



Gabriele Wilz



Psychotherapeutic Support for Family Caregivers of People With Dementia

The Tele.TAnDem Manual



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Marlena L. Itz (Translator)

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Foreword

Books for mental health professionals are published every year, sometimes updating what is already known, sometimes rewording what we already know, but rarely providing something very new and important – what we don't know and what is important for us to know. This book by Gabriele Wilz, *Psychotherapeutic Support for Family Caregivers of People With Dementia*, is a welcome, important, indeed much needed and exciting, contribution to the field. And I feel privileged to be able to write its Foreword.

As any practicing therapist knows, people rarely change by simply telling them to do something different. Yet, the extent to which therapists intervene when working clinically with a caregiver – and I must confess that I am guilty of this myself – is telling them “It is important to take care of yourself.” What is needed beyond this simple behavioral suggestion is how to deal with the emotions – guilt, stress, apprehension, resentment, depression, anger – that might make it difficult for them to care for themselves. What therapists need is to help the caregiver learn, sometimes painstakingly so, how to develop a new and very difficult caregiver script, one that involves significant changes in their emotions, thinking, and behavior. This volume provides clinicians with clinical guidelines for helping caregivers adopt this new, complicated, and emotionally difficult script.

This volume describes how therapists can work clinically with patients or clients who are caring for a significant other who is suffering from dementia. Among the many difficulties associated with dementia are short-term memory loss, language problems, orientation difficulties, difficulty in caring for themselves, and impaired cognitive functioning. Depending on the severity of impairment, cognitively impaired individuals typically require the assistance of others to get through the day. Currently, it is estimated that over 50 million people in the world suffer from some form of dementia – most typically Alzheimer's disease. Moreover, this alarming statistic is likely to increase as individuals live longer.

Although medical research has been focusing on ways to better understand dementia, it has yet to come up with a cure or even an effective treatment. Knowledge of the psychological aspects of dementia similarly leave much

to be desired, and we are limited in our understanding of what therapists need to know and do to help caregivers cope with the task of helping loved ones. In short, there is a crying need for clinical guidelines to help therapists in working with caregivers, and this volume fills this much-needed void.

Caring for a cognitively impaired significant other is probably one of the most difficult experiences one is likely to encounter in one's lifetime. I say this not only from my work as a therapist, but also from personal experience. It is a totally new world, whereby the rules for day-to-day interactions with a loved one are likely to be different from anything one has experienced in the past. It can be unbelievably challenging emotionally, cognitively, and behaviorally. Caregivers are likely to experience a myriad of emotions, such as stress, anger, guilt, depression, exasperation – just to mention a few. Cognitively, there is confusion – being at a loss in trying to understand what is happening to one's significant other along with confusion about what to do in day-to-day interactions. Behaviorally, a caregiver's own life is disrupted, and they find themselves having difficulty personally functioning as they had in the past. Without clinical guidelines for working with caregivers, therapists are likely to end up having their own emotional, cognitive, and behavioral difficulties professionally.

Psychotherapeutic Support for Family Caregivers of People With Dementia offers highly sophisticated clinical guidelines, describing everything a therapist needs to know in working with caregivers. It describes not only what to do and why to do it, but also the behavioral, cognitive, and emotional obstacles that can undermine therapeutic progress. Moreover, it contains several modules that can allow the practicing clinician to personalize the intervention to the specific needs of the patient.

In short, this is an invaluable volume that provides practicing therapists with clinically relevant and empirically grounded therapeutic guidelines for working with the ever-increasing number of caregivers who are confronted with the challenging task of caring for a loved one. In addition to offering helpful information about dementia, it also describes the burden put on caregivers and validates the very important role of support in their lives. The the-

rapy modules that can be tailored to the needs of the patient include guidelines on how to solve the numerous situational challenges one is likely to encounter in caring for a loved one; strategies for dealing with the wide range of emotions associated with caregiving; and ways to achieve the all-important goal of accepting those aspects of one's life circumstances that cannot be changed.

