Session 5: Management of Anxiety and Depression (for People with PD) and The Carer’s Challenge (for Carers)

Àngels Bayés Rusiñol, Mari Cruz Crespo Maraver and Anna Prats París
The content of this session differs significantly for carers and people with Parkinson’s disease (PD). The session content is therefore described in separate sections for each group.

**People with PD**

In this session, people with PD learn how to distinguish between serious emotional problems (affective disorders) and normal reactions to the disease. They also receive information about the symptoms of anxiety and depression, ways to deal with these symptoms, and the relationship between emotional changes and PD. The focus in this session is on both anxiety and depression because they so frequently occur together in people with PD, although greater emphasis is given to depression.

**Carers**

Carers learn about the possible impact of PD on the family and discuss psychosocial resources to help deal with these issues.
**Session 5: Management of Anxiety and Depression**

**Overview**

During this session, participants learn about depression and anxiety, the relationship between these symptoms and PD and how to deal with them. Different types of thoughts and behaviours that are associated with emotional discomfort are explored in an exercise. This practice is continued at home.

**Materials**

- Relevant handouts
- Flip chart, markers

<table>
<thead>
<tr>
<th>Part</th>
<th>Contents</th>
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</thead>
</table>
| 1    | Discuss homework  
Stress management  
Option 1: Discuss experiences with recent stressful situations (Trying Out Alternative Ways of Thinking)  
Option 2: Discuss experiences practising the Daily Relaxation Training |
| 2    | Active Information  
Management of anxiety and depression  
Definition: What are anxiety and depression? What is the difference between a serious disorder and a normal reaction to disease?  
Importance of understanding the nature, causes and treatment of anxiety and depression in PD  
Guidelines: List of practical suggestions for dealing with feelings of anxiety and sadness |
| 3    | Exercise  
Increasing feelings of wellbeing  
Option 1: Positive thoughts  
Option 2: Maintaining healthy activities |
| 4    | Homework  
Option 1: Thinking of a positive event  
Option 2: Maintaining healthy activities |
| 5    | Appetiser  
Social Competence  
Noticing situations in which you would like to express your thoughts and feelings but do not have the confidence to do so |
Part 1
Discuss Homework: Stress Management 0:30’

Goal:
- To support the application of knowledge and skills from the previous session (Stress Management) in everyday life.

<table>
<thead>
<tr>
<th>Contents</th>
<th>Instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discuss homework</td>
<td>Ask the participants to describe briefly their experiences with the homework given in the previous session – trying out stress-reducing ways of thinking in a real-life situation and using the reminder card made in the session.</td>
</tr>
<tr>
<td>Stress Management</td>
<td></td>
</tr>
<tr>
<td><strong>Option 1:</strong></td>
<td>You could ask such questions as:</td>
</tr>
<tr>
<td>Trying out</td>
<td>• What did you write on your card in the last session?</td>
</tr>
<tr>
<td>alternative ways</td>
<td>• Did you take out the card and read it, or simply think about it?</td>
</tr>
<tr>
<td>of thinking</td>
<td>• Did you experience any problems doing the homework? Do you have any suggestions for how these problems could be solved? (Ask other group members for suggestions.)</td>
</tr>
<tr>
<td></td>
<td>• Are there other stressful situations for which you would like to practise alternative ways of thinking?</td>
</tr>
<tr>
<td></td>
<td>It is often easier for the participants to talk about their behaviours (what they did in a situation) than about their cognitions (what they thought). Participants often emphasise the behavioural solutions and strategies they use to deal with stressful situations. If this happens, try to help participants become aware of their stress-reducing thoughts by asking specific questions about them while still paying attention to the practical solutions they used to deal with their problems.</td>
</tr>
<tr>
<td></td>
<td>Encourage participants to continue observing and changing their ways of thinking in stressful situations in the future. Remind them that keeping a card handy is one good way to remember alternative thinking strategies, especially in the beginning. With time, the card will no longer be needed.</td>
</tr>
<tr>
<td></td>
<td>Explain that the past session, current session and the next session (Stress Management, Management of Depression and Anxiety, and Social Competence) all draw on the idea of distinguishing between situation, thoughts and reactions.</td>
</tr>
</tbody>
</table>
Option 2: Daily relaxation training

Ask the participants to briefly describe their experiences with the homework given in the previous session: practising daily relaxation.

- When and where did you practise the relaxation exercise?
- How did you arrange to have time for yourself?
- What kinds of experiences did you have? How did you feel afterwards?
- Did you have any problems doing the relaxation exercises? Do you have suggestions about how these problems could be solved?

If participants found it difficult to relax you can suggest aids to relaxation, such as audiotapes/CDs with instructions.

If participants say that they did not have time for relaxation, remind them that they need a minimum of only 1 minute and that relaxation has many positive effects.

Encourage participants to continue to practise relaxation regularly. Through practice, relaxation becomes easier and easier.

Refer to the current session’s theme (Management of Depression and Anxiety) and tell participants that relaxation can also be used to deal with feelings of anxiety and to help prevent depression. Additional methods will be discussed in the current session.
Goals:
- To learn how to distinguish serious affective disorders from normal reactions to PD.
- To understand the relationship between feelings of sadness and anxiety and PD and to learn what treatments are available.

### Part 2
Active Information: Management of Anxiety and Depression  
0:30’ – 0:50’

<table>
<thead>
<tr>
<th>Contents</th>
<th>Instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Examples from the group</td>
<td>To start the session, encourage the participants to discuss the following questions:</td>
</tr>
<tr>
<td>Definition:</td>
<td>• What are anxiety and sadness?</td>
</tr>
<tr>
<td>Anxiety and sadness are emotional responses</td>
<td>• Why do we have these emotions?</td>
</tr>
<tr>
<td>of our bodies to help us adapt to difficult</td>
<td>• When do feelings of anxiety and sadness become a problem?</td>
</tr>
<tr>
<td>situations. When a person is diagnosed as</td>
<td></td>
</tr>
<tr>
<td>suffering from a neurological disease it</td>
<td></td>
</tr>
<tr>
<td>is normal to feel sad or anxious. In fact,</td>
<td></td>
</tr>
<tr>
<td>these are emotions that allow us to prepare</td>
<td></td>
</tr>
<tr>
<td>for action, to face up to the situation</td>
<td></td>
</tr>
<tr>
<td>through physiological changes in the body.</td>
<td></td>
</tr>
<tr>
<td>Sometimes our emotional responses are too</td>
<td></td>
</tr>
<tr>
<td>strong or go on longer than is necessary to</td>
<td></td>
</tr>
<tr>
<td>help us face up to the problem. In this case,</td>
<td></td>
</tr>
<tr>
<td>our reactions can be harmful, and can lead</td>
<td></td>
</tr>
<tr>
<td>to problems. Can anyone tell me what the</td>
<td></td>
</tr>
<tr>
<td>most common reactions are when we feel</td>
<td></td>
</tr>
<tr>
<td>anxious or sad for a long period of time, or</td>
<td></td>
</tr>
<tr>
<td>when the anxiety or sadness is very intense?</td>
<td></td>
</tr>
<tr>
<td>Write examples from the group on a flip chart.</td>
<td></td>
</tr>
<tr>
<td>Check whether the following problems (see</td>
<td></td>
</tr>
<tr>
<td>table) are included and add to the list any</td>
<td></td>
</tr>
<tr>
<td>that are not mentioned by the participants.</td>
<td></td>
</tr>
</tbody>
</table>
Can anybody think of negative thoughts that often accompany feelings of sadness or anxiety?

