in the sunshine. Think about where you feel most comfortable.

- Now sit quietly and feel that you are in this place of calmness, serenity.
- Is it warm or cool?
- What do you see? The sky? The woods? Plants? Animals? People?
- What do you hear? Sounds of nature? Animals? People? Music?
- What do you feel? On your hands? On your skin? On your face?
- Is there a scent in the air?
- As you imagine yourself in this place, how do you feel?

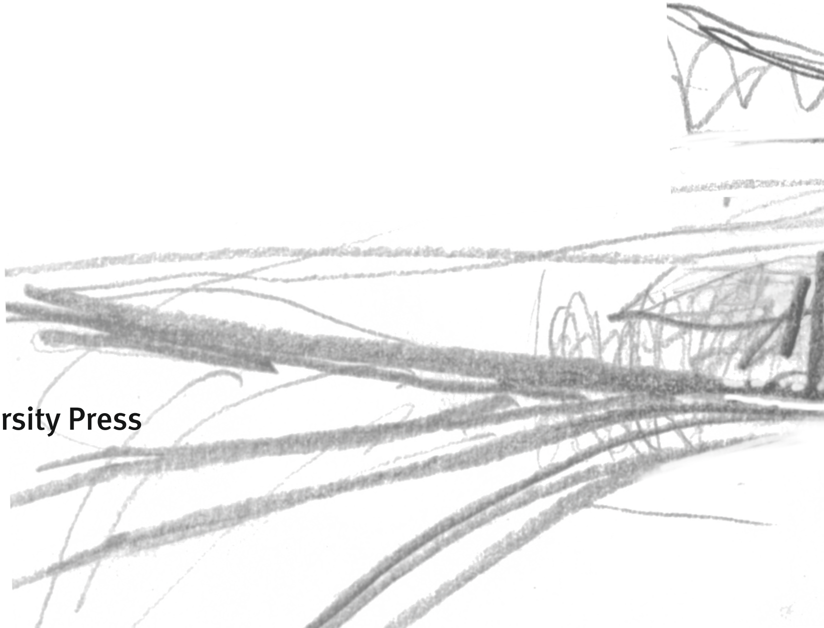
Keep this relaxing image in mind, as well as your feelings of relaxation, as you imagine that you are in this place. I will now be quiet for a few moments as you continue to immerse yourself in feelings of relaxation (*one-minute break*).

Now slowly prepare yourself to come back. Slowly stretch your body, your hands, bend your arms, sit up, take a deep breath, and open your eyes.

The need for mental health support within the Parkinson's disease (PD) community has never been greater, yet many practitioners lack the knowledge or experience to address the unique challenges associated with PD. This book serves as a practical guide for mental health professionals to assist individuals with PD and caregivers through the use of cognitive-behavioral therapy techniques, with the goal of enhancing their well-being and quality of life. The book includes a review of information about PD and mental health, and four structured group programs designed to address issues that are common in people with PD and caregivers:

- Coping with stress and illness
- Communicating about PD
- Emotional expression in PD
- Interventions for caregivers

The programs presented in this book can be utilized as they are, personalized for individual use, or adapted for research protocols. Additionally, the information can serve as a valuable resource for people with PD and their family members, who can learn about PD and be introduced to evidence-based strategies that can be used conjointly with professionals to improve their experience of living with PD.



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