Not only is this clinically meaningful, but research evidence exists that it indeed makes a significant positive impact on the psychological and physical well-being of caregivers.

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Preface

The majority of caregiving responsibilities for older people is shouldered by family members. Due to the increasing number of people with dementia worldwide and the amount of care and assistance they require, supporting caregivers is becoming an increasingly important issue in health care. Without family members who take on most of the care in private households, it would not be possible to ensure sufficient assistance for people with dementia, as well as for older family members who need help in general.

Although family caregivers are usually healthy, they are at great risk of developing mental and physical health problems such as depressive and anxiety symptoms, insomnia, and exhaustion.

This raises the question of why the enormously helpful strategies of psychotherapy are usually not provided for the heavily burdened caring relatives, to prevent mental illness and physical impairments. Up to now, cognitive-behavioral therapy (CBT) for family caregivers has been hardly addressed in the training of psychotherapists, even though some research studies have evaluated comprehensive psychotherapeutic concepts in this area. Moreover, as a significant preventive intervention, CBT for family caregivers is not regularly established in health care systems.

Because of this need, I have continuously pursued the goal of developing and evaluating specific psychotherapeutically sound support concepts for family caregivers. As a result, the Tele.TAnDem concept was created, which was published in 2015 in cooperation with Dr. Denise Schinköthe and Tanja Kalytta from my research group (Wilz, G., Schinköthe, D., & Kalytta, T. (2015). *Therapeutische Unterstützung für pflegende Angehörige von Menschen mit Demenz. Das Tele.TAnDem-Behandlungsprogramm*. Göttingen: Hogrefe (Psychotherapeutic support for family caregivers of people with dementia. The Tele.TAnDem concept).

Dr. Marlena L. Itz has translated the English version of the handbook in an intensive, careful, and outstanding manner. On basis of this translation, all parts of the text were considered in a joint exchange and linguistic revisions were discussed. Furthermore, I have undertaken

relevant updates and have adapted the topics with regard to international requirements.

The handbook is based on cognitive behavioral therapy. In 10 different modules main typical caregiving topics and useful intervention strategies such as cognitive restructuring, emotion regulation, problem solving, self-care, and coping with loss and grief are addressed. Furthermore, specific aspects of acceptance and commitment therapy are integrated, because many aspects of the disease and the caregiving situation cannot be changed. Helping caregivers to manage and accept the negative emotions and cognitions accompanying such a difficult experience (e.g. anger, grief, shame, guilt, anxiety, and depression) is another central objective of the intervention.

The book aims to provide comprehensive and specific guidance as how to work psychotherapeutically with family caregivers. This goal is realized through clear instructions, case examples, work sheets, exercises, and precise explanations. Special features of the book are the comprehensive dialogues of real therapy sessions and a focus on how to build and maintain a helpful therapeutic alliance and motivation to change for family caregivers. The intervention is suitable for various settings such as group, face-to-face, or remote therapy forms (telephone and online/web-based therapy). In several RCTs and qualitative studies, the therapy concept has been positively evaluated.

So far, the caregivers evaluated this specific psychotherapeutic support as particularly helpful, as the following quotations illustrate:

“Discussing and analyzing stressful situations when I got out of my skin at the end of my nerves and yelled at my innocent, ill husband. Working together on how to cope with these feelings, without affecting my husband. How I let off steam, was very helpful.”

“I have gained a much better understanding of the disease and can react more calmly to the problems.”

“By listening, responding to me, being taken seriously and noticed, problem solutions were worked out, emotions were captured and taken seriously, to develop other perspectives on situations helped me and strengthening my person.”

“Through the consultation, I have learned to take more care of myself and to do something for myself. I try not to lose sight of that. The word mindfulness has taken on a very special meaning for me!”

“I try hard to get space for myself. The realization that I can’t give up completely if I want to persevere, that this is even essential.”

“It was a blessing that I participated in this therapy and the only effective help. I am infinitely grateful for that!”

“The psychological support was perfect! Please don’t change anything!”