Do these thoughts influence our behaviour? In what ways?

Write examples from the group on a flip chart in two columns (“Negative thoughts” and “Changes in behaviour”).

Some examples might be:

<table>
<thead>
<tr>
<th>PHYSICAL</th>
<th>PSYCHOLOGICAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>headaches</td>
<td>grumpiness</td>
</tr>
<tr>
<td>high blood pressure</td>
<td>irritability</td>
</tr>
<tr>
<td>muscular tension</td>
<td>concentration difficulties</td>
</tr>
<tr>
<td>stomach upset</td>
<td>sadness</td>
</tr>
<tr>
<td>circulatory disorders</td>
<td>pessimism</td>
</tr>
<tr>
<td>sleep disorders</td>
<td>loss of self-esteem</td>
</tr>
<tr>
<td></td>
<td>negative thoughts</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>NEGATIVE THOUGHTS</th>
<th>CHANGES IN BEHAVIOUR</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am useless</td>
<td>Stop doing things</td>
</tr>
<tr>
<td>Nothing that I can do will change my disease</td>
<td>Don't follow the treatment correctly</td>
</tr>
<tr>
<td>I will no longer be able to go out with my friends</td>
<td>Refuse invitations to go out</td>
</tr>
<tr>
<td>I am going to end up in a wheelchair</td>
<td>Stay at home and stop going out</td>
</tr>
<tr>
<td>Everyone will realise that I've got Parkinson's</td>
<td>Stay at home</td>
</tr>
<tr>
<td>The effect of the medicine will wear off and I won't be able to move</td>
<td>Avoid being on my own</td>
</tr>
</tbody>
</table>

It is important to focus on the bidirectional relationship between negative thoughts and changes in behaviour – thoughts affect behaviours and behaviours affect thoughts. Highlight the importance of identifying negative thoughts.

Ask each participant to briefly describe their mood during the past week (referring to the Appetiser given in the previous session).
### Distinguishing between feelings of anxiety/sadness and affective disorders

Can anyone tell me how you can know if your feelings of anxiety are normal? How do you know if the sadness you feel is normal? Discuss participants’ opinions.

**Anxiety**

Anxiety is a normal emotion that we feel when faced with particular situations or thoughts. It is characterised by feelings of nervousness, tension and agitation, and may be accompanied by heart palpitations, sweating, trembling, or upset stomach. If these symptoms are long lasting or are so strong that they prevent you from leading a normal life, you should seek the advice of a professional.

**Sadness/Depression**

When certain difficult situations occur it is normal to feel sad. However, if this feeling of sadness persists, or is very intense, you might be suffering from a depressive disorder. Depression is a mood disorder that is characterised by some or all of the following symptoms:

- feeling sad for most of the day
- loss of interest in things, people and activities
- loss of appetite
- problems getting to sleep
- tiredness
- a feeling of uselessness
- concentration problems
- thoughts of wanting to die

It is important to consult a professional if you experience several of these symptoms nearly every day. Keep in mind that although PD is not curable at the present time, most emotional problems that occur with it can be treated.

**Examples**

The first example is Mr Johnson. He didn’t know anything about PD when he was first diagnosed one year ago. He remembers that at first he was shocked when doctors told him that PD had no cure and that it would get worse over time. He spent the first few days crying, had trouble sleeping and was very irritable with his family. However, these problems gradually went away as the days went by and he read and learnt more about the disease. Now he thinks that PD affects people in different ways and that it is still possible to enjoy many things.

Mrs Smith, on the other hand, stopped going out with her friends as soon as she was informed of the diagnosis of PD six months ago. She makes excuses to keep from seeing them or speaking with them on the telephone. She feels profoundly unhappy – she thinks that from now on everything will go badly for her, she has lost her appetite, she sleeps badly, she can’t concentrate on anything, and she is very worried about the future.
Discuss these two examples, noting that Mr Johnson displays thoughts, behaviour and emotions that are characteristic of a normal reaction to the disease, whereas Mrs Smith shows significant signs of depression, and should seek professional treatment.

**Can anyone tell me whether they think anxiety and depression are common in PD? If so, why are they so common?**

Discuss participants’ opinions.

Research suggests that these emotional disorders are very common in PD when compared with other groups of people with similar levels of physical disability. It is currently thought that between 40% and 50% of people with PD are depressed, although different studies have found figures ranging between 4% and 70%. Research shows that anxiety and depression are strongly related to each other in PD. In other words, most people with PD who suffer from depression also suffer from anxiety.

Usually when people with PD have these emotional problems, they are regarded as reactions to the physical limitations of the disease. However, anxiety and depressive disorders may occur for different reasons:

- because a person has not adapted to the changes produced by the PD
- as a direct result of the biochemical changes that are characteristic of PD
- a combination of these factors

**Can anxiety and depressive disorders be treated? If so, how?**

Discuss participants’ opinions.

Although PD itself is not curable at the present time, these emotional disorders can be successfully treated in a high proportion of cases. Depression is the factor that has the greatest impact on the quality of life in PD, and can contribute to problems with thinking and memory. (Note that cognitive problems do not occur in everyone with PD.) Health professionals can recommend the most suitable treatment. There are several treatment options for depressive and anxiety disorders, including medication, psychological treatment, or a combination of different methods.

Hand out **Practical Suggestions for Dealing with Feelings of Anxiety and Sadness**

Go through and discuss the suggestions described in the guidelines. Encourage participants to propose other suggestions.
### Goal:
- To learn to apply information about anxiety and depression in daily life.

### Part 3
**Exercise: Learning to Cope with Negative Thoughts and Dysfunctional Feelings Related to PD**  
*0:50’ – 1:20’*

<table>
<thead>
<tr>
<th>Contents</th>
<th>Instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Notes for group leaders</td>
<td>It is important to adapt the practical exercises to the level of the participants, taking into account their ability to write, capacity for introspection, cognitive level and other factors. For this reason, two different exercises are presented:</td>
</tr>
<tr>
<td><strong>Option 1:</strong> Cognitive approach.</td>
<td></td>
</tr>
<tr>
<td><strong>Option 2:</strong> Behavioural approach (a practical style concentrating on behavioural strategies).</td>
<td>If time allows, exercises from both approaches can be used in the session.</td>
</tr>
</tbody>
</table>
| Option 1, Step 1: Exploring worries | Divide the group into two or three subgroups, and give each subgroup a worksheet *(What Worries Me?)* with the following question:  
“What worries me?”  
Ask the subgroups to write down at least one comment from each participant for each question.  
Have a member of each subgroup read their comments to the larger group and ask all participants to discuss their experiences.  
For example, participants can discuss whether they share any of the worries described, whether they have had these concerns at any time since the onset of the disease and what other worries they may have. |
| Step 2: Identifying negative thoughts | We will now hear the story of a woman who has been affected by PD for several years. Through her testimony, she explains to us her experiences, feelings, attitudes and ways of behaving while faced with the disease.  
(Note: If available, you can instead show video excerpts of an actual interview with a person with PD, as long as the content is similar to the current transcript.)  
Read aloud the Transcript of an Interview with a Woman with PD. Depending on the group, the transcript can be given to the participants to read along.  
*Did any of the woman’s comments surprise you?*  
Discuss participants’ comments. |
**Step 3:** Generating positive thoughts about the present situation

Explain the relationship between thoughts and emotions, reminding participants of the content of Session 4, Stress Management:

*Remember that situations themselves are not stressful (as explained in the previous session, Stress Management). Rather, how we interpret (think about) the situations is most important. It is particularly important to recognise automatic stress-increasing thoughts, and to try to think of alternative thoughts that may be more likely to reduce stress.*

Ask participants if they can identify with the examples given in the interview, and whether they have ever experienced similar negative thoughts. Explain that some negative thoughts form part of the process of adaptation to PD. Encourage participants to try to notice these thoughts when they occur and to counteract them by focusing on positive aspects – the things that are going well.

Bring up negative thoughts that are frequently associated with PD, using examples from the interview. Then mention any positive thoughts the woman described. Finally, ask participants for additional positive thoughts that might help her.

Write on the flip chart:
- **Woman’s negative thoughts**
- **Woman’s positive thoughts**
- **Other positive thoughts from the group**

**Negative thought:** *I will have to be looked after and I will be a burden to others.*

**Woman’s positive thought:** *I can’t spend all my time thinking about the bad things that could happen to me.*

**Other positive thoughts that could help her (example):**

*Perhaps it will not happen exactly like that. Worrying about all the problems that may or may not occur is not going to help me now.*

Ask participants for additional positive thoughts and write them on the flip chart.

**Negative thought:** *I am going to end up in a wheelchair.*

**Woman’s positive thought:** *Maybe my disease will not progress in that way.*

**Other positive thoughts that could help her (example):**

*Whatever happens in the future, I will be able to deal with it then.*

Ask participants for additional positive thoughts, and write them on the flip chart.
To finish off the exercise, ask the group to reflect upon the advantages and disadvantages of anticipating problems. Encourage them to generate positive thoughts about their present situation, focussing especially on how these thoughts may reduce discomfort and help them to adapt to life with PD.

Divide the group into two or three subgroups, and give each subgroup the worksheet **Changes in Activities Due to PD**, asking them to think about these two questions:

- What have I stopped doing as a result of the disease?
- What have I started doing as a result of the disease?

Ask the subgroups to write down at least one comment from each participant for each question.

Have the participants read the comments to the group, whilst you write them down on the flip chart in two columns, “Stopped doing” and “Started doing.”

Ask participants to discuss the advantages and disadvantages of the changes described in each column. This exercise serves as an introduction to the idea that although PD represents a progressive change in lifestyle, it is important to keep engaging in activities as much as possible in order to avoid feelings of low self-esteem and to prevent depression. Remind participants about the relationship between mood and activity, referring back to the content of Session 3: Pleasant Activities.

In a brainstorming session, encourage participants to suggest different types of healthy activities (physical, mental and social activities) that increase self-esteem and reduce feelings of sadness and anxiety, such as relaxing, engaging in social activities and maintaining social relationships. Write the healthy activity and the positive emotions associated with it on the flip chart, in two columns:

- Activity (in the left column)
- Pleasant emotions (in the right column).
Part 4
Homework: Focusing on the Positive and Maintaining Healthy Activities Through Self-Reinforcement

Goal:
• To apply to daily life the principles of increasing positive thoughts and maintaining activities.

<table>
<thead>
<tr>
<th>Contents</th>
<th>Instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homework Option 1: Thinking of a positive event</td>
<td>1. Thinking of a positive event. For the next session, ask each participant to think about a positive upcoming event or the memory of a positive event in the past and then to complete the Reminder Card: A Positive Event.</td>
</tr>
<tr>
<td>Option 2: Maintaining healthy activities</td>
<td>2. Maintaining healthy activities. Ask the participants to think of three or more healthy activities they would like to do during the time between sessions and to write them down on the Maintaining Healthy Activities worksheet. Explain that after they engage in each activity they should complete the second part of the worksheet by writing down any positive feelings they experienced. Remind participants to congratulate themselves for having attempted to carry out their objectives, whether or not they were successful.</td>
</tr>
</tbody>
</table>

Handouts
Option 1: Reminder Card: A Positive Event
Option 2: Maintaining Healthy Activities
Part 5
Appetiser: Social Competence  1:25’ – 1:30

Goal:
• To help participants become aware of their experiences in situations in which they want to express their thoughts and feelings but do not have the confidence to do so.

<table>
<thead>
<tr>
<th>Contents</th>
<th>Instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observing your own behaviour in a social situation</td>
<td>Please make a note of situations in which you would like to express your thoughts and feelings but do not have the confidence to do so.</td>
</tr>
</tbody>
</table>
Session 5: Management of Anxiety and Depression

Materials

- Practical Suggestions for Dealing with Feelings of Anxiety and Sadness
- What Worries Me? (worksheet for Option 1)
- Changes in Activities due to PD (worksheet for Option 2)
- Reminder Card: A Positive Event
- Maintaining Healthy Activities
- Transcript of an Interview with a Woman with PD
Practical Suggestions for Dealing with Feelings of Anxiety and Sadness

On this sheet are several practical suggestions that may help you to feel better. If you have additional suggestions, please add them to the bottom of the list.

1. Organise your time. Diaries and timetables are good tools to help you. We recommend that you reserve time during the day for yourself so that you can do specific activities without any hurry.
2. Engage in some form of physical exercise. Set aside time during the day to go for a stroll and enjoy the sun or practise gymnastic exercises specifically developed for people with PD.
3. Perform mental exercises. Exercising your mind is as important as exercising your body. Engage in activities such as word puzzles, crosswords or reading, every day.
4. Keep in contact with the world around you, by reading newspapers and magazines, watching or listening to the news, or surfing the internet.
5. Plan realistic objectives, step by step.
6. Engage in interesting activities. Look for activities that you enjoy and that make you feel good. You may want to develop new hobbies (such as listening to music, playing dominoes, playing card games, going to the cinema or painting).
7. Don’t worry if pleasurable daily activities take more time than before: if you are still physically able to do them, go ahead!
8. Follow a healthy diet. Healthy food means a healthy body and mind!
9. Do not overindulge in substances that can make you feel nervous, such as coffee, tea or alcohol.
10. Keep in touch with friends and family through visits, telephone calls, letters or emails.
11. Engage in activities that help you relax, such as meditation, yoga and having a massage.
12. Get enough sleep, but don’t overdo it. Try to sleep/rest for an adequate number of hours each night (minimum of approximately 7 hours per night but not more than 9 hours per night).
13. Plan activities that require little effort for your ‘off’ moments.
15.
16.
17.
18.
Worksheet for Exercise Option 1, Step 1:

What Worries Me?

Please write down at least one thing for each group member that worries him or her. Discuss it amongst yourselves before sharing the comments with the rest of the group.