I am very happy that a translation of the manual is now available. I hope it will be helpful for therapists and other professionals, as well as for family caregivers.

Jena, in February 2023

Gabriele Wilz

1

Demands, Burden, and Health Impact of Caregiving

This chapter provides an overview of the specific burden caregivers may experience while providing care for a family member living with dementia. Models and predictors that may play a crucial role in the individual experience of burden are presented as well as coping strategies and positive aspects of providing care.

1.1 Introduction

There are currently 57.4 million people worldwide living with dementia, which is predicted to triple by the year 2050 (GBD 2019 Dementia Forecasting Collaborators, 2022). As there is presently no causal treatment for dementia, ensuring the care of people with dementia will become a challenge in the coming decades for health policy makers and families. Contrary to the stereotype of “nursing-home placement,” around 69% of people suffering from dementia are cared for at home, with almost two thirds of them cared for exclusively by family members, mainly wives, daughters, or daughters-in-law (Wimo et al., 2018).

Due to the specific symptoms of dementia, family members are confronted with particularly burdensome problem situations that can constantly change daily and as the disease progresses. Caring for someone with dementia can thus be described as an extremely demanding task. The caregiver must constantly overcome new challenges in daily life and in relation to the changes in the person with dementia. This large number of stressors often causes health-related impairments. In addition to the increased health impairments (Cheng, 2017) and mortality rates (Schulz & Beach, 1999), caregivers of people with dementia have considerably more severe impairments in mental and physical health compared to comparable healthy populations or caregivers of other chronically ill care recipients (Pinquart & Sörensen, 2003).

In particular, 30–60% of caregivers have reported clinically meaningful depressive symptoms (Barrera-Caballero et al., 2021; Collins & Kishita, 2020; Joling et al., 2015), higher prevalence rates of anxiety (32%, Kaddour & Kishita, 2020), and higher rates of comorbidity of both depression and anxiety (32–54%, Barrera-Caballero et al., 2021; Joling et al., 2015) and lower quality of life (Karg et al., 2018). Health impairments have also been shown for physiological parameters such as higher blood pressure, risk of cardiovascular diseases, reduced immune function, and a longer healing time for wounds (Gouin et al., 2008; Mausbach et al., 2007; von Känel et al., 2008). Particularly, female caregivers, who make up more than 70% of all caregivers, are especially burdened (Barrera-Caballero et al., 2021; Joling et al., 2015; Kaddour & Kishita, 2020). Accordingly, Collins and Kishita (2020) reported 1.45 times higher odds of women having depression compared to male caregivers.

Additionally, when caregivers receive insufficient support, their experience of burden is particularly pronounced (Holst & Edberg, 2011). Thus, due to the above-mentioned health consequences for the caregivers on the one hand, as well as the increasing numbers of dementia cases due to demographic changes, on the other hand, there is an urgent need to preserve at-home care and support caregivers in this challenging task.

1.2 Overview of Specific Caregiver Burden in Dementia

When caring for a family member with dementia, caregivers face an abundance of complex, challenging, and time-consuming demands. Experiences and results from our studies provide evidence of the long-lasting burden of being involved in caregiving, which lasted an average of 5 years. For example, family caregivers reported spend-

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Therapy Topics, Intervention Methods, and Framework

This chapter provides an overview of the topics, intervention methods, and framework of the Tele.TAnDem program as well as basic implementation guidelines.

In principle, specific topics and the appropriate interventions are determined individually for the family caregivers based on the respective problems, problem analyses, and goals and do not follow a fixed order. Instructions for therapists for the specific topics are presented in detail in Chapters 7–15. In general, a sound knowledge of dementia-specific issues is an essential prerequisite for delivering the therapy. Imparting dementia-specific know-

ledge is not part of this manual and is discussed only as an overview in Chapter 3.

An overview of the topics and corresponding interventions is provided in Table 2.