Worry 1: ___________________________________________________________

_______________________________________________________________

_______________________________________________________________

Worry 2: __________________________________________________________

_______________________________________________________________

_______________________________________________________________

Worry 3: __________________________________________________________

_______________________________________________________________

_______________________________________________________________

Worry 4: __________________________________________________________

_______________________________________________________________

_______________________________________________________________
Worksheet for Exercise Option 2, Step 2

Changes in Activities Due to PD

Please write down at least one activity for each group member that he or she has stopped doing as a result of PD, and one activity that he or she has started doing. Discuss it amongst yourselves before sharing the comments with the rest of the group.

Things that we have stopped doing as a result of the disease:

- 
- 
- 
- 
- 

Things that we have started doing as a result of the disease:

- 
- 
- 
- 
- 

Reminder Card: A Positive Event

Our emotional state is closely connected with our thoughts. We can improve how we feel by managing our thoughts. Thinking positively will help us to feel better.

In order to increase positive thoughts, the task for the next session is to think about a positive event (upcoming or past) and your thoughts and feelings related to this event.

My positive event is ........................................................................................................................................
.................................................................................................................................................................

and the positive thought is ...........................................................................................................................
.................................................................................................................................................................
.................................................................................................................................................................
I feel .............................................................................................................................................................
.................................................................................................................................................................
.................................................................................................................................................................


Maintaining Healthy Activities

To increase feelings of wellbeing, we recommend that you engage in healthy activities (physical, mental and social activities). These activities can be pleasant, social or relaxing activities; activities related to work and daily living; therapeutic activities or activities related to self-care; activities that increase self-esteem and reduce feelings of sadness and anxiety.

When we feel sad or distressed, we tend to think only about what we didn’t do well, or what we could have done better. We minimise the importance of what we did even if it has taken great effort. For this reason it is essential to pay attention to what we do well and give it importance, and then to reward ourselves for our progress.

This sheet is designed to help you engage in healthy activities and recognise what you do well!

Here you have some examples from a woman with PD. After engaging in the activity described on the left side of the table, she wrote down her positive feelings (right side of the table).

<table>
<thead>
<tr>
<th>Healthy Activity</th>
<th>Self-congratulations!</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Call my friend.</td>
<td>It wasn’t as difficult as I had imagined. I really enjoyed chatting with Laura and she was also happy to hear my news. She suggested that we meet on Tuesday. I am happy that I accepted her invitation. We will have a good time.</td>
</tr>
<tr>
<td>2. Look at photos of my daughter’s wedding.</td>
<td>It had been a long time since I had looked at these photos. It was pleasant to remember such beautiful and meaningful days in my life, like a little journey into the past. On Friday I will look at them again together with my family. Perhaps we will have a laugh remembering some of the funny things that happened.</td>
</tr>
<tr>
<td>3. Practise a relaxation technique.</td>
<td>Although I sometimes think that relaxation doesn’t solve anything, it is true that when I finished the relaxation exercise I felt very calm and relaxed. You look at things in a different way when you are calm.</td>
</tr>
<tr>
<td>4. Have a massage.</td>
<td>I felt like a new person after my massage.</td>
</tr>
<tr>
<td>5. Dance with my husband.</td>
<td>At first I thought that I would feel a little awkward and I was nervous that people would be looking at me or that my legs would lock up, but once we started everything went well. For a few moments I forgot about everything and felt happy. If I feel well on Saturday I would like to go again.</td>
</tr>
</tbody>
</table>
Now choose three or more healthy activities that you would like to do this week, and write them down on the left side of the table below. After engaging in each of the activities, write down your positive feelings and congratulate yourself on the effort you made.

<table>
<thead>
<tr>
<th>Healthy Activity</th>
<th>Self-congratulations!</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
</tr>
</tbody>
</table>
Transcript of an Interview with a Woman with PD

Part 1

“I am a Parkinson’s sufferer. I have had the disease for 4 years. I was 60 years old when I was diagnosed. At first I was confused, then I was worried and later angry.”

Part 2

“Suddenly I found that my legs became stuck. I was walking with short little steps and I was writing very badly. So I went to a doctor and he said to me that I might have Parkinson’s. Then I became very worried and I tried to find out more about the disease, although I had already heard about it. Later I felt sad and then I became very angry because I thought, ‘Look what an awful thing has happened to me.’

“I think that I haven’t got any choice in the matter, this has happened to me and there are worse things. I try to lead as normal a life as possible and I do my best to make sure that I’m always doing things so that I am not always thinking that I’ve got Parkinson’s, and so I can enjoy myself a little.”

Part 3

“I knew quite a bit about Parkinson’s disease because I had a cousin who had gone through it and died. He couldn’t stop himself from drooling, he couldn’t walk, he was in a wheelchair, he could hardly talk. When they diagnosed me as having Parkinson’s disease I remembered how my cousin ended up and I thought, ‘Well, it’s your turn now, the same as him.’ You think to yourself, ‘What’s coming next? I will end up in a wheelchair, they will have to look after me.’ I would have liked to have been an ordinary old woman: to be able to look after myself and not to be a burden to others. These things aren’t very nice to think about. But I also think that I don’t need to worry, that I don’t know that I won’t die next year of a heart attack before getting to the wheelchair, or maybe my disease won’t evolve in that way and I won’t get to the stage of needing a wheelchair, maybe I’ll end in some other way and, in any case, I can’t spend all my time thinking about the bad things that could happen to me.”
Session 5: The Carer’s Challenge

Overview

During this session, participants receive information about the possible impact of PD on family members and/or carers. Useful psychosocial resources are presented, together with examples and guidelines. Different ways in which attitudes and habits can protect the carer’s health are discussed. Coping strategies that can be used by carers are explored in an exercise and relaxing activities are discussed. This practice is continued between sessions at home.

Materials

- Relevant handouts
- Carers’ examples
- Flip chart, markers

<table>
<thead>
<tr>
<th>Part</th>
<th>Contents</th>
</tr>
</thead>
</table>
| 1    | Discuss homework  
Stress management  
Option 1: Discuss experiences with recent stressful situations (Trying Out Alternative Ways of Thinking)  
Option 2: Discuss experiences practising the Daily Relaxation Training |
| 2    | Active information  
Carer’s challenge  
Definition: What is the carer’s challenge? What are possible problems with the carer’s own health, and changes in the carer’s own life, that can occur as a result of caring for someone with PD?  
Importance of recognising burnout  
Guidelines: How to help maintain the wellbeing of the carer |
| 3    | Exercise  
Increasing feelings of wellbeing: Preventing care-related health problems |
| 4    | Homework  
Task 1: Maintaining relaxing activities  
Task 2: Dealing with distressing situations |
| 5    | Appetiser  
Social Competence  
Noticing situations in which you want to express your thoughts and feelings but do not have the confidence to do so |
Part 1
Discuss Homework: Stress Management 0:30’

Goal:

- To support the application of knowledge and skills from the previous session (Stress Management) in everyday life.

<table>
<thead>
<tr>
<th>Contents</th>
<th>Instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discuss homework Stress management</td>
<td>Ask the participants to briefly describe their experiences with the homework given in the previous session: trying out stress-reducing ways of thinking in a real-life situation and using the reminder card made in the session.</td>
</tr>
<tr>
<td>Option 1: Trying out alternative ways of thinking</td>
<td>You could ask such question as:</td>
</tr>
<tr>
<td></td>
<td>• What did you write on your card in the last session?</td>
</tr>
<tr>
<td></td>
<td>• Did you take out the card and read it, or simply think about it? What effect did it have?</td>
</tr>
<tr>
<td></td>
<td>• Did you experience any problems doing the homework? Do you have any suggestions about how these problems could be solved? (Ask other group members for suggestions.)</td>
</tr>
<tr>
<td></td>
<td>• Are there other stressful situations for which you would like to practise alternative ways of thinking?</td>
</tr>
</tbody>
</table>

It is often easier for the participants to talk about their behaviours (what they did in a situation) than about their cognitions (what they thought). Participants often emphasise the behavioural solutions and strategies they use to deal with stressful situations. If this happens, try to help participants become aware of their stress-reducing thoughts by asking specific questions about them while still paying attention to the practical solutions they used to deal with their problems.

Encourage participants to continue observing and changing their ways of thinking in stressful situations in the future. Remind them that keeping a card handy is one good way to remember alternative thinking strategies, especially in the beginning. With time, the card will no longer be needed.

Explain that the past session, current session and the next session (Stress Management, The Carer’s Challenge, and Social Competence) all draw on the idea of distinguishing between situation, thoughts and reactions.
**Option 2: Daily relaxation training**

Ask the participants to briefly describe their experiences with the homework given in the previous session: practising daily relaxation.

- *When and where did you practise the relaxation exercise?*
- *How did you arrange to have time for yourself?*
- *What kinds of experiences did you have? How did you feel afterwards?*
- *Did you have any problems doing the relaxation exercises? Do you have suggestions about how these problems could be solved?*

If participants found it difficult to relax, you can suggest aids to relaxation, such as audiotapes/CDs with instructions.

If participants say that they did not have time for relaxation, remind them that they need a minimum of only 1 minute and that relaxation has many positive effects.

Encourage participants to continue to practise relaxation regularly. Through practice, relaxation becomes easier and easier.

Refer to the current session’s theme (The Carer’s Challenge) and tell participants that relaxation can also be used to deal with burden of care. Additional methods will be discussed in the current session.
### Part 2

#### Active Information: The Carer’s Challenge

**Goals:**
- To increase understanding of the possible impact of PD on the family and/or carer, by identifying medical and psychosocial factors that are related to the challenge of caring, and distinguishing negative effects due to this challenge from adaptive emotional responses.
- To learn to recognise signs of burnout and how to take steps to maintain your wellbeing.

<table>
<thead>
<tr>
<th>Contents</th>
<th>Instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Examples from the group</td>
<td>To start the session, encourage participants to discuss the following questions:</td>
</tr>
<tr>
<td></td>
<td>- Have you noticed any problems with your own health as a consequence of caring for/living with a person with PD?</td>
</tr>
<tr>
<td></td>
<td>- What changes have you noticed in your own life since the person developed PD?</td>
</tr>
<tr>
<td>Flip Chart</td>
<td>Write examples from the group on a flip chart.</td>
</tr>
<tr>
<td>Carer’s challenge: Preventing the “burden of care”</td>
<td>Parkinson’s disease is often accompanied by physical, emotional and economic problems that can affect the wellbeing of the family.</td>
</tr>
</tbody>
</table>

**Definition of the “burden of care”:**

The concept of the burden of care has been defined as the perception on the part of the carer that his/her health, social life and financial situation have been adversely affected as a result of living with a person with PD or his/her dedication to the care of a person with PD.

The degree of burden on the carer is related to disease severity, to the number of hours devoted to caring, and to the presence of mental health problems in the person with PD.

Other problems that might affect the person with PD that can add to the burden of care include sleeping disorders, depression, cognitive dysfunction and disordered thinking, all of which can make the carer feel uneasy. These problems can be more difficult to deal with than the motor symptoms of PD. The psychosocial impact of the disease on the carers is inversely related to the perception of social support: the lower the perceived social support, the greater the negative psychosocial impact.
Each family member and family environment is different. For this reason, the burden experienced by the carer depends on the interrelationships amongst different medical and psychosocial factors (such as severity of PD, state of health, personality and coping style of the carer, coexistence of other important events, and economic resources).

How can you distinguish adaptive emotional responses of the carer from negative effects of the burden of care?

Encourage the participants to discuss this question, and write responses on a flip chart.

Answer: some negative emotions that you may experience are part of the normal adaptation to the disease (such as anger, guilt, sadness, fear) but if these emotions are maintained for a long period of time or at a high level of severity, they can interfere with your social and professional life, resulting in a state of “burnout.”

It is important for you to learn to recognise your limits, to identify warning signs of burnout, and to ask for family, social and/or professional help.

Hand out **Guidelines for Recognising Signs of Burnout**.

Give the participants the opportunity to read the main points of the handout (or go through it together) and then discuss the warning signs of burnout.

How can you cope with the effects of PD? What are your ideas?

There are many coping strategies that carers can use. Some of these strategies are recommended, but some are not.

For example, a coping strategy that is not recommended is to become overinvolved with the disease (overprotecting the person with PD, devoting all of your time to the disease, blaming yourself when faced with problems). These attitudes can be accompanied by feelings of depression, worry and low self-esteem. They increase the risk of becoming overburdened and may also keep people with PD from being able to adapt to the disease themselves.

Other coping strategies, shown on the handout, are more adaptive and are recommended.

Hand out **Suggestions for Maintaining the Wellbeing of the Carer**

Give the participants the opportunity to read the main points of the handout (or go through it together) and then discuss them.
Part 3
Exercise: Preventing Caring-Related Health Problems 0:35’ – 1:05’

Goal:
• To explore strategies that carers can use to cope with PD.

<table>
<thead>
<tr>
<th>Contents</th>
<th>Instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exercise: Acquiring healthier strategies for</td>
<td>We will now hear the stories of three different people, each of whom has been living with someone with PD for several years. Experiences, feelings, attitudes and ways of coping with PD are explored in these interviews.</td>
</tr>
<tr>
<td>coping with PD</td>
<td></td>
</tr>
<tr>
<td>Notes to group leader</td>
<td></td>
</tr>
<tr>
<td>Step 1: Identifying attitudes and habits</td>
<td></td>
</tr>
</tbody>
</table>

Read aloud the Transcripts of Interviews with Carers. The transcript can be given to the participants as well to read along.

Can you identify which attitudes potentially increase the carer’s risk of burden, and which attitudes may instead protect the carer’s health? Discuss participants’ comments.

It is important to recognise that there is no such thing as the “perfect carer”. All carers have their own particular attitudes and habits that help them handle the disease, and these should be maintained. However, carers may also have other attitudes and habits that are potentially damaging. Learning how to identify these unhelpful attitudes is the first step in changing them.

Did you identify with any of the people I read about? What things do you do or think about that help you to handle the effects of PD? Do you think that it would be helpful to change your way of coping with the disease in any way?