6.1 Individualized Therapy

Since dementia leads to very different demands and burden for the families concerned, a therapy tailored to the

Table 2. Topics and interventions

Topic	Intervention
First session and relationship building: Chapter 7	Shaping the first session and relationship building, exploring the problems, and determining the therapy goals.
Changing dysfunctional appraisals and thoughts: Chapter 8	Identifying and changing dysfunctional thoughts that aggravate caregiving.
Dealing with challenging behaviors: Chapter 9	Support for understanding and dealing with challenging behaviors.
Stress management and emotion regulation: Chapter 10	Imparting coping strategies for acute and burdening emotions such as anger and fury.
Self-care and scheduling pleasant and value-based activities: Chapter 11	Encouraging self-care and well-being.
Dealing with change, loss, and grief: Chapter 12	Assisting with processing and acceptance regarding changes, grief, and loss. Support in dealing with the redefinition of roles. Preparation for the death of the person with dementia.
Encouraging the utilization of informal and professional support: Chapter 13	Removing barriers to utilization, supporting caregivers in the search for and organization of professional help.
Limits to caregiving at home: Chapter 14	Support with respect to identifying the individual stress limit, decision making, planning and organization of institutional care.
Final session: Chapter 15	Shaping the final session and further recommendations.

“I Grew Up in the Countryside, and That Was a Given There”: Changing Dysfunctional Thoughts and Appraisals

“... and I noticed that he always needed more help, and well ... I’m his wife.” “‘In good times and in bad times’ is what we said many, many years ago, and yes, now I am trying to realize that.”

Caregiving and the associated stressful conditions are evaluated and experienced differently by different people. For some, care is a manageable task, while others suffer from the complex demands. Moreover, dysfunctional attitudes and appraisals regarding care increase the burden.

For many family members, taking on the responsibility of providing care is seen as a matter of course and is not reflected on. In this way, family care is classified as a necessary, unchangeable duty based on cultural, family, and personal values and norms. However, particularly for family members who are under a lot of burden, it can be very helpful to consciously reflect on and question the decision to take on caregiving.

Furthermore, excessive demands regarding the way in which care is to be carried out can exponentiate the requirements. For instance, many caregivers have perfectionistic standards regarding caregiving. This often coincides with nonutilization of professional support. Reasons for this are specific attitudes, for example that caregiving “must” be provided on one’s own or that “strangers” cannot provide adequate help for the person with dementia. The use of support can also be seen as a personal failure, so some caregivers do not ask for help out of shame or difficulties with accepting help.

Dysfunctional thoughts can also cause very burdensome feelings of guilt. For instance, some family members blame themselves for the disease, because in the past they behaved negatively and stressfully toward the person with dementia, or they feel guilty and have a bad conscience if they subjectively do not perform caregiv-

ing well enough, temporarily hand it over to someone else, or pay attention to their own needs. Caregivers also often have stress-promoting appraisals of the person with dementia’s behavior. Family members often experience the person with dementia’s behavior as an expression of spite, ignorance, and defiance. This misinterpretation can lead to conflicts with the person with dementia and can be emotionally burdensome.

Box 9 provides an insight into stress-promoting/dysfunctional thoughts and attitudes that are often expressed by caregivers.

Box 9. Examples of caregivers’ typical dysfunctional thoughts and attitudes

Sense of duty and perfectionism in caregiving

- I must always be available to my wife.
- I am solely responsible for the care.
- I only ask for help when I cannot do it anymore.
- I’m only doing well if he is well.
- I find it a disgrace to my husband when a nurse comes into the house.
- I am not allowed to make any mistakes during caregiving.
- Sometimes I think that I am a bad person because I cannot manage it any better.

Feelings of guilt

- Sometimes I think that I might be partly to blame for my loved one’s dementia.
- If my loved one is not doing well, I blame myself.
- I am to blame if she no longer wants to eat. Maybe I did not care well enough.
- I feel bad about doing something good for myself when my loved one might need me.
- I could not endure the feelings of guilt, if I would place my mother in a home.