Encourage participants to examine and consider modifying their coping style.
**Step 2: Learning to modify habits**

In order to help prevent health problems as a result of living with/caring for a person with PD, we recommend that you find time for yourself, and that you get enough rest, both mentally and physically.

*Is it difficult to find time for yourself? Which activities help you to rest, mentally and physically?*

Encourage participants to continue to engage in activities that relax them. Help participants to “brainstorm” possible relaxing activities.

You may want to remind them about what they learned in Session 3: Pleasant Activities.

On the flip chart, write down examples of relaxing activities suggested by participants.

**Examples from the group**

**Flip Chart**

**Step 3: Thinking about attitudes**

It is important to recognise your own limits, to identify warning signs of burnout, and to allow family members, friends and professionals to help if necessary.

*Why do we sometimes resist asking for help? What advantages and disadvantages are there in doing so?*

Write down advantages and disadvantages of asking for help on the flip chart.

Note that this subject will be dealt with in greater detail in Sessions 6 and 7.

**Examples from the group**

**Flip Chart**

**Handout**

Transcripts of Interview with Carers
**Part 4**

**Homework: Engaging in a Relaxing Activity and Dealing with Distressing Situations**  
**1:05’ – 1:25’**

**Goals:**
- To increase carers’ ability to identify warning signs of burnout.
- To promote strategies that will help carers cope with the effects of PD, and that will help prevent health problems.

<table>
<thead>
<tr>
<th>Contents</th>
<th>Instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homework Task 1: Maintaining relaxing activities</td>
<td>Relaxing activities can be helpful to carers. The first task for you to perform before the next session is to plan a relaxing activity and focus on your level of tension before and after doing that activity. Hand out the homework sheet entitled <em>Maintaining Relaxing Activities</em>. Go through the handout, ensuring that participants understand the task, and asking if they have any questions.</td>
</tr>
<tr>
<td>Homework Task 2: Dealing with distressing situations</td>
<td>The second task is to observe and record how you respond when faced with a potentially distressing situation. Hand out the homework sheets entitled <em>Dealing with Distressing Situations</em>, which includes an instructions/sample sheet and a worksheet. This chart will help you to observe what you do in distressing situations, and recognise ways you can cope. With the help of the chart, you can summarise the situation: the Antecedents (the situation, what was happening), your Behaviour (as well as thoughts and feelings), and the Consequences (how it ended). We will call this the ABC. 1. <strong>Antecedents.</strong> Describe the situation as briefly and objectively as possible, as if you were observing the situation without direct involvement. The questions in the left-hand column may help you to describe the situation, <em>What is happening? Where? With whom?</em> For example: “My husband walked very slowly when we crossed the road.” Write this information in Column 1 on your worksheet. 2. <strong>Behaviours.</strong> Observe how you responded to the situation.</td>
</tr>
</tbody>
</table>
In Column 2, reply to the question **What did I think and feel?** Try to answer the questions as truthfully as possible, without censoring your thoughts, and make particular note of whether your thoughts were “stress-increasing” thoughts or “stress-reducing” thoughts. For example: “I kept thinking that it will be even worse when the disease advances and that I won’t be able to put up with it. I felt very upset.”

In Column 3, answer the question **What did I do?** Describe your observable behaviours in the situation. For example: “I shouted at him!”

3. **Consequences.**

In Column 4, briefly answer the question **How was it resolved?** For example: “Right after it happened, I felt guilty and cried.”

In addition, describe whether this situation has enabled you to think of additional coping strategies that you could use to deal with the aftermath of this situation, or in the future, by answering the question **How else can I deal with it now?** For example: “This made me realise that I need to find time for myself” and “Sharing these feelings with members of the self-help group might make me feel better.” For more ideas, consult **Suggestions for Maintaining the Wellbeing of the Carer.**

In Column 5, congratulate yourself on your efforts! If you did use an alternative coping strategy, write down the positive feelings that you experienced. Even if you did not, think about what you have learned from this situation. Answer the question: **What positive consequences can I take from this experience?** For example: “This is an experience I can learn from. I am glad I shared my feelings with others so that I will be able to cope better in the future. Nobody is perfect.”

As explained in the previous session (Stress Management), situations themselves are not stressful. How we interpret the situations is essential. It is important to recognise automatic stress-increasing thoughts, and try to replace them with alternative thoughts about the specific situation, as was shown in the example.

---

<table>
<thead>
<tr>
<th>Column 2</th>
<th>Column 3</th>
<th>Column 4</th>
<th>Column 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>In Column 2, reply to the question <strong>What did I think and feel?</strong> Try to answer the questions as truthfully as possible, without censoring your thoughts, and make particular note of whether your thoughts were “stress-increasing” thoughts or “stress-reducing” thoughts. For example: “I kept thinking that it will be even worse when the disease advances and that I won’t be able to put up with it. I felt very upset.”</td>
<td>Describe your observable behaviours in the situation. For example: “I shouted at him!”</td>
<td>Briefly answer the question <strong>How was it resolved?</strong> For example: “Right after it happened, I felt guilty and cried.” In addition, describe whether this situation has enabled you to think of additional coping strategies that you could use to deal with the aftermath of this situation, or in the future, by answering the question <strong>How else can I deal with it now?</strong> For example: “This made me realise that I need to find time for myself” and “Sharing these feelings with members of the self-help group might make me feel better.” For more ideas, consult <strong>Suggestions for Maintaining the Wellbeing of the Carer.</strong></td>
<td>Congratulations! If you did use an alternative coping strategy, write down the positive feelings that you experienced. Even if you did not, think about what you have learned from this situation. Answer the question: <strong>What positive consequences can I take from this experience?</strong> For example: “This is an experience I can learn from. I am glad I shared my feelings with others so that I will be able to cope better in the future. Nobody is perfect.” As explained in the previous session (Stress Management), situations themselves are not stressful. How we interpret the situations is essential. It is important to recognise automatic stress-increasing thoughts, and try to replace them with alternative thoughts about the specific situation, as was shown in the example.</td>
</tr>
</tbody>
</table>

**Handout**

**Maintaining Relaxing Activities**

**Dealing with Distressing Situations**
Goal:

- To become aware of situations in which you want to express your thoughts and feelings but do not have the confidence to do so.

<table>
<thead>
<tr>
<th>Contents</th>
<th>Instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observing your own behaviour in a social situation</td>
<td><em>For the next session, please make a note of situations in which you want to express your thoughts and feelings but do not have the confidence to do so.</em></td>
</tr>
</tbody>
</table>
Session 5: The Carer’s Challenge

Materials

- Guidelines for Recognising Signs of Burnout
- Suggestions for Maintaining the Wellbeing of the Carer
- Maintaining Relaxing Activities
- Dealing with Distressing Situations
- Transcripts of Interviews with Carers
Guidelines for Recognising Signs of Burnout

It is important for you to recognise your limits, to identify the warning signs of burnout, and to ask for family, social and/or professional help.