Misjudgments of personality changes and challenging behaviors

- My loved one could be more thankful that I am always there for him.
- My family member deliberately makes life difficult for me.
- My loved one is not really trying. When others are there, he tries.
- He actually knows where everything is. He just wants to be served.

Feelings of shame and denial

- He makes a fool of both of us with his behavior.
- I would be embarrassed if others saw him like that. Therefore, I do not want a visiting service.
- No one should notice that he is ill.
- In winter he is usually worse off. In spring it will certainly get better again when we can be outside in the garden. Until then, I can manage it alone.

The dysfunctional thoughts and attitudes described in Box 9 were identified as an essential predictor of the degree of experienced mental stress (Losada et al., 2010). Furthermore, dysfunctional thoughts are associated with increased depressive symptoms (McNaughton et al., 1995), which in turn can considerably curtail everyday functioning and the quality of interpersonal relationships. Dysfunctional thoughts thus additionally complicate the caregiving situation as well as a healthy balance between taking responsibility for the person with dementia and maintaining one's own mental and physical well-being. Therefore, changing these dysfunctional thoughts is an essential intervention goal, which can be worked toward by using cognitive restructuring techniques.

8.1 Goals of the Module

Through cognitive restructuring methods, family caregivers can learn to identify their often debilitating and discouraging thoughts and develop alternative, more helpful thoughts.

In addition, the effect of thoughts on emotions and experience of burden are explained to the family caregivers. The underlying assumption is that the appraisal of an event determines one's own emotional state. Together with the family caregivers, therapists illustrate that neg-

ative thoughts elicit reactions that lead to tension and burdensome feelings and that these feelings in turn cause certain behavior. Therefore, caregivers' inadequate, unhelpful assumptions are questioned, possibilities for changing them are discussed, and alternative thoughts and behavioral patterns are developed. The alternative thoughts and behavioral patterns developed by using Socratic dialogue and guided discovery should then progressively be established in the individual life situation (transfer).

This chapter focuses in particular on cognitive interventions to work on the sense of duty, personal/family norms, and perfectionism. Cognitive interventions to modify dysfunctional assumptions regarding the person with dementia's behavior (misinterpretation of personality changes and challenging behaviors as well as dealing with feelings of shame) are addressed in Chapter 9, cognitive interventions to promote self-care in Chapter 11, and the critical examination of feelings of guilt in Chapter 12. However, the therapeutic approach follows the same basic principles of cognitive restructuring for all of the problem areas mentioned in Box 9. Box 10 contains an overview of the interventions covered in this chapter.

Box 10. Overview of the interventions

- Identification of dysfunctional thoughts, attitudes, and schemes
- Critical examination of dysfunctional assumptions (Socratic dialogue) including imagery exercises
- Development of alternative, helpful thoughts
- Imparting the ABC model (Ellis, 1977)

8.2 Therapeutic Approach

8.2.1 Identifying, Challenging, and Critical Examination of Dysfunctional Thoughts

Dysfunctional thoughts and attitudes are usually already evident in the initial consultation. However, the schemes and automatic thoughts, which are usually shaped biographically, are not perceived and addressed by the family caregivers as a problem. The therapist thus forms their own hypotheses about dysfunctional schemas and thoughts as well as the clients' backgrounds, triggers, and

“And What About Me?” – Self-Care and Value-Based Activities

Due to strong time constraints, the seldomly utilized professional support, existing dysfunctional thoughts and schemas (e.g., “I can’t do something nice for myself while my husband is suffering so much at home,” “It’s a given that one is completely and utterly there for the other person”) and the feelings associated with them (e.g., guilty conscience), there is a lack of self-care and balancing activities among most caregivers.

Exemplary statements on “lack of self-care and balancing activities”

- “I always say: ‘I don’t live at all anymore.’ That I undertake something or do something for myself doesn’t happen anymore. I want to live spontaneously, as I used to, visit a friend for an hour or half an hour. I can’t do any of that anymore. I am very limited in my activities.”
- “I don’t get out of here anymore, sometimes I feel like I’m locked in. And he just sleeps all day. I can’t even talk with him. What is left for me? Sometimes I feel really depressed, everything is so monotonous.”
- “I don’t have a life of my own anymore. I’m busy with her all day, from morning to evening, and I can’t leave here, because I can’t leave her alone anymore.”
- “It’s kind of unfair, he didn’t choose this either and then I always have a guilty conscience when I do something for myself.”