<table>
<thead>
<tr>
<th>The following may be warning signs of distress:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. High level of concern about the future.</td>
</tr>
<tr>
<td>2. Feelings of not having enough time for yourself.</td>
</tr>
<tr>
<td>3. Feelings of being essential to the care of the person with PD.</td>
</tr>
<tr>
<td>4. Feelings of lack of confidence and guilt due to the state of the person with PD.</td>
</tr>
<tr>
<td>5. Loss of sense of humour and an increase in irritability.</td>
</tr>
<tr>
<td>6. Decrease in interest in the “outside world”.</td>
</tr>
<tr>
<td>7. Reduced participation in social and leisure activities.</td>
</tr>
<tr>
<td>8. Excessive feelings of exhaustion.</td>
</tr>
<tr>
<td>9. Feelings that you should be making more effort.</td>
</tr>
<tr>
<td>10. An almost permanent feeling of loneliness.</td>
</tr>
<tr>
<td>11.</td>
</tr>
<tr>
<td>12.</td>
</tr>
<tr>
<td>13.</td>
</tr>
<tr>
<td>14.</td>
</tr>
</tbody>
</table>
Suggestions for Maintaining the Wellbeing of the Carer

In caring for a person with PD, try to avoid becoming overinvolved with the disease (overprotecting, devoting all your time to the disease, blaming yourself when faced with problems). These attitudes are often accompanied by feelings of depression, worry and low self-esteem. They may increase your risk of burnout, and ultimately may reduce the ability of the person with PD to deal with his/her disease.

Below are suggestions for ways of coping with the disease:

<table>
<thead>
<tr>
<th>COPING WITH PARKINSON’S DISEASE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Keep up with your social network.</td>
</tr>
<tr>
<td>2. Contact other people who are in a similar situation to share experiences and feelings.</td>
</tr>
<tr>
<td>3. Find time for yourself.</td>
</tr>
<tr>
<td>4. Take up some activity other than caring; get out of the house.</td>
</tr>
<tr>
<td>5. Get enough sleep.</td>
</tr>
<tr>
<td>6. Ask for help from family members, friends and professionals.</td>
</tr>
<tr>
<td>7. Give yourself a reward for your efforts (for example, go for a massage).</td>
</tr>
<tr>
<td>8. Learn from experience.</td>
</tr>
<tr>
<td>9. Think about the things that are going well.</td>
</tr>
<tr>
<td>10. Deal with day-to-day issues rather than worrying about the future.</td>
</tr>
<tr>
<td>11.</td>
</tr>
<tr>
<td>12.</td>
</tr>
<tr>
<td>13.</td>
</tr>
<tr>
<td>14.</td>
</tr>
</tbody>
</table>
Maintaining Relaxing Activities

In order to prevent health problems as a result of looking after a person with PD, find time for yourself, and get enough rest (mental and physical). Common excuses NOT to take care of yourself are:

“The important thing is that my partner is okay.”
“It does not matter that I am tired.”
“It would not be fair if I had a good time while my partner is not well.”
“I’m not in the mood to do something fun.”

It is important to set objectives – even very small ones – and to reward yourself for progress. Relaxing activities can be helpful for carers.

In order to maintain your involvement in activities that relax you, the task for the next session is to plan a relaxing activity and to focus on your level of tension before and after engaging in the activity.

To carry out the exercise:

1. Describe the relaxing activity in the left-hand column (for example: go for a walk)
2. In the second and third columns, write the date and the time that you will begin the activity (for example: “10 October, 5 p.m.”)
3. Observe whether you feel tense or nervous. Imagine that you have a “tension barometer” that ranges from 0 to 10, where 0 means “I don’t feel any tension” and 10 means “I feel extremely tense”. Try to choose the number on the “tension barometer” that best represents your level of tension and nervousness at that moment. Now write this number in the fourth column.
4. Do the relaxing activity that you have chosen.
5. At the end of the time period that you have set aside for your relaxing activity, observe your level of tension and nervousness again. Imagine the “tension barometer” that ranges from 0 to 10 (remember that 0 means “I don’t feel any tension” and 10 means “I feel extremely tense”). Choose the number on the “tension barometer” that best represents your level of tension and nervousness now, at this moment, and write it in the fifth column.
6. In the last column there is a blank space for you to write down the positive feelings that you have felt. Remember that it is important to congratulate yourself for your efforts.
<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th>DATE</th>
<th>TIME</th>
<th>LEVEL OF TENSION BEFORE (0 to 10)*</th>
<th>LEVEL OF TENSION AFTERWARDS (0 to 10)*</th>
<th>SELF-CONGRATULATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Taking a walk</td>
<td>10 Oct</td>
<td>5 p.m.</td>
<td>7</td>
<td>4</td>
<td><strong>Although I sometimes think that taking a walk doesn’t solve anything, it is true that when I came back I felt very calm and relaxed. You look at things in a different way when you are calm. It is important to look after myself so that I can help others.</strong></td>
</tr>
<tr>
<td>Playing with my grandson</td>
<td>12 Oct</td>
<td>12 noon</td>
<td>6</td>
<td>2</td>
<td><strong>For a little while I forgot about the disease and I felt as if there are important things in life other than sickness.</strong></td>
</tr>
</tbody>
</table>

*Level of tension: 0 = Not at all tense; 10 = Extremely tense*
Dealing with Distressing Situations

Instructions and Sample Sheet

This chart helps you to recognise ways of coping with negative and distressing situations. It is also an exercise in learning how to handle difficult situations. When such a situation arises, try to remember to use the alternative coping strategies suggested in the session and on the handouts. Do not forget to congratulate yourself on your progress.

1. **A = Antecedents.** Describe the situation (answering the questions in the first column on the left).

2. **B = Behaviours** (and thoughts and feelings).
   - Second column: Thoughts/Feelings. Observe what you were thinking and feeling (being sure to note any automatic negative thoughts). Summarise your thoughts without censoring them.
   - Third column: Behaviours. Observe what you did, answering each of the questions in the third column.

3. **C = Consequences.**
   - Fourth column: What happened? Describe how the situation resolved, and whether this situation has enabled you to think of additional coping strategies for now or in the future (perhaps consulting the handout *Suggestions for Maintaining the Wellbeing of the Carer*).
   - Fifth column: If you did use an alternative coping strategy, write down the positive feelings that you experienced. Even if you didn’t, think about what you have learned from this situation. Remember to congratulate yourself on your efforts!

On the next page is an example as a guide. Fill in your comments on the blank worksheet that follows.
### A: Antecedents

1. **Situation**
   - What was happening?  
   - Where?  
   - With whom?

2. **Thoughts/Feelings**
   - What did I think and feel?

3. **Behaviours**
   - What did I do?

### B: Behaviours (and Thoughts and Feelings)

4. **Resolution**
   - How was it resolved?  
   - How else can I deal with it now?

5. **Congratulations!!**
   - What positive consequences can I take from this experience?

### Example:

My husband walked very slowly when we crossed the road.

- Example: I kept thinking that it will be even worse when the disease advances and that I won’t be able to put up with it. I felt very upset.  
  - (Automatic stress-increasing inner speech, leading to feelings of distress.)

- Example: I shouted at him!

- Example: Right after it happened, I felt guilty and cried.  
  - This made me realise that I need to find time for myself.  
  - Sharing these feelings with members of the self-help group might make me feel better.

- Example: This is an experience I can learn from. I am glad I decided to share my feelings with others so that I will be able to cope better in the future. Nobody is perfect.  
  - (Alternative stress-reducing thought.)
### Dealing with Distressing Situations

**Worksheet**

<table>
<thead>
<tr>
<th>1 Situation</th>
<th>2 Thoughts/Feelings</th>
<th>3 Behaviours</th>
<th>4 Resolution</th>
<th>5 Congratulations!!</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What was happening?</strong></td>
<td><strong>What did I think and feel?</strong></td>
<td><strong>What did I do?</strong></td>
<td><strong>How was it resolved?</strong></td>
<td><strong>How else can I deal with it now?</strong></td>
</tr>
</tbody>
</table>

Session 5: Anxiety and Depression

Transcripts of Interviews with Carers

Carer 1

My mother was diagnosed as having Parkinson’s disease about four years ago. I don’t live with her in the same house because I have my own family.

I used to think of Parkinson’s disease as being something terrible. Now I still think that it is not a pleasant thing but perhaps because it is a slow disease, or because it is long, or perhaps because over time you start looking at it in a different way, I think that it’s a disease that you get used to and it becomes normal for you. You end up not remembering how things were before, and it lets you get on little by little from one day to the next.

I think about the future and I would like to live close to her. I would like to live close to her so that I can come and go when I need to. Maybe it is selfish but I have young children and I don’t want to have to leave them to have to go and look after my mother far away. So I think that the most convenient thing to do in the future would be for me to go and live close to my mother so that I can help her without having to leave my children because although there are carers and people who help you, I think that it’s always appreciated more if they are members of your own family who are helping you.

I want to make the time that she is well pleasant for her. I make the effort to go and have lunch at her house every day, go to see her every day and in this way I check up on her, make sure she has taken her pills, see how she feels... things that I am able to do at the moment because my children go to school. Diseases and problems normally unite you. They strengthen your bond with your family and the love and affection is multiplied because you show it more and you are more on top of everything that’s going on.

Am I overloaded? No. For the moment I am able to separate my life from that of my parents. For the moment I am able to keep things apart. Perhaps in two or three years my ideas on this will be very different but for the moment I am able to go about my life and although I go and see my parents every day, these are things that you might do even if there wasn’t Parkinson’s disease in the middle of things.

I think that the most important thing – the most important support that you can give – is your own love and affection, because I see that it is very depressing. I see how my mother doesn’t want to go to certain places because she isn’t able to eat well or because she isn’t able to do up her shirt, or do basic things, and I think that if this happens to you, you must feel as if you have very bad luck because there are many things that you can’t do or which you need to put a lot of effort into doing. When I imagine myself in her position I think that she must be very sad. So I think that you must give her love and affection, try and make her feel cared for because love and affection are the most important things.

Carer 2

My husband is the person who is ill. His Parkinson’s disease started 9 years ago. We were both 50.

We were living from day to day. I thought that the disease was going to remain stable or that it would progress ever so slowly. You’ve got to think that tomorrow is going to be the same as today or the same as yesterday.
Right now he is really well. He can do everything for himself, he does lots of things and he seems great to me. I really hope that tomorrow he’s the way he is today. I haven’t stopped doing anything. I lead a normal life like I did before. I work, and I devote myself to my work. My husband is able to look after himself very well for everything. He goes out a lot, he drives and does a lot of sports and he hasn’t taken time away from the things that I do.

Perhaps it is because I don’t think that something serious could happen to him but instead think that perhaps things will continue the way they’ve been until now, slowly and without becoming worse, that it will stay as it is. Today is the problem that I’ve got and whatever comes later on will come. I don’t think about the things that might happen, that he might not be able to care for himself. Rather I think that he is going to keep going. I don’t want to think about tomorrow, really.

Perhaps those of us who are with him don’t understand what it is that he is going through and this annoys him a bit, and this is a problem for us, that we don’t understand that he has a disease. You can see this at mealtimes, which is when there is a little bit of tension. We have a young daughter and I think that she is the one who understands the problem least. I think that she finds the situation a little annoying and this in turn annoys my husband.

Perhaps I am not as patient as I should be. My way of disconnecting is to fix myself up and to go out to work.

I don’t get any help because we don’t need it – well, because he doesn’t need it. For the moment I haven’t asked for help. It’s that I really don’t need assistance. He can care for himself, and I only help him from time to time to get dressed or to tie his shoelaces, but very rarely. And this is only for very short moments, then his bad moment goes away and that’s it, he’s fine again.

Sometimes I see that he has got a problem, for example, in putting on a jacket or something else and I look at him but ignore him. I want him to make an effort, and to be able to do it for himself.

Carer 3

Hello, good afternoon. My name is Anna and I am 55 years old. My husband is 85 years old and has suffered from Parkinson’s disease for the last 10 years.

In spite of the difference in age, my husband and I led a very active life: we went out a lot, we went on excursions, we went on trips, we went to the cinema a lot. When they diagnosed him as having the disease I couldn’t believe it. It seemed impossible to me that this could happen to us. At first I didn’t believe it; I thought that it was a joke.

I had quite an important job in a company that I enjoyed a lot but I asked for leave of absence and I left it all to look after him. Now, if I had to do things over again, perhaps I wouldn’t do it because I don’t think that the care that I give him is better because I spend all the hours that I do with him rather than just a few. It is very hard to be with him all the time. On the other hand, if I had a separate professional life, I am sure that it would be much better when I arrived home. By this I don’t mean that I am not okay with him, but there are moments when I miss my professional life. Now I wouldn’t make the same decision.

Do you leave time for yourself? Do you keep up with your hobbies?

Yes, but very little because I do practically everything with him. From time to time I try to get out with my friends or go shopping.
What I do is I leave the same things prepared for the person who is going to be with
him that we do when I am there, a crossword puzzle, a newspaper to read . . . but really
there are very few times. I am almost always with him.

I get help but I really think that the only person who can help him and that has to be at
his side is me. So even though it is great that people help me, I am the one who has to
be beside him constantly. You spend all the hours of the day with him, you are watching
after him until it is time to go to bed. Your whole life.

I get up at 7 a.m., I have a shower and I dress myself nicely. I try to look nice for him,
not because I really feel like it sometimes, but I do it. I go to get the newspaper, the
bread and I buy the things that I need. Then I return home and I help him to get up. In
fact, he can do it himself if I watch him and help him with little things like doing up his
buttons. He has breakfast and we begin reading the newspaper.

We go out for awhile almost every day unless it’s raining a lot or the weather is bad.
We go out even if it is just to take a walk around the block.

Then we return, we turn on the television and I begin to prepare lunch and we eat.
After lunch, he normally sleeps for a little while or we put the television on to see the
news and we comment on them, although at this time of day he tends to fall asleep and,
if the truth be told, so do I at times. After his nap, we listen to music, we read a book or
we play dominoes.

Sometimes we go to the cinema, but less and less often because it takes such a big
effort because we have to go to a cinema where there aren’t any stairs. But both of us
like to go so we try to keep it up.

We also reminisce a lot about when we went on trips together. As for our relationship
as a couple, not so much in the physical sense but in the sense of tenderness, of a
caress, of a kiss, we still have that and we value it a lot. In fact if that part ended, he
wouldn’t seem like my husband.