A constant lack of self-care and balancing activities can lead to long-term loss of quality of life, deterioration in mood, and ultimately the development of symptoms of depression. This not only has consequences for the caregiver, but also for the entire family system. Therefore, improving self-care and scheduling pleasant, meaningful activities presents an important topic in therapy with family caregivers.

11.1 Goals of the Module

The first goal of the module is to help caregivers realize the importance of self-care-related and balancing activities for their own health and well-being and to facilitate a motivation for change.

Afterward, caregivers’ existing possibilities for self-care and established pleasant activities can be discussed. Subsequently, the planning and implementation of new activities in everyday life can be prepared and reflected upon together with the caregivers. Other modules, such as dealing with dysfunctional thoughts (Chapter 8) or improving the utilization of professional support services (Chapter 13), can be used here as well. Further goals are the maintenance of self-care activities in the long term and the prevention of potential “relapses” into familiar dysfunctional behavior patterns. Box 16 contains an overview of the interventions covered in this chapter.

Box 16. Overview of the interventions

- Imparting and clarifying the importance and necessity of self-care and taking up balancing activities
- Collecting, selecting, and planning suitable possibilities for self-care and balancing activities
- Problem-solving training to support planning and implementation
- Reflecting on the implementation and maintenance of self-care and the planned pleasant activities
- Normalization and acceptance of feelings of guilt

Case Example 57. Assisted living is to be equated with “not taking care anymore”

The following excerpt stems from therapy with a 64-year-old caregiving wife.

Therapist: You had equated assisted living with being kicked out. Kicking out and living in, as it is now, are two poles. And I’m quite sure that there is a lot in between. For example, one can have their family members in assisted living and still have a lot of contact with them and be there for them. It’s not either/or. That doesn’t mean: “I’ll push him into the home and really let go and not care about him anymore.”

Caregiver: No, for God’s sake [laughing].

Therapist: So, here, there is very, very much in between.

Caregiver: Mm-hmm. I just simply can’t completely see what it’s like there.

Therapist: I had sessions with a daughter who was caring for her mother. At the beginning of the sessions, the mother was still at home. The conflict was there from the start. The thought of putting her in a home was associated with a guilty conscience. But she got to the point where she said: “But actually, I can’t take this anymore.” By now, the mother lives in the home. And the daughter is there 3 hours a day. She drives there, makes tea, they have a nice park. ... The nice quality time they have there together – how much is that? Three hours. Ok. How much was it before? If we don’t include the time spent cleaning, cooking, and personal hygiene, but rather the time where they really did something nice together. Well, in the end, the nursing work was so much that there might have only been an hour left for something nice. But now the daughter has 3 hours with her mother, in the park, walking, chatting, playing, and looking at photos and so on. So that’s what I mean, there is a lot in between. How are you now?

Caregiver: It’s like a glimmer of hope right now [laughing].

Therapist: What are you thinking?

Caregiver: I’m just thinking a little bit about what it would be like if I did, you know? If I dare to take this step.

Case Example 58. Reality check

The following excerpt stems from therapy with a 71-year-old caregiving wife.

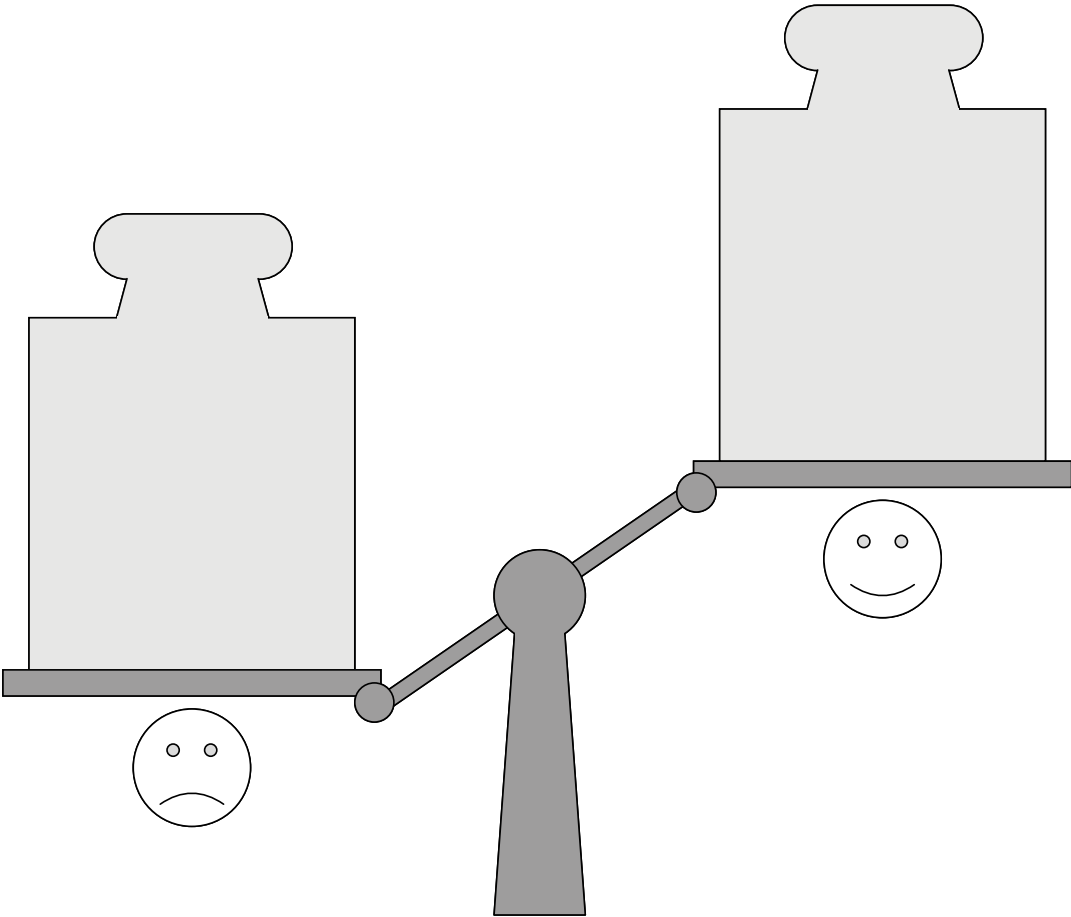
Therapist: You want your husband to be doing well in the nursing home, and you want that with all your heart, and you are very alert. You give everything, you are doing everything that you can to prepare for the transition properly. You inform the nursing staff there, and you have drawn up a list, so you do everything you can to ensure that it is implemented there. And yet I believe that you have a pretty high standard of how your husband is supposed to be cared for there. Maybe it helps to compare every once in a while: How was it actually at home? For example, you said that you found it sad that your husband sat there alone when guests came over or that it is important to you that your husband goes outside. My aim is to put that into perspective again. That is important to you, of course, but in the winter months, it was not possible to do that at home either. So, do a reality check between your standards and what is even possible. Yes? Your standards have probably always remained the same. They were already so high when your husband still lived with you, but you could not always live up to them either. You had to go to work, your husband struggled to use the stairs, there were just things that were the way they were such that reaching the optimum was not always possible. But that’s life.

Caregiver: Mm-hmm.

Therapist: And ... now your husband is in the nursing home, and you continue to measure with these standards that are too high. That’s why I recommend you do a reality check every now and then: What is realistic, and what were we even able to implement at home? And while, on the one hand, certain things may not be done in the same way as they were at home, on the other hand, there may be other things that were not possible at home.

Worksheet 11-1

Scale Model



What I want to remember about it:
