The Carer's Map

Caring, Challenges, Coping

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Jason S. Spendelow, PhD

For Charlotte

1976 – 2017

Strength, courage, loyalty, and love.

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Important Notice: This book is intended to be a useful source of information on psychological issues faced by carers. It is not intended to replace the advice of health professionals. The reader should seek help from an appropriate qualified professional if experiencing significant psychological distress, or any symptoms that may require formal assessment or treatment.

Contents

About This Book

This book began as a series of short diary entries to help me cope with my wife's long battle with cancer. I commenced writing six months before she died, then continued after her funeral. As the word count rapidly increased, I wanted to make sense of those recorded thoughts. I discovered several recurring themes after re-reading my diary entries. I then expanded on these themes by writing about them from my professional perspective as a clinical psychologist. This was essentially aimed at enhancing my understanding of the circumstances in which I found myself. The writing process gave rise to many questions, which I looked to answer by researching carer experiences. I eventually accumulated numerous diary entries, professional reflections and notes on various surveys and scientific studies. Being an over-achieving perfectionist, I did not want to let that pile of words sit around gathering dust. This book is the result of my attempts to give that material some shape and coherence.

The following pages provide perspectives on caring for someone with a long-term (chronic) illness or disability. While some of the content may be relevant to individuals who are supporting people with other issues (e.g., mental health problems), this book primarily centres on medical conditions. My goal was to create a helpful resource for carers and provide useful insights for non-carers (family, friends, professionals). I believe this book also touches on themes that reflect universal life experiences, including grief, loss, change, relationship issues, and personal well-being. Therefore, I hope this book has some value to a general audience, and not just carers (or those who know a carer).

There were lengthy periods of contemplation as I considered what personal accounts to include in the book. I have tried to tell my story without crowding out the unique aspects of each person's circumstances. I also had to bear in mind what my late wife would have allowed me to say! I describe my experiences as a husband supporting his wife with cancer,

but some carers will have a different relationship with the person they support (e.g., son, mother, friend) or face another type of medical condition. In the book, I have attempted to acknowledge both the similarities and differences in carer experiences. There is no standard way for carers to feel, think, or act. Nevertheless, getting the carer role 'right' in each situation is tough. I hope that you will go easy on yourself after reading about the real-life struggles of a psychologist (aka the guy who *supposedly* knows all the well-being tricks). I genuinely hope this book makes you feel more positive about the huge contribution you make to a care recipient's life.

The caring role entails positive and negative experiences, but this book focuses on the difficulties (few people need support to cope with the positives of life!). In this way, the book is intended to provide maximum value to your self-care efforts. Watching a loved one suffer is a painful experience, so it is crucial to acknowledge that a carer's life can be very challenging. We should realise that many carer psychological struggles and 'bad' thoughts or feelings are normal. We need to spread this message far and wide. I attempt to convey the importance of validating these struggles and valuing carer well-being in the book. I do not know the nature of the caring circumstances you face, but my heart goes out to you regardless. I hope this book provides some useful information and guidance to each one of you.

Outline of the Book

This book is organised in two parts. Part one covers key psychological issues related to the caring experience commencing with a general overview of this topic in Chapter 1. The next chapter discusses carer identity, followed by a chapter on psychological well-being. We consider relationship issues and social support in Chapter 4. Part two focuses on psychological self-care strategies for carers. The subject of Chapter 5 is foundation self-care skills. You will then find two chapters that discuss working with unhelpful and distressing thoughts. Self-management of difficult emotions constitutes the topic of Chapter 8, while Chapter 9 suggests ways to work with relationships and develop social support. The Epilogue considers the end of caring, grief, and post-caring well-being. You will then find appendices and a list of resources. These last two sections contain material to complement and extend upon topics presented in the book.

A Note on Research

Findings from numerous scientific studies underpin some of the material in the book with the objective of supplementing personal caring

accounts with informative research data. Specific details of individual studies (e.g., study design) are not the focus, and coverage of underlying psychological theory is limited. These omissions are in the interests of maximising practical relevance and minimising reader boredom! I want to avoid getting side-tracked and instead focus on the most practical aspects of research that apply to your day-to-day life. Research is open to criticism because no scientific study is perfect. Academic work included in the book is no different. I have steered clear of covering these criticisms in detail to save you wading through pages of technical detail. Hence, broad take-home messages are the focus. Unreferenced text usually represents my own opinion or anecdotal professional experiences. These perspectives are provided to complement cited research through real-life examples and additional ideas or comments. I will be very happy if you have alternative viewpoints to those presented in the book. The caring experience is diverse, so I welcome your own opinions.

Part One

Chapter 1

Mapping Carer Experiences

Introduction

This chapter provides an overview of carer experiences and outlines several topics that are expanded upon in subsequent sections of the book. These themes are introduced through an account of personal experiences and a description of the people who comprise the caring population, the support they provide, and psychological problems typically faced by this group. While no two carers will share the same story, some common ground often emerges through a discussion of this material. A useful starting point for this chapter is the introduction of two key terms: *Carer* and *Chronic Illness and/or Disability (CID)*. A basic working definition of each is provided to get us underway.

There is no universally accepted definition of carer (or caregiver)[1] but one description of this role is "…anyone, including children and adults, who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction, and cannot cope without their support."[2]. This definition is necessarily broad given carers are a diverse bunch of people. Some care recipients are not as dependent on carer support as the phrase 'cannot cope' would imply. Instead, daily life would be more challenging in the absence of this help. Any definition of carer would ideally recognise that carers also ease the burden associated with a CID. Given these observations, the description of carer used in this book is:

Someone who provides broad unpaid psychological and practical support to those affected by a chronic illness/disability. This support allows the care recipient to cope better with their condition and/or experience reduced burden from its effects.

Many people dislike the carer label. Some argue the term is of little practical use and forcefully reject the title. The image of carers sometimes portrayed in society entails a person who does little more than perform

personal care and housework tasks. This misleading characterisation draws attention away from other forms of support often provided. Many carers also emphasise the importance of an existing relationship that connected them to the supported person well before the onset of a CID (e.g., wife, son, or friend). This is often a rich relationship that goes well beyond the interactions involved in the performance of practical support tasks.

In light of these considerations, the use of the term carer in the book merely represents a convenient shorthand reference to what is a diverse and complex role. Your description of caring may be different from the above definition, and we should welcome these alternative perspectives. How we define carers is a relevant debate in certain circumstances (e.g., identifying academic research participants), but will not be covered in detail here. Such discussions are not provided in the book because of the intended practical focus as alluded to earlier (I would also like to avoid printed copies of the book ending up as the nation's favourite doorstop).

That hilarious diversion leads us to the point that the above definition refers to 'informal' carers or people who provide support in a non-paid capacity. These individuals commonly support family members[3,4], and we distinguish informal carers from their formal counterparts. The latter provide care on a paid basis (e.g., care workers, nurses). While some issues in the book will apply to formal carers, their informal equivalents face unique challenges that necessitate specific attention. For example, some informal carers are unable to have meaningful breaks from their responsibilities. This situation contrasts with paid carers whose commitments are contained by set working hours. The book also focuses on 'primary' informal carers. These people provide the bulk of the total support given to a care recipient. Nevertheless, many of the issues covered in this book apply to those providing less intensive support. 'Secondary' carers receive little attention from the public or researchers. This lack of recognition occurs despite the many benefits provided by these individuals, and secondary carers can help reduce primary carer burden[5]. We salute all secondary wing-people. You provide essential support, and you do make a difference.

Carers provide an enormous amount of support, but often fly under the acknowledgement radar and lack appropriate levels of assistance. Despite this, their contribution eases what would otherwise be an unmanageable burden on public health services across the world. An increasing number of people are taking on the carer role. This trend is partly due to the growing numbers of people living with a CID. Alongside increasing healthcare costs, there is a widening gap between the support required by people with a CID and what the state is able (or willing) to provide[1]. You may know a carer or someone living with a CID at this moment. If you are not caring for someone now, there is a good chance you will take on this role in the future. Caring matters to all of us.

CID is the other fundamental concept in this book. 'Chronic illness', 'chronic disease' and 'disability' are terms applied to numerous long-term medical conditions. 'Long-term' can involve various timespans, but usually refers to periods of several months or longer[6]. There is a different list of conditions that qualify as a CID depending on whose perspective you take. Notwithstanding this, common diagnoses include heart disease, stroke, cancer, diabetes, obesity, arthritis, dementia, epilepsy, HIV, and asthma. These are just a few examples, and you may be supporting someone affected by another condition.

Some forms of CID are life-threatening, while others are not. There is generally no cure (or complete cure) for these conditions whose severity can vary over time. Some conditions remain static, some involve periods of both wellness and relapse, and some entail a progressive deterioration in health. Functional impairment typically accompanies a CID. Impairment of this type refers to difficulties in performing day-to-day tasks (e.g., due to mobility issues, fatigue). No two people with a CID will share the exact same medical and functional circumstances, and this adds to the diversity of carer experiences. While some regard mental illness as a CID, this book does not focus on this area. The emphasis will instead be on medical conditions and disabilities.

Personal Experiences

My carer experiences entailed a long journey with Charlotte, my girlfriend then wife, as she battled a rare form of cancer. The years I spent supporting her had a major impact on my well-being and fundamentally changed me as a person. Psychologists have long been interested in 'major life events' (e.g., bereavement, divorce, marriage, retirement), and my experiences with a CID and caring certainly fell into this category. Major life events trigger changes in important life roles (e.g., husband, mother, friend[7]) and influence your well-being in both positive and negative ways[8,9]. These events can also lead to fundamental alterations at the individual level (e.g., personality change[10]). Injury and illness are major life events that have some of the most significant effects on well-being[11]. Thus, it is important not to underestimate the potential impact that caring has on your life, both during and following the conclusion of this role.

The role of carer was not foreign to me because I had previous experience of supporting people with mental and physical health issues. A component of this prior exposure involved several years as a formal support worker while studying at university. Despite this background, the carer role I undertook for my wife was an experience like no other. I was unprepared for the journey I was about to take. I am sure that any person commencing a carer role is not entirely ready for it. I qualified as a clinical psychologist in 2004. While I possessed existing knowledge of

psychological processes and issues related to a CID, living in the shoes of a spousal carer was a different ball game. My professional background did not set me on the seas of smooth psychological sailing.

I had also relocated to the UK (from New Zealand) just a few months before Charlotte's cancer diagnosis. I had left most of my support network (and regular sunshine) behind. Building a base of friends in a new country was a huge challenge given Charlotte's illness. Most new friendships develop slowly. Interactions are initially kept light and pleasantry-heavy, revealing more about oneself as time goes on. I was plunged into intense encounters with people I barely knew. I had to navigate a new health system, up-skill on the ABCs of a rare cancer, and cope with missing my home country and friends. I describe the most salient aspects of my carer life in the following personal account. While some of my story may be familiar, I am sure you will also have other experiences to reflect on. I did a far from perfect job over this period of my life, but I take comfort in the fact that Charlotte did not face cancer alone. I hope you can pause, pat yourself on the back, and apply some self-compassion to your situation (either as a current or former carer) as you read about my experiences.

Charlotte's Battle

Charlotte spent several years fighting metastatic mucinous appendiceal adenocarcinoma (you can see why I just prefer to use the word cancer when people ask). She battled this disease over three reoccurrences, receiving chemotherapy twice and undergoing a course of radiotherapy. She also underwent three major surgical procedures, two of which were over 11 hours in duration. She encountered numerous complications and additional medical problems through these attempts to treat the disease. Some of these consequences were truly awful. There were also imposing psychological challenges to confront. These were as considerable as the medical issues. We lived life in limbo from scan to scan knowing cancer would probably reoccur. I became overly familiar with the concept of 'scanxiety'. We were unable to plan our future, live abroad, or have children. We had to talk about death, funerals, do not resuscitate orders, living as a widower, wills, and power of attorney.

No one wants to have these conversations, especially in their thirties. I quickly learned that the challenges of caring go far beyond finding time to fulfil the required practical responsibilities. Numerous psychological problems exist for carers, and they often present themselves with no warning or opportunity to prepare. These psychological battles might be restricted to the confines of a caring relationship or small group of people (e.g., immediate family). The outside world can be oblivious to the mental adversity faced by people fighting serious illness. Confronting a CID with

this level of secrecy can result in a lack of support and feelings of isolation (amongst other problems).

Charlotte was a beautiful, strong, and courageous woman, like no one I have ever known. She liked watching trashy daytime TV, but I can forgive this given her many precious qualities. Charlotte was very dedicated to me. I perhaps did not realise how much so until after she died. We tried to be grateful for life where we could despite our many challenges. This approach made life simultaneously awful and wonderful. We lived in a strange alternate reality while the 'normal' world passed us by. We took the chance to travel during periods of relative wellness. These adventures capture some of the most special moments of my life; a family tuk-tuk race through the streets of Bangkok, a road trip around Sicily, speeding up the Mekong River on a long boat, or just sitting at home drinking a beer in the sun. These jaunts, while memorable, did not adequately hide the extremely stressful nature of our life, and we endured hundreds of awful days and nights (literally).

It is painful beyond words to witness suffering in someone you love. I would have given anything to reduce the physical and mental pain in Charlotte's worst moments. Like so much in life, her illness was something I had little control over. The disease reoccurred for the third and final time approximately one year before Charlotte died in 2017. The new tumours were metastases, and there was little that could be done for her. I distinctly remember the appointment where we were told of these new tumours. I had anticipated that appointment with dread for several years. My previous approach to 'bad news' appointments was to find something positive to say in the aftermath. I had nothing that day. No witty jokes to lift her spirits, and nothing in her favour to provide a sense of hope. Charlotte died in a local hospice after a rapid decline in her final few months. She is gone, and even today this remains a surreal fact. How can someone die? How can I look at her handwriting on a card but not be able to talk to her? The process of dealing with Charlotte's cancer will never end. In some ways, carers bereaved through this disease represent a group of cancer survivors in their own right. Forever changed by their experiences and left with new psychological challenges to confront.

Charlotte's ashes were scattered on the Thames a few weeks after she died. In typical London fashion, it was a dull and wet day. We picked a beautiful spot despite the conditions. I nearly fell into the river attempting to throw her ashes from an urn that, in retrospect, was not ash-scattering friendly. This place is a bittersweet spot to sit and watch the river, the people walking by, and the kids playing. She will always have a place in the hearts of many. Her legacy is reflected in the tribute at the start of this book; strength, courage, loyalty and love. Second only to her identity as a wife was the importance she placed on being a dedicated Aunt. She deeply loved her nieces and nephews. If they were to read this book one day, she

would want them to know that she is incredibly proud of them. She would want them to know that happiness through connections with the people you love is the only thing that truly matters in this world.

Emotional Challenges

Like many carers, I experienced frequent bouts of anxiety and low mood. These emotional challenges were some of the most significant issues I faced as a carer. Charlotte's health dominated our thoughts. Nothing happened without cancer coming along for the ride. The fight to prevent a CID from defining your life is a difficult and on-going battle. A CID can start to feel like another person has entered your life…a hideous, intrusive and demanding figure! This presence created high levels of stress, and an ever-increasing pile of related issues exacerbated this stress; uncertainty about our future, the restrictions placed on our lives by cancer, and the prospect of a limited life expectancy.

Another source of pressure came from my need to 'be ok', to 'keep going' and 'just get on with things'. After all, I had someone relying on me. Falling apart was simply not an option. This is a common concern for carers, especially those who are isolated or lack support. However, the drive to 'just get on' with caring can impair psychological functioning through neglected self-care[12]. I often feared the stress in our lives would push me to breaking point despite seeing myself as a reasonably resilient person. This concern grew as Charlotte's illness progressed. The spectre of a potential break-down fuelled the pressure to hold myself together. More stress. This was scary stuff given Charlotte was heavily reliant on me.

Herein lies a dilemma for carers. It does not matter how mentally or physically tough you are, psychological distress is a normal consequence of providing support to someone with a CID. Mental pain indicates that life is challenging, and not necessarily an indication of personal frailty. Ignoring this fact may further compromise well-being, but acknowledging such distress can be confronting due to the pressure to uphold carer responsibilities. I could not reflect on my circumstances for more than a few moments at a time. I asked myself 'What if further contemplation sent me over the edge of sanity cliff?' There are no easy answers to this dilemma but bear in mind that thoughts are not reality (just as telling myself I am a giraffe will not lead to a lengthening neck and penchant for eating foliage situated at lofty heights). There is no easy way to strike the right balance between acknowledging your difficulties and keeping yourself going. While avoidance of difficult thoughts is sometimes required to survive the day, there are often small opportunities to positively influence your well-being (more on this in Part two).

My psychological challenges went beyond the issues I have mentioned to this point. Some of the complexities I faced related to *how* these

problems appeared over time. Day-to-day life with a CID can be unpredictable. Your mental state can be equally variable, and I often found myself on an emotional roller coaster. Swinging unpredictably between sadness, anxiety, and anger was unpleasant. I felt like I was no longer in charge of the emotions I experienced each day. This perceived loss of control was scary, and I have seen many of my own clients/patients battle the same issue in my professional life. High levels of emotional intensity and unpredictability can 'sensitise' people to unpleasant feelings, creating a fear of them. Fear often leads to avoidance of these emotions (e.g., not talking about them, trying to ignore them), triggering bigger problems fed by a vicious cycle of trepidation and avoidance.

I once worked with a client who was concerned about his ability to contain anger. He believed his anger levels were unacceptably high and he was going to eventually snap. He would try to escape any situation in which he experienced anger. He would tell himself that anger was unacceptable, that he was a bad person, and he was a 'rage time bomb'. He had refused to talk to anyone about his anger until we met. After some in-depth discussion, I learned that his fears about anger had never manifested as actual acts of aggression. He had come to believe that *any* anger experienced was unacceptable and represented personal failure.

These unhelpful beliefs caused him to be anxious and afraid of situations in which he was annoyed, impatient or irritable. He came to see his anger as dangerous and something to fear. Avoiding these experiences left him unable to learn about them or devise healthy ways to respond. We reversed the avoidance by learning about the anger and irritability, and he was eventually able to relate to these emotions in a more helpful way. As a carer, I had similarly told myself that certain emotional experiences were unacceptable. My client and I were both spooked by normal emotions and responded in self-defeating ways. I sincerely wanted to portray an image of strength and stability. Unwavering pursuit of this façade often prevented me from obtaining support when I needed it most.

Thought Challenges

Many unhelpful thoughts accompanied the emotional challenges I experienced while caring. I alluded to some of these in the previous section. I was eventually able to distil these thoughts into several thinking themes. These themes drove most of the distress I experienced, but also prompted me to reflect positively on my life. As we will see in Chapter 3, it is not uncommon for people to simultaneously experience benefits and costs from caring. While I encountered numerous thinking themes, the most frequently occurring ones involved isolation, not having a life of my own, and the unfairness of the world.

Caring for a person with a CID can make one feel lost and cut-off from the world. I sometimes believed I was in a time vacuum. The lives of others pressed ahead without me. I wanted the world to somehow stop moving and acknowledge what was happening to us. I watched people enjoy the luxury of freedom to make major life decisions (e.g., having children, making career changes). I felt isolated because the world seemed to be moving on without me. The experience was like a second world splintering off from the 'real' world. Charlotte and I were the only people to inhabit this new place.

My unique role in Charlotte's life increased the isolation I felt. My position was incomparable to others. I had responsibilities that went well beyond the odd visit and phone call that comprised the support provided by most other people. No one held a position like me, but these responsibilities were often hidden. Nobody except Charlotte saw me up in the middle of the night helping her with pain medication, trying to provide comfort, or talking about what was keeping her awake. The uniqueness of my role gave me the impression there was no one I could identify with. While I sometimes tried to describe my experiences to others, it was often difficult to turn the jumble of thoughts in my head into a coherent narrative.

Another thinking theme was related to the belief that my life was not my own. The illness we faced took over my thinking, my schedule, and the ability to choose how I occupied my time. I spent many years living an unpredictable existence. These circumstances removed a great deal of choice from my life. Even the decision to spend time alone was often taken away. I am a person who is equally comfortable alone or with other people. But I do need some of both and having little time to myself was tough. A lack of alone time made me feel like the ownership of my life had been transferred to a bunch of tumours. I then felt selfish for wanting time to myself.

It was paradoxically difficult to give up caring responsibilities when opportunities presented themselves. I remember telling myself that I was not a bad person for letting someone else cook a meal or clean the bathroom. I started to think that my job as a carer was not complete unless I did absolutely everything. My psychologist brain found this thinking interesting given I knew this was a one-way ticket to Burnout City. With the benefit of hindsight, I believe that doing tangible and practical things helped me to keep alive the illusion that there were things I could control. Being a bloke, I like to fix things (especially for other people). It is perhaps not surprising that I clung to every available practical task like it was the last beer in the fridge.

The final thinking theme I will mention here is the unfairness of life. I often got hung up on the fact that I was trying my best as a carer but receiving no special treatment from the universe. I felt angry after Charlotte

died that other people went home to their families each day while I went back to an empty house. Caring can come at an enormous personal cost. Life doesn't take account of your efforts and say "You've had your fair share of nastiness, I'll go easy on you from here". Life isn't fair. This fact will be of no surprise to those of you who have been around the block a few times. But, experiencing this first-hand can be devastating. Caring can provide significant rewards but we can be quickly overwhelmed by the negatives. The life lesson here is that you may not be treated fairly and you may feel like there is no justice in the world. These are understandable thoughts. Such views are a natural consequence of having an involuntary membership to a club that no one wants to join.

Relationships

CID and my caring role had a significant impact on my relationships. Major life events can place the bonds you have with others under the microscope. I talk more about these issues in the coming chapters. To kick this topic off, I would say that I faced two main relationship challenges. The first was trying to have a positive relationship with Charlotte, and the second was trying to cope with the various responses from family and friends to our circumstances.

It makes me very sad to say that cancer caused a lot of strain between Charlotte and I. This disease changed most aspects of our shared life. It sent us on a course dramatically different to the one we would have freely chosen in the absence of cancer. We experienced periods of tension and conflict. We worked hard to minimise these incidents and always felt guilty after arguing. However, these problems did reduce the amount of enjoyment we got from our relationship. The presence of a CID understandably places relationships under pressure. Joint recognition and response to this is vital (regardless of the type of relationship). People can benefit from planning reactions to conflict ahead of time, rather than winging it when tensions flair (see Chapter 9 for more on this topic).

The other relationship issue was coping with how other people responded to our situation. Charlotte and I had many conversations around how individuals behaved towards us. Many people seemed conflicted about how best to respond to our situation. Their responses created tension when there was a mismatch between what Charlotte and/or I wanted from others, and what they did in practice. Knowing how best to respond to our situation was difficult for other people, and many factors drove their behaviour. Most people are well-meaning towards caring relationships. Yet their actions can be interpreted as unsympathetic, especially when a carer is battling stress, isolation, or issues of loss and grief. 'Keep the lines of communication open' is a well-trodden mantra, but certainly applies in this case. Stress can breed difficult thoughts and misperceptions that must be

weeded out by carers and non-carers trying to understand each other's perspective.

One of the Numbers

Cancer can seem more like a national pastime than a disease. This topic seems to hold a perpetual slot in news bulletins and people's minds. Everyone has or knows of a tragic cancer story. The ubiquity of cancer often made me feel like our story was drowned out by the sheer weight of total suffering. Nearly nine million people die from cancer each year globally[13]. That's about twice the population of my home country of New Zealand. There is so much suffering and pain wrapped up in those millions of stories. You can understand why people want to switch off from this misery. For this and other reasons (e.g., carer role uniqueness as mentioned earlier in this chapter), carer isolation seems almost unavoidable irrespective of how positively friends and family respond to your position.

CID represent just one cause of adversity. Millions more are affected by heart attacks, road accidents, divorce…the list goes on. You can easily feel like one of the numbers with all the suffering emanating from these painful life events. Thinking this way can be invalidating and increase a carer's felt sense of isolation. The times I perceived a lack of support were often moments where I was seeking, not a cup of tea and a sympathetic ear, but an acknowledgement of what I was facing. Validation is sometimes the best gift you can give to a carer. However, many people are uncomfortable in circumstances where they are powerless to help someone in a tangible way. Throw-away comments will sometimes be made in a futile attempt to grapple with this fact. You will hear phrases like "Keep your chin up" and "Things will get better" used by people who are attempting to manage the discomfort created by their own helplessness.

Charlotte wanted to battle her illness in privacy. I tried to respect her wishes but there was on-going tension around what to reveal to others (and when to do so). This situation made me feel unacknowledged at times and illustrates the need for balancing privacy and validation of carer experiences. People outside the immediate caring relationship can also get caught in this dilemma. Do I avoid or confront difficult topics? No wonder friends and family can find the process of providing support difficult and bewildering.

Who Cares?

The carer role is carried out by many people in countries around the world. Carers number in their millions, and typically make up at least 10% of a country's population. The proportion is approximately 10% in the UK[14], 11% in Australia, and over 16% in the US[15]. There were an estimated

6.5 million UK carers in 2011[3]. The number is ten times greater in the US at nearly 66 million[16]. Health systems around the world would not cope in the absence of this workforce. The contribution of informal carers has been put into monetary terms and is said to be equivalent in value to the total amount spent on the UK public health service (NHS) each year[17].

The carer population is dynamic. Carer numbers are increasing, and there is a high carer turnover (people who begin and end caring responsibilities in a given period of time[18]). Moreover, an increasing number of people are undertaking a carer role multiple times[18]. These trends are increasing the significance of caring and the number of people taking on the position (e.g., 60% of the UK population will be carers at some point in their lives[3]). The demand for carers will increase as our population ages and more people live with long-term health conditions[19,20]. Adequate recognition of carer well-being needs will become increasingly important. Yet carers often regard their needs as secondary, and the attention of health care services is often directed primarily towards people with a CID. This focus is understandable but impaired carer well-being brings adverse health outcomes for both carers and the people they support.

On average, carers tend to be female, middle-age or older, and support a family member[21,22]. Most care for just one person (e.g., 82% in the US[23]), but some support two or more care recipients. 'Sandwich carers' are those who simultaneously care for children and older adults[24]. While broad statistical trends can provide a useful snapshot of carers, these figures do not capture the diverse nature of this group. Carers differ on almost any variable you can think of, ranging from demographic factors (e.g., age, gender, ethnicity) to their relationship with the people they support (e.g., wife, brother, daughter, friend). Carers support people with various health issues of which drug dependency, mental health problems, terminal illness, and learning disabilities are examples[21]. Hours of care provided is highly variable, but many provide substantial amounts of support. Around 55% of people in Australia provide at least 20 hours care per week[22], while just over half (59%) of carers in England offer more than 35 hours[21]. Carer outcomes are equally varied in that they report both positive and negative experiences associated with their role[25].

What Carers Do

The diversity in caring is also illustrated by what is done to support care recipients. Some people might assist with a few practical tasks each week, while others provide round-the-clock care. Caregiving can be a complex role requiring various skills[12] and the scope of carer responsibilities has extended over recent years[26]. Carers today are expected to perform a variety of support roles and take on increasingly difficult or technical tasks (e.g.,

medication management, basic medical tasks and procedures). Carer duties include assistance with Activities of Daily Living (or 'ADLs', e.g., washing), helping a person with mobility issues access the community, coordinating care activities and decisions, providing emotional support, organising treatment from healthcare providers, providing companionship, maintaining records of healthcare, acting as an advocate, persuading and influencing others, and managing relationships on behalf of the supported person.

Carers can also have high levels of responsibility, particularly if they are the primary carer to someone with multiple or complex needs. In the US, 66% of those in receipt of Long-Term Services and Support (LTSS) have all their care needs met by a family member[16]. The changing nature of the caring role is another challenge[27] in that a care recipient's medical and psychological needs vary over time. I don't think people stop often enough to think about the complexity of the carer job description. Most carers are modest and downplay their role. I often hear the statement "I just do what needs to be done". However, nonchalant attitudes may contribute to inadequate acknowledgement and support for carers, and even the occurrence of psychological issues (e.g., carer isolation).

The Challenges of Caring

The above profile of carers suggests that the role has the potential to be incredibly demanding. The challenging nature of caring stems from the various psychological, practical, physical, and relationship issues encountered while providing support. The extent to which these issues are successfully managed depends on many variables (e.g., the intensity of caring, support received from others, the carer's own well-being history). Caring can also be rewarding, but people don't usually struggle with the good stuff in life! This section briefly outlines common well-being challenges. Most of the topics mentioned below will be discussed in more detail later in the book.

Psychological Issues

Low mood, stress, and anxiety are amongst the most common psychological issues encountered in our society[28]. These problems are also prominent amongst carers and can impair the ability to provide support (e.g., low mood leading to reduced energy levels). While these issues are perhaps the most frequently encountered forms of carer distress, this group reports other difficult emotional experiences. For example, the diagnosis of a medical condition in another person can lead to feelings of helplessness, shock, panic, fear, and a sense of unpreparedness[29,30,31].

There are several potential causes of psychological issues amongst the general population. These causes can be relevant to carers, but this group may also grapple with additional and unique sources of distress. For example, difficult emotional experiences can arise directly from the CID itself. Carers may know little about a medical condition or how to appropriately support someone diagnosed with it. Exchanges with medical professionals can be confusing, intimidating, and frustrating. Some report distressing emotions about their 'performance' as carers which can include feeling overwhelmed, inadequate, or unskilled[30].

Uncertainty and change frequently characterises life with a CID. The prognosis for many forms of CID is unclear and carers are sometimes left trying to predict the future based on limited information[32]. There may be ongoing alterations to roles, routines, relationships, priorities, and health[33]. Uncertainty can cloud a previously well-detailed life direction. Humans like predictability because it permits us to plan our lives. Carers can feel like essential parts of life have been taken away without this certainty (e.g., making decisions about where to live, travel, or what career path to follow). A previous life might be replaced by a 'never-imagined' existence[34], accompanied by issues of grief and loss. There are, of course, many other causes of psychological distress (e.g., impairment in the cared-for individual[35]). More detail on this topic is provided in Chapter 3.

Behavioural Issues

Some carers are subject to challenging, stressful, and even dangerous behaviour. We often shy away from this topic. This avoidance can come from fear, embarrassment, or a desire to preserve the image of the person we support. However, such behaviour can strain relationships and add complexity to a carer's life. Behavioural issues can also impair adjustment to the caring role[36]. The topic of behavioural difficulties has been perhaps most closely linked to those caring for people with some form of neurocognitive impairment. Challenging behaviour of people diagnosed with intellectual disabilities and dementia is much publicised in academic and research circles. In the case of dementia, challenging behaviour often presents in the form of agitation, aggression, and wandering[37]. These behaviours are often an inherent part of the underlying medical condition.

Other difficult behaviours may stem from the many psychological issues understandably faced by people diagnosed with a CID. There are numerous issues to grapple with once diagnosed. For instance, coping with consequences that emerge through physical changes to the body (e.g., increased fatigue, decreased mobility, concentration problems, pain). They must confront the need to adapt to the 'new normal', make concessions in life, and accommodate a CID. There can be identity changes (e.g., cease to be in paid employment), changes to social support and relationships, and a

different daily routine. These matters represent just the tip of the iceberg of adjustment challenges.

Attempts to cope with these issues can bring knock-on psychological effects. These effects can manifest in ways which are challenging for a carer to witness or experience. Carers can be on the receiving end of irritability, anger, silence, and tears (care-recipients can be on the receiving end themselves). The way in which carers make sense of such behaviour has implications for how they respond. For example, carers are more likely to feel aggrieved when they attribute challenging behaviour to the person rather than the medical condition[38]. These behavioural issues prompt a mix of psychological and practical responses. As one example, carers may remain loyal and continue providing support while simultaneously resenting how they are treated.

Practical Issues

Carers can encounter numerous practical and logistical issues on top of the psychological challenges they face. Finding the time and energy for work, children, friends, family, and personal interests is tough at the best of times. Maintaining these commitments when supporting a loved-one is even more difficult. Keeping up with individual interests is vital to managing well-being, but some carers feel like they don't have a life of their own. Many (38%) cancer carers, for example, report that caring affects their social and leisure activities[39]. Financial difficulties are common amongst carers. In one survey, 44% of UK carers declared problems making ends meet[40]. Around 45% of carers face higher living costs[17,40]. Lost income is estimated at more than US $300,000 over a carer's lifetime in the US[16]. As a group, carers experience reduced employment and working hours[4]. Almost half of carers report other adverse employment outcomes[39], such as lost promotion opportunities[40]. Approximately 315,000 working-age carers in the UK are not in paid employment. This absence represents a significant cost to the economy in terms of lost skills and experience[41].

Relationship Issues

Carers often face wide-ranging relationship difficulties, and these are noteworthy in the care partnership. Some carers face a decline in relationship quality with the person they support[39]. Carers report other relationship difficulties with the care-recipient including reduced levels of communication, less interest in interacting, missing pre-illness aspects of personality, and feeling less loved[37]. There are many causes of relationship strain. We cover some of these in Chapter 4.

The mismatch between desired and actual support received from others is another vital relationship issue. Most carers report a lack of practical help,

and often attribute health issues to this deficit[42]. Many of those providing intense levels of care receive little or no practical assistance in their role[17]. There are obvious implications here for both carer and care recipient, but there are also tensions inherent in efforts to increase support (more in Chapter 4). Some carers support people who receive assistance from additional carers (both formal and informal). One cost of this additional support is a loss of privacy, particularly with the provision of in-home help.

Another critical relationship concern is social isolation. As the carer role intensifies, other parts of life diminish. For example, carers may spend less time with friends and family. Social isolation and loneliness are unsurprising consequences for carers. Thirty-nine per cent of carers in England say they feel socially isolated[21]. Isolation and loneliness can have adverse health effects[43,44]. We will talk more about loneliness in Chapter 3.

Summary & Your Experiences

In this chapter, we have provided a profile of carers and discussed key psychological issues faced by this group. A diverse range of people provide care, and their experiences of caring are equally varied. There is no truly typical carer experience, but there are often similar psychological, relationship, and practical challenges. We will focus on some of these issues in upcoming chapters of the book. We have not yet discussed the variety of ways in which people cope with the challenges of caring. Self-care and coping will be our focus in Part two.

Reflection Points

You might find it helpful to consider the following questions if you would like to think further about the material presented in this chapter.
- What tasks does your caring role involve?
- Which of these tasks were unfamiliar or most difficult to take on?
- What are the main psychological challenges of caring in your circumstances?
- What makes these challenges demanding?
- Which of the carer issues presented in this chapter are most relevant to you?
- How have these issues influenced or changed your day-to-day life?
- What are the strengths and weaknesses of your support network in supporting your caring efforts?

You can reflect on these questions in your head, or you might choose to record your thoughts. You could even keep a journal of your responses

to the questions posed throughout this book. Do whatever is most useful for you.

Chapter 2

Carer Identity

Introduction

This chapter introduces the concept of identity and its relevance to carers. Identity is an extensively studied psychological concept that explores the 'Who are you?' question[45]. Identity guides a person's thinking and behaviour[46] and this influence extends to carers. Yet some people may not naturally think to use identity as a framework to understand one's approach to caring. Reflecting on identity can help you to better understand your caring beliefs, behaviours, and experiences. After defining the concept of identity in more detail, we will discuss several identity-related issues of relevance to carers.

Identity & The Caring Context

Identity involves central beliefs about who you are as a person and goes far beyond personality traits. The construct of identity is influenced by many facets of your life such as gender, occupation, social class, and relationships to name a few. Identity extends to incorporate how we associate ourselves with certain characteristics, behaviours, or groups. We all have different roles in life (e.g., teacher, parent, friend), and there are different types of identity (e.g., social, personal[47]). The way we think about and describe these representations is fundamental to our self-image and the story of our lives. Characteristics that could be used to describe yourself do not necessarily form part of your identity. These elements are only incorporated if you ascribe personal relevance to them[45]. Identity is also comprised of subjective beliefs about who you *think* you are[45].

Identity is influenced by both individual and external forces (e.g., government organisations, major illness or disability), and can exist at the individual, relational, or collective level[48]. It not only involves how you define yourself, but also how you relate to others. Thus, 'you' in the 'Who

are you?' question can refer to individuals, couples, or groups. This collective identity is the process by which people describe themselves as part of a broader group[49]. Collective or shared identity is a central concept in our discussion because caring takes place in the context of multiple relationships.

Major life events often result in changes to your social roles and identity[50,51]. The process of caring can reshape your identity as you incorporate this role into your life. Caring can involve major upheavals to daily routines, the tasks you perform, and the way you think about the world. People may rethink their own identities as life changes through caring. Identity reformation can be a complicated process, especially when caring responsibilities sit uncomfortably with pre-existing identities. For example, people who view themselves as relatively unemotional may struggle to confront psychological distress in a care recipient. Identity restructuring may be an equally difficult process in those with a CID (e.g., people might not relate to well-known labels linked to a medical condition, such as 'cancer survivor')[52]. The extent to which you associate with the carer identity will influence your approach to providing support, but a person's affinity with the carer role may evolve through the course of caring experiences[53]. In other words, a carer's identity unfolds and changes over time.

Personal Experiences

My identity was not something I had given much conscious attention to before becoming a carer. I probably held a relatively simplistic view of the concept in my personal life. I tended to use broad labels such as 'brother', 'husband', 'psychologist' and 'tragic amateur guitarist' to define myself. Taking on a carer role was not difficult for me, and I did not give it much conscious thought. I had been working as a psychologist for several years by then. The notion of supporting another person was something that felt natural. I did not think to apply the carer label to myself in the initial stages of Charlotte's illness. I was just 'doing things that needed to be done'. Grouping those 'things' under a defined identity was not something that occurred to me.

While I had no major difficulties in assuming the carer role, I came to believe that it was gradually taking over my previous identities. I fought to retain existing parts of my life, like my professional identity, my love of music, and my circle of friends. The sense that these parts of myself were slipping away created uncertainty around my own identity. Would these changes be temporary, or was this the new normal? Carers are frequently required to cope with the loss of a pre-carer existence. An example of this would be a teenage carer missing out on experiences they would typically

expect to have at that age (e.g., school trips, socialising with friends on weekends[54]).

Caring for Charlotte was my top priority, but I still felt a sense of pre-illness identity loss as my life changed. Holding these two viewpoints in my mind was uncomfortable. This mental state was comparable to the phenomenon of 'cognitive dissonance' identified by psychologist Leon Festinger[55]. Cognitive dissonance refers to the presence of inconsistent thoughts, beliefs, or attitudes. I simultaneously believed that supporting Charlotte was my priority while wishing I had more time for other things in my life. Cognitive dissonance can be particularly relevant to carers. Conflicting thoughts are bound to occur when grappling with the competing interests of self and care recipient. This is a normal and expected phenomenon, rather than a sign that you are a bad person.

My ability to be 'strong', resilient, and 'in-control' was threatened as Charlotte's illness gradually progressed. I had to start re-considering who I thought I was. I would have previously brushed off people who suggested that I liked to be in control: "Rubbish! You don't know what you're talking about. I'm no control freak…". In reflecting on my carer identity, I came to realise that I indeed strived to be in control more often than not. What followed this eureka moment was a forced re-think and a new perspective on my identities. I later started to question whether I even wanted to get parts of 'old me' back. Caring forced a global rethink of who I thought I was, and who I wanted to be. My experiences reflect points made at the beginning of this chapter; caring represents a significant life event which can shape and re-shape your identity.

I developed a clear sense of my carer identity over time. Advocating for Charlotte became a principal focus of my role (e.g., asking questions at medical appointments). My professional background was likely to have provided the impetus for this. It is not unusual for carers to 'do' caring in a way that plays to their (perceived) strengths or areas of relative confidence. The spanner in the works comes when you must take on uncomfortable or unfamiliar responsibilities. This is a likely scenario given the many duties assigned to carers. This point was made in the previous chapter when referring to a carer's elaborate 'job description'. Taking on new tasks can lead to a sense of unpreparedness. What's more, carer responsibilities are likely to change over time[27]. Carers can feel incompetent, and this psychological state can be extremely confronting (especially if you are a perfectionist control-freak such as myself).

My carer identity sometimes clashed with other personal identities. Carers can feel pulled in several directions at once, with each identity competing against the other. For instance, there were 'arguments' between my spousal and carer identities. Charlotte would often become annoyed with me when I would rush around the house mopping floors, mowing the lawn, and organising medication. "I just want you to be my husband!" she

would legitimately protest. I have never regretted a missed housework opportunity, but I have often regretted missing the chance to spend a quality moment with someone I care about. My approach to caring also affected how Charlotte portrayed herself. Charlotte felt less a wife and more a patient in some instances. This demonstrates how people influence each other's identities. No wonder my constant obsession with 'doing stuff' was difficult for her.

After Charlotte died, I was unceremoniously dumped into a surreal post-carer universe in the blink of an eye. I was abruptly made redundant from my caring role. This event sharply contrasted the gradual intensification of caring responsibilities at the front end of Charlotte's illness. My identity and purpose in life had been deleted quicker than an unwanted computer file, with no instructions on how to reboot my life. Thankfully, I came to realise that I was not 'lost'. The Lego pieces of my identity were still there. Some a-hole had just decided to scatter them across the room saying "Good luck with that" as they walked out the door. My caring dramatically altered the direction in which my identity was heading. I am sure that over the course of my life the carer role will be one of several experiences to massively influence my identities.

I'm Not A Carer…Or Am I?

People vary in the degree to which they take on the title of carer[56], and we mentioned the differing attitudes towards this term in Chapter 1. The extent to which one associates their identity with the carer label has both practical and psychological implications. For instance, deliberately distancing oneself from the carer title might result in refusing offers of practical support[57]. This non-identification is common and can even extend to intensive caring circumstances such as palliative care[58]. Alternatively, stark differences between one's carer and other identities can cause psychological difficulties[59]. Perhaps life would be slightly easier if the carer role remained static, but the concept of caring is changing. Identity is being shaken up by recent moves to provide formal training to carers[60]. This trend may be blurring the lines of identity by creating a group of semi-professional carers. These developments raise further questions about what it means to be a carer and whom this label represents.

As mentioned in Chapter 1, there are many instances where people reject the term carer and instead talk about a pre-existing relationship with the supported person. Moreover, some people describe themselves as 'caring' but not as a carer[53]. Providing support can be framed as a normative form of assistance that occurs in the context of an existing relationship thereby rendering the carer label unnecessary or even invalid[61]. Giving CID-related support merely forms part of a broader relationship identity in these instances[61].

Another reason people are not keen on the carer label is the fact that a person with a CID may not want their identity to revolve around being cared-for[62]. Charlotte often yelled "I'm sick of being called a cancer patient" (swearing omitted). She was making an incredibly important point. People with deteriorating health sometimes reduce their contact with others because they do not want to be identified as a 'sick person'. Just as the carer role can take up increasingly large parts of one's overall identity, a CID can swallow big chunks of a person's previous life. There are valid reasons for why the carer label may not sit comfortably. Rejecting the label does not impair your ability to help someone. Carers need support to exercise the greatest possible degree of freedom in determining their identities. Expressing non-carer parts of one's identity is important whenever possible.

The nature of a pre-caring relationship may also influence adjustment to and identification with the carer role. The less 'normal' or natural the carer role feels, the more struggles you may have in adopting it. Moreover, sudden changes can make the transition to the carer role difficult. This scenario might apply, for example, when a severe physical injury occurs to a loved one. At the other end of the spectrum is a gradual intensification of the carer role. In one view of the transition to a caring relationship in the case of progressive conditions (e.g., dementia[59]) existing roles between people change gradually over time as care needs increase.

Invisibility

There is evidence from various quarters supporting the notion of 'carer invisibility'. There are identity-related and psychological implications associated with a lack of role recognition (e.g., feeling undervalued). More than half of people in the general population believe that they do not know a carer[14] despite the countless numbers of carers in society. In addition, health services are often heavily focused on the person with a CID[27] which can draw attention away from carers[27,63]. It is perhaps unsurprising that many carers believe that society does not adequately understand, acknowledge, or value their role[64,65].

There are other potential reasons why carers can feel invisible. Committing many hours to providing support often comes at the expense of decreased involvement with other activities and people. What we do as carers is often unseen (e.g., a supportive phone call made in private). This may be especially relevant to psychological support where there might be limited tangible evidence of its provision. Some carers that I have spoken to say that friends and family know little of their day-to-day efforts. A type of isolation can result from this limited awareness. A carer might ultimately prioritise the cared-for person's needs[66] and understate the importance of receiving support themselves[67]. Carers do not tend to support a loved one

for money or glory. A desire for acknowledgement or recognition is often sought as evidence that people appreciate what the caring role truly entails.

There can also be an unquestioned expectation that certain people will take on the carer role. In this way, a carer's efforts may appear unremarkable based on the nature of an existing relationship. People sometimes have little or no choice in becoming a carer[27]. Examples here might include a middle-aged daughter of an elderly parent, or the belief that a 'good' spouse will always take on a carer role for their partner[68]. Societal pressure of this nature can make a person feel like the carer role has been imposed on them. Such an imposition can curtail much-deserved acknowledgement of the demands and sacrifices made when rendering care. Earlier in this chapter, I mentioned that people with a CID often do not want to be identified by their condition. Existing relationship loyalties might mean that carers keep quiet about their responsibilities to help the care recipient maximise an appearance of independence[69].

I once worked with a woman who was the primary carer for her disabled son. Her care responsibilities involved a ferocious fight with authorities to get him the educational, medical, and psychological support he needed. Such was her quiet commitment and skill that few saw her efforts as remarkable. Her life was exclusively focused on her son, but she wanted no praise or extra attention. The battles fought to obtain services came at a significant personal cost. My client was suffering from high levels of anxiety and depressed mood. There was also insufficient recognition of the exhausting nature of her situation. The desire to keep her efforts quiet inadvertently led to inadequate support and reduced well-being. Moreover, she had no sense of who she was outside of her caring responsibilities. We worked over several months to rebuild a sense of non-carer identity and improve her overall functioning.

Carer Role Dominance

When the carer's role intensifies, it can grow to the extent of becoming the central feature of a person's life alongside a corresponding diminishment of other identities[46,70]. We have alluded to this earlier in the chapter through comments about the loss of pre-caring identity and activities. Priorities change as the caring role becomes the primary focus of life. Some carers believe that they must do everything, and they experience high levels of stress associated with the (at-times) huge sense of responsibility[71]. Alterations in daily routines occur to provide space for caring commitments[72]. Some carers describe a fading of previous roles[73] and even complete loss of their own identity[49]. The slightly ominous title of 'master identity' has been given to this process. This term refers to a situation when the carer role becomes dominant in a person's life[46]. Few areas of life remain uninfluenced by the carer role. The resulting identity

changes may occur gradually as caring responsibilities become an increasingly overriding component of a care relationship[74].

Shared Identity & Change

As mentioned above, formation of a carer's identity partially emerges from relationships with other people. The carer-care receiver relationship is particularly relevant in this respect. This dyad has an important influence on carer experiences[18]. Many carers have a relationship with the supported person before the onset of a CID, and a sense of shared identity may partially protect couples from stress related to caring responsibilities[75]. However, the process of caring can change this shared (pre-CID) identity[46]. For example, relationships may merge in a way where it is difficult for carers to differentiate their experiences from those of the people they support[66]. Several psychological forces can contribute to changes in shared identity, ranging from the direct effects of illness symptoms on communication (e.g., cognitive decline in dementia[76]) to people trying to come to terms with physical impairment and the social meaning of their disability[77].

People must try to adjust in the face of shared identity changes[78]. This process can be very difficult, yet care partnerships rarely receive help in this area. Many people try to keep the status quo of life in response to such changes[79] by trying to maintain a 'normal' (pre-illness) life. Resisting change in this way represents attempts to push back against the effects of a CID. People might try to hold on to pre-CID shared identities because these are the foundations on which their relationships were formed. To lose this would mean losing part of who they are.

You are influencing the identity of the person you support when you are defining your carer role and responsibilities. When talking about my personal experiences earlier in the chapter, I alluded to the fact that the intensity with which I performed the carer role ultimately shaped Charlotte's identity. She felt more like a patient than a wife at times. Noble as it may be to try and take on every caring responsibility under the sun, this may bring unintended negative consequences. Caring is not always about doing everything. Skilful caring sometimes involves stepping back and resisting the urge to do 'stuff' (when safe to do so). Removing your hands from the wheel in this way may assist carer and care recipient to feel an increased sense of control over individual and shared identities.

Males As Carers

There are more female than male carers overall, but the numbers of male carers are increasing with the latter comprising the majority of carers in the over-85 age group[80,81]. Caring has traditionally been a 'feminised' role.

This characterisation has assumed that women possess personality characteristics that naturally suit care provision[82]. Furthermore, men in feminised or 'non-traditional' roles may be portrayed in a negative light[82]. This view of male carers has potentially harmful implications for identity and well-being. In addition to carer-role stress, male carers may face additional challenges in conforming to expected masculine behaviour. For these reasons, we need to pay attention to the unique issues faced by male carers.

Men adopt a range of coping strategies when supporting a loved one. These strategies can involve searching for meaning or purpose to the carer role, defining masculinity flexibly in the context of providing care, attempting to maintain a pre-illness life, and exhibiting traditional masculine characteristics (e.g., down-playing emotional aspects of caring[79]). Identifying with this conventional view of masculinity might influence carer identity and the approach taken to providing support. For example, some men approach the caring role as if it were a job. They might attempt to apply occupational skills to the caring context[83]. While male carers generally report less distress than females, a coping approach that de-emphasises emotion might yield mixed outcomes. Trying to block emotion from the caring role could potentially help males get through distressing situations, but there might also be negative implications (e.g., relationship difficulties with the person you support).

Summary & Your Experiences

This chapter has introduced the concept of identity. We have looked at some ways in which this psychological construct is relevant to carers. Identity is a multifaceted phenomenon that can incorporate many aspects of a person's life and be influenced by others. Identity can involve an array of thoughts, beliefs, and behaviours. As a result, a carer's views about his or her role may determine their overall approach to caring. Identity can be tied to an individual or shared with a care recipient. If responsibilities are significant, the carer role can become a dominant identity. Despite the sometimes all-consuming nature of the carer role, it often goes under-recognised and unacknowledged by society.

Reflection Points

There are several issues you can consider if you are interested in thinking further about identity in the context of your caring responsibilities. The following questions may help you to further explore your carer identity.

- What were the essential elements of your identity before you became a carer?
- What and who has influenced the formation of your pre-carer identity?
- How easily did you take on the carer role?
- How much has the carer role aligned with your pre-carer identity?
- What aspects of your carer identity most influence how you 'do' caring?
- How would you describe the shared identity that you have with the person you support?
- How much has a CID altered this shared identity?

Chapter 3

Well-being & Psychological Difficulties

Introduction

Well-being has been defined in many ways, but one view is that it consists of positive emotions (and lack of negative emotions), satisfaction with life, and feeling fulfilled[84]. Carer well-being is an important issue in its own right, but becomes more crucial when we consider the high proportion of psychological difficulties found amongst this group. The mental health of carers may also influence the health of care recipients[85]. This chapter expands on the well-being overview in Chapter 1 by providing more detail about the types of psychological issues that can occur for carers. We will focus on psychological difficulties, but will also consider positive outcomes of caring. In Part two, we will cover several strategies to help carers manage the challenges discussed in this chapter.

Personal Experiences

My caring experiences encompassed many of the psychological struggles common to other carers. I gained a real sense of purpose in being there for Charlotte, but providing support was also stressful and demanding. The carer role has been described as a 'double-edged sword'[86] because it has been linked to both positive and negative outcomes. This contrast illustrates a paradox that many carers face: While providing support to a loved one is important and meaningful, caring can sometimes entail significant personal costs. Feelings of guilt can spring from the mere acknowledgment of these effects. Carers might feel selfish for recognising

any form of psychological struggle. Sometimes the costs of caring spark 'unforgivable' thoughts like 'I wish I didn't have to go through this' or 'I can't cope'. However, it is perfectly reasonable to find caring a demanding and stressful role. Characterising these thoughts as wrong tends to undermine your well-being.

My most formidable psychological struggles were with stress, anxiety, and anger. I also developed stress-related physical health issues. We will see later that these are all-too-familiar outcomes for carers. The fact that I, as a psychologist, experienced well-being struggles should not demoralise you. I mention my difficulties to illustrate that these problems may be unavoidable. Chronic stress was a major contributor to my health problems because I supported Charlotte for several years, and she was unwell for most of our time together. Witnessing suffering in someone I cared about was the most stressful aspect of caring for me. This suffering seemed to be never-ending, and my ability to intervene was limited. I often felt helpless with little ability to influence what I most wanted to be different. There are no easy responses to this situation. A CID can expose you to a world where control is either a luxury or a myth. Prolonged periods of stress also create unique challenges that might not be faced otherwise. There is good evidence that chronic stress is bad for physical and psychological functioning[87,88].

Ongoing stress can test resilience levels and the effectiveness of your coping responses. I made life harder for myself through some unhelpful coping strategies. I frequently told myself that I *should* have been coping better. Carers may naturally gravitate towards this type of thinking. Why wouldn't you if you hold the bulk of caring responsibilities? The weight of attention from friends, family, and professionals is typically directed towards the person with a CID. This emphasis can inadvertently take much-needed focus away from the carer. Moreover, a carer might be reluctant to reveal their well-being issues through fear of diverting attention away from the care recipient. Alternatively, the presence of psychological difficulties might fuel fears of perceived carer incompetence (as mentioned in the last chapter).

Anger

Anger is an unsurprisingly neglected carer topic given the often-assumed social unacceptability of this emotion. The guilt and shame that can occur when one admits anger is a possible reason for ignoring this subject[89]. The taboo surrounding anger also envelops its cousins' frustration, irritability, and impatience. There are other 'forbidden' carer thoughts and feelings such as boredom and restlessness[66]. These emotional experiences need to be brought out of the shadows and into mainstream discussion (as is partly the purpose of discussing my experiences here).

These emotions occur frequently and are often suppressed. Be it carers, parents, friends, or professionals; no one is immune to them. They do not make you guilty of some emotional crime. Understanding the source of these emotions is a better use of energy than attempting to suppress them. Hiding unwanted feelings under a blanket of shame will not help to address the problems they cause.

I grappled with the existence of angry feelings. I would think to myself 'I am not allowed to be angry at this person who has cancer'. I reluctantly acknowledge that I did experience annoyance and frustration towards Charlotte. I imagined telling people of these emotions but feared this would conjure up an image of my vulnerable wife cowering in the corner while I yelled at her for not stacking the dishwasher correctly. The fact is that we were both angry at times and occasionally yelled at each other. How could this be surprising when two people were fumbling their way through a living hell? Cancer was the unwelcome third member of our relationship and was the true source of our anger. I think of those two people today and feel great compassion for what they were enduring. We managed to remain a cohesive unit overall which saved us from further misery. Some people sadly do not survive similar situations.

The anger I experienced whilst caring generalised across my life. Many situations sparked this emotion. Increased anger prompted a corresponding rise in shame levels. I felt embarrassed that life was making me so angry. This reaction created a sense of isolation from the world. I later saw that these were understandable reactions to events in my life. Resentment sometimes accompanies anger and is a logical emotion when you realise that life is mostly uncontrollable (and bloody unfair). Why wouldn't you be angry at the world? I felt jealous of those who lived a 'normal' life. I often thought about what I had (willingly) given up to provide care. Other carers have reported these types of thoughts and emotions[90].

I have seen anger cause major problems for other people too. I have witnessed the urge in clients to run from this emotional state in my professional life. People can come unstuck when judging emotions as 'acceptable' and 'unacceptable'. Categorising feelings in this way can cause additional distress and prevent a willingness to learn from these emotions. The less you understand an unwanted feeling, the less equipped you are to manage it effectively. I generated excessive guilt by telling myself that anger was not allowed. I initially ran from anger which blocked efforts to understand this emotion. Further discussion on attitudes towards difficult emotions can be found in Chapter 8.

Balancing Perspectives

There is no chance of being at our best under stressful circumstances. I tried to cope by holding two equally valid points in mind: (1) I was falling short of my expected behaviour, and (2) I was trying to do my best in an extreme situation. Both points contained an element of truth and were therefore relevant to me. You too might develop a preoccupation with being below your best. The brain is designed to look out for this type of threat. Perceived substandard performance is one modern-day equivalent of a caveman versus sabre-toothed tiger hazard. Focusing on point one with no acknowledgement of point two did not accurately reflect my situation. Yes, I could have done better when I look back at my time supporting Charlotte. I also think I did a reasonable job overall under circumstances that were too painful for words.

Many carers (and people in general) place high standards on themselves. Intensive caring does not easily allow for respite or self-pity. I have often heard carers say "I have no choice but to keep going". I have even said this myself. You do not want to let people down, especially the person you are supporting. You often do need to keep going under challenging circumstances, but an unrelenting 'never-stop' attitude can lay the foundation for self-neglect. The theme of carer well-being as secondary was introduced in Chapter 1 with reference to circumstances where care-recipient needs are placed above those of the carer. We see another manifestation of this theme here through carers pushing themselves to chase high standards and not seeking respite. This scenario is unsustainable for yourself and the person you support. The drive to keep going is a double-edged sword (yes, another one). It can help you keep it together during tough moments, but you need to watch out for corresponding neglect of your well-being.

One client I worked with was a husband and a father to three young children. He imposed expectations on his professional and personal life which were unobtainable. He believed that he should be the perfect employee, husband, and father. He decreed many years ago that he should always be 'on the clock'. He characterised himself as a failure when he fell short of his unrealistic standards. He pushed himself harder to compensate, imposing further impossible expectations. The reason why he felt so bad, he concluded, was that he was not pushing himself hard enough. The supposed solution to his difficulties was actually the cause of them; not an unfamiliar scenario from my professional work. We can observe a similar pattern in carers. We all want to support loved ones as well as we can, but it is vital to avoid applying inappropriately high standards to our circumstances. Better to try and address the discomfort associated with achieving less than the ideal, than stoking the fires of psychological distress with unrealistic expectations.

Becoming Worn Out

Being on an emotional roller coaster was one of the most significant psychological challenges I faced. I experienced a range of emotions, mainly when stress levels were high. Some of these did not naturally fit together. Making sense of my inner world was tough in the face of these contrasting emotions. This roller coaster was somewhat akin to bereavement and grief. Psychologist Susan Roos[91] has described similar experiences as 'chronic sorrow' (discussed later in the chapter). It is equally common to experience a mix of emotions when someone dies. Containing intense and painful feelings is a challenge. Because these emotions were unpredictable and unstable, I did not know whether I should trust or pay attention to them (Chapter 8 contains suggestions for balancing or 'regulating' emotions).

My resilience levels gradually dropped because of the stress accumulated over several years. I was more easily knocked about by day-to-day problems. I felt ashamed of this and believed I had let people down (another understandable but unhelpful interpretation of my actions). The ability to hold myself together for several years was surprising, but everyone has a breaking point (even you tough guys). The term 'breaking point' is actually a bit misleading to me. People do not always 'snap' during a prolonged period of stress. Negative effects tend to accumulate gradually, and warning signs can be unclear initially. 'Realisation point' might be more helpful than the breaking point concept. The former being the moment you become conscious of feeling overwhelmed by stressful circumstances.

One coping approach I developed involved paying attention to small positives in life; a strum on my guitar or admiring a spectacular landscape. I became closer to a few of my friends, having some great moments and valuable conversations with them. Talking about positives is not an attempt to minimise the bad stuff. Believe me, I would not wish my time with cancer on anyone. However, thinking about positive moments can help you through life's bad times and allow you to see the full range of your experiences.

Psychological Challenges

We know that psychological issues are amongst the most commonly reported carer difficulties[92]. Nearly 90% of people say that providing care has a negative impact on their mental health[42]. The specific issues that arise will partly depend on a carer's individual circumstances. For example, age is important whereby children with caregiving responsibilities are at increased risk for bullying at school and have lower educational aspirations[93]. By contrast, older adult carers may have to contend with age-related health issues (e.g., reduced mobility). Additional

challenges such as these make the caring role more demanding. We will see later that age is one of many factors that can influence carer well-being.

Carer burden is a crucial well-being concept and refers to the adverse psychological consequences of providing care[94]. Burden can manifest in various forms, ranging from physical and mental health issues to relationship difficulties, financial problems, and negative occupational consequences[95,96]. Levels of burden vary between individuals but tend to be significant in around two-thirds of carers[97]. Increased burden is associated with gender (higher in female carers), social isolation, financial stress, living with the care receiver, spending large amounts of time caring, and being given no choice in becoming a carer[98]. Related to the concept of carer burden is unmet need. Carers have various practical and psychological support requirements (e.g., information, training, stress management suggestions[99]). Yet received assistance often falls short of required levels[96] thereby creating 'unmet support needs'. Unmet need is prevalent amongst carers supporting people with various health conditions[100], and is a substantial contributor to carer burden[101,102].

Low mood and depressive symptoms comprise a substantial proportion of overall carer burden[103,104]. Other key psychological issues include elevated levels of stress and anxiety[104,105] and lower quality of life[106]. Rates of depressive and anxiety disorders are higher in adult carers compared to the general population. While this difference applies across many conditions (e.g., dementia[107], cancer[108], asthma[109], eating disorders[110]), the gap between carers and non-carers is most considerable for symptoms of depression and stress[111]. Carers are not doomed to develop psychological issues, but these figures indicate they are at elevated risk.

The relationship between time spent caring and well-being is germane to psychological functioning. Providing increasing hours of care tends to be associated with declining carer health[112]. One considerable UK investigation of over 200,000 people[113] found that those providing 'light' care (less than 20 hours per week) did not appear to suffer adverse health consequences. Carers were in poorer health (relative to non-carers) when providing 'heavy' care (20 hours or more per week). Providing general social support to others has been associated with positive health outcomes[114,115]. Supporting someone is not necessarily bad for well-being and can even be beneficial under certain circumstances. Nonetheless, caring for someone with a CID may be entirely different from providing social support to healthy individuals. Intensive caring may entail unique demands not typically encountered in other relationships.

Low Mood & Depression

Given that carers are at increased risk for low mood and depression, we need to recognise when these issues occur. One important task is to distinguish low mood from clinical depression. The latter is a diagnosable psychiatric condition. Clinical depression tends to persist for several months[116] and goes far beyond the usual ups and downs of life. The term 'clinical' is simply used to denote a level of severity and cluster of symptoms that represent a diagnosable illness. Low mood (non-clinical) tends to improve after a relatively short period and does not lead to the type of disruption caused by clinical depression[117]. The lowered mood associated with clinical depression significantly affects day-to-day life. Clinical levels of depressed mood can also be highly distressing for people. Depression can adversely affect daily life in several ways. Some examples include an inability to get out of bed, frequently missing work, and avoiding social contact. Loss of interest or enjoyment in activities (anhedonia) is another vital sign of clinical depression.

Those who develop clinical depression experience additional problems including poor sleep (insomnia) or sleeping much more than usual (hypersomnia), appetite and/or weight changes (increase or decrease), fatigue, reduced motivation and/or concentration, social withdrawal, unpleasant thoughts about self (e.g., believing one is worthless, feelings of guilt), and thoughts of suicide or death. As mentioned earlier, caregiving is more difficult when experiencing psychological difficulties. Seeking professional help is essential if you suffer from persistently low mood accompanied by any of the additional symptoms described here. Seek urgent professional help if you are experiencing thoughts of self-harm or suicide.

There are a variety of psychological approaches to treating clinical depression, but aspects of a carer's circumstances can present obstacles to implementing these interventions. This can be illustrated by a 'behavioural' approach to tackling depression. A central premise of a behavioural treatment is that (along with changes in a person's environment) people stop engaging in positive activities[118], such as spending time with friends and family, hobbies, and so on. The more depressed you become, the less you engage in these 'reinforcing' pursuits. A downward spiral of decreasing activity and mood results. Reinstating positive activities is a goal of behavioural treatment, but carer circumstances might mean that engaging in positive acts is difficult. A situation like this may occur when spending long periods of time supporting a loved one. There may also be psychological barriers to increasing positive activities (e.g., feelings of guilt when doing something for oneself). This example of treating depression demonstrates that carers may face unique circumstances that require attention when tackling psychological distress. Taking account of these

circumstances is necessary to manage well-being issues successfully. Suggestions for addressing some of these circumstances are presented in Part two.

Stress

Stress is the body's physical response to the demands of the environment around us. This phenomenon is an unavoidable part of life but can be a useful call to action when a productive response results (e.g., writing a budget when under financial pressure). There are very thick books devoted to theories of stress and it would be ironically stressful to spend several pages discussing these here. I will just say that there are various ideas about how and why stress develops. These suggestions range from having insufficient coping skills to the importance of a person's attitude towards stressful events.

Stress becomes a concern when it compromises your health and ability to function in key areas of life. These difficulties can intensify when your stress response is unhelpful (e.g., using alcohol, avoidance of essential tasks). We acknowledged above that carers face elevated stress levels across various forms of CID. You must be able to recognise stress before addressing it successfully. Here are some potential signs of high stress levels.

- Increase in emotional difficulties, such as elevated levels of irritability, anger, and anxiety.
- Low mood.
- Behavioural changes including an increase in unhealthy activities (e.g., smoking, becoming more sedentary), rushing through activities, and avoiding essential tasks.
- Reduced motivation.
- Sleep and/or appetite changes.
- Thinking (cognitive) problems (e.g., concentration and memory difficulties).
- Physical symptoms (e.g., headache, dry mouth, stomach upset, aching muscles and joints, racing heart).
- Increased fatigue.

You should first seek medical advice if you experience any of the above signs to rule out medical or more serious psychological difficulties (e.g., clinical depression). You can turn your attention to stress management if there are no other underlying problems. Positive stress management can take many forms. You can find several suggestions on this topic in Part two. It can be challenging to manage stress if you are a carer facing

persistently stressful circumstances. An appropriate goal in this situation may be a reduction in stress to manageable levels.

Anxiety

Every person experiences anxiety at some stage in their life. Like stress, anxiety can be useful in manageable doses. One of the main differences between stress and anxiety is that the latter involves apprehension about something specific that may occur in the future. Contrast this with stress which typically relates to issues existing in the here-and-now. Stress can be a precursor to anxiety that ultimately leads to a mental health condition (e.g., panic attacks, social anxiety). Excessive anxiety can precipitate major disruption in daily life, significant distress, and other psychological problems. These issues signal that extra help is needed. As with depression and stress, being aware of anxiety signs is the first step down the path of effective intervention. Anxiety has physical, cognitive, and behavioural components. Each of these can contribute to the development and maintenance of anxiety problems. Here are some examples of each element.

- Physical: Racing heart, shortness of breath, chest pain/tightness, 'butterflies' in the stomach, headache, dizziness or feeling lightheaded, tingling sensations or numbness, sweating.
- Cognitive: Thinking catastrophic thoughts (e.g., 'I'm going crazy'), trying to reduce anxiety with thinking 'rituals' (e.g., counting objects).
- Behavioural: Avoiding people, places, or thoughts that make you anxious, trying to cope with anxiety through ineffective or self-defeating strategies (e.g., pretending to talk on your mobile phone when socially anxious, only going to the supermarket with a friend, using alcohol or drugs to change how you feel).

We are discussing anxiety in very general terms here. People can develop specific types of anxiety issues, ranging from panic attacks to social anxiety and uncontrollable worry (generalised anxiety). However, these types of anxiety issues share common physical, cognitive, and behavioural signs. You will probably have noticed that low mood, stress, and anxiety share common features (e.g., physical symptoms, behaviour change, troubling thoughts). You should be on the lookout for these core difficulties in appraising the need to seek professional help (rather than putting your efforts into self-diagnosis or consulting Dr Google!).

Physical Health In Carers

Several physical problems were referred to in the previous section. The occurrence of these symptoms illustrated that, in addition to psychological difficulties, carers can experience issues related to their physical health[106,119]. Carers are at increased risk for medical problems compared to non-caregivers[120] and over 80% of carers say their role negatively affects their physical health[42]. Examples of physical health problems include fatigue, insomnia, headache, and gastrointestinal issues[106,121].

There may be many reasons for these problems. For instance, physical health issues in carers may represent signs of depression, may be a consequence of behaviour problems in the care recipient, relate to being of older age, or result from decreased social support[122]. This illustrates the fact that physical issues in carers can develop via multiple pathways. Physical health problems can add additional strain to those supporting a person with a CID. It is useful to know that all sorts of physical/medical issues do occur. Carers should be extra wary of this possibility and seek medical advice if any such problems emerge. Most of us know that quickly catching medical and psychological problems usually improves treatment outcomes.

Positive Carer Experiences

We have focused on carer psychological challenges to this point. Positive experiences are also a feature of carer lives[94] and refer to the satisfaction and benefits that can come from caring[123]. Carers can encounter positive and negative outcomes simultaneously[124]. Discussing this topic is not intended to minimise the difficulties you face, but instead facilitate effective coping and a balanced perspective on life. For example, not recognising positive experiences can hinder the provision of appropriate support[125]. Carers are often able to identify at least one positive aspect of their role[126,127]. Some of these include being able to help or give back to someone, particularly if there was a previous reversal of caring roles (e.g., the person with a CID had looked after the carer as a child)[128,129]. Being able to help is a source of satisfaction for many[130], while finding meaning and purpose through caring has been reported in several instances[79]. Knowing the person is being well cared for, improved relationships and personal growth are other cited benefits[30,124,131].

Attempts have been made to categorise the positive experience of carers. One suggestion has been to divide these into benefits relating to the quality of relationships, feelings of accomplishment, and degree of meaning taken from the carer role[132]. A similar approach was adopted in a study involving dementia carers. Suggested categories of benefit from this research were increased family cohesion (relationship benefits), personal accomplishment and gratification, and personal growth/purpose in life[129].

To simplify this work, you could say that benefits are 'internal' (e.g., increased meaning and purpose) or 'external' to the carer (e.g., improved relationships). Internal benefits are wide-ranging. To demonstrate, one large US study of cancer carers reported positive outcomes in terms of acceptance (of their situation), empathy (for other people), appreciation (of growth and other people), positive self-view (a stronger person), and re-prioritisation in life[133]. One striking aspect of internal benefits is that big-picture changes can occur whereby life is viewed in fundamentally different ways. Such changes are not uncommon in carer research[27].

As you can see, carers report many positive experiences. Favourable carer outcomes link to a branch of research called positive psychology. This area of research has been described as the study of strengths that enable people and communities to prosper[134]. A particularly relevant phenomenon in this domain is called 'benefit finding'. Defined as "…an individual's perception that major positive changes have occurred as a result of challenging life events such as major illness or trauma…", benefit finding is akin to the adage 'When life hands you lemons, make lemonade'[135]. Seeking to identify positive experiences may be one mechanism by which benefit finding operates in carers. Interestingly, while benefit finding can lead to improved mood and psychological well-being, it can also be associated with unpleasant (intrusive and avoidant) thoughts[136]. One possible explanation here is that people who put time into trying to make sense of their circumstances are more able to see the full range of their experiences, both good and bad. At the start of this section, I mentioned that identifying positive carer experiences can promote a balanced view of life circumstances. Processes such as benefit finding may help people move towards this.

A concept related to benefit finding is 'sense-making'. This concept involves people attempting to form explanations for events, such as the development of a CID. Carer and care-recipient may jointly undertake the process of sense-making thereby facilitating the derivation of meaning or purpose. Sense-making may even contribute to shared identity. Sharing experiences with supportive people might also help the process of sense-making to occur[131]. We will look at relationships and social support in the next chapter, and again in Part two.

What Influences Carer Well-Being?

Academic research has identified several important contributors to carer well-being. I do not want to bore the life out of you with a lengthy summary of this research, but it is useful to provide a feel for what we know. Several key factors emerge when considering determinants of well-being in the general population. One is having your basic needs met (e.g., housing, income), while another is being in good physical health. Positive

relationships and a secure support network are also important[137]. We see the impact of these factors in carer well-being, particularly positive relationships and the provision of adequate financial resources[103,138,139,140,141]. Experiences unique to a carer's circumstances may also influence well-being. These include witnessing suffering in a care recipient, feeling unprepared for the caring role, and contending with high caregiver burden[142]. The extent of illness symptoms in the care-recipient also contributes in that higher symptom levels have been associated with increased carer mental health difficulties[142].

Happiness is a component of well-being (there are similarities and differences between the two concepts). Richard Layard, an authority in this subject, argued that similar factors to those cited in the paragraph above influence happiness levels, namely relationships with family and friends, your work and financial situation, and your physical health (amongst others). Income has some role to play, but its effect diminishes as wealth increases[143]. Happiness and well-being also appear to have some genetic contribution which prompted the concept of a happiness 'set-point'. Despite this, over half of happiness is due to factors we have some control over[144].

How & Why Well-Being Problems Develop

Many theories exist in an attempt to explain the development of psychological problems. We have attributed these difficulties to biological, neurological, cognitive, behavioural, social, cultural, environmental, and economic factors. Many explanations for mental health problems encompass several of these factors simultaneously. A full review of this topic is (way) beyond the scope of this chapter. I will instead provide a few examples of how the development of psychological distress in carers has been explained. We can see these factors (cognitive, behavioural, etc) operating in each of the three cases below.

In one approach, identity is a central concept in the development of psychological distress. People might develop an identity by seeing themselves and their lives as an on-going narrative or 'story'. Forming a story is one way to develop a sense of who we are as people. Day-to-day events fit into this bigger story. These eventually combine to provide a stable impression of who we are, and how we relate to others and the world. A CID might not fit with this narrative. The inability to make illness or disability 'fit' with your wider life story may be a major cause of psychological distress[145]. Chronic illness and disability can take over a person's life story, causing further problems. We might see this occur when people assume a master (carer) identity (as discussed in Chapter 2). For a person with a CID, health issues dominate and drown out other parts of a person's story or identity.

Chronic sorrow[146] is another concept used to explain the occurrence of psychological difficulties in the context of a CID. The phenomenon of chronic sorrow occurs when exposed to on-going losses resulting from illness or disability[91]. Chronic sorrow can ultimately reflect the gap between a hoped-for life and the reality of living with a CID[147]. I spoke of the change in life course I experienced due to cancer in Chapter 1. Chronic sorrow provides one way to characterise the effects of diverting from a planned or expected life. The distress caused by these losses (or the discrepancy between a planned life and life with a CID) often goes unrecognised or unacknowledged by others. There are usually no events (e.g., ceremonies, memorials) to directly mark this loss[145]. Furthermore, the opportunity to experience grief is usually limited because carers are preoccupied with their responsibilities. While carers may endure chronic sorrow, they may also witness losses encountered by the person they support. This situation creates additional strain for the carer as they watch the cared-for person confront loss in the domains of bodily function, relationships, autonomy, identity, and an imagined life[148].

Issues of loss extend beyond the concept of chronic sorrow. We referred to the various psychological difficulties carers face earlier in this chapter. The theme of loss features in many of these problems. Here, more general themes include loss or change in relationship with the cared-for person[149,150,151,152], loss of hope[150], loss of social and recreational activities[153], loss of certainty and the ability to plan[32,154], and loss of a taken-for-granted future[32]. These can be complex issues that are not always obvious or emerge quickly, but the resulting well-being impact can be highly significant. Identifying and addressing these issues are essential self-care tasks.

Considering *how* well-being problems develop extends the points made in this section. We can characterise the emergence of carer psychological distress in at least two ways[155]. One is a wear-and-tear approach which suggests a build-up of stress over time. The implication is that the adverse effects of caring will gradually pile up. The second approach is an adaptation perspective. This viewpoint suggests that negative aspects of caring are most noticeable in the initial stages, followed by a plateau or even a decrease over time. This trajectory manifests as a dip in well-being early in the caring experience followed by stabilisation or returns towards pre-caring levels. These pathways of carer psychological distress over time continues the theme of uniqueness in carer experiences.

Summary & Your Experiences

We have taken a brief tour of carer well-being issues in this chapter. We have focused on common psychological challenges but have also considered positive carer experiences. The development of psychological

problems is a large and complex topic, but we have some understanding of this process amongst carers. This group is more susceptible to mental health issues than the general population, and it is vital to take action when these difficulties exist. The good news is that there are many ways in which carers can promote their well-being. Part two introduces several of these strategies.

Reflection Points

What well-being issues do you face? Perhaps you have thought about these many times or have not explicitly considered them until this point. Either way, the following questions may be a useful starting point to think further about your well-being, particularly concerning the topics covered in this chapter.

- How would you describe the well-being issues that you face (i.e., what signs of psychological distress, if any, have you noticed)?
- How do well-being issues affect your day-to-day life?
- How do well-being issues affect your caring role and your relationships with others?
- Were these issues present before becoming a carer? If so, how has the caring role impacted upon these?
- Have you had any positive experiences associated with caring (no matter how small)?
- Can you think of any ways in which positive experiences can be used to improve your well-being?

Chapter 4

Relationships & Social Support

Introduction

Whether meeting with a health professional, parenting a sick child, or talking to a friend, managing life with a CID involves interactions with many people. Chronic health issues can add complexity to these interactions and carers must contend with a range of unique interpersonal matters. Some of these issues include coping with altered relationships, responding to unwanted or stigmatising behaviour from others, and maintaining control over contact with family and friends[156]. Not surprisingly, relationship issues such as these can have an impact on carer well-being. We have touched upon the psychological significance of relationships and social support in earlier parts of the book. This chapter will delve further into this area by considering the topics of loneliness, reciprocity, barriers to social support, and burnout. We will also take a brief look at two key relationships; carer-partner/spouse and carer-professional.

Personal Experiences

Relationship dynamics and the support provided by others were key well-being influences as Charlotte and I managed life with a CID. Many of our interpersonal concerns revolved around getting the right type of support at the right time. Some friends tended to keep their distance, and this prompted me to think about how relationships change when coping with long-term medical conditions. I also contemplated how my own behaviour shaped interactions with others. The way in which cancer altered the nature of the relationship between Charlotte and I was perhaps the biggest relationship issue of all.

Changing Relationships & Roles

Charlotte and I encountered significant relationship change over the course of her illness. What started as an 'ordinary' relationship quickly transformed after the initial medical crisis that led to her eventual cancer diagnosis. I took increasing responsibility for her physical and psychological needs. I did not expect to have these responsibilities in my thirties, however they may be a more natural component of other caring relationships (e.g., supporting children or an elderly parent). Cancer altered our shared identity as a couple as it became the unwelcomed third member of our relationship. Our identity as a couple also changed through grappling with the loss of control over our lives and the future. I was so relieved that my wife was not alone, but there was much grief and loss to contend with as we involuntarily travelled down this new path.

Charlotte largely kept her battle with cancer private. I was her chief confidant, and she rarely revealed the true nature of her challenges to others. Confining her illness in this way was intended to protect people and manage her appearance to the outside world. This approach also exemplified her bravery and concern for others. But there were unintended effects of this well-meaning strategy. We became more isolated as individuals and as a couple. I am unsure if we had foreseen these consequences, at least in the early stages. We sometimes disagreed on how others should be involved with her illness. As a carer, I felt that Charlotte's wishes were more important than mine because she had the cancer diagnosis. I went along with her desire to keep most aspects of our situation hidden. Other carers may also feel that their preferences are secondary in this situation (at least to a point). "Cancer always wins the argument" said a fellow carer at a workshop I once attended. Despite this, a carer's needs are no less important than those of the person with a CID. Guilt, a sense of responsibility, pity, and sorrow. All these may drive the urge to defer to the supported person's wishes. To go against these wishes may feel like an act of betrayal, but the way in which carers involve other people will have significant well-being implications.

Many carers face relationship changes such as the ones that I have described. Carers might not notice them early on as they can occur gradually. At least that is what happened to me. These changes can represent the loss of an imagined or hoped-for relationship. One may be caring for an adult child long after they were expected to have left home and started their own family. These losses have been previously cited and are as legitimate as any other relationship-related loss (e.g., end of a romantic relationship, an adult child leaving home). I have mentioned that caring may be a relatively natural component of some relationships. Even in this context, a CID may draw people away from an imagined or expected

life-course. Acknowledging the grief and loss felt through these altered journeys is an important piece of the coping puzzle.

Changing People & Lives

People may undergo a process of questioning pre-illness values and beliefs when living with a CID. Charlotte became more focused on existential aspects of her life. She regularly reflected on the meaning of her existence in conversations with me. Charlotte developed a more definite sense of her priorities and attempted to live in a way that reflected her underlying values more authentically. She changed a great deal over the course of our relationship, and this demonstrated to me the profound effects that a CID can have. Witnessing rapid changes in the person one supports may be unsettling. A CID can accelerate an existing process of change or send lives in an entirely new direction. I am sure Charlotte witnessed changes in me as well. I grew up a lot. I needed to. This horrible period of my life paradoxically created a sense of stillness in my mind that I had not previously possessed. This state is difficult to describe. I felt like I saw my life more clearly. The unimportant noise of life became less of a distraction. My priorities changed. Money, material possessions, and career progression became less important.

I welcomed Charlotte questioning her life and beliefs, but there was an element of sadness as I was forced to acknowledge the different paths we were on. A surreal feeling came with being married to someone who, on some levels, was living an entirely different life than me. We shared many forms of adversity, but I did not encounter some of her specific battles (nor could she confront some of mine). We were on increasingly divergent paths once we knew her time was limited. I had to consider a future where I was on my own. This reality was heart-breaking and painful to accept. A CID can put people on different life trajectories even in the context of life-limiting (rather than life-threatening) conditions. The changes talked about in this section can add yet more unpredictability to life. People must balance the desire to retain a 'normal' life with accepting change and the need for adjustments.

De-Emphasising the Carer

Charlotte's psychological needs became an increasing focus of our interactions. Again, I felt great relief in being there for her. Supporting Charlotte was important to me, but not always something I did successfully! I knew far more about her battle than any other person, but this appropriate focus on her needs changed the dynamics of our relationship. She often felt like a cared-for person and not a relationship equal. I focused on *her* needs and rarely allowed her to care for me. I lost sight of the value that

comes from allowing mutual support. The approach I took was perhaps understandable given I was grasping for the tiniest sense of control over her health. She simultaneously valued my support and became frustrated at blocked attempts to give back to me. This dynamic illustrates the shared identity concept as discussed in Chapter 2. I should have jumped out of carer mode more often to help preserve Charlotte's non-illness identities and our relationship as a couple.

I gradually talked less with Charlotte about my own experiences. My well-being became less of a priority to me. The deal was that she spoke and I listened, with no negotiation (on my part). At the risk of stating the obvious, that was a massive denial of my psychological challenges. Most people want a relationship to be a shared experience of communication and support. I lost sight of this and came to believe that her needs were more important than mine. It took time to genuinely accept that looking after my health was also good for *her* health. Sometimes you do need to put off your own needs, but this is a problem when it becomes habitual. Part of being a carer paradoxically involves being cared for yourself when the opportunity arises. Passing off this support would be like a marathon runner failing to take on fluids when running past a drinks station.

The lack of self-care contributed to the decline in my well-being, and this speaks to some of the points made earlier in the book. I placed little importance on my welfare, thereby reducing the prominence of my well-being to other people. Perhaps this course of action was understandable because I had little control over Charlotte's illness. I could not cure Charlotte's disease, but I could actively choose to put all my energy into her. I suggested earlier that part of my approach to coping with well-being issues involved a focus on practical tasks to feel a sense of control. Ah, the illusion of control! I was trying to hide behind something to distract myself from this lack of influence, and the awfulness of life. I wanted to protect this person, but I could not. This reality was too difficult to face.

Through the futile pursuit of increased control and de-emphasis of my well-being, I came to suspect that I had lost some of Charlotte's support. I had inadvertently manufactured this situation because I did not want to burden Charlotte with my difficulties. I believed she was grappling with too much without tending to my well-being struggles. This mistake is a well-trodden path in life. We seem more comfortable to prioritise the pursuit of personal financial stability to later help others with money matters than we are to seek well-being stability as a foundation on which to support others psychologically.

I hope others can learn from my experiences here. A lack of control in life is a reality that carers should acknowledge rather than shy away from. Better to share the experience of helplessness than hiding behind a mop or pile of washing. While it is good to have a clean supply of underwear, you don't remember a productive day's housework like you remember making

a meaningful connection with someone through discussing a difficult subject. A moderate dose of distraction can be useful in managing distress, but outright avoidance does not do people any favours. No need to beat oneself up over this; avoiding avoidance is hard to pull off in practice. Confronting matters did bring benefits, and my relationship with Charlotte would have been much different if one of us refused to talk about sensitive topics. We did not shy away from difficult issues and these discussions did bring us together. While very painful, talking brought a sense of relief and connection.

Experiencing & Responding to Relationship Conflict

We know the carer role can be an extremely stressful one. This stress can affect carer relationships, especially the care partnership itself. It can be a cruel blow to suffer relationship problems on top of all the other crap that can occur. Charlotte and I experienced fluctuations in the cohesiveness of our relationship, and I have mentioned moments of conflict earlier in the book. Caring relationships can be intense. You may spend long periods of time together, and there are multiple sources of stress that test your connection to each other. These are conditions in which conflict can readily occur. Carers can harshly judge themselves for contributions made to this conflict. Having said this, relations can improve or deteriorate in the context of a CID[27]. Charlotte and I were proud of each other's efforts to keep working together despite our difficult moments. We frequently talked about this pride in the final few months of Charlotte's life. These discussions provided me with comfort in the months following her death.

My exposure to tension and conflict in the caring relationship taught me always to try to acknowledge what you do well as a partnership, no matter how small these achievements seem. Looking for these positives can provide a mental foothold when tensions are high. There is real skill in accepting that you cannot be at your best all the time, and tough moments can overshadow what you do well. Acknowledging stressful life circumstances is equally important. Judging your relationships and carer behaviour with criteria applied during 'normal' life is just plain unfair. You need to adjust expectations to take account of the challenges brought about by a CID. Relationship tension and conflict may be part of the deal in your caring role, but you can work to manage this positively.

I worked with a woman whose husband was diagnosed with Chronic Fatigue Syndrome (CFS or ME). In this condition, people experience periods of debilitating fatigue, exhaustion, and additional medical issues. Those with CFS often get caught in a boom-and-bust cycle of over-exertion followed by a period of illness. My client admitted to frustration and anger that her husband seemed sick one day and healthy the next. The couple had experienced increased relationship difficulties in the months

leading up to my involvement. My client felt resentful when she had to take on her husband's responsibilities. She felt there was an insufficient acknowledgement of her care efforts. She was able to cope better after realising that these emotions were understandable when seen in the context of her situation. We worked on ways to discuss these issues with her husband in a constructive way. We also learned that she was fearful of eventually letting her family down if unable to manage periods of extra responsibility (feeling under skilled or incompetent was a carer concern raised in Chapter one). We identified people who could be on stand-by to offer extra help when needed, and challenged the belief that others would be disappointed in her at some point in the future.

Social Support

I have frequently reflected on the amount of support offered and received from friends and family when caring for someone with a CID. Social support is essential, especially in times of adversity. My personal experience was that people fell into one of three groups. The first group comprised those who were in regular contact. These people went above and beyond the call of duty. Then there was a group who vanished off the radar, providing little, if any support. The most extensive group comprised people who were somewhat sporadic in their contact and offers of assistance (according to me at least!)

I occasionally felt let down by people in my support network. What I often wanted was more proactive support from people. When especially unhappy, I interpreted statements such as "Let me know if you need anything" as lazy or passing the buck. I wanted to yell "Don't you think I have enough #*$!@ things to think about without having to remind myself to call you?!!". Proactive contact from others was essential to me, and I came to realise that I was mostly seeking validation for the battle I was fighting. Proactive contact was not about offers of help. More importantly, it said to me "I am acknowledging what you are going through".

I came to realise why people did not reach out as often as I wanted. My behaviour influenced that of others first and foremost. I could be slow to respond to phone calls and text messages when feeling stressed or low. I often cancelled meet-ups with friends, sometimes because I didn't have the energy or the right attitude to socialise. I declined offers of help when I should have accepted. I sometimes kept clear of others because I wanted to protect people from how awful our situation was. I was worried about upsetting others and was intent on preventing others feeing compelled to take on an unwanted increase in relationship intensity. It was little wonder that my relationship-related thoughts and behaviours were confused and disorganised with so much going on inside my head.

Repeatedly discussing my difficult carer experiences was uncomfortable, and this probably influenced the amount of support that I received. I was worried about burnout in others. Supporting someone in difficult circumstances is tiring. I don't think we acknowledge this as much as we should. It seems socially unacceptable to feel exhausted by another person's suffering. I did not want people to get sick of me, and I did not want to make life more difficult for others. People sometimes said to me "There's no limit to how much support I give you". While this statement was genuine, burnout and compassion fatigue does occur. I have occasionally felt burned out and overwhelmed in my professional life. We are not bad people when feeling overpowered by someone else's difficulties.

There were other reasons for not getting my desired level of support. Life is busy and several weeks can pass without talking to a friend. I benefitted when reminding myself that life happens, and I should not take this personally. People usually do not want to overstep what is appropriate given the type of relationship you have. This brings up the tricky issue of relationship boundaries. Am I close enough a friend to be pushy in asking how someone is *really* doing? I have seen people worry about doing 'too much' more so than not doing enough. There seemed to be a tendency for people in my life to hold back and not proactively reach out. This inaction was unsurprising on reflection; most people do not want to overstep a relationship boundary. What if the person thinks less of you, or it damages the relationship? I have already noted that humans are hardwired to notice threats ahead of other information. It is perhaps not surprising that people are cautious and would rather risk doing too little than too much. People also have different expectations of what 'sufficient' contact or support is. Perhaps my expectations were too high, and no one was going to measure up to my standards. My disappointment in other people may have reflected a discrepancy between their expectations and mine. Alternatively, other people may have found our situation too scary to play a supporting role. People understandably want to limit exposure to pain and suffering in life. Finally, people can be lazy and you can genuinely be let down by others.

Carers need to hold many possible explanations in mind when attempting to understand support behaviours in other people. Perhaps the most harmful conclusion you can make is to assume that you are to blame for a perceived lack of support (e.g., thinking 'I'm not worthy enough to have their support'). Remember that many factors drive the help provided by others. People continually make decisions about how to prioritise their time, as is their right. I tried to remind myself of this when feeling unsupported. The universe did not owe me any level or a particular type of support. Yes, most people would agree that I deserved extra help given my caring circumstances. However, I had to let go of the resentment I felt towards others because it was going to screw me up. Receiving support is

not something you can demand but is something you hopefully receive in sufficient quantities. I perhaps made the mistake of being overly-fixated on the amount of support I received, rather than reflecting on the quality of that support. I was generally lucky in regard to the latter.

Ensuring I gave back to those who provided support was vital to me. Psychologists call this type of give-and-take 'reciprocity'. Reciprocal relationships occur when benefits received are equivalent to contributions made towards the other person[157]. Most people do not want to take a disproportionate amount of support from others. While reciprocity may not be possible in periods of adversity, contributions hopefully even out over the long-run. There are times when you take more help than you give, but some people are too uncomfortable with this imbalance whereby assistance is refused or not sought. My carer role involved a commitment of several years, but I still tried to offer support to others. I tried to be more flexible in my definition of reciprocity to cope with my limited capacity to give back. I tried to support friends and family in different or 'little ways' (e.g., asking about a friend's children more regularly). I also told friends that keeping their own struggles from me made me feel isolated. While curtailed in my capacity to help, I still wanted to be kept informed about their lives.

Experiences with Professionals

I came across numerous health professionals as a carer. These encounters represented a curious role-reversal for me. I was now a witness of health service delivery. Some professionals were magnificent, with a mix of clinical skill and genuine compassion. These people will always remain in my memory. Other professionals were… well, adequate. They did their job competently. No more, no less. Finally, there were a few who fell far below the expected standards of care, but were thankfully few and far between. Working in a healthcare environment is not easy. Many services are under-resourced in light of patient demand, but there is never an excuse to lack basic empathy. Healthcare staff are not superhuman. We do not need to hold them in a state of reverence. One must acknowledge the demands of working in healthcare but never accept poor treatment. We should expect a lot from healthcare staff, but society should aspire to providing optimal working conditions in order for professionals to perform at their best (e.g., not being overloaded with work, having the required resources, being adequately trained).

I was lucky to have a healthcare background. I was not intimidated or overawed in medical settings. I was happy to challenge staff and ask whatever questions I wanted. Other people do not have this level of confidence. I worry about these people when confronted by staff who are unprofessional, rude, or arrogant. Assertiveness does not come easily to

some. Nonetheless, carers find themselves in a role where they are required to advocate for the person that they support. There is nothing wrong with seeking additional help in this area when needed. There are vulnerable care partnerships out there, and not everyone is confident enough to speak up against disrespectful behaviour.

Unfortunately, some of the professionals I met appeared to be disinterested in my presence and the support I was trying to provide. In one case, a group of staff did not even acknowledge I was in the room when Charlotte was receiving chemotherapy. On multiple occasions they made no eye-contact or said hello to me. Perhaps not intentionally rude, but still unbelievable behaviour. Charlotte was the clear and obvious focus, but such behaviour is disrespectful and ignorant to the importance of the care partnership. I know carers who seek no credit for the considerable contribution they make, but they should be acknowledged and supported by professionals in tangible ways.

The Role Of Social Support

Support from friends and family protects people from various sources of stress in life[158], but a lack of social support is a society-wide issue. More than 50% of people would like additional assistance in their lives[159]. This situation is a concern because social support brings many benefits. These range from reduced depression and anxiety[160,161], to improved cognitive functioning[162] and (cheerfully) reduced mortality[163]. Researchers have offered several explanations for the association between social support and positive health outcomes. Some have claimed that improved self-esteem links the two, while others argue that benefits come from an increased sense of belonging or social influence[164]. One popular idea is that social support 'buffers' people from the effect of stress[165]. We can debate these theories at length, but will not be doing so in this book. The critical point for carers is that social support matters for well-being.

Social support is similarly crucial to quality of life in carers[166]. Supportive relationships have been linked to improved psychological and physical functioning[167]. Social support may also be necessary for reducing carer burden[168]. Alternatively, negative social interactions may increase burden[169]. Carer burden tends to reduce as perceived adequacy of social support increases[170]. Social support is therefore vital to the psychological and physical health of carers. It is useful to make a distinction between perceived (what social support you *believe* you have) and received (actual) support. Lower levels of perceived support increase carer burden more so than received support[171]. In other words, the support you *think* you receive is perhaps more significant for your well-being than the help you actually get.

Loneliness & Social Support Quality

Social isolation is a concern for many carers[172], and loneliness is a substantial issue for this group. Perceived social isolation is equivalent to loneliness, the latter of which represents the distress caused by the belief that your social support needs are not being met[173]. Loneliness is an unpleasant psychological state that has been associated with physical and mental health problems. These include cardiovascular disease, reduced cognitive functioning, and depression[173,174]. Several issues may drive carer loneliness and encompass a lack of freedom in deciding how time is spent, loss of relationships, lack of understanding and acknowledgement of the carer role, feelings of helplessness, and a sense of sole-responsibility for the cared-for person[175].

Loneliness also appears to be driven by low relationship quality, rather than the quantity of social contact[176]. We should not necessarily assume that 'more is better' when it comes to social support for carers[177]. The quality of interactions is important, and this is not surprising given the demands faced by many carers. In times of great stress, people need to be genuinely heard, understood, and given appropriate support. Social interactions can be positive, negative, or a combination of the two. Negative interactions occur when someone's actions cause distress to another person (e.g., being critical, failing to provide promised help)[178]. There is some suggestion that negative interactions have a stronger effect on well-being than positive ones[178]. Appropriate social support for carers requires consideration of the type, and not just the amount of assistance provided.

Receiving Help & Reciprocity

Related to relationship quality is the concept of reciprocity, or the give-and-take of social support. Some studies have found that being able to receive and give back to people in similar circumstances is beneficial for well-being[179,180]. There can be costs associated with a lack of reciprocity. For instance, family support may be unhelpful if it leaves carers feeling overly-dependent on this group of people[179]. While reciprocity is an essential element of relationships, the ability for carers to provide support to those beyond the care-recipient may be limited[181]. Limited carer capacity to give back may be especially relevant when health is deteriorating in the care receiver[182]. Despite these barriers, carer burden can be reduced when reciprocity exists between carer and care recipient[183,184]. Loss of function that often accompanies a CID means that people are sometimes no longer able to perform important tasks or roles. The ability to contribute back to the carer, even in relatively simple ways, can be of great benefit to both.

The benefits of relaxing the 'must always be in carer' mode may well outweigh its costs.

Barriers To Social Support

Social support burden is a concept similar to carer burden. We define the former as the barriers or negative costs that arise in seeking and receiving support[178]. While many people in society would like to have more support, carers may encounter barriers not faced by other people. Carers routinely encounter physical or logistical impediments to social participation. For example, it may be difficult for a carer to socialise if a care recipient's needs are high[185]. Scheduling and attending medical appointments may be time-consuming, carers can be geographically isolated, or not free to see other people at convenient times.

Psychological barriers are also significant social support impediments. We will focus on psychological obstacles in this section because they can be less visible than physical ones. Psychological barriers to social support include feared negative interactions with others, and insufficiently close relationships[186]. Historical factors may be relevant, such as past negative experiences of social support seeking[187]. One may experience loneliness if confined to the house, but simultaneously experience a lack of privacy if many people visit[27]. Carers may encounter feelings of guilt at the prospect of being away from the supported person. Carers may also feel the need to take advantage of periods of relative wellness by spending time with the care recipient.

One small, but interesting piece of research illustrates the broader range of psychological barriers that can hinder the receipt of social support. Hospice family carers were interviewed in this study about social support burden[177]. The help asked of others was determined by carer perception of relationship closeness. The study revealed carer reluctance to overstep a relationship boundary by asking for more support than was appropriate. Other barriers were reported. Carers did not want to pressure people into providing help. They also wanted to restrict friendships to ensure sufficient time for caring. Some carers were self-confessed 'control freaks'. This orientation resulted in a reluctance to delegate tasks and inhibited the receipt of practical help. Pre-existing communication issues between family members also hindered support seeking. For instance, if family members historically had 'never really talked', this would cross over into the period of caring.

The above information tells us that there are many barriers faced by carers in obtaining support. Considering what barriers exist in one's own life can provide clues to addressing insufficient support levels. The above barriers suggest there can be strong incentives to avoid seeking necessary assistance. Help-seeking may only occur with people whom carers share a

close relationship. This selectivity can limit support options but is understandable given the many personal struggles that carers encounter. Carers may benefit from strategically delegating support tasks. For example, it may be best to avoid sending their closest friend to the supermarket, leaving this task to a neighbour or an acquaintance. There are more serious psychological issues preventing increased social support. These may require professional assistance to identify and manage. For example, one may be reluctant to spend time with others because they are affected by high levels of social anxiety. In these circumstances, it may be beneficial to work professionally with someone who can provide specialist expertise to help minimise the impact of such issues.

Relationship Quality In Couples

Many carers support their partner and relationship quality between couples can affect adjustment to a CID for both persons[188]. Couples are required to cope with changes to relationship roles and dynamics, and these changes can be wide-ranging. In one series of interviews[189], carers reported emotional and personality changes in the care recipient, altered communication patterns, and changes to intimacy. These changes can cause distress which may be partly due to the sadness that results from losing elements of a pre-illness relationship[190]. Couples frequently respond to this by trying to keep life 'normal' and attempting to retain pre-CID relationship elements.

Maintaining an open dialogue with your partner helps to cope with these challenges, but discussing such difficult topics is not always easy. Positive communication practices can be helpful in these conditions. Effective communication is vital to all relationships, and particularly relevant when confronting a CID. Behaviours that restrict open discussion can undermine well-being[191] while effective communication amongst couples can reduce stress levels[192]. Good communication involves open discussion, talking about oneself, and talking about the relationship[192]. Open communication also represents a relationship-enhancing coping strategy, as does supportive behaviour, positive coping, and joint problem-solving[193].

Positive relationship experiences that occur through a CID can also improve relationship quality. Couples battling cancer have reported favourable outcomes that include facing cancer in a united way, having a collective sense of reality with respect to the challenges faced, and a sense of increased appreciation for care duties[27]. Relationships can be hard work and need significant investment. These facts are especially apparent when facing the additional strain of a CID.

Relationships With Professionals

The quality of carer-health professional relationships is important because they affect carer well-being[194]. Carers can have a range of positive and negative experiences with healthcare professionals[195]. These relationships can be complex and change over time[196]. For example, the knowledge and skill of informal carers can gradually increase, reducing the 'expertise gap' with professionals[197]. Carer-professional relationships are moulded through family dynamics, the extent of joint staff-carer decision making, and levels of trust amongst other elements[198]. Someone with a CID may simultaneously receive support from both informal and formal carers. The involvement of these two providers can raise various challenges and issues (e.g., delegation and coordination of care responsibilities).

Given the complexity of these relationships, things sometimes go wrong. One frequently occurring issue is an insufficient acknowledgement of carer expertise by formal carers[199]. There is a distinction to be made between carer 'work' and carer 'expertise', or knowledge about the supported person[200]. Calls have been made for healthcare staff to make better use of this expertise. We must also acknowledge this expertise if we are to place increased value on the carer role. This lack of acknowledgement can sometimes stem from power imbalances between staff and family members, and speaks to the need for more collaboration with informal carers[201]. Some professionals report a degree of restriction in how they can work with carers[202]. Concerns have also been raised about unimplemented organisational policies designed to facilitate collaboration with informal carers[203]. Moreover, the delegation of caring responsibilities between informal carers and professionals is not always clear[204]. Calls for improvements in this area are perhaps of little surprise to carers. Healthcare staff hold influential positions in the lives of carers and the people they treat.

Communication difficulties are another issue that can arise in informal-formal carer relationships. There can be uncertainty about what information exchange is appropriate between staff and informal carers[202]. Concerns around communication style exist in that there have been calls for professionals to be more empathic in their interactions with carers[205]. Effective communication is all the more vital because discrepancies can exist between carers and professional opinions about the extent to which the needs of a cared-for person are met[102].

Carers react in various ways to sub-standard treatment from health professionals. Carers should speak up when they are not happy, but this is not always easy. People can be so weighed down by caring responsibilities that they lose the will to fight for excellent service. They may also lack confidence or worry about confrontation. Additional advocacy support can be an option to consider in these situations. This may simply involve an

extra person coming to appointments and sitting in the waiting room. More formal options could be patient or carer advocacy groups and utilisation of clinic feedback/complaint services.

Because of my job, I understand the need for professionals to practice good self-care and avoid burnout. We cannot lose the human-to-human nature of health care. Carers and patients can often be scared, anxious, and upset. I have regularly seen professionals become robot-like to protect themselves from the heartache to which they are exposed. However, the answer does not lie in switching off the empathy button. Healthcare staff must also remind themselves that the environments they work in can be scary to the uninitiated. Staff may have performed a routine procedure or seen the inside of an operating theatre hundreds of times. Such familiarity desensitises them to these settings, but patients and carers are usually far less familiar with these. Remembering this and acting accordingly can facilitate good relationships between staff and carers.

Burnout & Compassion Fatigue

Compassion fatigue is an issue that has relevance to any discussion on caring relationships. This concept has not been clearly defined or differentiated from related phenomena such as burnout[206]. Despite this, it is a useful topic for carers to consider. Compassion fatigue is the 'cost of caring' manifested as emotional and physical exhaustion[207]. Compassion fatigue contrasts with 'compassion satisfaction' which encompasses the positive emotions generated through helping others[208]. Signs of compassion fatigue include items on the following list.[209]

- Physical and emotional exhaustion.
- Sleep disturbance.
- Headaches.
- Increased vulnerability to illness.
- 'Somatic' symptoms: stress converted to physical symptoms (e.g., tension headaches, nausea).
- Increased drug and alcohol use.
- Work absenteeism.
- Anger and irritability.
- Over-inflated sense of responsibility for others.
- Decision-making difficulties.
- Memory problems.
- Relationship issues.
- Low mood and anxiety.
- Resentment and other negative feelings.

Physical symptoms may manifest as feeling 'worn out' and emotional difficulties as 'walking on a tightrope'[210]. These types of symptoms could also represent a different kind of psychological issue. For this reason, carers should seek some professional input if they experience any of the above symptoms. Compassion fatigue amongst informal carers has received less attention but does exists in this group[211]. Researchers have described the development of compassion fatigue[212]. This phenomenon occurs when a carer has concern and empathy for a person's suffering. 'Compassion stress' is encountered when no satisfaction is derived from caring, and there is no corresponding detachment from caring circumstances. This stress becomes compassion fatigue when the situation persists in the presence of traumatic memories (about the cared-for person or caring experience) and life demands.

Summary & Your Experiences

This chapter has taken a broad look at relationships and social support. These are vast topics, so it has not been possible to cover every issue that may apply to carers. Perhaps the essential message of this chapter is that relationships and social support are crucial to carer well-being. An array of challenging and complex relationship issues can confront carers. Relationships can be influenced in positive and negative ways by a CID. Carers will have key relationships (e.g., with a cared-for person, health care professionals) that will be particularly influential in their overall well-being. Concepts such as loneliness and compassion fatigue can be useful in framing relationship difficulties that can occur for carers. Coping with relationship and social support issues is discussed further in Chapter 9.

Reflection Points

Having read this chapter on relationships and social support, you might want to spend some time thinking about these topics as applied to your circumstances. Here are some questions to help you ponder the state of social support and relationships in your life.

- What topics in this chapter were most relevant to your caring circumstances?
- How satisfied are you with the social support that you receive?
- If you feel you are receiving less social support than you would like, why do you think that is the case?
- What changes would you like to see in the way people respond to your caring role?
- If you are happy with the support you receive, how can you maintain this level of satisfaction?

- What are the most significant challenges in the relationship with the person you support?
- In what ways do the two of you work well together in managing a CID?
- In what ways could you improve the quality of your relationship?

Part Two

About Part Two

We covered many aspects of carer experiences and well-being in Part one where we focused on the themes of identity, well-being, relationships and social support. We explored these themes in greater detail through topics ranging from carer burden to loneliness, compassion fatigue, and barriers to social support. We also drew attention to the varied and unique nature of carer experiences. We observed that caring occurs amongst relationships with others, and that carer well-being has many individual, interpersonal, and environmental determinants.

We take these discussions further in Part two by focusing on several self-care strategies to promote carer well-being. This section of the book is important because many carers experience psychological distress yet do not receive the support that they require. Carers need to proactively identify their well-being needs and look to address them as much as their circumstances allow. While the capacity for self-care may seem limited, seemingly modest efforts can yield meaningful psychological benefits. Coping is a complex process that involves characteristics of the individual carer (e.g., personality), aspects of the environment (e.g., social support), and features of the stressor (e.g., duration of stressful situation)[34]. Successfully managing your mental health requires that attention be paid to these different elements where possible, as we will attempt to do so in this part of the book.

Too many rubbish self-help books exist in this world. My intention is not to write another one. There are no promises of magic strategies here or the latest life-changing philosophy. We will instead cover several straight-forward tools which I have found to be helpful with many of my own clients. Research evidence also supports many of these approaches. The strategies are designed to help carers cope with many of the issues raised in Part one. Trying a new self-care or coping technique can be anxiety-provoking, but there are benefits in broadening your well-being toolkit. Your ability to cope flexibly is enhanced when this toolkit contains several items. Possessing several coping strategies helps to avoid over-reliance on one approach and increases your ability to utilise a strategy that fits a particular situation. Distracting yourself from painful emotions might be necessary when you must 'keep yourself together' (e.g., coping with a medical crisis), but an ability to focus on and discuss the same emotions may be important when addressing relationship difficulties with the person you support. Moreover, some strategies that seem helpful in the short-term might cause problems over the longer-term, especially when used repeatedly. Possessing a range of coping options can help to prevent these unfavourable outcomes.

We cover several strategies in Part two in order to give you a variety of options to try. I am a pragmatist in my work with clients and I encourage

you to have a similar philosophy. Utilise what works for you in Part two and don't worry about the rest. This part of the book is not an instruction manual that needs to be followed sequentially. If one section is not useful, move on to the next one.

Professional Support

It is essential to have realistic expectations when attempting to improve your psychological well-being. You should see this book as one piece of a larger self-care project. A degree of emotional distress may be unavoidable if you are providing support to a loved-one in a stressful environment. Professional support is sometimes required in this situation and strategies contained in this book may not be sufficient to reduce difficulties to manageable levels. I encourage you to seek a professional therapist if your difficulties have become too severe to manage on your own.

While on the topic of professional assistance, we know quite a lot about the effectiveness of various psychological interventions (led by professionals) for common psychological problems. We know less about the efficacy of interventions designed specifically for carers, and this is partly due to the mixed quality of evidence in some studies[213]. To date, attempts have been made to evaluate carer support groups, stress management programmes, befriending services, and complementary therapies. There is some indication that these interventions are associated with benefits such as increased social support and confidence. Despite this, we know little about why these changes might occur, whether they can be linked to the intervention itself, and whether these benefits are sustained over time[213].

There are other types of interventions, particularly psychological and counselling services. These sources of help can be appropriate for carers provided they account for their unique circumstances. Apart from these organised/formal interventions, there are other ways in which one can promote carer well-being. Some of these are straightforward, common sense strategies that can potentially provide a significant amount of benefit. Online interventions delivered to carers are becoming increasingly popular. Information and education programmes are the most common forms of assistance found on the internet[214]. More research is needed to determine the effectiveness of e-Health interventions for carers[214].

Chapter 5

The Basics & General Strategies

Introduction

We are going to cover some well-being groundwork in this chapter. Our focus will be on general self-care strategies. These strategies lay the foundation for techniques presented in other chapters in Part two. Some of the topics in this chapter are covered briefly. For this reason, additional material is provided in the Resources section at the end of the book. This chapter starts with a discussion on identity issues, goals, and barriers to self-care, followed by information on diet, exercise, sleep, and self-monitoring. We conclude with an introduction to the concepts of gratitude and optimism.

Much of what is mentioned in this chapter is related to lifestyle. People should not underestimate the power of healthy lifestyles in promoting good mental health. Self-care does not have to involve complex techniques. A routine that includes regular physical and mental activity, modest alcohol consumption, not smoking, and maintaining a healthy weight is associated with lower psychological distress and higher life satisfaction[215]. Lifestyle considerations not only involve diet and exercise, but also having positive relationships, recreational time, relaxation, interactions with nature, and spirituality[216]. While lifestyle approaches may be straightforward conceptually, implementing these strategies can be difficult for reasons referred to earlier in the book. Suggestions are provided on how to manage these demands throughout the chapter.

The Good, Bad, & Over-Used

I have suggested earlier that some (but not all) coping strategies are neither 'good' nor 'bad'. Many tools can be beneficial when used in moderation and in the right context (i.e., used at the right place and right time). Sure, some things will never be a good idea, such as a line of cocaine

before breakfast to get you revved up for the day. But aside from these exceptions, people should primarily guard against inappropriate and overuse of coping strategies. Mixing up coping tools relates to the skill of 'coping flexibility', which is the ability to appraise the effectiveness of an existing coping strategy and initiate new approaches where needed[217]. Well-being improves as coping flexibility increases[218]. Effective coping is not just about picking a strategy and going with it. Coping flexibility suggests that well-being can be enhanced when we consider the effectiveness of the strategies we use and be prepared to try something different when required.

Strategies can become overused in the absence of coping flexibility. Overuse may also occur for other reasons, for example, when a person possesses a limited set of coping tools, or narrowly focuses on (perceived) short-term benefits (e.g., reduction in anxiety by putting off a dreaded phone call). Some benefit can be gained from thinking about the effectiveness of coping strategies over the long-term, and in relation to your well-being goals. In this way, you are actively evaluating the effectiveness of existing coping approaches. If I put off seeing my GP about stomach pain, I might avoid the fear of being told I have a serious illness. However, if I think about how this strategy plays out over the long-run, there are potentially dire consequences for my health. If my well-being goal is to improve my mood over time, the presence of on-going stomach pain will not help to achieve this desired outcome.

To provide you with more examples, coping strategies that tend to cause especially big problems when used excessively include those on the list below[219].

- Denial strategy: Refusing to recognise aspects of your circumstances (e.g., ignoring facts). This strategy can manifest in various ways, such as questioning the accuracy of information, and down-playing problems. Such tactics might involve a person ignoring or minimising signs they are not coping with caring responsibilities (e.g., failing to accept extra help).
- Rejection of loss strategy: This is refusing to suffer at the hands of an illness. Carers may tell themselves that they refuse to let a cared-for person's CID impact their (carer's) life any further.
- Preservation strategy: Trying to hold on to positive aspects of life that existed before illness or disability. We discussed attempts to retain a 'normal' or pre-CID life in Part one. This strategy can yield detrimental effects when pursued vigorously (e.g., becoming over-committed to non-caring activities at the expense of reduced self-care).
- Self-numbing: Trying to evade psychological pain by changing how you are feeling. For example, a carer may drink excessive amounts of alcohol or eat large quantities of junk food to prompt a desired change in emotions.

We can see a lack of reflection and flexibility in the above strategies. A preservation strategy, for instance, may involve a lack of flexibility through an unwillingness to use new coping approaches.

In addition to actively evaluating coping strategy effectiveness, it can be helpful to consider what you are trying to achieve through using a particular approach. A preservation strategy may represent an attempt to fight the life-changing effects of a CID. Carers may want to avoid facing the power an illness has over their life by attempting to maintain pre-CID family routines. How effective is this preservation strategy? Are there more useful ways to achieve the outcome you desire (e.g., addressing a lack of control by joining a relevant charitable organisation)? You could also consider the appropriateness of the preservation strategy in relation to your self-care. Does this aim match an existing well-being goal? If not, what is a more appropriate goal?

Identity & Your Definition Of Carer

You can begin addressing self-care basics by considering personal beliefs about caring. This activity involves detailing your perspective on what the carer role is (and is not) to you. These reflections will likely touch upon identity issues discussed in Chapter 2. The point of this exercise is to help you identify thoughts and beliefs that might drive self-care and support-seeking behaviour. For instance, you may not access professional support services if you do not see yourself as a carer[220]. Alternatively, you might feel you have no time to look after yourself because a carer should be on call 24/7. You consequently make no plans for essential self-care activities, even when circumstances allow. You could also experience negative feelings towards yourself (e.g., guilt) when you let someone else take over caring responsibilities. This demanding level of self-imposed commitment may place you in a state of 'high alert' leading to increased anxiety levels.

You can consider your responses to the questions below if you would like to spend some time thinking about personal carer beliefs. These questions are intended to kick-start reflections on your views of the carer role. If you have difficulties answering these questions you could discuss them with a sensible friend or even a fellow carer (by 'sensible', I mean someone who is non-judgemental, a good listener, and open-minded to your thoughts and ideas).

- How would you define the term carer or describe what carers do day-to-day?
- Are there differences in how you define the term carer for yourself and other people? If there are differences, why might these exist?

- How do you think your definition of carer compares to how society defines this role?
- To what extent do friends and family acknowledge your caring role? How does this acknowledgement (or lack of) influence your identity as a carer?
- How does your definition of carer fit with who you are as a person (e.g., is this role a natural one for you)?
- What are the similarities and differences when comparing the carer role with your own (pre-carer) identity?
- How does your carer definition influence your relationships with others? Does it affect how, when, or where you meet with people, and what you talk to them about?
- In what ways does your carer definition influence how you look after your physical and psychological well-being?
- How have your self-care practices changed (if at all) since becoming a carer?
- What do you think would be unacceptable behaviour towards a care recipient?
- Why are these behaviours unacceptable, and what does this say about your view of caring?
- How does your approach to caring influence your well-being?

Next, you can look for the presence of any helpful and unhelpful self-care beliefs from your responses to the questions above. Unhelpful beliefs might involve, for example, a definition of carer that consists of the prioritisation of a supported person's needs above all else. This approach might cause you to stop spending time with friends to ensure you are always available to meet those needs. Alternatively, you may believe it is unacceptable for a carer to be upset around the person they support. This belief may prevent you from sharing difficult aspects of your experiences with others. These two examples illustrate assumptions leading to behaviours that ultimately undermine self-care. Looking for these belief-behaviour connections may help you to understand the role of identity in your well-being practices. To take this exercise to the next stage, you could consider how to address unhelpful thoughts and behaviours. You can find some options for doing so in the working with thoughts material found in Chapters 6 and 7.

Carer stress may occur when there is a mismatch between carer tasks and behaviours associated with a pre-carer identity[59]. People may experience distress when required to perform tasks that do not fit with 'who you are/were' outside the caring role. Benefits can come from considering strategies that target this mismatch where it exists. Such changes may be difficult to implement in practice, but you may be able to

work towards them over time. Remember that small changes can yield tangible results. There are at least three ways to approach this mismatch[59].

- Change behaviours or reduce tasks that are inconsistent with a pre-caring identity and relationship with the cared-for person. This change will not be possible in some instances, but there may be scope in other circumstances. For example, a wife may ask a secondary male carer to help her husband with showering and grooming. This request may help to preserve aspects of a 'normal' spousal relationship.

- Reconsider or challenge thoughts that create a mismatch between your identity and being a carer. This reframing might include expanding aspects of your identity to include caring tasks. You may see yourself as empathetic but become upset at someone's suffering to the point where you believe you are letting that person down. This perspective could be re-interpreted as showing compassion and genuine understanding of that person's circumstances.

- Reframe your identity to one which involves some of the carer tasks you undertake. For example, being a 'supportive person' may have previously referred to providing emotional support only. You could expand the definition to include practical tasks, such as taking a person to a medical appointment.

Goals

Several reflection questions were provided at the end of Chapter 3 to help you start thinking about your well-being. Following on from these, you can move on to consider your self-care priorities. What self-care actions would you like to take, but are not currently adopting? Most people cannot undertake all the self-care activities on their wish-list, otherwise most would be at a beach resort sipping mojitos. The process of identifying well-being goals and values can help clarify your priorities. This moves us to the topic of goals. Sorry, I had to mention this at the risk of making you feel like you've gone on a self-improvement coaching retreat. I want to talk just a little bit about goals because they can be used to guide self-care and complement some of the coping techniques covered in Part two of the book. In this chapter, we have already seen an example of considering well-being goals to evaluate the effectiveness of a preservation strategy.

Stressed people can find it difficult to know what type of coping response to use in response to psychological difficulties. Friends and family (if you dare tell them) may give a mixed bag of suggestions in an attempt to be helpful. This input can sometimes be contradictory or represent plain bad advice. We can instead use goals to help guide coping and self-care decisions. Identifying well-being goals can help clarify what strategies might

move you in a desired direction. An added bonus of goals is that you cannot get them 'wrong'. They are for you alone to determine.

An important caveat with the use of goals in this domain is that they should be used as a general guide for behaviour, and not as an explicit target to be reached[221]. You want to strike a balance between detail and flexibility by formulating a goal that provides a clear sense of direction without being overly prescriptive. You can use various questions and exercises to help identify well-being goals. You have probably heard about SMART goals (Specific, Measurable, Achievable, Realistic, Time-limited). The SMART approach can be useful, but you do not necessarily need to follow this formula strictly. You might wish to spend some time recording your well-being goals, bearing in mind the question 'Where do you want to get ultimately with your well-being and self-care?'

Some elements of SMART goals may be useful when you get stuck generating desired well-being outcomes. The principle 'Achievable' is a good example. It would be unrealistic to aim to progress from serious, prolonged levels of psychological distress to quickly feeling like a million dollars. A not-so-useful goal would be worded, 'I want to feel better'. This statement is not specific enough and does not necessarily encourage positive coping. A more effective phrasing might be, 'I want to achieve a sustained improvement my mood'. In the second statement, you have specified in what way you wish to feel better. Highlighting a desire for sustained improvement acts as a reminder to select coping strategies that are healthy in the long-run (e.g., connecting more regularly with friends, rather than using drugs or alcohol to achieve a change in mood). The next time you're feeling rubbish and deciding between going to bed early and calling a friend, you can consider which of those two coping options is most consistent with your well-being goal. Another unhelpfully worded goal might be 'I want to get along with my partner better'. It may be more useful to go for something like 'I want to make more joint decisions with my partner'. The second statement specifies what aspect of the relationship you want to change without going into excessive detail. Goals do not guarantee decisive action when needed, but they at least provide a reminder of what you are trying to achieve.

Barriers To Self-Care

We know from Part one that carers experience health problems at higher rates than non-carers. Carers may not prioritise their health and well-being in the face of self-care barriers. Many sources of advice on self-care emphasise things you probably know you should be doing; get plenty of sleep, exercise, and eat vegetables. While this is all true and fundamental to your health, perhaps a more useful exercise is asking 'What barriers prevent me from taking better care of myself?' and more importantly, 'How can I

mitigate or remove these barriers?' The best self-care plan in the world fails when these barriers are ignored. You may have begun to think about obstacles via the questions presented earlier in this chapter. Some constraints are physical (e.g., believing there is insufficient time to look after yourself), while other barriers are psychological (e.g., assuming self-care activities will fail to bring tangible benefits). Appraising the barriers present in your life can assist you to identify what might be responsible for unsuccessful self-care efforts. While you cannot remove all obstacles, you can at least recognise them and attempt to reduce their impact.

Numerous barriers to self-care and help-seeking exist for carers. One review of research in this area[222] suggested that barriers can be listed under the following categories.

- Characteristics of health professionals (e.g., holding unhelpful stereotypes about carers, not sufficiently recognising carers).
- Characteristics of service providers (e.g., failing to identify those individuals who are carers, long waiting times for health-related appointments).
- Language and culture (e.g., racial prejudice, language barriers).
- Care recipient characteristics (e.g., attitudes towards both CID treatment, and carer involvement)
- Information/knowledge issues (e.g., not being informed of available carer support services).

Considering barriers in all these areas may be overwhelming. A good starting point may be an initial focus on a carer's own physical and psychological barriers.

- What are the practical or logistical barriers to improved self-care?
- What are the psychological or mental (self-care) barriers?

If you wish, you could move on to considering impediments in other domains. These might include barriers related to other people (e.g., negative attitudes towards self-care) and the broader environment (e.g., lack of access to appropriate carer services). Once you have listed some of the barriers, you can consider how you might address them. We will use the examples of 'taking breaks' and 'lack of time' to illustrate the process of identifying and addressing barriers.

Taking Breaks

Taking breaks from caring, whenever possible, is essential for well-being. Carers say that having some time away from caring responsibilities is beneficial[5], but physical and psychological barriers make this challenging to implement. A substantial number of carers don't ask for support or respite[223]. Carers may find it helpful to take stock of the physical and

psychological barriers in this area. You can use the worksheet 'Barriers to taking breaks' in Appendix 1 to help with this. This worksheet is divided into two sections; one for physical/logistical barriers, and the other for psychological obstacles. Spend some time thinking about each type of barrier and write these down. Common physical obstacles reported by carers include the following. Note that some of these barriers may have a psychological component (if based on subjective opinion).

- Lack of time to take breaks.
- Lack of people to provide caring support (in the primary carer's absence).
- Insufficient expertise/knowledge of the care recipient's needs in those who might otherwise provide alternative caring support.
- Care recipient reluctance in allowing other people to provide support.
- Tiredness/lack of energy.

Examples of common psychological barriers include the following.

- Feelings of guilt and selfishness (about taking breaks).
- Lack of confidence in others to provide care.
- Concerns that a care recipient might respond unfavourably to carer breaks.
- Embarrassment associated with asking for help.
- Feeling unworthy of having time to yourself.

Begin to brainstorm potential responses to these barriers once you have listed them. You want to focus on recording as many ideas as possible at this stage. Ask someone to help with your brainstorming if you become stuck at this point. Help may come from family or friends, support group members, or from appropriate online forums. Record responses in the 'Potential solution(s) or who/what could help to find solution' column.

'Feeling guilty' for taking a break might be a psychological barrier that prevents you from scheduling more me-time. Thinking about why you feel guilty may be a helpful strategy in this case. Considering the source of guilt is a way of checking for unhelpful beliefs that might be driving this emotion. Some questions to help you learn more about the origins of this emotion might include the following.

- What do I fear the cared-for person will think if I take a break?
- What do I fear other people will think if I take a break?
- Does taking a break clash with any personal beliefs about how I should be 'performing' my carer role?
- Are there any beliefs that I have about caring which might be contributing to break-taking guilt?

- Do I fear something terrible might happen if I didn't feel guilty about taking a break?
- Are there any other reasons why I don't feel more positive about taking a break from caring?

(Lack of) Time & Activity Diaries

'Lack of time' is one of the more common physical barriers that carers face when trying to plan breaks. We can first consider to what extent this is a real versus perceived barrier. Lack of time is an unmistakable reality for some people. In other instances, this issue is unintentionally used to mask a psychological barrier which the carer would rather avoid (e.g., fear of having to discuss taking breaks with the person you support). Here are some suggestions to free space for yourself when time constraints are genuine.

- Consider very short breaks a few times per day. Use this time for self-care activities. These breaks may be easier to take in certain situations (e.g., when the cared-for person is resting).
- De-prioritise non-essential tasks. You might be placing too much importance on activities that can be put off or done less frequently.
- If friends visit regularly, use part of this time to do something for yourself (while friends support the care-recipient in your absence).
- Ask people to visit for the specific purpose of allowing yourself to have some time-out.
- Look at any available options for utilising volunteers to create time for yourself.
- Consider any jobs/tasks you do that the cared-for person could perform at least some of the time.

If you suspect a lack of time to have physical constraint origins, insights can come from keeping an activity diary. I am regularly surprised at how useful this seemingly simple exercise can be. This diary allows the chance to analyse how time is actually spent (rather than relying on unreliable memory and biased thinking). Break your day into one-hour segments and keep an account of what you do in each of these segments for 1-2 weeks. You will find an example in Appendix 2. Next, review your activities and consider what this information says about how you are spending your time. These are a sample of questions you can use to extract informational value from your activity diary.

- What patterns do you notice in your activity diary?

- Are you surprised by any aspect concerning how you spend your time?
- Are there ways to structure your activities differently to free-up some extra time?
- Are there instances of procrastination that you could address?
- If there is no current space in your schedule for self-care time, are there tasks that you could ask someone else to do?

General time management suggestions include the following.
- Keep a to-do list and rank tasks in order of importance. Carer-related tasks may automatically go to the top of the list. Be aware of this and try to ensure that self-care activities are not always placed at the end.
- Work through your to-do list one item at a time and do not try to multitask (trust me; you're not as good at it as you think!).
- Delegate tasks wherever you can. You may face both practical and psychological barriers to this, but even small amounts of delegation can be beneficial.
- Break down overwhelming tasks into smaller chunks, then tackle these activities in stages where possible.

Diet

Neglecting your own nutritional needs is easy to do when you are busy caring for another person. The individual you are supporting may have specific dietary requirements that take precedence, or you may have poor appetite. I won't repeat information on nutrition and eating well that is readily available. In the Resources section, there are links to websites that provide nutritional guidance and how to overcome common blocks to maintaining a healthy diet (e.g., not having the time to cook, eating on a budget). Psychological distress is often associated with dietary and appetite changes. For example, reduced/increased appetite in depression was mentioned in Chapter 3. An unhealthy diet is also associated with poorer mental health because adequate nutrition is vital for healthy brain function[216,224,225,226].

Access to reliable information on proper nutrition is essential, but so is identifying barriers to healthy eating. Unfortunately, obstacles to good nutrition are not always given the attention they deserve. Some of the barriers identified by researchers include time constraints, lack of cooking skills, not enjoying the taste of healthy foods, and low motivation to change eating habits[227,228]. There are also influences in the broader environment including what people around you eat, and the wide availability of unhealthy foods[229]. The nutrition picture can be a complex one, but you

should reflect on your attitudes towards eating. Perhaps there are unhelpful habits you can address using the techniques in Chapters 6 and 7. Here are some other questions to consider.

- Are there any apparent barriers to eating healthy?
- What has changed in your eating habits since becoming a carer?
- What aspects of caring make it difficult for you to eat a healthy diet?
- How can people around you help to improve your diet?
- Are there aspects of your living environment that make healthy eating a challenge? How might you address these factors?

Reviewing your answers to these types of questions may help identify real and perceived barriers towards eating healthier. This review will hopefully get you thinking about what positive steps you can take if your diet is inadequate. Addressing psychological problems such as low mood, stress, and anxiety can help alleviate issues with appetite and nutrition. Poor appetite is common in this context, but straightforward responses are available to try. You can prepare healthy snacks in advance or choose to eat little and often. You do not have to stick rigidly to a three meal per day routine. You can also try eating mindfully (see Chapter 6).

Exercise

Physical exercise benefits our mental health in areas such as mood, stress, anxiety, and self-esteem amongst others[230,231,232,233]. Various types of exercise can be beneficial for these issues be it resistance (weight) training[234], yoga[235], or walking[236,237]. We do not have a clear understanding of what specific aspects of exercise are beneficial for mental health, but it is likely that biological (e.g., chemical changes in the brain) and psychological effects (e.g., sense of achievement[238]) are involved. The physical environment may also be relevant to exercise benefits. The natural environment has been linked with positive psychological well-being[239]. Exercising in nature improves mood and self-esteem, even for short periods of time[240].

We all know that exercise is good for our physical and mental health. What you may be more interested in are the barriers to exercise. The most common reasons for not exercising include insufficient time, inconvenience, lack of motivation, exercise being unenjoyable (or tedious), not having enough confidence, fear of being injured, lack of exercise goal-setting, and lack of support from others[241,242]. Some of these barriers are very real when you are a carer, particularly finding time, having sufficient energy, and having a convenient exercise option. Here are suggestions for addressing some of these exercise barriers.

- Exercise in small chunks of time.
- Investigate possibilities for exercising at home (e.g., stationary exercise bike, stair climbing).
- Ask for some caring support to exercise (e.g., have someone sit with the person you care for while you exercise).
- Exercise with others.
- Exercise when with the person that you care for (e.g., push them in a wheelchair, take them to a location you can readily exercise, such as a park).
- Look for times when exercise might be relatively easier to do (e.g., when the person you support is resting).
- 'Book' exercise in as an 'appointment'.
- Take some advice around how to avoid injury (e.g., instruction on proper muscle stretching technique).
- You may be able to borrow, hire or buy used exercise equipment.
- Look to fit in extra exercise when doing routine tasks (e.g., climbing stairs rather than using an elevator).
- Focus on the fun or beneficial aspect of exercising[238].
- Consider employing SMART goals for exercise.

Sleep

Disturbed sleep is a common problem in society. People are at increased risk for sleep problems when well-being is compromised. Insomnia is the most common form of sleep disturbance and involves difficulties going to or staying asleep, non-restorative sleep, associated daytime problems or distress, and can continue for several days per week over a period of one month or longer[243]. These sleep problems exist despite having the opportunity for adequate sleep and a favourable sleeping environment. Sleep disturbance is quite common in carers[244]. The resulting fatigue can compromise self-care and the support provided to a care recipient.

If you are experiencing sleep difficulties, you should first look to rule-out any underlying medical or mental health issues. Next, it can be helpful to improve your knowledge of insomnia. The cognitive-behavioural perspective is one framework in which to understand sleep problems. This approach suggests that insomnia is the result of the interaction between behavioural, cognitive, emotional, and environmental factors. Adequately addressing insomnia requires attention to each of these elements. There are many useful online resources providing sleep tips and advice. You can find some of these in the Resources section.

Once you understand the nature of sleep problems, the next step is to keep a sleep diary. You can find an example diary in the Resources section. A sleep diary can help you to identify patterns and potential contributors to sleep disturbance. Typical cognitive-behavioural recommendations to promote good sleep are included on the list below[245,246,247,248].

- Ensure that your sleep environment is conducive to good sleep:
    - Try to keep the temperature, noise and light at a comfortable level. Usually, a dark, quiet, cool room is optimal.
    - Your mattress should be comfortable.
    - Keep the bedroom for sleeping. Don't do other activities in there such as working, eating, etc.
- Keep a regular sleep-wake routine:
    - Go to bed and get up at consistent times.
    - Consider utilising a pre-bedtime routine that includes a sequence of relaxing, wind-down activities (e.g., a bath followed by reading for 30 minutes before turning the lights out).
    - Avoid napping during the day.
    - Do not spend an excessive amount of time in bed.
- Pay attention to eating, drinking, and drug use habits:
    - Do not eat large meals within 2-3 hours of bedtime.
    - Minimise caffeine intake, especially in the evening.
    - Minimise or avoid alcohol use.
    - Avoid smoking.
- Watch out for trouble-making thoughts:
    - Keep sleep expectations realistic.
    - Do not blame sleep problems for all your difficulties.
    - Try not to think the worst after a lousy night's sleep.
- Don't lie in bed if you are awake and can't get back to sleep. Get up for a short period (approx. 20 mins), do something relaxing, then try going back to bed.
- Regularly practice relaxation.
- Do not 'overcompensate' for a bad night's sleep by cancelling commitments (e.g., appointments), reducing activity levels, or going to bed early the following night.

Self-Monitoring

A diary can be used to monitor sleep difficulties as demonstrated in the last section. Many psychologists use diaries to help understand and treat other problems including low mood and anxiety. The information collected through a diary method can allow for insights that would otherwise not be

possible if relying solely on mental recall. I once worked with a young man who had a complex set of mental health difficulties. Previous attempts to clarify and address these issues had been unsuccessful in improving his well-being. We used a diary over several weeks to measure crucial pieces of information about his physical and mental functioning. The data collected through this method allowed us to describe and understand the issues responsible for his difficulties. The months that followed saw a major improvement in his mental health. This change would not have been possible without the insights provided by diary information.

It is very easy for people to have a false impression of psychological problems. For example, your brain tends to latch on to negative experiences when you are depressed, at the expense of recalling more positive or neutral events. A more helpful perspective is possible when objective information is available. We know from Part one that low mood, stress, and anxiety are common issues faced by carers. It is thus useful to understand how to maintain a diary for them. You can find example diaries for each of these problems in Appendix 3. These example diaries are intentionally simple. There are other versions available, some of which are more complex. I have tried to keep these diaries straightforward because people are rarely enthusiastic to fill in lengthy forms.

Start reviewing information once you have about two weeks' worth of daily entries. You can first look at your average mood, stress or anxiety score over time to find any pattern to these ratings (e.g., is your score higher or lower on a particular day?). The longer you collect this information, the more useful it will become. You may need to keep an average score for several weeks. This persistence will be important if there is something that impacts your average rating but happens infrequently (e.g., a six-monthly scan or blood test). If you do find a pattern with your average score, the next step is to take a closer look at your mood diary on these days and look for additional patterns (e.g., the frequency of a specific event, experiencing exhaustion at certain times of the week).

Next, you can look for frequently occurring events that correspond with your highest and lowest score. For instance, you may find your mood score to be the highest (the best) after spending time with friends. You can look for any commonly occurring thoughts present when your score is at its lowest/highest (see Chapter 7 for suggested strategies to address 'thinking errors'). Finally, you can look to identify which of your existing coping strategies appear to be the most effective approaches to mood, stress, or anxiety management. The most effective ones can be used more regularly to help manage your difficulties (in addition to learning new tools in upcoming chapters of the book).

Gratitude

Gratitude has been defined as "…the appreciation of what is valuable and meaningful to oneself and represents a general state of thankfulness and/or appreciation"[249]. This concept is potentially useful to carers because gratitude exercises are associated with improvements in various aspects of well-being. Gratitude benefits mood[250,251], general anxiety[252], stress[144], sleep[253], relationship quality[251,254], and physical health[255]. There are several possible ways in which gratitude benefits people. One is that it encourages positive coping, while another involves an increase in positive emotions[256].

There are several ways to practice gratitude. One of the most well-known exercises involves a gratitude journal. In this exercise, you list three to five things for which you are grateful. These sources of gratitude can be 'little' or 'big'. For example, 'I'm grateful for the pair of shoes I'm wearing', 'I'm grateful for the sunshine today', 'I'm grateful to be in good physical health', 'I am grateful for the meal I had with my friend today', 'I am grateful to have a supportive brother/sister in my life'. Writing at least once a week in your gratitude journal is recommended to keep the activity fresh and avoid boredom[144]. Another approach is to express gratitude directly to someone[144]. This gesture can be made in-person, by phone, or letter (yes, a letter!). You could write to someone who did something positive for you. You could talk about something you value in a person or point out cherished aspects of a relationship.

You can choose to practice gratitude with the person you support. This activity can help draw attention away from difficulties and remind each other of any positives in your lives. My wife gave me a card before she died in which she wrote a quote that summed up the potential value of being grateful for the relationship you have with the person you support. Part of this quote read "…right in that moment, there you are, alive and here with me. I was so lost in pain that I couldn't celebrate the real moment of being together…In this present moment, we are alive and the only thing to do is to feel grateful" (author unknown). You should not underestimate your power as a carer to provide comfort by encouraging reflection on the positive connection you share with the person you support.

Carers can quickly focus on the negative elements of their situation. They can get dragged down by how unfair the world is, and be overwhelmed by hard times and suffering, focusing only on the past or the future. Gratitude may be a way to help direct attention to a few positive elements in your life. Being reminded of positive micro-moments can provide a short break from the relentlessness of negative big-picture concerns. Sometimes, these small positives are all you have when the going is tough.

Optimism

Optimism is a hopeful state in which a person believes that adverse events are typically one-off, not due to him/her, and not likely to influence other events[257]. Like gratitude, optimism is a concept of great interest in positive psychology. Optimism is linked to increased happiness, well-being, and the use of positive coping strategies[258]. It has also been related to positive physical and psychological health outcomes in people with chronic disease[259]. There is also an indication that optimism is related to levels of depression in the early stages of caring[260]. Optimism is associated with reduced carer strain[261]. Conversely, pessimism is related to poor carer physical and mental health[260].

Notwithstanding these benefits, people should be aware of unrealistic optimism, which represents the belief that future outcomes will be better than what is possible[262]. Unrealistically optimistic people believe that, compared to others, they are more likely to experience positive events and less likely to experience adverse ones[263]. This style of thinking could be a big problem in some circumstances (e.g., spending more than you can afford on a lottery ticket). Alternatively, you may unrealistically believe the person you care for is going to improve, where improvement is not possible.

Psychologist Martin Seligman believes that optimism can be learned[264]. There have been several techniques suggested to develop optimism. One popular approach is called 'best possible self'. You can find a link to the instructions for this exercise in the Resources section. In this exercise, a person is asked to visualise and record, in detail, the best possible life imaginable across different domains (e.g., family life, work). There is some evidence that this exercise leads to an increase in optimism and other well-being benefits, including improved mood[265,266,267].

Summary

In this chapter, many basic self-care and well-being strategies were introduced, along with several physical and psychological self-care tools. We should not underestimate the importance of straight-forward and lifestyle well-being interventions. They can yield valuable benefits and lay a solid foundation for the acquisition of other self-care tools.

Chapter 6

Working With Thoughts 1

Introduction

Identifying and actively working with thoughts responsible for emotional distress can be a useful way to address psychological strife. Our brains are capable of advanced mental skills, like the ability to plan, imagine, and use language. However, these abilities are (dare I say it once again) a double-edged sword in that they also increase the potential for psychological suffering[268]. Distressing thoughts frequently drive this suffering, and we need effective tools to manage them. Such thoughts tend to increase in number and frequency during times of elevated stress.

We will focus on thoughts that cause emotional distress in the next two chapters. Experiencing emotional pain is not an entirely bad thing (although it can understandably feel that way). Unpleasant emotions are as normal and legitimate as positive ones. While most people do not want to experience uncomfortable feelings, they do exist for a reason. They are essential signals from our bodies. Trying to get rid of them is not only impossible but can also intensify difficulties. There can even be benefits from unpleasant thoughts and emotions, such as directing our brain's attention to important pieces of information[269]. The approaches described in the next two chapters are intended to help you make sense of difficult thoughts and manage them more effectively.

We will look at ways to create mental 'distance' from difficult thoughts in this chapter. I will discuss ways to challenge the accuracy of these thoughts more directly in the next chapter. There are several techniques available when trying to achieve mental distance from thoughts. One is called 'cognitive defusion' and comes from Acceptance and Commitment Therapy (or ACT). Other techniques are mindfulness and meditation. We will look at these three approaches in this chapter.

Thinking Woes

I experienced many difficult and distressing thoughts during Charlotte's illness; 'I cannot bear seeing her in pain', 'How long will she live?', 'Will this ever end?', 'What will happen to me after she has gone?'. I wondered if carers in similar circumstances had equivalent thoughts. These were difficult things to hold in my head, and no doubt contributed to my distress. The thoughts also triggered a set of existential debates in my mind about the meaning of my life and how I lived it. For instance, I questioned climbing the career ladder. 'What was the point of it?', 'Where was I trying to get to?', 'What was I trying to achieve?'. I had no clear answers to these questions. Life was complex enough with Charlotte's cancer. The presence of these issues in my head only made life more bewildering and confusing, but I knew these thoughts were normal. This realisation at least stopped me from thinking that I was losing my mind!

I refer to the 'content' of my thoughts in the previous paragraph (the actual words and messages) and the role played by stress in generating them. Stress and other psychological problems can also impair the 'process' of thinking, or 'how' we think. Consistent with this phenomenon, I experienced a mental fog in that my thoughts became more disorganised and muddled over time. We know that on-going stress can have detrimental effects on thought process abilities[270,271], and so my experiences were not surprising. I started to question my capacity for rational thinking. This rising doubt dented the confidence in my own judgements. The results were unsettling, particularly when I had critical caring responsibilities and decisions to make.

My professional experiences gave me some helpful coping strategies. Efforts to step back from these thoughts brought some reward. In addition to defusion and mindfulness, keeping a personal diary allowed me to have a rational conversation with myself. I would sometimes play devil's advocate or imagine how another (sensible) person might react to my thoughts. These were attempts to break free of my muddled thinking. Even the simple act of writing down my thoughts during a bleak moment provided a helpful snapshot to reflect on at a later time.

Judging Inner Experiences

Unpleasant but believable thoughts can result in a distressing emotional response. The power of these thoughts is enhanced when they are accepted without being challenged. We can forget that thoughts are just thoughts; a mental product of our brain. No more real than the tooth fairy. A person is less likely to believe the thought 'I am an elephant', than 'I am a failure' because the first seems more implausible. However, they are the same. Nothing more than the product of firing neurons. Thoughts cause further

distress when used to evaluate emotions in unhelpful ways. Experiencing an unpleasant emotion is not fun, but unpleasantness increases when we believe that certain emotions represent some personal shortcoming. You might tell yourself you are weak or pathetic for crying. This negative evaluation can amplify the distress that triggered the crying. Thoughts can also be used to criticise other thoughts. Have you ever experienced the evaluation 'I am bad for thinking X'? 'X' might be 'I've had enough of being a carer' for example. Telling oneself 'I am bad' is a negative judgement that only leads to further distress.

Why make these harsh evaluations of thoughts and feelings if they are so counterproductive? The brain is hard-wired for negative thinking because its primary job is to keep you alive. Successful survival depends on an ability to register potential threats. Modern-day threats can come in many forms; failure at work, being socially rejected, perceived underperformance as a carer. Critical self-evaluation can be a means by which people try to guard against these adverse outcomes. Think of this inner critic as a type of alarm that gets set off when underperformance is suspected. The reality is that this approach can undermine our welfare over the long-term because our inner critic becomes responsible for repeated false alarms. Carers may be particularly prone to harsh evaluations of their feelings and thoughts. I have previously suggested that carers often believe they have no choice but to keep going or no room exists for their own frailties. We might react to understandable distress with the thoughts 'I've got no time for this' or 'I cannot fall apart now'. The presence of invalidating thoughts like these will eventually create additional psychological difficulties.

Doing Vs Being

The 'doing mode' of thinking refers to the process of evaluating our thoughts[272]. In the above example of crying, there is a gap between how things are, and how you believe they should be. If you think crying is unacceptable, a discrepancy between expectation and reality can form. This gap creates mental discomfort and stress (or cognitive dissonance as introduced in Chapter 2). There may be no standing back and objective observation of thoughts in the doing mode. If this happens, we can get caught in our thoughts and find it difficult to appraise their usefulness.

In the doing mode, we think, imagine, plan, make judgements, and evaluate. The alternative to this is the 'being mode' which involves observation of our experiences without judgement or evaluation. We step back and look at our inner experiences instead of interpreting and evaluating. This unhooking can decrease unhelpful judgements about our mental experiences that cause distress. This state can be particularly useful

in circumstances which cannot be easily changed, like a carer supporting someone with a CID.

Most of us spend a lot of our time in the doing mode (including me!). The being mode can consequently feel like a dull, unnatural, or even uncomfortable experience. However, the being mode has much to offer. I view the being mode as a mental state whereby you are an observer of your inner experiences; taking in information, while holding off the 'processing' (evaluating). Doing and being modes are neither good nor bad. They are just different states of mind. Both modes need to be practised to derive their respective benefits. Coping flexibility is enhanced if you can operate in both doing and being modes. We will now look at the 'how to' of the being mode through cognitive defusion and mindfulness.

Cognitive Defusion

Cognitive defusion is a method of stepping back from thoughts into a being mode. To understand this concept, a group of researchers[273] developed a questionnaire to measure defusion. Here are some examples from the development of that questionnaire which indicate a lack of defusion: 'My thoughts cause distress or emotional pain', 'I find myself preoccupied with the future or past', 'I make judgements about whether my thoughts are good or bad', 'My thoughts are facts', 'I over-analyse situations to the point where it is unhelpful to me'. These statements demonstrate that being fused involves being 'buried' in your thoughts and buying into them with great commitment.

Consider the thought, 'I am going to turn into a hippopotamus'. You might laugh at this and probably not take it seriously. There would be no fear of this thought turning into reality. If a friend told you they had this thought (and believed it), you might swiftly send them off for psychiatric evaluation. Why would you react in this way? The statement is so implausible that you recognise it as a thought and nothing more. Now consider your reaction to the thought 'I am not patient enough towards the person I support'. You may be less likely to explicitly recognise this as a thought because it falls more within the realms of possibility. You cannot be a hippopotamus, but it is possible to be impatient. Your reaction may be to take the latter thought more seriously. Perhaps this thought resonates with you because there have been times when you have lost your temper. You are more fused with this thought because it has more personal significance.

Neither the hippo or impatient thought physically exist in the real world like a table, a tree, or a glass of water does. The idea of being impatient might trigger an uncomfortable self-judgement, such as 'I am not good enough'. The brain is operating in doing mode. The objective of defusion is to encourage a being mode of thinking to create mental distance from

thoughts that trigger unpleasant responses. You have defused if you can recognise this thought as something produced by your brain (rather than representing reality). You are less likely to be blindly driven by your thoughts when defused. You can examine them in a more objective, rational way. Herein lies the rationale for practising defusion.

As a carer, I used to feel guilty when doing something for myself (e.g., going out to meet a friend). I was able to consider where that belief originated when I tried to defuse from that thought. I worried that visiting a friend took me away from my wife's care. However, she did not always need 24/7 attention from me. Getting out of the house for a couple of hours did not compromise her care at all. In fact, she was probably glad to get rid of me for a while. Defusing from the thought 'I am selfish' allowed me to ask some important questions about that thought and I discovered more about my carer-related identity and beliefs. I would have continued to feel guilty in the absence of defusion. That emotion would have been unhelpful to everyone.

How do you defuse? One advantage of defusion is that you can get creative in the ways you practice it. If you have previously been able to step back from thoughts into the being mode, you have probably defused successfully. Your early practice with defusion should be with thoughts that do not prompt a strong negative emotional response. You can move on to more difficult thoughts as you develop your defusion skills. Having said this, I have also worked with people who can apply defusion to difficult thoughts immediately. Either way, you can do some experimentation and see what works for you.

There is sometimes a reduction in the emotional heat behind a thought when defusion occurs. People can then evaluate thoughts more objectively. I remember a client who frequently thought 'being a carer is not natural to me'. That belief filled him with anxiety and led him to believe he was the wrong guy for the job. He could more easily discuss the origins of this thought after defusing successfully. We discovered that this thought reflected the discomfort he experienced when witnessing emotional distress in the person he supported. He was competent and supportive in many other areas. We successfully worked on his ability to remain calm when witnessing this distress.

Long-standing difficult thoughts tend to run on autopilot. They do their psychological damage, then briefly disappear with little or no active response from the person. Defusion encourages you to put a stop to this automatic process and make an active decision about how to react. Below are some suggested ways to defuse. These are just a few examples. Mentioned below is some information that comes from the book 'Get Out of Your Mind and Into Your Life', by Steven Hayes and Spencer Smith[268]. Russ Harris[274] has also written some helpful material on defusion. His book

'The Happiness Trap' is an excellent source of information and exercises in this area.

Verbally Labelling Thoughts

Explicitly labelling a thought for what it is (a thought) represents one useful defusion method. This technique can act as a reminder that you are experiencing a thought, and not reality. For example, in response to 'I am a useless carer', you might remind yourself that a thought has occurred by simply saying to yourself 'There goes the thought- I am a useless carer'. Hayes and Smith[268] talk about labelling thoughts in this way. This defusion technique is intended to act as a reminder that your brain has produced a 'thing' called a thought (rather than mistakenly believing the contents of a thought are reality). You can preface a thought with any statement that is similar to 'There goes the thought…' (e.g., 'I am having the thought…', 'My brain has produced the thought…'). Alternatively, you can simply say the word 'thought' or 'thinking'. Perhaps make these statements in your head rather than saying them out loud. You probably have enough to manage without people thinking you're losing your mind.

Using Voice & Music

You can change the way a problematic thought 'sounds' in your head by using an attention-grabbing voice. This manipulation acts as a reminder that you can alter thoughts in any way you choose (far more so than your ability to manipulate reality). Humour can be a particularly good way to defuse. You might re-state a difficult thought in your mind by using the voice of an amusing character or person. I have used the voices of Yoda, Homer Simpson, and favourite comedians. Use any voice you find to be funny or entertaining. Hayes and Smith[268] recommend saying difficult thoughts 'in a different voice'. You could alternatively set the thought to a piece of music. This approach can be useful when the piece of music is comical or is an odd match for the thought (e.g., setting a negative thought to an overly-cheerful tune). You can even sing the thought back to yourself as a humorous song.

Observing Thoughts

If you are a visual-type of person, observing difficult thoughts may be a useful way to defuse. Again, Hayes and Smith have suggested this by picturing thoughts as leaves on a stream. Imagine your thoughts written on these leaves. You watch them float away without trying to influence their movement. As soon as you try to control the behaviour of the leaves (e.g., make them move faster), you are becoming fused with your thoughts.

Trying to fight or change the thoughts in any way is not what we want. The reason is that the 'struggle' with thoughts is what creates the psychological distress that we are trying to address. You can replace leaves on a stream with anything in nature that comes and goes in a similar way, like clouds, breeze, or snowflakes.

Externalising

Externalising the thought means doing something to separate it from your mind and body. You are trying to represent the thought as an entity unconnected to yourself. The possibilities here are almost endless. The unpleasant thought could be a character from a book, TV programme or movie (e.g., rebellious teenager). You can use objects, such as a computer (perhaps infected with a virus) or a mobile phone that keeps bothering you with thoughts delivered via text message. I suggest to clients that any character used should not be 'evil' because this can create an unpleasant emotional response that fuses you back with the thought. I like characters that are ultimately well-meaning, even if they bumble through life (e.g., a friendly but incompetent waiter, an untrained puppy).

Mindfulness

Mindfulness carries on the idea of cognitive defusion but extends the being mode to a more general way of relating to your experiences. There are many good books solely devoted to the topic of mindfulness, so we will only take a brief look at this tool. 'Mindfulness for Dummies' by Shamash Alidina[275] is a handy place to start and there are other books listed in the Resources section. Perhaps the most popular definition of mindfulness is offered by Jon Kabat-Zinn who is a key figure in bringing mindfulness to western health practice. He says that mindfulness is a type of awareness that happens through intentionally paying attention to what is going on in the present moment without being judgemental[276].

You may see similarities with defusion here, but there are important differences. Defusion is a way of observing your thoughts, whereas mindfulness can involve a broader range of phenomena both inside and outside the body (e.g., breathing, bodily sensations, sounds in the environment). Accepting the way things are in the present moment is another essential component of mindfulness, but not necessarily explicit with defusion. Distress can occur when you want some aspect of life to be different from current circumstances. This links with the earlier discussion about the doing mode creating a discrepancy between how the world is, and how you want it to be. Mindfulness can help to reduce the amount of psychological strife that comes from judging our experiences (but we will

see that we try not to expect any specific outcome from mindfulness practice).

Some people grapple with the language of mindfulness. You may hear expressions such as 'being fully present', 'being connected to the world around you', and 'a stream of conscious experience'. If this language makes sense to you then great, but if it does not, don't get too bogged down by it. I have tried to minimise jargon here. To me, mindfulness is basically about a type of attention where you are consciously aware of what's going on in your head (getting off autopilot) without trying to label experiences as 'good' or 'bad'. Mindfulness can be much more, however, I find this conceptualisation to be a useful starting point. Those who use mindfulness regularly develop their own way to practice it and formulate a definition that makes sense to them.

The 'how to' of mindfulness is simple, at least on paper, but lots can happen under the surface. Let's look at a basic approach to a mindfulness exercise. Mindfulness expert Rebecca Crane[272] says there are three steps to any mindfulness activity. First, you pause to prepare and focus on the exercise. For example, you might follow instructions to 'become present' through an initial focus on your body and the surrounding environment. Next, you move attention to a focal point. The breath and body are commonly used anchors. Third, you observe that anchor while noticing any sensations or experiences along the way (thoughts, feelings, physical sensations, sounds). This observation should occur curiously and non-judgementally. You can develop this ability with practice. The curious, non-judgemental approach sharply contrasts instances of self-criticism or subjective evaluations of your experiences that can sometimes occur in the doing mode.

Practising Mindfulness

One standard way to practice mindfulness is through a focus on breathing. There are some breathing exercise examples in the Resources section. Another regularly practised form of mindfulness is a body scan. Again, see the Resources section for examples. These mindfulness exercises are common because they make use of resources which are always available to you (breath and body). If you frequently operate in the doing mode, mindfulness can feel like a foreign approach. When you start this practice, you are learning a new skill that may be very different from the usual experience of your inner world.

Other Forms of Mindfulness

There are many ways to practice mindfulness through planned and unplanned activities. We briefly mentioned diet and nutrition in the last

chapter. Mindful eating is another example of applying this technique to your life. Mindfulness and related practices may have positive benefits for people, such as maintaining a healthy weight[277]. Stressed carers sometimes feel like they do not have the time to feed themselves properly. Stress can also affect appetite and what is eaten[278]. Working with a mindful eating exercise can be a helpful way to experience eating deliberately and engagingly. When eating feels like a real chore, mindful eating can help to make the experience less aversive and more interesting. You can find an example of a mindful eating exercise in the Resources section.

You can also practice mindfulness with a drink (e.g., a cup of tea) by engaging all your senses in a deliberate manner. You can choose to experience any routine activity in a mindful way, such as the commute to work, washing the dishes, or simply standing from a seated position. There is also the option to walk mindfully. You can find a link to a useful blog post on mindful walking in the Resources section. The point is that you can practice mindfulness in a variety of contexts. Do not be afraid to experiment.

Points to Remember

When practising mindfulness, it is essential to keep the following points in mind to remain on track with your efforts.

- Start small. Just a few minutes a day is enough in the early stages of practising mindfulness. If you are not used to the being mode, then it is wise to ease your body into this state.
- Regular practice is essential to develop the skill of mindfulness.
- You can't get things 'wrong' with mindfulness. For instance, a wandering mind or frustration are valid experiences. Noticing the mind wandering is mindful in itself. Retaining an open attitude to the experience is essential.
- Your mind is bound to wander. The main aim is not to stop this, but to notice when it wanders. You are exhibiting awareness of your internal goings-on (being mode) when you catch mind wandering. The point is to know where your brain is at any given moment. Try not to force your brain to keep focused on one thing without becoming distracted. When you realise your mind has wandered, congratulate yourself, then gently draw attention back to the intended focus (e.g., breath).
- If you wish for the experience of mindfulness to be a certain way, you will probably be disappointed. We cannot always fulfil such an expectation. You should approach every practise session as a unique, one-off experience. Sometimes you may feel a sense of calm and relaxation, and sometimes you may not. The point is not

to try and replicate a desired experience, but mindfully observe whatever arises.

Being Present-Focused

We have previously discussed the stress and challenges involved in living with a CID. Difficulties can be intermittent or on-going. Your existence can be played out in a state of limbo. You can spend (relatively) good times in fear of possible bad moments to come. One way to manage these issues is by being focused on the here-and-now. This approach can be a useful way to see your experiences with a broader perspective, rather than being focused on a specific element. It can be easy to focus on the bad aspects of life when the going gets tough. This narrow focus can further exacerbate psychological difficulties. Seeing your present situation for all its good and bad characteristics can help balance your thinking. We can make smarter coping decisions from this more objective position.

Being present-focused means directing your awareness to the here-and-now which often involves leading your attention to a specific activity. Several potential well-being benefits can result from the ability to be present-focused[275,279]. We have already looked at defusion and mindfulness as tools to step back from thoughts and be present-focused. Mindfulness does not suit everyone, and this tool has received some criticism[280]. No need to worry. There are other ways to be present-focused that do not explicitly involve mindfulness. The two examples covered here are flow and savouring.

Flow

Flow is the term used by psychologist Mihaly Csikszentmihalyi to describe a state in which people fully immerse themselves in an activity. Several potential benefits arise from flow experiences[281]. You have a clear sense of desired outcomes when in a state of flow. There is total concentration or absorption. Actions seem merged with thoughts (behaviours seem automatic). You lose yourself in the activity. Time passes faster (or slower) than expected, and the activity itself feels rewarding[282]. Flow experiences can be beneficial when they make life more positive and meaningful, but you should be aware of the potential for adverse consequences (e.g., spending so much time on an activity that you neglect important tasks). If flow experiences are absent from your life, here are some suggested means to help promote a more regular occurrence of this state[282].

- Try activities that are of moderate difficulty or in the 'Goldilocks zone' (not too easy, not too hard).
- Be open to trying new experiences.

- Set challenges or goals for routine activities.
- Look for flow activities where you might not expect to find them (e.g., at work, during conversations).
- Try potential flow activities that involve other people.

I would recommend Mihaly Csikszentmihalyi's book called 'Flow' for more on this subject. You can find the reference for this book and some useful articles on the 'how to' of flow in the Resources section.

Savouring

Savouring is another form of present-focused experience and is the ability to focus on, appreciate and strengthen positive life experiences[283]. Savouring has been linked to several positive well-being outcomes. Examples include an association with lower levels of depression[284], higher levels of happiness[285], and increased satisfaction with life[286]. Savouring can take place in a variety of ways and is different to mindfulness (see the link to an article on this in the Resources section). Examples include taking time to enjoy the scenery while on holiday, thinking or talking about the flavours experienced while having a favourite drink, or giving your full attention to a favourite piece of music. There are various dimensions to savouring.

- Sharing with others.
- Memory building (e.g., reminiscing about an event with others).
- Self-congratulation (e.g., giving yourself credit for an achievement).
- Intensifying experiences through full sensory engagement (e.g., closing eyes to focus on sounds and smells when sitting in the forest).
- Making a favourable comparison (e.g., 'This is better than being at work!').
- Trying to immerse oneself in an activity (as with the case of flow).
- Reminding yourself when an experience is temporary (and should thus be enjoyed in the moment).
- Being grateful for an experience.

These suggestions can be combined to intensify savouring. For instance, you could listen to a piece of music with someone (sharing with others) while minimising distractions (immersing yourself), closing your eyes (intensifying experience), then talking about the music with the other person (sharing with others). You may be able to use savouring to get more out of the 'little things' in life when caring for another person. Simply reminiscing about good times and experiences (e.g., a memorable holiday,

nice walk) can increase savouring. Some more tips for savouring are included here for you to consider.

- Keep a record or savouring diary. Regularly read back over this material.
- Build a memory diary with the person you support. Collectively discuss and describe positive events in detail.
- Take photos and videos of positive moments. Replay these and share with others.
- Use gratitude to generate topics, events, and positive aspects of life to think about.
- Spend time explicitly enjoying positive news and events (e.g., having a 'mini' party).
- You can find links to further information about savouring in the Resources section.

Summary

We have explored several being mode strategies in this chapter as an approach to managing difficult thoughts. Operating in the being mode may be unfamiliar for many carers but can bring well-being benefits. The over-arching aim of a being mode strategy is to encourage present-moment awareness of internal psychological experiences or the environment that surrounds you. This awareness can be used to unhook from painful emotions, increase objectivity, suspend unhelpful judgements and intentionally experience life as it occurs.

Chapter 7

Working With Thoughts 2

Introduction

Wchapter. We will continue to look at ways e discussed being mode approaches to managing difficult thoughts in the last chapter. We will continue to look at ways to respond to these thoughts in this chapter by considering approaches that utilise the brain's doing mode. Distressing, inaccurate, and biased thoughts frequently accompany psychological distress. What's more, caring for someone can take you into a world that feels somewhat different or separate from real life. You may encounter shifting opinions and beliefs that cloud objective reality. One way of responding to such thoughts is to test their accuracy. There are several doing mode techniques to help us with this 'reality testing'. Some of these techniques are the subject of this chapter.

Keeping A Thought Diary

Our first doing mode tool is a thought diary. Thought diaries can help us to identify and challenge inaccurate thinking. Diaries can also facilitate an understanding of the links between thoughts, emotions, and behaviour. Recording thoughts helps us to recall them accurately. Our brains are not like computers. We do not have perfect recall of our inner experiences. Using a diary to assist with recollection can help compensate for these cerebral shortcomings. When in possession of a reliable record of difficult thoughts, we can look for key pieces of information (e.g., recurring thinking themes) that help us to understand and respond effectively to these mental processes. Thought diary information can also help you to reflect on your beliefs and attitudes towards caring and your carer identity. Keeping a record of problem thoughts has several other benefits.

- A thought diary encourages you to spend time actively considering your thoughts. Difficult thoughts often go

unchallenged. A diary helps you to step back from these thoughts and objectively examine them.

- A thought diary helps you to record thoughts in specific detail. Some thoughts seem to occur automatically, with a lack of form or clarity. Sometimes they barely register in our conscious mind. Keeping a record prompts you to clearly articulate thinking.

- Diary entries can help reveal unhelpful thinking patterns. You can look to work with underlying thinking themes instead of trying to tackle several difficult thoughts separately. Some people find this to be a more efficient way to work with thoughts.

- A diary can give you more time to work with your thoughts. Difficult thoughts can disappear from our minds in an instant. You can return to them at a future time when you take the time to record them.

There are many pieces of information you can collect when keeping a thought diary, but we will keep things simple and focus on three essential areas. See an example diary in Appendix 4 (do not worry about the Comments column now, we will discuss this later in the chapter). The first three columns of this diary are used to record important descriptive information.

- Situation: Information about the circumstances in which the thought occurred. Note where you were, who you were with, time of the day, and what you were doing immediately before the thought happened. Perhaps the most important use of this information is to help us identify 'triggers' for difficult thoughts.

- Thought: Record the thought itself. Recording thoughts can be tricky because we often don't pay conscious attention to them, especially if they have occurred many times before. I have often heard clients say "I didn't have any thoughts, I just felt emotion x". This perception may be evidence of being locked in doing mode. You may surprise yourself with what you dig up when you devote some specific attention to your thinking. Thought defusion can be a helpful way to identify thoughts when struggling to bring them to conscious awareness. The book 'Mind over Mood'[287] is a useful source of questions to help generate thoughts for your diary. This book also guides you through a more detailed thought diary should you wish to take this technique further. In general, you should ask questions such as 'What was going through my mind' or 'What was I saying to myself' in the situation being recorded in your diary?

- Emotion(s) experienced: Note the type of emotion experienced alongside the recorded thought. This column may be a good place to start if you cannot bring a thought immediately to mind. First

identifying the feeling(s) can provide the necessary information to recall the corresponding thought. We are recording this information to look for links between difficult thoughts and corresponding emotions. The next chapter has suggestions on developing awareness of feelings if you find it difficult to label your emotions.

Here are a few additional pointers to bear in mind when maintaining a thought diary.

- Only record essential information as suggested above (at least in the early stages of keeping your diary).
- Record your thoughts as soon as they occur to ensure accurate record keeping.
- Review your thought diary on a regular basis. I have found that reviewing after every ten entries is a useful guide, at least in the early stages. Look for patterns and other valuable pieces of information as outlined in the next section.

Reviewing Your Thought Diary

Thought diary information can yield valuable insights. Firstly, focus on general impressions. Here you are looking for overall patterns or observations that stand out. There may be a thought that frequently appears in the diary. Alternatively, you might be prone to experiencing distressing thoughts in specific situations (e.g., when away from the person you support). Record noteworthy patterns regardless of the observations made. You can also look for unexpected or surprising information. This scenario might represent new information or a challenge to existing beliefs. For example, you might believe that anxiety is not a major problem for you, yet your diary is packed full of anxious thoughts. New or surprising information can provide a different perspective on thinking patterns.

Take a close look at the information recorded in the Situation column. Any repetition here might signal the presence of triggers for difficult thoughts or feelings. For example, people who feel low often have more frequent unpleasant thoughts at certain times of the day (e.g., in the morning). You may experience problem thoughts more frequently with certain people (e.g., an annoying in-law), or in certain places (e.g., a hospital). Triggering situations could involve a combination of location, time, and people (e.g., some individuals are prone to experience depressing thoughts when home alone). The second entry for the thought record in Appendix 4 suggests that waiting for a scheduled medical appointment can trigger distressing thoughts. Perhaps this waiting time gives the person 'too much time to think' (which would suggest a need to keep occupied or distracted at these times).

When reviewing the Thoughts column, you can often obtain additional information about vague or overgeneralised thoughts (e.g., 'I am anxious') by posing additional questions. Example questions could include any of the following.

- What is the worst that could happen from this scenario?
- What does this situation say about me as a person?
- What aspect of this situation is most distressing to me and why?

You can find many other prompting questions in the book 'Mind over Mood' as mentioned above. This questioning may help access useful additional thoughts which are related to your originally-recorded thought. For example, a carer may experience the thought 'I am anxious' in situations where the person they support is in physical pain. Asking 'What is most difficult for me about this situation?' may reveal that the carer feels helpless and not in control in this scenario (thereby triggering anxiety).

Thinking Errors

You can scan your thought diary for specific types of unhelpful thinking patterns called 'thinking errors'. These are biases in our thinking that can lead to problem thoughts or thinking patterns. Thinking errors occur when people don't take all available information into account, make illogical conclusions, or assume our brains possess impossible abilities (e.g., the power to see into the future). Some of the more common thinking errors are listed below.

- Catastrophising. This is where a person predicts the worst-case outcome in a given situation. Some examples are 'It will be the end of my career if I don't get this job', 'Life will be over for me if my partner leaves me', 'Our lives will totally fall apart if there is no medication to manage her pain'.
- Mind Reading. A person believes they can read the thoughts of another. Examples include 'I know that they don't like me', 'He thinks I'm an idiot for asking that question', 'She thinks it's unfair that I can't take a break for myself on weekends'.
- Fortune Telling. A person thinks in a way that suggests he/she can predict the future. Examples include 'I know I am going to fall apart at this appointment tomorrow', 'We will definitely argue when we talk about this later', 'I will always be miserable'.
- Overgeneralisation. A person makes sweeping conclusions about self, others, or the world around them based on an absence or lack of information. Examples include 'I will never be good at talking about our relationship', 'I always mess up the drive to the hospital', 'Everybody is nasty to me'.

- Emotional Reasoning. This is when you use your emotions as evidence for beliefs. Examples include 'I feel like a failure, so I *must* be', 'I am always depressed, so I am obviously not coping', 'I feel resentful at having to be a carer so that must mean I am selfish'.

There are several other thinking errors, but many of these overlap with the above types. The above errors are the most common in my experience and therefore represent the most useful to bear in mind. I do want to pay specific attention to a thinking error not mentioned in the above list. The word 'should' is a problematic little word in our language. As a thinking error, use of should demands that life must occur in a certain way. Examples include 'I should always keep my emotions together no matter how upsetting the situation is', 'I should never think that I can't cope with caring for him/her', 'I should always be the best at X'. Should creates undue pressure to be or do something according to unwritten rules. The word should does not care how achievable something is. The resulting expectations are often arbitrary. Whether I tell myself 'I *should* be a unicorn' or 'I would *like* to be a unicorn', I am no more likely to make this magical transformation simply by demanding it.

Use of should usually does not improve performance, but many people believe it does by encouraging them to aim high. In my professional life, I have seen the impact of overusing 'should' in the form of stress, perceived lack of control over life, and poor self-image (amongst many other outcomes). Well-being is often improved when people adopt realistic expectations. Performance in many life domains can paradoxically improve when expectations are revised to more modest levels. I have long thought that setting unrealistic expectations is a strategy that belongs in a book titled 'The Seven Habits of Highly Self-Sabotaging People'. Use of the word should applies to many carers. People can expect too much of themselves when responsibility levels are high. Carers need to consider the long-term implications of this thinking error. What might seem appropriate in the short-term (setting high standards/expectations) can be counterproductive, and even harmful in the long-run.

If one or more of the thinking errors discussed in this section are familiar to you, there is a good chance you will find them in your thought diary. When you have several thoughts recorded in your diary, you can start to mark the thinking errors when you see them. You can perhaps have a column in your thought diary labelled 'Comments' where you identify the type of thinking error contained in a recorded thought.

Responding to Thinking Errors

You can begin to challenge thinking errors once you have identified them. Here are some suggested responses for each of the above errors.

- Catastrophising
    - Consider the known evidence that proves the worst-case scenario will *actually* happen.
    - Consider how likely this worst-case scenario is to occur. Is there another, more probable outcome?
    - Consider the past. How often has the worst-case scenario occurred in your life?
    - Consider how you would cope with the worst-case scenario. How could you make this situation survivable? What coping strategies could you employ?
    - Think of other abilities or resources that could be used to cope (e.g., talking to a supportive friend).
- Mind Reading
    - What objective evidence exists for this person thinking the way you have assumed?
    - Could any of this evidence be misinterpreted?
    - Has the person previously acted in a way that would be inconsistent with what you believe?
- Fortune Telling
    - On what information do you base this prediction? How credible or reliable is this information?
    - Have there been occasions in the past where your future predictions did not occur the way you anticipated?
    - What skills and resources will help you cope if this future event does happen?
- Shoulds
    - Are any of the following more accurate replacements for the word should: 'wish', 'would like', 'feel pressured to', 'would feel disappointed if' (e.g., 'I feel pressured to be the perfect carer')?
    - Do you apply this particular 'should' to everyone else? If there are exceptions, why do they exist?
    - What are the disadvantages of having this 'should' in your life?
    - What is the worst-case scenario if you did not live up to this 'should'? How would you cope?
- Overgeneralisation
    - Where is your evidence for 'never' and 'always' (e.g., How would you prove that you never get things right when having conversations)?

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- o Is it possible that one or a small number of stand-out events have caused this overgeneralisation?
        - o Is it possible that an intense emotion is driving the tendency to overgeneralise?
- Emotional Reasoning
        - o What evidence do you have for making this conclusion about yourself or the situation?
        - o Have there been times you have not thought this way about yourself? What is different in this situation?
        - o What might a trusted, sensible friend say about the statement/conclusion you have made?

Challenging Problem Thoughts

Another way to tackle difficult thoughts is to evaluate their accuracy. As suggested in the introduction to this chapter, our thoughts can go to some wacky places when we are distressed. I sometimes thought (erroneously) that I was of little use to my wife. This assumption would tend to emerge at my lowest points. Inaccurate thinking can have a massive influence on well-being. We can respond by holding our thoughts to account, much like we might expect a scientist to back-up a theory with supporting evidence. Evaluating the validity of thoughts is one way to prevent inaccurate ones disproportionately influencing our lives. We will now look at straightforward ways to challenge difficult or distressing thoughts. We will then discuss a specific thought challenging exercise. We start with some general points to consider when faced with a challenging thought.

Is it true?

At times it can be helpful to directly ask yourself whether a problematic thought is indeed true. Would a wise and measured person automatically believe this thought? Is this thought based on fact, mental biases, thinking errors, or false assumptions? Are there times where this thought seems less true? Difficult emotions can drive unhelpful thoughts. 'I am a useless carer' may not be a thought you believe wholeheartedly, but it could reflect underlying feelings of helplessness and frustration.

Try to find a more helpful alternative if the problematic thought does not appear to be true. What would a calm, non-distressed version of you say in response to the difficult thought? Write down the alternative and re-read it when the inaccurate thought appears next. Be patient; the erroneous thought may have held the limelight for some time. The new thought may take some time to gain a foothold in your brain (and you will probably need to combine this technique with other self-care strategies to achieve

noticeable benefits). You can take this 'Is it true?' approach further with the 'Evidence for and against' technique below.

Focus on Goals

'Does this thought help me move towards my well-being goals?' Your answer to this question can represent a productive response to difficult thoughts. The query draws out the usefulness of such thoughts relative to your well-being goals. Perhaps you want to improve your mood or feel less anxious. When a problem thought occurs, you can ask yourself the extent to which that thought supports your goal. For instance, if you want to improve your mood, ask yourself 'how helpful is this thought in lifting my mood?' An appropriate response to unhelpful thoughts is searching for a replacement thought that aligns with well-being goals. This question does not rely on accuracy, truth, or evidence. When you find yourself endlessly debating the merits for and against a thought, focusing on usefulness can help stop you from overthinking or 'paralysis by analysis'. Think of this focus on goals as a short-hand alternative to the evidence for/against technique detailed later in this section.

Stepping Back

Analysing a problem thought from a distance may help generate a positive alternative perspective. You can achieve this distancing in at least a couple of ways. Imagine the scenario where a sensible friend has learned about your difficult thought. How would they respond? What would they say? What action would they recommend in response to this thought? What alternative thought would represent a more helpful perspective? You could also imagine observing yourself from a distance (taking a 'bird's eye view') while this thought occurs. What do you notice about the broader situation? How do you interpret your response to the circumstances? Is there an alternative response more consistent with your well-being goals?

Be Specific

Another approach is to get specific with your thought by asking it to 'explain' itself through clarification or by providing further details. You can regard vague thoughts as a type of overgeneralisation thinking error. These thoughts can trigger a disproportionately large psychological response because they seem to be all-encompassing. Some people find these thoughts difficult to challenge. Thoughts such as 'I am scared', 'I am a failure', or 'Life will never change' can be investigated further with questions such as 'What exactly is meant by scared, failure or never change?', 'How long have I felt this way?', 'In which situations is this

thought strongest (where, when, with whom, doing what)?', 'Were there times when this thought seemed less true/relevant?'

The aim in answering such questions is to clarify an overgeneralised thought with the purpose of distilling it down to a more specific statement. The outcome can be a thought which is less overwhelming, thereby reducing the adverse emotional reaction. The thought 'Life will never change' may cause less distress if clarified to 'I feel emotionally overwhelmed caring for my mother and fear that I will never feel any different'. The additional detail provided in the second thought helps to recognise the most salient aspects of the situation and provides clues as to what an appropriate response might look like. The carer in this example might work to develop distress tolerance skills (see Chapter 8).

Evidence For and Against

Testing the validity of a thought can also be achieved by looking for 'evidence'. This strategy is more complex than those discussed above but can be a useful technique once mastered. The approach involves considering information that endorses or refutes a thought's accuracy and can appeal to people who prefer a methodical, logical approach to challenging thoughts. We often use a courtroom analogy with this technique. The difficult thought is on trial. One lawyer argues the thought is accurate, and the other claims the thought is inaccurate. Both lawyers are trying to persuade the jury to rule in their favour.

Some problem thoughts are accurate, while others are not. The evidence for/against technique provides a method to know the difference. When you discover that a distressing thought is indeed accurate, another approach is needed (e.g., problem-solving; see the Resources section for weblinks to more information on this). The evidence for/against approach takes you off automatic pilot, challenging you to explore thoughts actively. Opinion-based thoughts are usually the most appropriate to use with this technique because opinions are subjective and particularly prone to inaccuracies such as thinking errors. Here are the steps you can follow for the evidence for/against approach.

1. Write the thought down. This should comprise a simple, short, and specific statement that contains one idea. You can take thoughts directly from your thought diary if you have one. Examples of opinion-based thoughts include 'I am a terrible carer', 'I always lose my temper', and 'Life will never be any easier'. These thoughts are vague and overgeneralised. You could also apply the 'be specific' approach to all these thoughts. The evidence/against technique can be an extension of the 'be specific' approach because gathering evidence usually provides clarification of a thought.

2. Divide a piece of paper into two columns. One column should be labelled 'Evidence for' and the other 'Evidence against'. Then think of all the pieces of information that would support the accuracy of the thought in the 'Evidence for' column. After that, write the information that could indicate inaccuracy of the thought. Place this in the 'Evidence against' column. For the thought 'I am a terrible carer', supporting information might include 'I get frustrated with the person I support', 'I don't know much about his/her medical condition', and 'I feel uncomfortable when the person gets upset'. Information recorded in the 'Evidence against' column might include 'I have consistently provided support for the past three years', 'I genuinely try my best to be there for the person', 'Other people tell me that I do a great job'.

3. Review the information you have in both columns. Considering all the information you have collated, what would you say about the accuracy of the problem thought? If you think the thought is accurate, think about how to respond in a way that is consistent with well-being goals. If the thought seems inaccurate, think about a replacement thought that more accurately reflects the evidence collected. In response to the 'I am a terrible carer' thought, you might conclude 'I find it challenging to manage the emotions related to my carer role, but I have generally provided good support over time'. This replacement thought should be recorded and referred to often, especially when the thought 'I am a terrible carer' reappears.

The evidence for/against technique is designed to help you think more accurately. The steps detailed above represent a simplified approach to this technique. You can find a complete example in Appendix 5. Here are some additional steps for this technique if you wish to take it further:

4. Go back to the evidence for/against columns. Think about the quality of evidence recorded. Would the evidence hold up in an actual courtroom (e.g., one piece of 'evidence' may merely be an opinion)? Bearing the quality of evidence in mind, does this change your conclusions about the accuracy of the difficult thought? Does this strengthen your conclusion or change it?

5. Looking at the 'Evidence for' column, are there any common patterns in the information you have written down? Are there instances of mind reading? If so, does this represent an important way in which problem thoughts develop in the first place? (e.g., you tend to engage in mind reading, and this generates inaccurate thoughts that make you anxious).

You can also look for thoughts or themes commonly experienced by carers in your thought record. Some of these are good candidates for evaluation through evidence for/against, while others may represent some of the thinking errors discussed earlier in this chapter. Remember, some unpleasant thoughts are accurate, or at least contain a degree of truth. Common carer thinking themes include the following.

- I am/feel helpless.
- I am not prepared.
- I can't do this.
- I am overwhelmed.
- I know nothing about this medical condition/disability.
- I am not doing good enough.
- I can't cope with this uncertainty.
- I've lost a life of my own.
- I don't know how to talk to this person.
- People don't realise what my caring role involves.
- I don't have the support I need.

Summary

This chapter has introduced numerous doing mode strategies designed to help you respond effectively to difficult thoughts. The techniques covered can be used to explore and confront the thoughts that create psychological distress in your life. We take a systematic approach to these doing mode strategies by collecting information and logically evaluating thoughts. Through these methods, we seek to dispute thoughts which are unsupported by evidence or based on biased thinking processes.

Chapter 8

Emotion Regulation

Introduction

Carers commonly face challenging situations that create difficult emotions. These emotional responses are sometimes so potent that they seem to control our behaviour. We can even experience a degree of regret when strong feelings influence our actions in undesired ways. This chapter focuses on the management of difficult emotions. Our emphasis is on improving emotional control instead of dwelling on unpleasant feelings. We use the term 'emotion regulation' which refers to intentional efforts to influence emotional states. Emotion regulation strategies come in different forms, and several examples exist in daily life.

We have already covered some techniques where emotion regulation is a component, but not the central focus of our efforts. Mindfulness and thought challenging can indirectly help regulate emotions by making use of the being and doing modes. These tools can help us change our relationship to thoughts, thereby changing the type and intensity of emotion experienced. We will add to techniques covered in previous chapters by focusing on strategies specifically designed to develop emotion regulation capacity. We start by discussing our general attitude or approach towards emotions, followed by emotional awareness and a selection of emotion regulation strategies.

Acceptance & Normalisation Of Difficult Emotions

The general attitude or approach towards difficult emotional experiences can itself be an emotion regulation skill. 'Normalising' or understanding that difficult emotions are a natural part of the caring experience can help you to manage them more effectively. Normalising

these emotions may facilitate your acceptance of them which, in turn, is linked to positive psychological well-being[288]. You do not have to welcome difficult thoughts, but it may be useful to expect them as a typical part of the human experience. For example, you can replace 'I shouldn't be experiencing this feeling' with 'This feeling is unpleasant but is not surprising given the stress I am under'.

A CID entwines us in distressing circumstances and invariably produces difficult emotions. A carer's attitude towards such emotions is important because the ultimate source of distress (illness/disability) often cannot be removed. Many of my previous clients have responded to difficult (but understandable) emotions by labelling them as unacceptable. A natural response might be to suppress, ignore or avoid these emotions. This practice is particularly tempting when feelings are incompatible with an idealised carer or other identity. However, such tactics are not sustainable or beneficial over the long-term. The labelling of difficult emotions as abnormal (e.g., unacceptable, weird) intensifies distress and makes them more difficult to manage.

Labelling emotions in this way can also lead to unhelpful evaluations of yourself and/or the situation. There can be a strong temptation to suppress difficult emotions, especially when they are perceived to be socially unacceptable. A good example is the experiences I had with anger (as discussed in Chapter 3). Examples of other 'unacceptable' emotions reported by carers include ambivalence, resentment, irritability, boredom, disgust, embarrassment, frustration, and fear[289]. The physical experience of such emotions may be unpleasant (e.g., the racing heart and churning stomach that accompanies anxiety), but this is different to the thoughts associated with these emotions (e.g., 'I don't want to be anxious').

We can look to other contexts in which certain difficult emotions are more accepted. Even the most satisfying job comes with a degree of frustration, disappointment, or anger. Yet many would frown upon these emotions in a caregiving context. The fact that we are dealing with a person, and not a spreadsheet or customer, means that expectations of carer conduct are high. So-called unacceptable thoughts are actually quite common amongst the general population and are more likely to occur when experiencing psychological difficulties[290,291]. Carers need to talk about these experiences more openly as a potential way to normalise difficult emotions.

We talked about judging yourself negatively when experiencing an undesired thought or emotion in Chapter 6 (e.g., 'I have nothing to feel depressed about' or 'I should be sympathetic, instead of being angry in this situation'). I suggested that fighting your inner experiences in this way increases distress. Some people assume you are surrendering to unwanted emotional states if you do not suppress or control them. You may fear that these emotions might otherwise take over your behaviour. This approach

to emotion management is associated with various adverse consequences, such as reduced social support and relationship satisfaction[292]. Moreover, emotion suppression can actually intensify negative emotional experiences[293].

Another way to normalise painful emotions is to avoid labelling them as good/bad or positive/negative. You might be able to achieve this by focusing on their informational value. A willingness to learn about difficult feelings can help you to manage them. Emotions are signals from the brain designed to make us act[294] and provide essential information about our psychological state. While sustained avoidance of painful feelings may seem logical at first glance, this approach can lead to more significant problems. For instance, ignoring a sustained dip in mood may lead to an unchecked 'downward spiral' of knock-on effects (e.g., social withdrawal, increased procrastination).

We are pushed towards valuing a positive mindset and feeling good in modern society. The resulting danger is that people start to believe that painful emotions are unnatural. This stance ignores the fact that both pleasant and horrible feelings are equally valid. Why the hell would you feel fantastic about life when living in times of adversity? Psychological suffering is normal under these circumstances (provided this suffering does not increase to clinically-significant levels). Thankfully, there has been a backlash against the drive towards relentless positivity. You are entitled to feel angry, upset, sad, or whatever emotion you encounter. You should not have to suppress these emotions because they make others feel uncomfortable (provided they are not causing harm to yourself or others). However, you should not sit on your hands and instead take personal responsibility for managing difficult emotions. The book 'The Upside of Your Dark Side' by Todd Kashdan and Robert Biswas-Diener[269] is a fascinating read about the value of difficult emotions and the importance of accepting the full range of our inner experiences.

Awareness Of Emotions

An awareness of emotional states is the first step in the development of emotion regulation skills, but focusing on (difficult) emotions is a challenging task for many people. There is even a phenomenon called alexithymia which refers to difficulty in identifying, describing, and distinguishing emotions[295]. Alexithymia has been associated with adverse carer outcomes including depression[296] and prolonged grief[297]. Knowledge of emotional states can help you understand your behaviour and select appropriate coping responses. Emotional awareness forms part of a broader psychological skill called emotional intelligence, which is associated with positive well-being[298]. Emotions have four components; thoughts, feelings, sensations, and behaviours[294]. When you experience

happiness, for instance, you may register the thought 'I am really enjoying myself', the feeling of joy or excitement, a physical sensation of lightness in the body, and the urge to hum an annoyingly cheerful song.

One straightforward way to practice emotional awareness is to regularly stop and notice your experiences through each of the four emotion components. You can keep a record of this in an emotions diary. See Appendix 6 for an example. This activity may be challenging at first, particularly if you are not accustomed to focusing on emotional experiences. Here are some suggested strategies for those who struggle with this task.

- Start by recording small pieces of information (e.g., just focus on behaviour) and look to gradually expand your description over time.
- A body scan exercise can be a helpful tool to develop awareness of your physical self. You can refer to physical sensations detected during a body scan as a starting point for identifying and describing emotions.
- You could ask friends and family to describe their emotional experiences. These real-life examples can act as prompts to articulating your own emotional states.
- Use an activity that reliably triggers a moderate emotional response, and then note your experiences. For example, a particular piece of music may produce a reaction you can describe.

The task of identifying emotions is often easier when you possess a set of labels to help describe your experiences. Psychologist Robert Plutchik has suggested that there are eight primary types of emotions; joy, sadness, acceptance, disgust, fear, anger, surprise, and anticipation[299]. These emotion labels can help you to characterise your own emotional experiences, and help form the basis for other emotional states. There is a link to an article on Plutchik's work in the Resources section.

Similar to the thought diary presented in the previous chapter, you can use emotion diary information as a foundation for a growing understanding of your emotional states. Here are examples of helpful questions for your emotion diary.

- Why might I be experiencing this emotion at this particular time?
- How is this emotional state influencing my thinking and behaviour?
- Is this how I want to be thinking and acting in this situation?
- If not, what can I do to move towards the type of behaviour I want to exhibit?

By reflecting on such questions, you may be able to understand your emotions better, their effects on your behaviour, and how behaviour fits with your well-being goals.

Acceptance & Compassion

Acceptance of emotions encompasses an ability to acknowledge, experience and reflect on them. These components make acceptance an experiential process (e.g., scanning the body for physical sensations associated with an emotion) and a cognitive one (e.g., telling yourself that it is ok to experience a given emotion). Acceptance is the opposite of avoiding feelings. The former involves mentally 'approaching' emotions, or willingly experiencing them. A curious and interested attitude helps with emotional acceptance, so mindfulness can be one way to develop this skill. Alternatively, maintaining an emotion diary (as described above) can assist with acceptance if you use the diary to learn more about your emotions (e.g., identifying triggers and discovering the thoughts that typically accompany an emotion).

Psychologist Paul Gilbert[300] has led the charge to establish and utilise compassion in psychological treatment. Developing the capacity for compassion is based on the assumption that humans are hard-wired to respond favourably to compassion and kindness. The skill of compassion can integrate with emotion regulation. Kirsten Neff[301] has said that self-kindness, an awareness of our common humanity, and mindful awareness are fundamental elements of self-compassion. There are many ways to develop these elements. One approach is to practice 'lovingkindness' meditation. There is a link to this meditation in the Resources section. Other techniques are 'imagining the compassionate self' and 'compassionate letter writing'. You will also find links to compassionate writing in the Resources section.

Tolerance Of Distressing Emotions

Alongside emotional awareness, acceptance, and reframing, another essential emotion regulation skill is the ability to tolerate or 'sit with' difficult emotions. Tolerance can help us avoid unhealthy attempts to block unpleasant feelings (e.g., denial, substance use). We can develop emotional tolerance through various means. Applicable approaches include distraction, self-soothing, and relaxation training. Distress tolerance skills may be useful in stressful situations you cannot easily change. Thus, distress tolerance can be particularly helpful for carers in the context of a CID. Some of the distress tolerance techniques listed here come from the work of therapist Marsha Linehan, who is well-known in this area[302].

Distraction

Distraction is an important distress tolerance skill, and you can practice this technique in many ways. Like every coping strategy, use distraction in moderation. It should be a tool used on appropriate occasions. For example, it may be useful to practice distraction when you need to 'keep it together' (e.g., the person you support has a medical crisis), but not in the case of a worsening mental health problem. Here are some potentially useful distraction activities.

- Immerse yourself in a favourite activity (refer to the section on Flow in Chapter 6).
- Undertake activities that demand your full attention, or require high levels of skill (e.g., playing a complicated piece of music).
- Try an activity that is new or unfamiliar.
- Have a conversation with someone about a topic unrelated to the source of your distress.
- Undertake an activity that has a high probability of altering your emotional state (e.g., watching a funny movie).

Self-Soothing

Self-soothing involves engagement of the five senses to enhance the enjoyment of activities. You can pick an activity that incorporates several senses at once. Savouring (as discussed in Chapter 6) can be used to enhance self-soothing efforts. Self-soothing can comprise any of the following activities.

- Visual: Spending time looking at favourite scenery, photos, or artwork.
- Hearing: Listening to a favourite piece of music, playing an instrument, listening to nature sounds while out on a walk.
- Smell: Enjoying a favourite scent (e.g., aromatherapy).
- Taste: Eating a favourite food.
- Touch: Touching a favourite texture, pat an animal, have a bath or shower.

Other Distress Tolerance Activities

There are many other distress tolerance activities not mentioned to date in this section. Some of these include daydreaming or visualisation, reflecting on the positives of caring (e.g., an enhanced sense of purpose), yoga, meditation, Pilates, utilisation of spiritual beliefs and practices (e.g., prayer, chanting), going on a trip or holiday, and encouraging yourself through positive coping statements (e.g., 'I can get through this').

Relaxation Training

Relaxation training is another way to practice tolerance of unpleasant emotions and involves various types of exercises designed to promote the body's relaxation response (e.g., lowered heart rate and breathing[303]). We discuss examples of more commonly used relaxation approaches below, but there are many more options in this area. Relaxation techniques have shown promise for alleviating anxiety[304,305], depression[306] and insomnia[303]. These are some of the more common difficulties experienced by carers as previously discussed.

Questions exist around the merits of relaxation training, which often leads to the labelling of some relaxation techniques as 'promising' rather than 'proven'. Moreover, there is a restriction of purported relaxation benefits to a small number of outcomes. I am not going to evaluate the evidence for relaxation techniques further in this book. The primary take-home message is to do what works for you. Pursue this avenue further if one or some relaxation techniques provide meaningful benefit. Some of the attractive aspects of relaxation training are that they are generally safe (provided you take appropriate medical advice for any pre-existing medical conditions) and free from side-effects.

Progressive Muscle Relaxation (PMR)

PMR involves the tensing and relaxing of muscles throughout the body. Jacobson Relaxation is another name for this technique (after Edmund Jacobson, the pioneer of this approach). The rationale behind PMR is that the physical relaxation of the body can 'relax' the mind[307]. PMR has been applied to people with various physical and mental health issues. While the quality of studies evaluating the effectiveness of PMR is not always high, there appear to be some benefits for carer well-being[308]. There is also some potential for gains in people with various physical conditions[309], those undergoing medical treatments such as chemotherapy[310], and those affected by mental health conditions[311].

There are many good examples of PMR exercises (or 'scripts') that you can access online. You can find some of these provided in the Resources section. A typical PMR exercise has two phases for each muscle group; a tension and relaxation phase. You 'teach' the body to notice the difference between the sensations of tension and relaxation in the muscles. As with any relaxation training exercise, it is essential to practice regularly (i.e., daily), particularly while learning the technique. You should practice PMR in comfortable clothing and at a time and place where you will not be disturbed. If you are at risk of falling asleep, then it is best to sit on a chair. PMR shouldn't cause pain or discomfort. You should consult a qualified

health professional before beginning PMR if you have any medical conditions or injuries.

Guided Imagery

We mentioned visualisation in our discussion of distress tolerance techniques. Guided imagery is a similar concept where a person makes use of their imagination to visualise a relaxing scene (e.g., a beach or forest)[307]. This technique aims to exert a positive influence on your psychological or physiological state[312], such as reducing pain or anxiety[313]. As with PMR, evaluation of guided imagery effectiveness has been undertaken in the context of various medical and mental health conditions. Again, there are issues with the quality of this research, but there is some evidence that guided imagery is useful. For example, it has been evaluated in several medical contexts including cancer[314] and musculoskeletal pain[315]. There are many guided imagery resources available online. You can find some examples in the Resources section.

Summary

In this chapter, we have discussed emotion regulation by considering attitudes towards difficult emotions, awareness of emotional states, and the use of several techniques to manage emotions positively. Emotion regulation incorporates a key set of tools to manage difficult emotions, but it is important to experiment and find what works best for you.

Chapter 9

Working With Relationships & Social Support

Introduction

We discussed several issues relevant to carer relationships and social support in Chapter 4. This chapter is concentrated on strategies to address some of those issues. We start by taking stock of current and desired levels of social support. This discussion is followed by suggestions to develop and strengthen existing relationships. We will then talk about ways to increase levels of social support, and the role that can be played by social media in this regard. The chapter ends with some comments on coping with relationship changes.

Coping Within A Social Context

We have focused mainly on individual coping strategies in Part two of the book, but we can also think about coping in the context of relationships. Our coping decisions are embedded in our interactions with other people and have implications for those around you[316]. For instance, excessive use of alcohol to manage anxiety might lead to conflict with family members. Your coping efforts both influence and are influenced by other people. Elements of social circumstances that can shape coping include the number and type of friendships you have, and the frequency and nature of contact with other people[317]. While this mutual coping influence exists, you can attempt to choose the extent to which you involve others in your coping decisions. At one end of this continuum, you may attempt to cope with life's challenges in total isolation. At the other extreme sits close collaboration with other people[318].

While you can choose to go it alone, there are benefits to involving others in your coping efforts. Collaboration can provide coping resources

which may be otherwise unavailable to you. Social support can be framed as a form of coping assistance because strategies used to help others are the same as those used by people to help themselves deal with stress[319]. The message for carers is that you should consider what resources or support is available through people in your network. Viewing coping as something that occurs amongst relationships can open self-care options which may not exist in the absence of these people.

Taking Stock: Perception & Reality

We talked about the distinction between perceived and actual social support in Chapter 4. Your perceptions of social support influence your well-being, even when these impressions do not reflect reality. One reason for this discrepancy is that perceptions can form from subjective and unreliable information. Objectively taking stock of your social support circumstances represents a vital well-being activity for carers. Reflecting on assistance provided by friends and family may help to identify inaccurate social support assumptions and beliefs. You can consider this topic by evaluating ideal, realistic, and actual social support in your life.

Ideal Social Support

What would be your ideal (hoped-for) level of social support? Perhaps you are currently receiving this level, but we saw in Chapter 4 that most people would like more social support in their lives. Carers often express a desire for more help and suffer from high rates of loneliness and isolation. If dissatisfied with your current level of social support, it is essential to have a clear sense of how you want things to be different. Spend some time considering this by writing down what your ideal level of social support would look like in practical terms. You can use the worksheet in Appendix 7 to record this information. Consider some of the following questions when completing the first section of this worksheet.

- Which people would you see and spend time with?
- How often would you see them?
- What would you talk about?
- What activities would you do together?
- What would they do for you (e.g., practical tasks they would help with)?
- In what ways would you support them?
- How would you keep in contact with each other (e.g., phone calls, texts, in-person)?
- How would you signal to each other when help is needed?
- How would others behave towards you in your carer role?

- What beliefs and attitudes would other people have about carers?

Realistic & Actual Social Support

Feeling let down by others might indicate a discrepancy between ideal social support and what you can realistically expect from people. When ideal and actual support levels are aligned, you are unlikely to feel disappointed. But how do you know whether your support expectations are appropriate? One way to explore this question is by estimating what realistic social support looks like given your circumstances. People do not always provide the amount and type of desired support. In fact, ideal social support is rarely (if ever) achieved. We saw in Chapter 4 that many factors influence the social support received by carers. Other people have their own lives to live and various priorities to juggle. You can add compassion fatigue, lack of understanding, and barriers to seeking support to this mix. The result is the extent of unfulfilled support needs detailed earlier in the book.

You can consider your ideal level of support from the perspective of realistic social support. Estimating realistic social support helps to place ideal support into context. Appraising realistic social support can draw out unhelpful thoughts connected to ideal levels of assistance. Thinking errors might spring from ideal support expectations (e.g., 'My partner *must* always be there for me when I need to talk'). What does realistic social support look like given your current life circumstances and caring responsibilities? Remember to consider both quantity and quality (type) of assistance. You can record your response to this question in section two of the worksheet in Appendix 7. Find some additional questions to help you complete this section in the following list.

- How much time can members of your support network realistically devote to each other?
- What social support resources are available to you (e.g., who are the friends and family you can count on, which support groups do you attend, what online forums do you belong to)?
- What types of support are you able to access from friends and family (e.g., are there people who 'really get' your situation, is there someone you could call in the middle of the night, is there somebody you can have a 'light' distracting conversation with)?
- What are the barriers to accessing your social support resources (e.g., wanting to conceal aspects of your caring circumstances)?
- What relationship issues impair your ability to receive the support you need? How likely is it that you can successfully address these issues?

An essential point about realistic social support is that most people can only sustain a certain number of close friendships. Psychologist Robin Dunbar suggests there are 'layers' of friendships, with few very close relationships, a larger group of friends, and general acquaintances representing the most substantial of these layers[320]. Your social network might lack the capacity to provide the full range of ideal support needs if there are insufficient friendship 'resources' in one or more of these layers. You can also experience relationship 'churn' over time whereby it is natural for friendships to end. You should not necessarily see this as a failure. People's circumstances and general outlook on life can change. The carer role can dramatically alter your previous existence, thereby creating a new set of priorities, challenges, and social support needs that cannot be adequately met by an existing network of friends and family.

You can now consider actual social support received. Section three of the worksheet in Appendix 7 can be used to evaluate this aspect of assistance. Use this section to keep a simple diary of tangible assistance received from others. Keeping a record for two weeks should give you an adequate sample to represent usual levels of actual support. Try to pick a 'typical' fortnight where there are no major changes to your routine or behaviours. Social support comes in many forms, so be sure to note assistance received through a wide range of channels (e.g., in-person conversations, text messages, practical help). You can reflect on the information collated in this diary by referencing it to ideal and realistic support levels.

You can draw various conclusions from an estimation of ideal, realistic, and actual social support. You might conclude that you are closer than you realised to your ideal support circumstances. This discovery might prompt you to use the evidence for/against technique from Chapter 7 to challenge the belief 'No one supports me'. Alternatively, you might have previously over-estimated how close you are to your ideal social support. This scenario might indicate the use of strategies outlined later in this chapter. If actual support received falls short of realistic expectations, you might seek additional help. Whatever the conclusions made from this exercise, identifying social support concerns could highlight the need for adjustments to thoughts, expectations, or behaviours in yourself and other people. While you may not be able to make all these adjustments, you can at least use this exercise to have a clearer sense of your social support circumstances and the impact on well-being.

General Suggestions

Now that you have thought about the above aspects of social support, this section contains some general suggestions around strengthening your support network.

Practice Reciprocity

We talked about reciprocity in Part one of the book. Being reciprocal entails and openness to giving *and* receiving of support with others (bearing in mind your caring responsibilities). People tend to view relationships more positively when there is a degree of this give-and-take. Reciprocity does not have to involve grand acts. Simple gestures such as sincere interest in the response to a "How are you?" question can be of great value to a relationship. While reciprocity is important, you should always look after yourself first and foremost. Caring may be such a big part of your life that you over-identify with this role, and effectively become a carer to multiple people. Remember the receiving component of reciprocity!

The person you support may struggle when unable to provide practical or emotional assistance back to you. You can respond by jointly generating ideas of how they can make manageable but meaningful contributions to your daily life. People affected by a CID sometimes battle guilt about the demands faced by carers and/or encounter thoughts of being 'useless' or unproductive. Reciprocation can provide some relief under these conditions. Doing something for the carer may come at a cost (e.g., increased fatigue), but this cost may be less significant than the benefits brought about through reciprocity (e.g., strengthening of valued identities).

Being Informed About CID

Many carers I have met are very knowledgeable about the medical condition or disability affecting the person they support. Yet friends and family may be less informed. Learning about a disease can help people to understand the physical and psychological challenges involved with caring. Friends and family may struggle to respond in a helpful way when they do not understand some of the realities of your life. My experience is that people often want to be supportive, but they are unsure how to put this into practice. Learning about a CID may be an excellent way to counter any helplessness they might be experiencing. You may wish to vary the topics and amount of detail provided to each person, and you are totally entitled to do so. You are not obliged to spill the full realities of your life to an unrestricted public view.

Providing an accurate understanding of your life as a carer may be uncomfortable. As previously mentioned, carers can be motivated to conceal or downplay the difficulties faced by themselves or care recipients. There are many ways to manage this discomfort and I will mention a few approaches here. One way to communicate carer challenges indirectly is to suggest concrete ways in which people can be most helpful to you. I have suggested this approach to carers who are uncomfortable talking directly

about the psychological difficulties they face. You can encourage people to learn about a medical condition or caring challenges in general terms if you feel awkward about disclosing information about your specific circumstances. Writing about your caring challenges might be more comfortable than speaking face-to-face with others. You could share this account with selected people at a time that feels appropriate. Asking other people to share the challenges they face in supporting you as a carer may encourage a more reciprocal conversation that reduces the attention on you to a more acceptable level.

Taking Breaks

Irrespective of your ability to temporarily step away from your caring responsibilities, a break or respite is vital for the well-being of the carer (particularly within intense caring situations). There is some evidence that formal respite provides benefits for carers and the people they support[321,322,323], but additional high-quality studies are required to confirm these preliminary positive outcomes[322]. Taking breaks from caring may be difficult. Carers can experience uncomfortable emotions such as guilt or anxiety when handing over caring responsibilities to others. You might worry about the care recipient's response to your need for time-out. Carers can also experience conflicting thoughts and feelings when returning to their caring situation[324].

The strategies discussed in Chapters 6 and 7 may be a useful starting point to tackle these hurdles. You may also benefit from addressing these issues directly with the person you support (if possible and appropriate). You can consider this in a general way by initially talking about the importance of breaks for both people. Alternatively, you could have a discussion with trusted friends or family members. If surrendering caring responsibilities is difficult, you could do this gradually where possible. For instance, you could have a friend spend a short period with the person who requires support while you do something for yourself. This support may only need to be an hour or two.

Practising Listening Skills

Listening skills are fundamental to healthy relationships. Employing effective listening practices can be especially tricky under stressful circumstances. Effective listening comes under the umbrella of communication skills. The latter has significant links with relationship satisfaction[325]. There are many resources available on general communication skills (see the Resources section for more). Listening skills are the aspect of communication targeted here because they involve

abilities that most people can develop. Here are some pointers if you want to build positive listening skills.

- Focus on the person
    - Make appropriate eye-contact.
    - Minimise distractions (e.g., put away your mobile phone).
    - Try to be patient and do not rush the person to talk.
- Listen intentionally
    - Do not interrupt.
    - Listen as if you will need to tell someone else what you heard.
    - Support the person who is speaking with positive body language (e.g., nodding appropriately, facing the person) or use encouraging sounds and speech (e.g., "Tell me more about that").
- Provide occasional summaries
    - Make short, regular summaries of what the person tells you.
- Clarify
    - Ask questions for elaboration purposes when you hear something you don't understand.

Utilise Groups

Psychologist Robin Dunbar suggests that doing activities within groups can be particularly beneficial for our well-being[320]. Engaging in positive group-based activities (e.g., singing, dancing, playing a sport, taking an art class) can trigger a physiological response (e.g., release of endorphins) that delivers a sense of belonging with others. Taking up hobbies that involve interaction with like-minded people can be another way to enhance your social network. There are also many support groups available for carers in most major towns and cities.

Social Media

Some carers can feel detached from the lives of friends and family. This perception may be particularly intense when supporting someone at home with minimal outside assistance. Disconnection and social isolation feel unpleasant and can lead to other problems (e.g., unchecked negative thinking patterns). Maintaining a connection with others is therefore essential to well-being. We now have various means by which we can communicate with people. Carers often need to take advantage of multiple

communication mediums to overcome physical and psychological barriers to accessing social support.

Social media can be an effective means to obtain or increase support and informational resources. Social networking sites and blogs are the most commonly accessed forms of social media for carers, and these resources are primarily used by this group for self-care[326]. Carers use social media for other psychological or emotional purposes including documenting the course of an illness, disclosing the emotional impact of caring, awareness and advocacy, sourcing support, and communicating appreciation for help received[327].

One social media platform, Facebook, has been shown to help with relationship continuity, and particularly with practical support[328]. There are potential benefits here for carers (e.g., supporting those who cannot easily visit friends in-person), but you should consider the way in which social media is used. Online communication directed specifically towards friends may have positive relationship effects, whereas disclosures to a broad social media audience (e.g., 'broadcast posts') may be associated with adverse outcomes[329]. Targeted communication can enhance relationships via multiple mediums (of which social media represents one channel[324]). Hence, carers should use various communication avenues to stay connected with friends and family, and not rely too heavily on social media.

Coping With Relationship Changes

A CID can change relationships with friends, family, and the care recipient. For instance, you may experience a loss of intimacy when the cared-for person is your partner, or relationship ties may weaken as you see friends less regularly due to care commitments. Such changes can represent major life losses. Acknowledging these losses is vital along with seeking support to aid coping. Efforts to keep relationships 'normal' is a common reaction to relationship changes as discussed previously in the book. Jointly discussing this process can help you to adapt to these changes effectively. Relationships are always altering, but illness and disability may speed up this process or set your relationship on an unwanted course. Accepting the principle that change is inevitable may help you to focus on positive adjustment efforts, rather than holding on to pre-CID life in unhelpful ways.

Some people find it useful to think about 'the new normal', rather than a pre-illness state of normality. The former acknowledges that change happens but can be accommodated. The new normal may involve finding new or different ways to feel connected with the person you support. For couples, the loss of intimacy can be particularly challenging. A loss of intimacy represents a change to a relationship element that is unique and usually not shared with others. The new normal in other circumstances

might involve an unexpected extension to a pre-caring relationship (e.g., a parent caring for an adult son or daughter) or taking on a role earlier than expected (e.g., caring for a parent from a young age).

Change in a relationship is usually not formally acknowledged, so it is important to discuss this issue with the relevant people where possible. You might want to specifically grieve these losses through events or activities that feel appropriate for you (e.g., write letters, have conversations, share memories, photographs, mark anniversaries of treasured holidays). You may generate ways to create a new normal. If your relationship with the person you support allows for open conversation about shared identity and relationship changes, you may wish to discuss some of the following questions with each other.

- In what ways is our relationship different to before our caring partnership began?
- What have we lost and what have we gained in our relationship?
- How would our relationship be different if the CID had never occurred?
- How have the changes in our relationship impacted us as individuals?
- What are we doing well to cope with these changes?
- In what way could we improve our joint coping or where do we need extra help to manage better as a partnership?
- When is it helpful to act as a team, and when is it healthy to focus on our own identities or needs?

Summary

Relationships and social support lie at the heart of your carer role and efforts to maintain your well-being. In this chapter, we have seen that reflecting on your social support and relationship circumstances is an important way to accurately appraise your relationship challenges. Communication with others is equally important and can help you to negotiate these issues through sharing of adversity, defining support roles, and allocating tasks to ease the burden of caring. This chapter has illustrated some of the many ways in which carers can strengthen relationships and their social support network.

Epilogue

Bereavement & Beyond Caring

Caring eventually ends for most people. This might occur through a change in health status of the person you support, bereavement, or by handing over care responsibilities. You are likely to experience an enormous mix of feelings and thoughts, irrespective of the circumstances. There may be a sudden and dramatic change to your routine, particularly if you provided intensive support. There may be new challenges, roles, or opportunities to navigate; starting or returning to work, a loosening of restrictions on your time, facing a changed relationship with the person you support, or dealing with their death. The changes encountered may trigger a period of reflection on your experiences and even a remoulding of identity. There may be a stocktake of how you thought, felt, and behaved as a carer. These issues represent substantial challenges and adjustments to negotiate. We reflect on some of these topics in this section of the book.

Loss & Adjustment

People often experience an end to their carer role through bereavement, but the grief process may commence well before the death of a loved one as multiple losses are encountered (e.g., loss of companionship, freedom[330]). It seems a cruel blow to face mourning at the end of what can be a stressful and even painful period of life. Charlotte's death occurred suddenly in my case. She was admitted to the local hospice 12 days before she died. Her stay was initially intended to be temporary. She was supposed to have some treatment for a couple of weeks then go home.

I was called by a hospice staff member early one morning. I was putting my shoes on before heading out the door to see Charlotte. "I am sorry Jason, but your wife has died". Like so many times in my caring experience, I turned into robot mode to survive the immediate situation. I asked some practical questions during the phone call, then had a friend take me to see

Charlotte. While the news of her death itself was not a shock, the speed of her final decline was disturbing and numbing. Her death was part of an ongoing grief process which started when she was first diagnosed. On one level, Charlotte's cancer survived her death and the disease continues to be battled. The form it takes and the issues to confront have morphed over time. While making life difficult, this has also presented valuable new opportunities for reflection and learning.

Seeing Charlotte's body just an hour or so after she died was a surreal experience. I had accumulated many hundreds of hours watching her resting or sleeping over the years. She looked as if she was napping when I saw her body. I waited for her to open her eyes and look at me, but of course, she did not. Charlotte's body was in front of me, but the woman I knew was gone. I was with her for only a few minutes in that room. I told her that I loved her and that I was sorry for not doing a better job at being a carer, husband, and friend.

For many months, Charlotte's disappearance from my life did not seem real. Exposure to a person's death is an experience so earth-shattering that your brain can take a long time to catch up with reality. I cannot think of any other situation where you are so utterly removed from life's steering wheel. Mourning the death of a loved one is like trying to ride a wild horse. One-minute, grief is quietly grazing, next you are on its back as it violently attempts to throw you off. My brain started to repeat the hundreds of awful moments I had experienced while Charlotte was alive. I operated in survival mode for much of my caring experience. I could not afford to dwell on our circumstances while Charlotte was needing my support. I simply would not have coped. That handbrake was released once she was gone. My body was full of the worst memories and my brain had begun the necessary task of trying to process all that had happened in the previous years.

Talking to other people is an important way to help cope with your brain's attempts to process difficult and traumatic periods of life. But I was cautious about whom I spoke to. There was too much awful stuff in my head. The importance of selective disclosure was magnified when on the receiving end of inadvertently unhelpful responses; "Things will get better", "Give it a year". Each grieving person's needs are different. These needs can change from day-to-day, and even moment-to-moment. Being encouraged to talk might be useful one day and totally unhelpful the next. This makes life difficult for those who want to provide support.

The profound changes in my life were difficult to understand and come to terms with. The death of an immediate family member rocks every corner of life. The changes and challenges I had to contend with were unique and not experienced by others in my social circle. Other people were coping with an excruciating loss but had their partners and/or children and routines to provide a sense of continuity. I was a carer one day, and seemingly nothing the next. Caring had become a master identity,

but the intense purpose brought by this role was swiftly wiped out. I felt like a traveller who had lived many years away from home, then unwillingly arrived back to my place of origin only to find it to be unrecognisable. I had to remould an identity based on a non-carer life. I had to find a new purpose.

The world's best carer will have regrets about their approach to supporting a loved one. I was *not* the world's best carer. You can see where this is going! Charlotte's suffering existed only in my mind once she had gone. The emotional pain intensified because I could do nothing to make up for the times I was grumpy or took her for granted. I could not try to rectify the behaviour that disappointed me. I burned out and depleted my energy stocks before Charlotte died. I would do anything to go back in time and give that version of myself a shot of superhuman strength. Some carers simply run out of puff when a care recipient survives beyond an expected point[27]. Death is a powerful reminder of the fact that you cannot change your past behaviour. You cannot eliminate regret from your life, but you can encourage yourself to keep learning and moving in a direction whereby you have an increasingly positive impact on the world. I am not the first to say that mistakes can be our best teacher.

Meaning & Perspective

A CID that involves prolonged suffering can make you think about the meaning of life. Some people assume there is a purpose to pain, and that's fine. I do not personally believe this though. As a living organism with a central nervous system and capacity for higher-order cognitive functioning, we humans cannot escape physical or psychological anguish. Some people will be incredibly unlucky and experience a terrible illness that results in several lifetimes' worth of adversity. Life is not fair. The more you fight this fact, the more suffering you will probably endure. Acceptance does not have to be about giving in. It can be about wisely acknowledging what you can and cannot control in life.

The caring role left me with a new lens through which to view the world. The many unique experiences encountered can reshape who you are as a person, changing your view on life and people. Caring will often represent an influential phase of life entailing both positive and negative changes. You may come to see the world as an incredibly unfair place and/or develop a strong desire to make the most of your health, time, and relationships. You are not defeated if you acknowledge that the world is not all candy floss and kittens. Seeking a balanced perspective on life is a useful well-being strategy.

No Longer A Carer

I have mentioned above the monumental adjustment I had to make when my caring role ended. I had to start reminding myself that I no longer needed to listen out for Charlotte's cries or groans of pain. I was no longer a faux-medic. I had to tell myself that I could make plans to see friends. All the while I was battling to convince myself of my new reality. 'How can someone die?' There was modest respite gained through an end to Charlotte's suffering, but there was also much grief and anxiety about what was in store for my post-caring life. A weird mix of thoughts and emotions that could not be understood or processed quickly. These were just a few of the massive psychological challenges I faced.

My entire body was telling me to crawl down a hole and not come out after Charlotte died. I couldn't allow this to happen. Charlotte would not want this for me, and I could not allow a second tragedy to occur by giving up on life. I kept going by thinking about what made me happy. In the end, I recalled my happiest moments have involved spending time with other people and feeling connected to them. It doesn't matter what makes *you* happy, provided you're not beating people up, running a drug cartel or supporting the wrong rugby team. A degree of courage is sometimes required to admit what's important to you, particularly if this is something not valued by the mainstream. I believe the experience of caring made me a better person, and I was motivated to build on this. Psychological adversity tested my confidence in achieving this progression, but I tried to remain hopeful about the future.

Well-Being After Caring

Post-caring well-being outcomes vary considerably from person-to-person. Some people report poor psychological functioning after caring responsibilities cease[133,139], while others experience improved mental health (e.g., decline in depressive symptoms[331]). The death of a loved one can provide a degree of relief after a prolonged period of care[331], but a substantial proportion of carers are practically and emotionally unprepared for bereavement[332]. Grief severity appears to be associated with psychological distress before the death of a loved one[333,334], the nature of the caring relationship (grief tends to be more severe for spouses), the intensity of caring, and financial disadvantage[335,336]. Irrespective of the way caring ends for you, it is important to remember that no two carers will travel down the same post-caring pathway. Obtaining psychological assistance after caring is as important as receiving support while actively providing care. The presence of other identities or roles at the end of caring may also help people transition into a post-carer life[49].

Summary & Reflection

We identified and described a range of carer psychological experiences in this book. We learned that carers are a varied group of people, both in their personal characteristics and caring circumstances. Identity issues play a role in determining the approach to and coping with the carer role. We also saw that carers can face many individual psychological challenges and relationship issues. These difficulties are a normal consequence of the battles undertaken by people dealing with a CID. Promoting positive well-being in carers requires us first to normalise (non-clinical) psychological difficulties, address the basics of self-care, and utilise a range of additional strategies in service of a flexible coping style responsive to the demands of a given situation. Coping does not take place in a vacuum. Developing supportive relationships and working with others to promote positive well-being strategies allows carers to maximise available support.

Adequately summarising my carer experiences is tricky. Caring for a loved one simultaneously exposed me to life's beauty and harsh realities. You are asked to be at your best at the worst of times. The expression of love, loyalty, compassion, and support through caring can represent the best of us. Supporting someone with a CID might expose you to your greatest fears: Pain, suffering, injustice, and the discovery that you have minimal control over life. A willingness to care requires an agreement to suffer alongside the person you support. This sacrifice is made to honour another person's life and to protect that which can be preserved of an existence compromised by illness and disability.

It is easy to forget that the worth you apply to another person's life through caring is equal to the value that should be applied to your own life. We discussed the many ways carers can suffer throughout the book. The focus of care and support naturally gravitates towards the person with a CID, but a carer's welfare is equally important. Carers and care recipients should be seen as a team, jointly living with a life-defining challenge. A CID has a physical manifestation (e.g., tumour, pain, bodily malfunction), but it also has psychological and interpersonal consequences. Carers experience psychological and interpersonal effects alongside the person in whom the condition physically resides. When this is genuinely recognised and backed up with appropriate support, we will be truly forging a map for the carer's journey.

Charlotte

And finally. As a tribute to Charlotte and all those who loved her, here is a section of the eulogy I gave at her funeral:

...So, we are here today. I have thought about this day for many years and wondered what it would be like. I think this is a beautiful day. Beautiful because all the love Charlotte gave and received has been captured in this room, right at this moment. She has left an enormous hole, but she wants us to fill that hole by loving and supporting each other. She is free, she is happy, she will watch, and she will wait until we are all together again. Charlotte has gone before us because her bravery provides her the strength to lead the way. She loved all of me, and we all love her.

Appendices

Appendix 1: Barriers To Taking Breaks

Physical/logistical barriers	Potential solution(s) or who/what could help to find solution	Psychological Barriers	Potential solution(s) or who/what could help to find solution

Appendix 2: Example Activity Diary*

	Monday	Tuesday	Wednesday	Thursday	Friday
7am	*Helping John shower etc*	*Helping John*	*Helping John*	*Helping John*	*Helping John*
8am	*Breakfast and housework*	*Breakfast*	*Breakfast*	*Home help visit*	*Shopping*
9am	*Housework*	*Dr appt*	*Community nurse*	*Home help visit*	*Shopping*
10am	*Talking to John*	*Dr appt*	*Community nurse*	*Hospital appointment*	*Housework*
11am	*Housework*	*Dr appt*		*Hospital appointment*	*Took John for a walk*
12pm	*Lunch*	*Lunch*	*Lunch*	*Hospital appointment*	*Lunch*
1pm	*Work*	*Work*	*Work*	*Lunch*	*Rest*
2pm	*Work*	*Work*	*Work*	*Household paperwork*	*Visit from community nurse*
3pm	*Work*	*Work*	*Work*	*Household paperwork*	*Phone calls to home support*
4pm	*Work*	*Work*	*Work*	*Took John to the mall*	*Housework*
5pm	*Work*	*Work*	*Work*	*Took John to the mall*	*Visit from friend*
6pm	*Cook dinner*	*Cook dinner*	*Cook dinner*	*Cook dinner*	*Cook dinner*
7pm	*Eat dinner*	*Eat dinner*	*Eat dinner*	*Eat dinner*	*Eat dinner*
8pm	*Shower*	*Housework*	*TV*	*Visit from friend*	*TV*
9pm	*Got to bed*	*Housework*	*TV*	*Visit from friend*	*TV*
10pm	*-*	*Go to bed*	*Go to bed*	*Housework*	*TV*
11pm	*-*	*-*	*-*	*Go to bed*	*Go to bed*
12-7am	*-*	*-*	*-*	*-*	*-*

* Saturday and Sunday omitted to fit page

Appendix 3: Mood, Stress/Anxiety Diaries

Mood Diary

Date	
Average mood score today*	
What was happening at the point of your highest (best) mood score?	
What was happening at the point of your lowest mood score? **What thoughts can you recall from the point of your lowest mood score?**	
What did you do to cope with low mood today? **How effective was this/these strategies?****	
What have you learned today about what influences your mood and how you can effectively respond to low mood?	

*Use a scale from 0-10 where 0= Lowest mood ever, 5=Neither happy nor sad, 10= Happiest mood ever

**Use a scale from 0-10 where 0= Totally ineffective, 5= Moderately effective, 10= Very effective

Stress/Anxiety Diary

Date	
Average anxiety/stress level today*	
What was happening at the point of your highest score? **What thoughts can you recall from the point of your highest score?**	
What was happening at the point of your lowest score?	
What did you do today to cope with anxiety/stress? **How effective was this/these strategies**?**	
What have you learned today about what influences your stress/anxiety and how you can effectively respond to high stress/anxiety levels?	

*Use a scale from 0-10 where 0= no stress/anxiety, 5= Moderate stress/anxiety, 10= severe stress/anxiety

**Use a scale from 0-10 where 0= Totally ineffective, 5= Moderately effective, 10= Very effective

Appendix 4: Thought Diary

Situation	Thought	Emotion(s) experienced	Comments
Sitting at home alone on Saturday night 9pm watching TV	'Nobody wants to spend any time with me'	Sad, angry	Overgeneralising ('nobody')
Waiting at the hospital for a consultant appointment on Friday 3pm	'I can't cope with all these hospital trips. I'm going to fall apart'	Anxious, stressed, scared	Catastrophising ('fall apart')
Talking to the GP on the phone Thurs 10am about medication	'She's ignoring me, she doesn't care'	Angry, frustrated	Mind reading ('she doesn't care)
Lying in bed wide awake 3am Tues morning	'This is not the life I wanted for myself. Life will never improve'	Helpless, angry, sad	Fortune telling ('life will never improve')

Appendix 5: Completed Evidence For/Against Example

Step 1: Write down the thought
I can't emotionally cope with my child's illness

Step 2: Record evidence for and against

Evidence for	Evidence against
I always get upset when my child looks unwell	I have survived to this point despite many difficult moments
I don't ever seem to feel happy anymore	Last week I held it together well at the hospital appointment
I have far more anxiety in my life than before	I have been able to talk positively with my child at times
I rely on other people more to make me feel better	I am able to distract myself from feeling bad when it is important to do so

Step 3: Evaluate accuracy of thought
I generally manage to cope and get important jobs done despite feeling bad.

<div align="center">OPTIONAL</div>

Step 4: Consider the quality of the evidence
The first two points in the 'evidence for' column is an example of overgeneralisation.

The forth (last) point in the 'evidence for' column makes it seem like it is not ok to get support from others. It is normal and healthy to get support from others, especially given the situation I am in.

This evidence would not stand up well in a court room and unhelpful thoughts might occur more often when I overgeneralise.

Step 5:
There seems to be frequent overgeneralising
It might be helpful to think of specific times when I feel upset/unhappy and times when I feel a bit better

Appendix 6: Emotions Diary

Setting	Thoughts	Feelings	Sensations	Urges
Tues 4th August, 2pm	'How am I possibly going to get all my work done today	Anxious, panic	Tingling in my arms, churning stomach, racing heart	Hit the desk, run out the door
Sat 8th August, 4am	'This going to be another stressful weekend'	Stressed, apprehensive	Churning stomach, lightheaded, aching muscles	Run away
Monday 10th August 9am	'I want my old life back'	Depressed, resentful	Heaviness in the legs, headache,	Yell at someone

Appendix 7: Ideal Social Support

Section 1: Ideal Social Support
Describe your ideal social support circumstances below. Use the questions on pg. 107 to help you with this.

Section 2: Realistic Social Support
Describe what would be a realistic level of social support given your current life and caring circumstances.

Section 3: Social Support Diary

Resources

Chapter 5: The Basics & General Strategies

<u>Diet</u>
https://www.carersuk.org/help-and-advice/health/nutrition/eating-well

https://nutriciahomeward.co.uk/upload/SCC2980_Carers_UK_eating_well_for_carers.pdf

https://www.nutrition.org.uk/healthyliving/healthydiet/eatwell.html

http://www.rcpsych.ac.uk/healthadvice/problemsanddisorders/eatingwellandmentalhealth.aspx

http://foodandmoodcentre.com.au/

<u>Exercise</u>
https://www.huffingtonpost.com/dave-smith2/free-online-workout_b_7722024.html

https://www.hhs.gov/fitness/resource-center/physical-activity-resources/index.html

https://makeyourbodywork.com/how-to-exercise-at-home/

<u>Sleep</u>
www.sleepio.com

https://www.mind.org.uk/information-support/types-of-mental-health-problems/sleep-problems/#.WpVltpfLiUk

www.sleepfoundation.org

https://www.nhs.uk/Livewell/insomnia/Pages/bedtimeritual.aspx

Sleep diary:
https://www.nhs.uk/Livewell/insomnia/Documents/sleepdiary.pdf

Edinger, J D., & Carney, C. E. (2008). Overcoming insomnia: A cognitive-behavioural therapy approach workbook (Treatments that work). Oxford: Oxford University Press.

Espie, C. A. (2006). Overcoming insomnia and sleep problems: A self-help guide using cognitive behavioral techniques. London: Constable & Robinson.

Optimism
'Best possible self' instructions:
https://greatergood.berkeley.edu/pdfs/optimism_intervention.pdf

Chapter 6: Working With Thoughts 1

Cognitive Defusion/Acceptance & Commitment Therapy (ACT)
Hayes, S. & Smith, S. (2005). *Get out of your mind & into your life*. Oakland: New Harbinger.

Harris, R. (2008). *The happiness trap*. London: Constable & Robinson.

Mindfulness
Alidina, S. (2015). *Mindfulness for dummies*. Chichester: John Wiley & Sons Ltd.

Williams, M., & Penman, D. (2011). Mindfulness: A practical guide for finding peace in a frantic world. London: Piatkus.

Collard, P. (2014). The little book of mindfulness: 10 minutes a day to less stress, more peace. London: Gaia.

Hanh, T. N, (1987). The miracle of mindfulness. Boston: Beacon Press.

Breath/breathing:
https://www.mindful.org/a-five-minute-breathing-meditation/
https://www.getselfhelp.co.uk/docs/MindfulBreathing.pdf

Body scan:

https://www.youtube.com/watch?v=CyKhfUdOEgs

Mindful eating:
http://www.mindfulnessdiet.com/program/articles/a-mindfulness-eating-exercise-simple-instructions

Other mindfulness resources:
https://www.actmindfully.com.au/free_resources_audio

https://www.headspace.com/blog/2014/11/19/walk-into-a-mindful-moment/

Flow
https://www.psychologytoday.com/gb/blog/raising-happiness/201509/3-steps-finding-your-flow

https://www.psychologytoday.com/us/articles/199707/finding-flow

https://www.ted.com/talks/mihaly_csikszentmihalyi_on_flow

Csikszentmihalyi, M. (2002). *Flow: The classic work on how to achieve happiness* (Revised Ed.). London: Rider.

Savouring
https://www.psychologytoday.com/us/blog/what-matters-most/201602/being-positive-it-s-not-mindfulness-it-s-savoring

https://greatergood.berkeley.edu/article/item/10_steps_to_savoring_the_good_things_in_life

Chapter 7: Working With Thoughts 2

Problem-Solving
http://www.slamrecoverycollege.co.uk/uploads/2/6/5/2/26525995/cfy_5_problem_solving_and_goal_achievement.pdf

http://www.heretohelp.bc.ca/wellness-module/wellness-module-4-problem-solving

http://www.cci.health.wa.gov.au/docs/Info-Problem%20Solving.pdf

Chapter 8: Emotion Regulation

Awareness of Emotions

https://en.wikiversity.org/wiki/Motivation_and_emotion/Book/2014/Plutchik%27s_wheel_of_emotions

Tolerance of Emotions
Progressive Muscle Relaxation (PMR):
https://www.youtube.com/watch?v=86HUcX8ZtAk

Self-Compassion
Lovingkindness meditation:
https://www.tarabrach.com/guided-meditation-loving-kindness/

Compassionate writing exercises:
http://self-compassion.org/exercise-3-exploring-self-compassion-writing/

https://chrisgermer.com/wp-content/uploads/2017/01/Compassionate-Letter-to-Myself.pdf

https://ggia.berkeley.edu/practice/self_compassionate_letter#

Epilogue: Bereavement & Beyond Caring

https://www.mariecurie.org.uk/help/support/being-there/end-of-life-preparation/life-after-caring

Carer Organisations

<u>International</u>
International Alliance of Carer Organisations
http://www.internationalcarers.org/

Embracing Carers
https://www.embracingcarers.com

<u>Online Information & Support</u>
Carers rights movement (Wikipedia):
https://en.wikipedia.org/wiki/Carers_rights_movement

Unpaid Carers Support Group
https://www.facebook.com/groups/43692899949/

Shine Cancer Support Plus Ones
https://www.facebook.com/groups/shineplusones/

Memory People
https://www.facebook.com/groups/180666768616259

Dementia Caregivers Support Group
https://www.facebook.com/groups/672984902717938

Alzheimer's Online
http://alzonline.phhp.ufl.edu/

Caregivers Assist Support Group
https://www.facebook.com/groups/CaregiversAssistSupportGroup

The Caregiver Space
http://thecaregiverspace.org/

<u>UK</u>
Carers UK
https://www.carersuk.org/

Carers Trust
https://carers.org/

Carers Network
http://carers-network.org.uk/

Carer's Federation
https://www.carersfederation.co.uk/

Carers Direct
https://www.nhs.uk/conditions/social-care-and-support/

Young Carers Research Group
http://www.ycrg.org.uk/

Barnardo's young carers
http://www.barnardos.org.uk/what_we_do/our_work/young_carers.htm

Rest of Europe
Eurocarers
http://www.eurocarers.org/

Care 2 Work
http://www.care2work.org/

Coface
http://www.coface-eu.org/campaigns-2/family-carers-eu/

US
National Caregivers Library
http://www.caregiverslibrary.org/home.aspx

Caregiver Action Network
http://caregiveraction.org/

National Alliance for Caregiving
http://www.caregiving.org/

Aging Care
https://www.agingcare.com/

Caring.com
https://www.caring.com/

Alzheimer's and Dementia Caregiver Centre
https://www.alz.org/care/

Cancer Support Community
https://www.cancersupportcommunity.org/caregivers

Resources

CancerCare
https://www.cancercare.org/tagged/caregiving

Cancer Net
https://www.cancer.net/coping-with-cancer/caring-loved-one

<u>Australia</u>
Carers Australia
http://www.carersaustralia.com.au/

Carer Gateway
https://www.carergateway.gov.au/

<u>Canada</u>
Carers Canada
http://www.carerscanada.ca/

<u>New Zealand</u>
Carers New Zealand
http://carers.net.nz/

<u>Singapore</u>
NUS carer groups
http://www.nus.edu.sg/uhc/resources/articles/caregiver-support-grps.html

Carers SG
https://www.facebook.com/CarersSg/

Caregivers Alliance
http://cal.org.sg/

<u>South Africa</u>
Young Carers SA
http://www.youngcarers.org.za/

General Online Mental Health Resources

<u>UK</u>
Mental Health Foundation
https://www.mentalhealth.org.uk/

Mind
https://www.mind.org.uk/

Rethink
https://www.rethink.org/

British Psychological Society
https://www.bps.org.uk/

<u>Rest of Europe</u>
Mental Health Europe
https://mhe-sme.org/

European Federation of Psychologists' Associations
http://www.efpa.eu/

<u>US</u>
National Institute of Mental Health
https://www.nimh.nih.gov

Anxiety and Depression Association of America
https://adaa.org/

MentalHealth.gov
https://www.mentalhealth.gov/

National Alliance on Mental Illness
https://www.nami.org/

Canadian Mental Health Association
https://cmha.ca/

American Psychological Society
http://www.apa.org/

<u>Canada</u>
Mental Health Commission of Canada
https://www.mentalhealthcommission.ca/English

Canadian Psychological Association
https://www.cpa.ca/

Australia
Mental Health Australia
https://mhaustralia.org/

SANE Australia
https://www.sane.org/

Australian Psychological Society
https://www.psychology.org.au/

New Zealand
Mental Health Foundation of New Zealand
https://www.mentalhealth.org.nz/

New Zealand Psychological Society
http://www.psychology.org.nz/

References

1. Burgio, L. D., & Gaugler, J. E. (2016). Caregiving for family members with chronic illness. In L. D. Burgio, J. E. Gugler, and M. M. Hilgeman (Eds.), *The spectrum of family caregiving for adults and elders with chronic illness* (pp. 1-14). Oxford: Oxford University Press.

2. NHS England. (2018). *Carer facts- why investing in carers matters*. Retrieved from https://www.england.nhs.uk/commissioning/comm-carers/carer-facts

3. Carers UK. (2015). Facts about carers 2015. Retrieved from https://www.carersuk.org/for-professionals/policy/policy-library/facts-about-carers-2015

4. OECD. (2011). *Help wanted? Providing and paying for long-term care.* OECD Health Policy Studies. Paris: OECD Publishing. Retrieved from https://read.oecd-ilibrary.org/social-issues-migration-health/help-wanted_9789264097759-en#page1. doi: 10.1787/9789264097759-en

5. Barbosa, A., Figueiredo, D., Sousa, L., & Demain, S. (2011). Coping with the caregiving role: Differences between primary and secondary caregivers of dependent elderly people. *Aging & Mental Health, 15*(4), 490-499. doi: 10.1080/13607863.2010.54366

6. Bernell, S., & Howard, S. W. (2016). Use your words carefully: What is a chronic disease? *Frontiers in Public Health, 4*, 159. doi: 10.3389/fpubh.2016.00159

7. Luhmann, M., Orth, U., Specht, J., Kandler, C., & Lucas, R. E. (2014). Studying changes in life circumstances and personality: It's about time. *European Journal of Personality, 28*(3), 256-266. doi: 10.1002/per.1951

References

8. Calhoun, L., & Tedeschi, R. (2006). The foundations of posttraumatic growth: An expanded framework. In L. Calhoun and R. Tedeschi (Eds.). *Handbook of Posttraumatic Growth* (pp. 1-23). New York: Routledge.

9. Lucas, R. E. (2007). Adaptation and the set-point model of subjective well-being: Does happiness change after major life events? *Current Directions in Psychological Science, 16*(2), 75-79. doi: 10.1111/j.1467-8721.2007.00479.x

10. Bleidorn, W., Hopwood, C. J., & Lucas, R. E. (2018). Life events and personality trait change. *Journal of Personality, 86*(1), 83-96. doi: 10.1111/jopy.12286

11. Hentschel, S., Eid, M., & Kutscher, T. (2017). The influence of major life events and personality traits on the stability of affective well-being. *Journal of Happiness Studies, 18*(3), 719-741. doi: 10.1007/s10902-016-9744-y

12. Miller, K. I., Shoemaker, M. M., Willyard, J., & Addison, P. (2008). Providing care for elderly parents: A structurational approach to family caregiver identity. *Journal of Family Communication, 8*(1), 19-43. doi: 10.1080/15267430701389947

13. Union for International Cancer Control (2018*). What is world cancer day?* Retrieved from www.worldcancerday.org./about.

14. Carers UK. (2017). Unpaid carers missing out on vital support as 'public is unable to recognise friends and family that care'. Retrieved from https://www.carersuk.org/news-and-campaigns/press-releases/unpaid-carers-missing-out-on-vital-support-as-public-is-unable-to-recognise-friends-and-family-that-care

15. National Alliance for Caregiving. (2015). Caregiving in the U.S: Executive summary. Retrieved from http://www.caregiving.org/wp-content/uploads/2015/05/2015_ Caregivinginthe US_Executive-Summary-June-4_WEB.pdf

16. Family Caregiver Alliance. (2015). Selected long-term care statistics. Retrieved from https://www.caregiver.org/selected-long-term-care-statistics

References

17. Carers UK. (2016). State of caring report 2016. Retrieved from https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2016

18. Larkin, M., Henwood, M., & Milne, A. (2018). Carer-related research and knowledge: Findings from a scoping review. Health and Social Care in the Community. Advanced online publication doi: 10.1111/hsc.12586.

19. Department of Health (2012). *Long-term conditions compendium of information* (3rd Ed.). Leeds: Long Term conditions.

20. Office for National Statistics. (2017). Overview of the UK population: July 2017. Retrieved from https://www.ons.gov.uk/ peoplepopulationandcommunity/populationandmigration /populationestimates/articles/overviewoftheukpopulation/july2017

21. Adult Social Care Statistics Team, NHS Digital. (2017). Personal social services survey of adult carers in England (SACE). Retrieved from http://digital.nhs.uk/catalogue/PUB30045

22. Carers Australia. (2016). Statistics. Retrieved from http://www.carersaustralia.com.au/about-carers/statistics/

23. Family Caregiver Alliance. (2016). Caregiver statistics: Demographics. San Francisco: Family Caregiver Alliance. Retrieved from https://www.caregiver.org/caregiver-statistics-demographics

24. Carers UK. (2014). Sandwich generation concern is growing. Retrieved from https://www.carersuk.org/for-professionals/policy /expert-comment/4604-sandwich-generation-concern-is-growing

25. Seltzer, M. M., & Li, L. W. (2000). The dynamics of caregiving: transitions during a three-year prospective study. *Gerontologist, 40*(2), 165-178.

26. Reinhard, S.C., Levine, C., & Samis S. (2012). *Home alone: Family caregivers providing complex chronic care*. AARP Public Policy Institute. Retrieved from http://www.aarp.org/content /dam/aarp/ research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf.

27. Seal, K., Murray, C. D., & Seddon, L. (2015). The experience of being an informal "carer" for a person with cancer: A meta-synthesis of

qualitative studies. *Palliative and Supportive Care, 13*(3), 493-504. doi: 10.1017/S1478951513001132

28. National Collaborating Centre for Mental Health. (2011). Common Mental Health Disorders: Identification and Pathways to Care. Leicester (UK): British Psychological Society; 2011. (NICE Clinical Guidelines, No. 123.) 2, Common Mental Health Disorders. Retrieved from: https://www.ncbi.nlm.nih.gov/books/NBK92254/

29. Anderson, E. W., & White, K. M. (2017). "It has changed my life": An exploration of caregiver experiences in serious illness. *American Journal of Hospice & Palliative care, 35*(2). doi: 10.1177/1049909117701895

30. LeSure, P., & Chongkham-ang, S. (2015). The experience of caregivers living with cancer patients: A systematic review and meta-synthesis. *Journal of Personalized Medicine, 5*(4), 406-439. doi: 10.3390/jpm5040406

31. Nemati, S., Rassouli, M., Ilkhani, M., & Baghestani, A. R. (2017). Perceptions of family caregivers of cancer patients about the challenges of caregiving: a qualitative study. *Scandinavian Journal of Caring Sciences, 32,* 309-316. doi: 10.1111/scs.12463

32. Olson, R. E. (2014). Indefinite loss: the experiences of carers of a spouse with cancer. *European Journal of Cancer Care, 23*, 553-561.

33. Duggleby, W., Tycholiz, J., Holtslander, L., Hudson, P., Nekolaichuk, C., Mirhosseini, M., Parmar, J., Chambers, T., Alook, A., Swindle, J. (2017). A metasynthesis study of family caregivers' transition experiences caring for community-dwelling persons with advanced cancer at the end of life. *Palliative Medicine, 31*(7), 602-616. doi: 10.1177/0269216316673548

34. Livneh, H., & Martz, E. (2007). An introduction to coping theory and research. In E. Martz and H. Livneh (Eds.). *Coping with chronic illness and disability: Theoretical, empirical, and clinical aspects* (pp. 3-28). New York: Springer.

35. Molyneux, G. J., McCarthy, G. M., McEniff, S., Cryan, M., & Conroy, R. M. (2008). Prevalence and predictors of carer burden and depression in carers of patients referred to an old age psychiatric service. International Psychogeriatrics, 20(6), 1193-1202. doi: 10.1017/S1041610208007515

References

36. Gaugler, J. E., Davey, A., Pearlin, L. I., & Zarit, S. H. (2000). Modelling caregiver adaptation over time: The longitudinal impact of behavior problems. *Psychology and Aging, 15*(3), 437-450. doi: 10.1037/0882-7974.15.3.437

37. Feast, A., Orrell, M., Charlesworth, G., Melunsky, N., Poland, F., & Esme Moniz-Cook. (2016). Behavioural and psychological symptoms in dementia and the challenges for family carers: Systematic Review. *The British Journal of Psychiatry, 208*(5), 429-434. doi: 10.1192/bjp.bp.114.153684

38. Williamson, G. M., Martin-Cook, K., Weiner, M. F., Svetlik, D. A., Saine, K., Hynan, L. S., Dooley, W. K., & Schulz, R. (2005). Caregiver resentment: Explaining why care recipients exhibit problem behaviour. *Rehabilitation Psychology, 50*(3), 215-223. doi: 10.1037/0090-5550.50.3.215

39. YouGov and Macmillan Cancer Support. (2016). *Estimating the population of cancer carers in the UK-Phase two*. YouGov, London.

40. Carers UK. (2016). Caring and family finances. Retrieved from https://www.carersuk.org/for-professionals/policy/policy-library?task=download&file=policy_file&id=219

41. Pickard, L., King, D., Brimblecombe, N., & Knapp, M. (2018). Public expenditure costs of carers leaving employment in England, 2015/2016. *Health and Social care in the Community, 26*(1), e132-e142. doi: 10.1111/hsc.12486

42. Carers UK. (2012). In sickness and in health. London: Carers UK. Retrieved from https://www.carersuk.org/for-professionals/policy/policy-library/in-sickness-and-in-health

43. Junttila, N., Kainulainen, S., & Saari, J. (2015). Mapping the lonely landscape: Assessing loneliness and its consequences. *The Open Psychology Journal, 8*, 89-96. doi: 10.2174/1874350101508010089

44. Leigh-Hunt, N., Bagguley, D., Bash, K., Turner, V., Turnbull, S., Valtorta, N., & Caan, W. (2017). An overview of systematic reviews on the public health consequences of social isolation and loneliness. *Public Health, 152*, 157-171. doi: 10.1016/j.puhe.2017.07.035

45. Vignoles, V. L., Schwartz, S. J., & Luyckx, K. (2011). Introduction: Toward an integrative view of identity. In S. J. Schwartz, K. Luyckx, & V.

References

L. Vignoles (Eds.), *Handbook of Identity Theory and research* (pp. 1-27). New York: Springer.

46. Eifert, E. K., Adams, R., Dudley, W., & Perko, M. (2015). Family caregiver identity: A literature review. *American Journal of Health Education, 46*(6), 357-367. doi:10.1080/19325037.2015.1099482

47. Levine, C. (2003). Introduction: Structure, development, and identity formation. *Identity: An International Journal of Theory and Research, 3*(3), 191-195. doi: 10.1207/S1532706XID0303_01

48. Sedikides, C., & Brewer, M. B. (2001). Individual, relational, and collective self: partners, opponents, or strangers? In C. Sedikides & M. B. Brewer (Eds.), *Individual self, relational self, collective self* (pp. 1–4). Philadelphia: Psychology.

49. Orzeck, P. (2016). Identities in transition: Women caregivers in bereavement. *Journal of Social Work in End-of-Life & Palliative Care. 12*(1-2), 145-161. doi: 10.1080/15524256.2016.1165162

50. Banaji, M. R., & Prentice, D. A. (1994). The self in social contexts. *Annual Review of Psychology, 45*, 297-332.

51. Burke, P. J. (2006). Identity change. *Social Psychology Quarterly, 69*(1), 81-96. doi: 10.1177/019027250606900106

52. Cheung, S. Y., & Delfabbro, P. J. (2016). Are you a cancer survivor? A review on cancer identity. *Journal of Cancer Survivorship, 10*(4), 759-771. doi: 10.1007/s11764-016-0521-z

53. Hughes, N., Locock, L., & Ziebland, S. (2013). Personal identity and the role of 'carer' among relatives and friends of people with multiple sclerosis. *Social Science & Medicine, 96*, 78-85. doi: 10.1016/j.socscimed.2013.07.023

54. Ziemba, R. A., & Lynch-Sauer, J. M. (2005). Preparedness for taking care of elderly parents: "First, you get ready to cry". *Journal of Women & Aging, 17*(1-2), 99-113. doi: 10.1300/J074v17n01_08

55. Festinger, L. (1957). *A theory of cognitive dissonance*. Stanford: Stanford University Press.

References

56. O'Connor, D. L. (2007). Self-identifying as a caregiver: Exploring the positioning process. Journal of *Aging Studies, 21*, 165-174. doi: 10.1016/j.jaging.2006.06.002

57. Dobrof, J., Ebenstein, H. (2003). Family caregiver self-identification: implications for healthcare and social service professionals. *Generations, 27*(4), 33-38.

58. Smith, P. (2009). The family caregivers journey in end-of-life care: Recognising and identifying with the role of carer. *International Journal on Disability and Human Development, 8*(1), 67-73. doi: 10.1515/IJDHD.2009.8.1.67

59. Montgomery, R. J. V. (2016). Caregiver identity theory overview. Retrieved from https://www.researchgate.net/publication /265260328_Caregiver_Identity_Theory_Overview

60. Sadler, E., & McKevitt, C. (2013). 'Expert carers': An emergent normative model of the caregiver'. *Social Theory & Health, 11*(1), 40-58. doi: 10.1057/sth.2012.17

61. Molyneaux, V., Butchard, S., Simpsom, J., & Murray, C. (2011). Reconsidering the term "carer": a critique of the universal adoption of the term "carer". *Ageing & Society, 31*, 422-437. doi: 10.1017/S0144686X10001066

62. Knowles, S., Combs, R., Kirk, S., Griffiths, M., Patel, N., & Sanders, C. (2016). Hidden caring, hidden carers? Exploring the experience of carers for people with long-term conditions. *Health & Social Care in the Community, 24*(2), 203-213. doi: 10.1111/hsc.12207

63. Pierce, L. L., Thompson, T. L., Govoni, A. L., & Steiner, V. (2012). Caregivers' incongruence: Emotional strain in caring for persons with stroke. *Rehabilitation Nursing, 37*(5), 258-266. doi: 10.1002/rnj.35

64. Carers UK. (2018). About carers week. Retrieved from http://www.carersweek.org/about-us

65. Heath, A., Carey, L. B., & Chong, S. (2018). Helping carers care: An exploratory study of factors impacting informal family carers and their use of aged care services. Journal of Religion and Health, 57(3), 1146-1167. doi: 10.1007/s10943-018-0593-3

66. Carlander, I., Sahlberg-Blom, E., Hellstrom, I., & Ternestedt, B-M. (2010). The modified self: Family caregivers' experiences of caring for a dying family member at home. *Journal of Clinical Nursing, 20*(7-8), 1097-1105. doi: 10.1111/j.1365-2702.2010.03331.x

67. Erikkson, H., Sandberg, J., & Hellstrom, I. (2013). Experiences of long-term home care as an informal caregiver to a spouse: Gendered meanings in everyday life for female carers. International *Journal of Older Person Nursing, 8*(2), 159-165. doi: 10.1111/j.1748-3743.2012.00340.x

68. O'Connor, D. L. (1999). Living with a memory-impaired spouse: (Re)cognizing the experience. *Canadian Journal on Aging, 18*(2), 211-235.

69. Moore, H., & Gillespie, A. (2014). The caregiving bind: Concealing the demands of informal care can undermine the caregiving identity. *Social Science & Medicine, 116*, 102-109. doi: 10.1016/j.socscimed.2014.06.038

70. Mutch, K. (2010). In sickness and in health: experience of caring for a spouse with MS. *British Journal of Nursing, 19*(4), 214-219. doi: 10.12968/bjon.2010.19.4.46782

71. Plank, A., Mazzoni, V., & Cavada, L. (2012). Becoming a caregiver: New family carers' experience during the transition from hospital to home. *Journal of Clinical Nursing, 21*(13-14), 2072-2082. doi: 10.1111/j.1365-2702.2011.04025.x

72. Pozzebon, M., Douglas, J., & Ames, D. (2016). Spouses' experience of living with a partner diagnosed with a dementia: a synthesis of the qualitative research. *International Psychogeriatrics, 28*(4), 537-556. doi: 10.1017/S1041610215002239

73. Heward, K., Gough, B., & Molineux, M. (2011). Change of identity: The psychological and emotional impact of caring for someone with multiple sclerosis. *Social Care and Neurodisability, 2*(1), 21-32. doi: 10.5042/scn.2011.0081

74. Montgomery, R J. V., & Kolsloski, K. D. (2012). Pathways to caregiver identity and implications for support services. In R. C. Talley, R. J. V. Montgomery, & R. C. I for Caregiving (Eds.). *Caregiving Across the Life Span: Research, Practice, Policy*. New York: Springer.

References

75. Badr, H., Acitelli, L. K., Taylor, C. L. C. (2007). Does couple identity mediate the stress experienced by caregiving spouses? *Psychology & Health, 22*(2), 211-229. doi: 10.1080/14768320600843077

76. Hayes, J., Boylstein, C., & Zimmerman, M. K. (2009). Living and loving with dementia: Negotiating spousal and caregiver identity through narrative. *Journal of Aging Studies, 23*(1), 48-59. doi: 10.1016/j.jaging.2007.09.002

77. Forber-Pratt, A. J., Lyew, D. A., Mueller, C., & Samples, L. B. (2017). Disability identity development: A systematic review of the literature. *Rehabilitation Psychology, 62*(2), 198-207. doi: 10.1037/t50166-000

78. Coeling, H. V., Biordi, D. L., & Theis, S. L. (2003). Negotiating dyadic identity between caregivers and care receivers. *Journal of Nursing Scholarship, 35*(1), 21-25. doi: 10.1111/j.1547-5069.2003.00021.x

79. Spendelow, J. S., Adam, L., & Fairhurst, B. (2017). Coping and adjustment in informal male carers: A systematic review of qualitative studies. *Psychology of Men & Masculinity, 18*(2), 134-143. doi: 10.1037/men0000049

80. Hirst, M. (2014). Transitions into and out of unpaid care. Working paper no. CUK 2644. York: Social Policy Research Unit, University of York. Retrieved from https://www.york.ac.uk/inst /spru/pubs/pdf/CUK2644.pdf

81. Schwartz, A. J., & McInnis-Dittrich, K. (2016). Meeting the needs of male caregivers by increasing access to accountable care organizations. *Journal of Gerontological Social Work, 58*(7-8), 655-670. doi: 10.1080/01634372.2015.1067852

82. Thompson, E. H. (2002). What's unique about men's caring. In B. J. Kramer and E H. Thompson Jr (Eds.). *Men as caregivers: Theory, research, and service implications*, (pp. 20-50). New York: Springer.

83. Black, H. K., Schwartz, A. J., Caruso, C. J., & Hannum, S. M. (2008). How personal control mediates suffering: Elderly husbands' narrative of caregiving. *Journal of Men's Studies, 16*(2), 177–192. doi: 10.3149/jms.1602.177

84. Centres for Disease Control and Prevention. (2016). Chronic disease overview. Retrieved from http://www.cdc.gov/chronicdisease /overview/index.htm

References

85. Elliot, T. R., & Pezent, G. D. (2008). Family caregivers of older persons in rehabilitation. *NeuroRehabilitation, 23*(5), 439-446.

86. Ranjbar, V. (2014). The HIV/AIDS caregiver identity as a double-edged sword: A discourse analysis on HIV/AIDS caregiving in South Africa. *African Journal of AIDS Research, 13*(3), 261-269. doi: 10.2989/16085906.2014.952650

87. McEwen, B. S. (2017). Neurobiological and Systemic Effects of Chronic Stress. Chronic Stress (Thousand Oaks, Calif.), 1. doi: 10.1177/2470547017692328.

88. Schneiderman, N., Ironson, G., & Siegel, S. D. (2005). Stress and health: Psychological, behavioral, and biological determinants. *Annual Review of Clinical Psychology, 1*, 607-628. doi: 10.1146/annurev.clinpsy .1.102803.144141

89. Crespo, M., & Fernandez-Lansac, V. (2014). Factors associated with anger and anger expression in caregivers of elderly relatives. *Aging & Mental Health, 18*(4), 454-462. doi: 10.1080/13607863.2013.856857

90. Burton, M. (2006). Grounding constructions of carers: Exploring the experiences of carers through a grounded approach. *British Journal of Social Work, 38*(3), 493-506. doi: 10.1093/bjsw/bcl350

91. Roos, S. (2002). *Chronic sorrow: A living loss*. New York: Brunner-Routledge.

92. Stenberg, U., Ruland, C. M., & Miaskowski, C. (2010). Review of the literature on the effects of caring for a patient with cancer. *Psycho-Oncology, 19*(10), 1013-1025. doi: 10.1002/pon.1670

93. Lloyd, K. (2013). Happiness and well-being of young carers: Extent, nature and correlates of caring among 10 and 11 year old school children. *Journal of Happiness Studies, 14*(1), 67-80. doi: 10.1007/s10902-011-9316-0

94. Nijboer, C., Triemstra, M., Tempelaar, R., Mulder, M., Sanderman, R., & van den Bos, G. A. M. (2000). Patterns of caregiver experiences among partners of cancer patients. *The Gerontologist, 40*(6), 738-746. doi: 10.1093/geront/40.6.738

References

95. Landfeldt, E., Edstrom, J., Buccella, F., Kirschner, J., & Lochmuller, H. (2018). Duchenne muscular dystrophy and caregiver burden: A systematic review. *Developmental Medicine & Child Neurology*. Advance online publication. doi:10.1111/dmcn.13934

96. Temple, J. B., & Dow, B. (2018). The unmet support needs of carers of older Australians: Prevalence and mental health. International Psychogeriatrics. doi: 10.1017/S104161021800042X

97. Papastavrou, E., Kalokerinou, A., Papacostas, S. S., Tsangari, H., & Sourtzi, P. (2007). Caring for a relative with dementia: Family caregiver burden. *Journal of Advanced Nursing, 58*(5), 446-457. doi: 10.1111/j.1365-2648.2007.04250.x

98. Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden: A clinical review. *JAMA, 311*(10), 1052-1060. doi: 10.1001/jama.2014.304

99. O'Brien, M. R., Whitehead, B., Jack, B. A., Mitchell, J. D. (2012). The need for support services for family carers of people with motor neurone disease (MND): Views of current and former family caregivers a qualitative study. *Disability and Rehabilitation: An International, Multidisciplinary Journal, 34*(3), 24-256. doi: 10.3109/09638288.2011.605511

100. Brimblecombe, N., Pickard, L., King, D., & Knapp, M. (2017). Perceptions of unmet needs for community social care services in England. A comparison of working carers and the people they care for. *Health & Social Care in the Community, 25*(2), 435-446. doi: 10.1111/hsc.12323

101. Molassiotis. A., Wilson, B., Blair, S., Howe, T., & Cavet, J. (2011). Unmet supportive care needs, psychological well-being and quality of life inpatients living with multiple myeloma and their partners. *Psycho-Oncology, 20*(1), 88-97. doi: 10.1002/pon.1710.

102. Sharpe, L., Butow, P., Smith, C., McConnell, D., & Clarke, S. (2005). The relationship between available support, unmet needs and caregiver burden in patients with advanced cancer and their carers. Psycho-Oncology, 14(2), 102-114. doi: 10.1002/pon.825

103. Braun, M., Mikulincer, M., Rydall, A., Walsh, A., & Rodin, G. (2007). Hidden morbidity in cancer: Spouse caregivers. *Journal of Clinical Oncology, 25*(30), 4829-4834

References

104. Easter, G., Sharpe, L., Hunt, C. J. (2015). Systematic review and meta-analysis of anxious and depressive symptoms in caregivers of children with asthma. *Journal of Pediatric Psychology, 40*(7), 623-632. doi: 10.1093/jpepsy/jsv012

105. Pinquart, M. (2017). Parenting stress in caregivers of children with chronic physical condition- a meta-analysis. *Stress and Health*, 34(2), 197-207. doi: 10.1002/smi.2780

106. Li, Q. P., Mak, Y.W., & Loke, A. Y. (2013). Spouses' experience of caregiving for cancer patients: A literature review. *International Nursing Review, 60*(2), 178-187. doi: 10.1111/inr.12000

107. Schulz, R., O'Brien, A. T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *The Gerontologist, 35*(6), 771-791. doi: 10.1093/geront/35.6.771

108. Grov, E. K., Dahl, A. A., Moum, T., & Fossa, S. D. (2005). Anxiety, depression, and quality of life in caregivers of patients with cancer in late palliative phase. *Annals of Oncology, 16*(7), 1185-1191. doi: 10.1093/annonc/mdi210

109. Brown, E. S., Gan, V., Jeffress, J., Mullen-Gingrich, K., Khan, D. A., Wood, B. L., Miller, B. D., Gruchalla, R., & Rush, J. (2006). Psychiatric symptomatology and disorders in caregivers of children with asthma. *Pediatrics, 118*(6), e1715-e1720. doi: 10.1542/peds.2006-1119

110. Zabala, M. J., Macdonald, P., Treasure, J. (2009). Appraisal of caregiving burden, expressed emotion and psychological distress in families of people with eating disorders: A systematic review. *European Eating Disorders Review, 17*(5), 338-349. doi: 10.1002/erv.925

111. Pinquart, M., & Sorensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychology of Aging, 18*(2), 250-267. doi: 10.1037/0882-7974.18.2.250

112. Carers UK. (2004). In poor health: The impact of caring on health. London: Carers UK. Retrieved from http://static.carers.org /files/in-poor-health-carers-uk-report-1674.pdf

References

113. Vlachantoni, A., Robards, J., Falkingham, J., Evandrou, M. (2016). Trajectories of informal care and health. *SSM Population Health, 2*, 495-501. doi: 10.1016/j.ssmph.2016.05.009

114. Brown, S. L., Nesse, R. M., Vinokur, A. D., Smith, D. M. (2003). Providing social support may be more beneficial than receiving it: results from a prospective study of mortality. *Psychological Science, 14*(4), 320-327. doi: 10.1111/1467-9280.14461

115. Liao, C. C., Yeh, C. J., Lee, S. H., Liao, W. C., Liao, M. Y., Lee, M. C. (2015). Providing instrumental social support is more beneficial to reduce mortality risk among the elderly with low educational level in Taiwan: a 12-year follow-up national longitudinal study. *The Journal of Nutrition, Aging & Health, 19*(4), 447-453. doi: 10.1007/s12603-014-0545-x

116. ten Have, M., Penninx, B. W. J. H., Tuithof, M., van Dorsselaer, S., Kleinjan, M., Spijker, J., & de Graaf, R. (2017). Duration of major and minor depressive episodes and associated risk indicators in a psychiatric epidemiological cohort study of the general population. *Acta Psychiatrica Scandinavica, 136*(3), 300-312. doi: 10.1111/acps.12753

117. NHS (2016). *Low mood and depression*. Retrieved from https://www.nhs.uk/conditions /stress-anxiety-depression/low-mood-and-depression/

118. Carvalho, J. P., & Hopko, D. R. (2011). Behavioral theory of depression: Reinforcement as a mediating variable between avoidance and depression. *Journal of Behavioral Therapy and Experimental Psychiatry, 42*(2), doi: 10.1016/j.jbtep.2010.10.001

119. Shaffer, K. M., Kim, Y., & Carver, C. S. (2016). Physical and mental health trajectories of cancer patients and caregivers across the year post-diagnosis: a dyadic investigation. *Psychology & Health, 31*(6), 655-674. doi: 10.1080/08870446.2015.1131826

120. Vitaliano, P. P., Zhang, J., & Scanlan, J. M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin, 129*(6), 946-972. doi: 10.1037/0033-2909.129.6.946

121. Jassem, J., Penrod, J. R., Goren, A., & Gilloteau, I. (2015). Caring for relatives with lung cancer in Europe: an evaluation of caregivers' experience. *Quality of Life Research, 24*(12), 2843-2852. doi: 10.1007/s11136-015-1028-1

References

122. Pinquart, M., & Sorensen, S. (2007). Correlates of physical health of informal caregivers: a meta-analysis. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences, 62*(2), 126-137. doi: 10.1093/geronb/62.2.P126

123. Hilgerman, M. M., Allen, R. S., DeCoster, J., & Burgio, L. D. (2007). Positive aspects of caregiving as a moderator of treatment outcome over 12 months. *Psychology and Aging, 22*, 361-371. doi: 10.1037/0882-7974.22.2.361

124. American Psychological Association (2018). Positive aspects of caregiving. Retrieved from http://www.apa.org/pi/about /publications/caregivers/faq/positive-aspects.aspx

125. Greenwood, N., MacKenzie, A., Cloud, G. C., & Wilson, N. (2009). Informal primary carers of stroke survivors living at home-challenges, satisfactions and coping: a systematic review of qualitative studies. *Disability and Rehabilitation, 31*(5), 337-351. doi: 10.1080/09638280802051721

126. Cohen, C. A., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving: Rounding out the caregiver experience. *International Journal of Geriatric Psychiatry, 17*(2), 184-188. doi: 10.1002/gps.561

127. The Associated Press-NORC Centre for Public Affairs Research. (2014). Long-term care in America: Expectations and reality. Retrieved from http://www.longtermcarepoll.org/PDFs/LTC% 202014/ AP-NORC-Long-Term%20Care%20in%20America_FINAL%20WEB.pdf

128. Ribeiro, O., & Paúl, C. (2008). Older male carers and the positive aspects of care. *Ageing and Society, 28*(2), 165–183. doi: 10.1017/S0144686X07006460

129. Yu, D. S. F., Cheng, S-T., & Wang, J. (2018). Unravelling positive aspects of caregiving in dementia: An integrative review of research literature. *International Journal of Nursing Studies, 79*, 1-26. doi: 10.1016/j.ijnurstu.2017.10.008

130. Buchanan, R. J., Radin, D., Chakravorty, B. J., & Tyry, T. (2009). Informal care giving to more disabled people with multiple sclerosis. *Disability and Rehabilitation, 31*(15), 1244-1256. doi: 10.1080/09638280802532779

References

131. Pakenham, K. I. (2010). Benefit-finding and sense-making in chronic illness. In S. Folkman (Ed.). *The Oxford handbook of stress, health, and coping*, (pp. 242-270). Oxford: Oxford University Press. doi: 10.1093/oxfordhb/9780195375343.013.0013

132. Carbonneau, H., Caron, C., & Desrosiers, J. (2010). Development of a conceptual framework of positive aspects of caregiving in dementia. *Dementia, 9*(3), 327-353. doi: 10.1177/1471301210375316

133. Kim, Y., Carver, C. S., Spiegel, D., Mitchell, H., & Cannady, R. S. (2017). Role of family caregivers' self-perceived preparedness for the death of the cancer patient in long-term adjustment to bereavement. *Psycho-Oncology, 26*(4), 484-492. doi: 10.1002/pon.4042

134. Positive Psychology Centre. (2018). *Positive psychology definition*. Retrieved from https://ppc.sas.upenn.edu/

135. Lechner, S. C. (2009). Benefit finding. *The encyclopedia of positive psychology*. doi: 10.1111/b.9781405161251.2009.x Retrieved from http://www.blackwellreference.com/public/tocnode?id=g978140516125 1_chunk_g97814051612514_ss1-3

136. Helgeson, V., S., Reynolds, K. A., Tomich, P. L. (2006). A meta-analytic review of benefit finding and growth. *Journal of Consulting and Clinical Psychology, 74*(5), 797-816. doi: 10.1037/0022-006X.74.5.797

137. Centres for Disease Control and Prevention. (2016b). Well-being concepts. Retrieved from https://www.cdc.gov/hrqol/wellbeing.htm

138. Balfe, M., Maguire, R., Hanly, P., Butow, P., O'Sullivan, E., Timmons, A., Gooberman-Hill, R., & Sharp, L. (2016). Distress in long-term head and neck cancer carers: a qualitative study of carers' perspectives. *Journal of Clinical Nursing, 25*, 2317-2327. doi: 10.1111/jocn.13242

139. Grobe, J., Treml, J., & Kersting, A. (2017). Impact of caregiver burden on mental health in bereaved caregivers of cancer patients: A systematic review. *Psycho-Oncology, 27*(3), 757-767. doi: 10.1002/pon.4529

140. Mehta, A., Chan., L. S., & Cohen, R. (2014). Flying blind: Sources of distress for family caregivers of palliative cancer patients managing pain at home. *Journal of Psychosocial Oncology, 32*(1), 94-111. doi: 10.1080/07347332.2013.856057

References

141. Schrank, B., Ebert-Vogel, A., Amering, M., Masel, E. K., Neubauer, M., Watzke, H., Zehetmayer, S., & Schur, S. (2016). Gender differences in caregiver burden and its determinants in family members of terminally ill cancer patients. *Psycho-Oncology, 25*(7), 808-814. doi: 10.1002/pon.4005

142. Vaingankar, J. A., Chong, S. A., Abdin, E., Picco, L., Shafie, S., Seow, E., Pang, S., Sagayadevan, V., Chua, B. Y., Chua, H. C., & Subramaniam, M. (2016). Psychiatric morbidity and its correlates among informal caregivers of older adults. *Comprehensive Psychiatry, 68*, 178-185. doi: 10.1016/j.comppsych.2016.04.017

143. Layard, R. (2005). *Happiness: Lessons for a new science*. London: Penguin.

144. Lyubomirsky, S. (2007). *The how of happiness*. New York: The Penguin Press.

145. Roos, S., & Neimeyer, R. A. (2007). Reauthoring the self: Chronic sorrow and posttraumatic stress following the onset of CID. In E. Martz and L. Hanoch (Eds.). *Coping with chronic illness and disability: Theoretical, empirical, and clinical aspects*, (pp. 89-106). New York: Springer.

146. Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Casework, 43*, 190-193.

147. Roos, S. (2001). Theory development: Chronic sorrow and the Gestalt construct of closure. *Gestalt Review, 5*, 289-310. doi: 10.5325/gestaltreview.5.4.0289

148. Ahlstrom, G. (2007). Experiences of loss and chronic sorrow in persons with severe chronic illness. *Journal of Clinical Nursing, 16*(3A), 76-83. doi: 10.1111/j.1365-2702.2006.01580.x

149. Aoun, S. M., Connors, S. L., Priddis, L., Breen, L. J., & Colyer, S. (2012). Motor Neurone Disease family carers' experiences of caring, palliative care and bereavement: An exploratory qualitative study. *Palliative Medicine, 26*(6), 842–850. doi: 10.1177/0269216311416036

150. Collins, C., Liken, M., King, S., & Kokinakis, C. (1993). Loss and grief among family caregivers of relatives with dementia. *Qualitative Health Research, 3*(2), 236–253. doi: 10.1177/104973239300300206

References

151. Garand, L., Lingler, J. H., Deardorf, K. E., DeKosky, S. T., Schulz, R., Reynolds, C. F., & Dew, M. A. (2012). Anticipatory grief in new family caregivers of persons with mild cognitive impairment and dementia. *Alzheimer Disease and Associated Disorders, 26*(2), 159–165. doi: 10.1097/WAD.0b013e31822f9051

152. Large, S., & Slinger, R. (2015). Grief in caregivers of persons with Alzheimer's disease and related dementia: A qualitative synthesis. *Dementia: The International Journal of Social Research and Practice, 14*(2), 164–183. doi: 10.1177/1471301213494511

153. Loos, C., & Bowd, A. (1997). Caregivers of persons with Alzheimer's disease: Some neglected implications of the experience of personal loss and grief. *Death Studies, 21*(5), 501–514. doi: 10.1080/074811897201840

154. Hebert, R. S., Schulz, R., Copeland, V. C., & Arnold, R. M. (2009). Preparing family caregivers for death and bereavement: Insights from caregivers of terminally ill patients. *Journal of Pain and Symptom Management, 37*(1), 3–12. doi: 10.1016/j.jpainsymman.2007.12.010

155. Bookwala, J. (2009). The impact of parent care on marital quality and well-being in adult daughters and sons. *Journal of Gerontology B: Psychological Sciences and Social Sciences. 64*(3), 339-347. doi: 10.1093/geronb/gbp018

156. Miller, J. F. (1999). *Coping with chronic illness: Overcoming powerlessness* (3rd ed.). Philadelphia: Davis

157. Horwitz, A. V., Reinhard, S. C., & Howell-White, S. (1996). Caregiving as reciprocal exchange in families with seriously mentally ill members. *Journal of Health and Social Behaviour, 37*, 149-162. doi: 10.2307/2137270

158. Ozbay, F., Johnson, D. C., Dimoulas, E., Morgan, C. A., Charney, D., & Southwick, S. (2007). Social support and resilience to stress: From neurobiology to clinical practice. *Psychiatry, 4*(5), 35-40. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2921311/

159. American Psychological Association (2018). Emotional support. Retrieved from www.apa.org/helpcenter/emotional-support

160. Gariépy, G., Honkaniemi, H., & Quesnel-Vallée, A. (2016). Social support and protection from depression: systematic review of

current findings in Western countries. *The British Journal of Psychiatry, 209*(4), 284-293. doi: 10.1192/bjp.bp.115.169094

161. Roohafza, H. R., Afshar, H., Keshteli, A., Mohammadi, N., Feizi, A., Taslimi, M., & Adibi, P. (2014). What's the role of perceived social support and coping styles in depression and anxiety? *Journal of Research in Medical Sciences, 19*(10), 944-949.

162. Kelly, M. E., Duff, H., Kelly, S., Power, J. E. M., Brennan, S., Lawlor, B. A., & Loughrey, D. G. (2017). The impact of social activities, social networks, social support and social relationships on the cognitive functioning of healthy older adults: a systematic review. *Systematic Reviews, 6*, 259. doi: 10.1186/s13643-017-0632-2

163. Holt-Lunstad, J., Smith, T. B., Layton, J. B. (2010). Social relationships and mortality risk: A meta-analytic review. *PLoS Medicine, 7*(7), e1000316. doi: 10.1371/journal.pmed.1000316

164. Thoits, P. (2011). Mechanisms linking social ties and support to physical and mental health.*Journal of Heath and Social Behavior, 52*(2), 145-161. doi: 10.1177/0022146510395592

165. Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin, 98*(2), 310-357.

166. Choi, Y. S., Hwang, S. W., Hwang, I. C., Lee, Y. J., Sim, Y. S., Kim, H. M., Youn, C. H., Ahn, H. Y., & Koh, S-J. (2016). Factors associated with quality of life among family caregivers of terminally ill cancer patients. *Psycho-Oncology, 25*(2), 217-224. doi: 10.1002/pon.3904

167. Reblin, M., Donaldson, G., Ellington, L., Mooney, K., Caserta, M., & Lund, D. (2016). Spouse cancer caregivers' burden and distress at entry to home hospice: The role of relationship quality. *Journal of Social and Personal Relationships, 33*(5), 666-686. doi: 10.1177/0265407515588220

168. Ong, H. L., Viangankar, J. A., Abdin, E., Sambasivam, R., Rauziana, R., Tan, M-E., Chong, S. A., Goveas, R. R., Chiam, P. C., & Subramaniam, M. (2018). Resilience and burden in caregivers of older adults: moderating and mediating effects of perceived social support. *BMC Psychiatry, 18*, 27. doi: 10.1186/s12888-018-1616-z

169. Rodakowski, J., Skidmore, E. R., Rogers, J. C., & Schulz, R. (2012). Role of social support in predicting caregiver burden. *Archives of*

References

Physical and Medical Rehabilitation, 93(12), 2229-2236. doi: 10.1016/j.apmr.2012.07.004

170. Lai, D., & Thomson, C. (2011). The impact of perceived adequacy of social support on caregiving burden of family caregivers. *Families in Society. 92*(1), 99-106. doi: 10.1606/1044-3894.4063

171. del-Pino-Casado, R., Frias-Osuna, A., Palomino-Moral, P. A., Ruzafa-Martinez, M., & Ramos-Morcillo, A. J. (2018). Social support and subjective burden in caregivers of adults and older adults: A meta-analysis. *PLoS One, 13*(1). e0189874. doi: 10.1371/journal.pone.0189874

172. Stoltz, P., Uden, G., & Willman, A. (2004). Support for family carers wo care for an elderly person at home- a systematic literature review. *Scandinavian Journal of Caring Sciences, 18*(2), 111-119. doi: 10.1111/j.1471-6712.2004.00269.x

173. Hawkley, L. C., & Cacioppo, J. T. (2010). Loneliness matters: A theoretical and empirical review of consequences and mechanisms. *Annals of Behavioral Medicine, 40*(2), 218-227. doi: 10.1007/s12160-010-9210-8

174. Masi, C. M., Chen, H., Hawkley, L. C., & Cacioppo, J. T. (2011). A meta-analysis of interventions to reduce loneliness. *Personality and Social Psychology Review 15*(3), 219-266. doi: 10.1177/1088868310377394

175. Vasileiou, K., Barnett, J., Barreto, M., Vines, J., Atkinson, M., Lawson, S., & Wilson, M. (2017). Experiences of loneliness associated with being an informal carer: A qualitative investigation. Frontiers in Psychology*: Clinical and Health Psychology, 8*, 585. doi: 10.3389/fpsyg.2017.00585

176. Hawkley, L. C., Hughes, M. E., Waite, L. J., Masi, C. M., Thisted, R. A., & Cacioppo, J. T. (2008). From social structural factors to perceptions of relationship quality and loneliness: The Chicago Health, Aging, and Social Relations Study. *The Journals of Gerontology B: Psychological Sciences and Social Sciences, 63*(6), 375-384.

177. Wittenberg-Lyes, E., Washington, K., Demiris, G., Oliver, D. P., & Shaunfield, S. (2014). Understanding social support burden among family caregivers. *Health Communication, 29*(9), 901-910. doi: 10.1080/10410236.2013.815111

References

178. Lincoln, K. D. (2000). Social support, negative social interactions, and psychological well-being. *The Social Service Review, 74*(2), 231-252. doi: 10.1086/514478

179. Donnellan, W. J., Bennett, K. M., & Soulsby, L. K. (2017). Family close but friends closer: Exploring social support and resilience in older spousal dementia carers. *Aging & Mental Health, 21*(11), 1222-1228. doi: 10.1080/13607863.2016.1209734

180. Oster, I., Hedestig, O., Johansson, M., Klingstedt, N., & Lindh, J. (2013). Sharing experiences in a support group: Men's talk during the radiotherapy period for prostate cancer. *Palliative and Supportive Care, 11*, 331-339.

181. Call, K. T., Finch, M. A., Huck, S. M., & Kane, R. A. (1999). Caregiver burden from a social exchange perspective: Caring for older people after hospital discharge. *Journal of Marriage and the Family, 61*(3), 688-699. doi: 10.2307/353570

182. Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583 – 591.

183. Dwyer, F. W., & Miller, M. K. (1990). Differences in caregiving network by area of residence: Implications for primary caregiver stress and burden. *Family Relations, 39*, 27-37.

184. Reid, C. E., Moss, S., & Hyman, G. (2005). Caregiver reciprocity: The effect of reciprocity, carer self-esteem and motivation on the experience of caregiver burden. *Australian Journal of Psychology, 57*(3), 186-196. doi: 10.1080/00049530500141022

185. Pinto, J. M. (2016). Barriers to social participation in caregivers of older people: A systematic review. *Research in Health Science, 1*(2). doi: 10.22158/rhs.v1n2p78

186. Smith, M. Y., & Rapkin, B. D. (1996). Social support and barriers to family involvement in caregiving for persons with AIDS: implications for patient education. *Patient Education and Counseling, 27*(1), 85-94. doi: 10.1016/0738-3991(95)00792-X

187. Greenwood, N., & Smith, R. (2015). Barriers and facilitators for male carers in accessing formal and informal support: A systematic review. *Maturitas, 82*(2), 162-169. doi: 10.1016/j.maturitas.2015.07.013

References

188. Kayser, K., Acquati, C., Reese, J. B., Mark, K., Wittmann, D., & Karam, E. (2017). A systematic review of dyadic studies examining relationship quality in couples facing colorectal cancer together. *Psycho-Oncology, 27*(1), 13-21. doi: 10.1002/pon.4339

189. Ussher, J M., Wong, W. K. T., & Perz, J. (2010). A qualitative analysis of changes in relationship dynamics and roles between people with cancer and their primary informal carer. *Health, 15*(6), 650-667. doi: 10.1177/1363459310367440

190. Davis, L. L., Gilliss, C. L., Deshefy-Longhi, T., Chestnutt, D. H., Molloy, M. (2011). The nature and scope of stressful spousal caregiving relationships. *Journal of Family Nursing, 17*(2), 224-240. doi: 10.1177/1074840711405666

191. Regan, T. W., Lambert, S. D., Kelly, B., Falconier, M., Kissane, D., & Levesque, J. V. (2015). Couples coping with cancer: exploration of theoretical frameworks from dyadic studies. *Psycho-Oncology, 24*(12), 1605-1617. doi: 10.1002/pon.3854

192. Li, Q., & Loke, A. Y. (2014). A literature review on the mutual impact of the spousal caregiver-cancer patients dyads: 'Communication', 'reciprocal influence', and 'caregiver-patient congruence'. *European Journal of Oncology Nursing, 18*(1), 58-65. doi: 10.1016/j.ejon.2013.09.003

193. Traa, M. J., De Vries, J., Bodenmann, G., Oudsten, B. L. D. (2015). Dyadic coping and relationship functioning in couples coping with cancer: A systematic review. *British Journal of Health Psychology, 20*(1), 85-114. doi: 10.1111/bjhp.12094

194. Chen, C. K., Sabir, M., Zimmerma, S., Suitor, J., & Pillemer, K. (2007). The importance of family relationships with nursing facility staff for family caregiver burden and depression. *The Journals of Gerontology: Series B, 62*(5), 253-260. doi: 10.1093/geronb/62.5.P253

195. McCann, T. V., Lubman, D. I., & Clark, E. (2012). Primary caregivers' satisfaction with clinicians' response to them as informal carers of young people with first-episode psychosis: A qualitative study. *Journal of Clinical Nursing, 21*(1-2), 224-231. doi: 10.1111/j.1365-2702.2011.03836.x

196. Ward-Griffin, C., & McKeever, P. (2000). Relationships between nurses and family caregivers: Partners in care? *Advances in Nursing Science, 22*(3), 89-103.

References

https://journals.lww.com/advancesinnursingscience/Abstract/2000/030
00/Relationships_between_Nurses_and_Family.8.aspx

197. Ward-Griffin, C. (2002). Boundaries and connections between formal and informal caregivers. *Canadian Journal on Aging, 21*(2), 205-216. doi: 10.1017/S0714980800001471

198. Haesler, E., Baurer, M., & Nay, R. (2010). Recent evidence on the development and maintenance of constructive staff–family relationships in the care of older people – a report on a systematic review update. *International Journal of Evidence-Based Healthcare, 8*(2), 45-74. doi: 10.1111/j.1744-1609.2010.00165.x

199. Sutherland, A. (2014, June 11). Hospital staff should recognise carers' skills and knowledge. *The Guaridan*. Retrieved from https://www.theguardian.com/healthcare-network/2014/jun/11/hospital-staff-recognise-carers-skills-knowledge

200. Tuffrey-Wijne, I., Giatras, N., & Goulding, L. et al. (2013). Identifying the factors affecting the implementation of strategies to promote a safer environment for patients with learning disabilities in NHS hospitals: A mixed-methods study. *Health Services and Delivery Research*, No. 1.13. https://www.ncbi.nlm.nih.gov/books/NBK259498/

201. Haesler, E., Baurer, M., & Nay, R. (2007). Staff–family relationships in the care of older people: A report on a systematic review. *Research in Nursing & Health, 30*(4), 385-398. doi: 10.1002/nur.20200

202. McPherson, K. M., Kayes, N. K., Moloczij, N., & Cummins, C. (2014). Improving the interface between informal carers and formal health and social services: A qualitative study. International *Journal of Nursing Studies, 51*(3), 418-429. doi: 10.1016/j.ijnurstu.2013.07.006

203. van Wieringen, M., van Groenou, M. I. B., & Groenewegen, P. (2015). Impact of home care management on the involvement of informal caregivers by formal caregivers. Home Health *Care Services Quality, 34*(2), 67-84. doi: 10.1080/01621424.2015.1029185

204. Wittenberg, Y., Kwekkeboom, R., Staaks, J., Verhoeff, A., & Boer A. (2017). Informal caregivers' views on the division of responsibilities between themselves and professionals: A scoping review. *Health & Social Care in the Community, 26*(4), e460-e473. doi: 10.1111/hsc.12529

205. Rowe, J. (2012). Great expectations: a systematic review of the literature on the role of family carers in severe mental illness, and their relationships and engagement with professionals. *Journal of Psychiatric and Mental Health Nursing, 19*(1), 70-82. doi: 10.1111/j.1365-2850.2011.01756.x

206. Najjar, N., Davis, L. W., Beck-Coon, K., & Doebbeling, C. C. (2009). Compassion fatigue: A review of the research to date and relevance to cancer-care providers. *Journal of Health Psychology, 14*(2), 267-277. doi: 10.1177/1359105308100211

207. El-bar, N., Levy, Levy, A., Wald, H. S., & Biderman, A. (2013). Compassion fatigue, burnout and compassion satisfaction among family physicians in the Negev area - a cross-sectional study. *Israel Journal of Health Policy Research, 2*(31). doi: 10.1186/2045-4015-2-31

208. Stamm, B.H. (2002). Measuring compassion satisfaction as well as fatigue: developing history of the compassion satisfaction and fatigue test In C. R. Figley (Ed.). *Treating compassion fatigue*, pp. 107–119. New York: Brunner-Routledge.

209. Mathieu, F. (2012). *The compassion fatigue workbook*. New York: Routledge.

210. Nolte, A. G. W., Downing, C., Temane, A., & Hastings-Tolsma, M. (2017). Compassion fatigue in nurses: A metasynthesis. *Journal of Clinical Nursing, 26*(23-24), 4364-4378. doi: 10.1111/jocn.13766

211. Lynch, S. H., & Lobo, M. L. (2012). Compassion fatigue in family caregivers: a Wilsonian concept analysis. *Journal of Advanced Nursing, 68*(9), 2125-2134. doi: 10.1111/j.1365-2648.2012.05985.x

212. Figley, C. R., & Roop, R. G. (2006). *Compassion fatigue in the animal-care community*. Washington: Humane Society Press.

213. Victor, E. (2009). *A systematic review of interventions for carers in the UK: Outcomes and explanatory evidence*. London: The Princess Royal Trust for Carers.

214. Sin, J., Spain, D., Cornelius, V., Chen, T., & Gillard, S. (2018). eHealth interventions for family carers of people with long term illness: A promising approach? *Clinical Psychology Review, 60*, 109-125. doi: 10.1016/j.cpr.2018.01.008

References

215. Velten, J., Lavallee, K. L., Scholten, S., Meyer, A. H., Zhang, X-C., Schneider, S., & Margraf, J. (2014). Lifestyle choices and mental health: a representative population survey. *BMC Psychology, 2*, 58. doi: 10.1186/s40359-014-0055-y

216. Walsh, R. (2011). Lifestyle and mental health. *American Psychologist, 66*(7), 579-592. doi: 0.1037/a0021769

217. Kato, T. (2015). The impact of coping flexibility on the risk of depressive symptoms. *PLoS One, 10*(5), e0128307. doi: 10.1371/journal.pone.0128307

218. Kato, T. (2012). Development of the Coping Flexibility Scale: Evidence for the coping flexibility hypothesis. *Journal of Counseling Psychology, 59*(2), 262-273. doi: 10.1037/a0027770

219. Sharoff, K. (2004). *Coping skills manual for treating chronic and terminal illness*. New York: Springer.

220. Andreasson, F., Andreasson, J., & Hanson, E. (2017). Developing a carer identity and negotiating everyday life through social networking sites: An explorative study on identity constructions in an online Swedish carer community. *Ageing and Society,* 1-21. doi: 10.1017/S0144686X17 000551

221. Luoma, J. B., Hayes, S. C., & Walser, R. D. (2007). *Learning ACT: An acceptance & commitment therapy skills-training manual for therapists*. Oakland, CA: New Harbinger.

222. Arksey, H., Jackson, K., Wallance, A., Baldwin, S., Golder, S., Newbronner., E., & Hare, P. (2003). Access to health care for carers: Barriers and interventions. National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO). Retrieved from https://www.york.ac.uk/inst/spru/pubs/pdf/access.pdf

223. van Exel, J., de Graaf, G., & Brouwer, W. (2008). Give me a break!: Informal caregiver attitudes towards respite care. *Health Policy, 88*(1), 73-87. doi: 10.1016/j.healthpol.2008.03.001

224. Gomez-Pinilla, F. (2008). Brainfoods: The effect of nutrients on brain function. *Nature Reviews Neuroscience, 9*(7), 568-578. doi: 10.1038/nrn2421

225. Jacka, F. N., Arnstein, M., Berk, M., Bjelland, I., & Tell, G. S. (2011). The association between habitual diet quality and the common mental disorders in community-dwelling adults: The Hordaland Health Study. *Psychosomatic Medicine, 73*(6), 483-490. doi: 10.1097/PSY.0b013e318222831a

226. O'Neil, A., Quirk, S. E., Housden, S., Brennan, S. L., Williams, L. J., Pasco, J. A., Berk, M., & Jacka, F. N. (2014). Relationship between diet and mental health in children and adolescents: A systematic review. *American Journal of Public Health, 104*(10), e31-e42. doi: 10.2105/AJPH.2014.302110

227. Hughes, G., Bennett, K. M., & Hetherington, M. M. (2004). Old and alone: barriers to healthy eating in older men living on their own. *Appetite, 43*(3), 269-276. doi: 10.1016/j.appet.2004.06.002

228. Kearney, J., & McElhone, S. (1999). Perceived barriers in trying to eat healthier–results of a pan-EU consumer attitudinal survey. *British Journal of Nutrition, 81*(S1), S133-137.

229. Munt, A. E., Partridge, S. R., & Allman-Farinelli, M. (2017). The barriers and enablers of healthy eating among young adults: a missing piece of the obesity puzzle: A scoping review. *Obesity Reviews, 18*(1), 1-17. doi: 10.1111/obr.12472

230. Emerson, N. D., Merrill, D. A., Shedd, K., Bilder, R. M., & Siddarth, P. (2016). Effects of an employee exercise programme on mental health. *Occupational Medicine, 67*(2), 128-134. doi: 10.1093/occmed/kqw120

231. Penedo, F. J., & Dahn, J. R. (2005). Exercise and well-being: A review of mental and physical health benefits associated with physical activity. *Current Opinion in Psychiatry, 18*(2), 189-193.

232. Stathopoulou, G., Powers, M. B., Berry, A. C., Smits, J. A. J., & Otto, M. W. (2006). Exercise interventions for mental health: A quantitative and qualitative review. *Clinical Psychology: Science and Practice, 13*, 179-193. doi: 10.1111/j.1468-2850.2006.00021.x

233. Stubbs, B., Vacampfort, D., Rosenbaum, S., Firth, J., Cosco, T., Veronese, N., Salum, G. A., & Schuch, F. B. (2017). An examination of the anxiolytic effects of exercise for people with anxiety and stress-related disorders: A meta-analysis. *Psychiatry Research, 249*, 102-108. doi: 10.1016/j.psychres.2016.12.02

References

234. Gordon, B. R., McDowell, C. P., Lyons, M., Herring, M. P. (2017). The effects of resistance exercise training on anxiety: A meta-analysis and meta-regression analysis of randomized controlled trials. *Sports Medicine, 47*(12), 2521-2532. doi: 10.1007/s40279-017-0769-0

235. Hendriks, T., de Jong Joop, & Holger, C. (2017). The effects of yoga on positive mental health among healthy adults: A systematic review and meta-analysis. *The Journal of Alternative and Complementary Medicine, 23*(7), 505-517. doi: 10.1089/acm.2016.0334

236. Heesch, K. C., van Gellecum, Y. R., Burton, N. W., van Uffelen, J. G. Z., & Brown, W. J. (2015). Physical activity, walking, and quality of life in women with depressive symptoms. *American Journal of Preventative Medicine, 48*(3), 281-291. doi: 10.1016/j.amepre.2014.09.030

237. Robertson, R., Robertson, A., Jepson, R., & Maxwell, M. (2012). Walking for depression ordepressive symptoms: A systematic review and meta-analysis. *Mental Health and Physical Activity, 5*, 66-75. doi: 10.1016/j.mhpa.2012.03.002

238. Biddle, S. J. H., & Mutrie, N. (2008). *Psychology of physical activity* (2nd Ed.). London: Routledge.

239. Countryside Recreation Network. (2006) A Countryside for Health and Wellbeing: The Physical and Mental Health Benefits of Green Exercise [Online]. Retrieved from: http://www.thehealthwell.info/node/3900

240. Barton, J., & Pretty, J. (2010). What is the best dose of nature and green exercise for improving mental health? A multi-study analysis. *Environmental Science & Technology, 44*(10), 3947-3955. doi: 10.1021/es903183r

241. Sallis, J. F., & Hovell, M. F. (1990). Determinants of Exercise Behavior. *Exercise and Sport Science Reviews*, 307-30.

242. Sallis, J. F., Hovell, M. F., & Hofstetter, C. R. (1992). Predictors of Adoption and Maintenance of Vigorous Physical Activity in Men and Women. *Preventive Medicine, 21*(2), 237-51.

243. Roth, T. (2007). Insomnia: Definition, prevalence, etiology, and consequences. *Journal of Clinical Sleep Medicine, 15*(3), S7-S10.

References

244. McCurry, S. M., Song, Y., & Martin, J. L. (2015). Sleep in caregivers: what we know and what we need to learn. *Current Opinion in Psychiatry, 28*(6), 497-503. doi: 10.1097/YCO.0000000000000205

245. Edinger, J D., & Carney, C. E. (2008). *Overcoming insomnia: A cognitive-behavioural therapy approach workbook (Treatments that work)*. Oxford: Oxford University Press.

246. Morin, C. M. (2004). Cognitive-behavioural approaches to the treatment of insomnia. *Journal of Clinical Psychiatry, 65*(suppl. 16), 33-40.

247. NHS (2016). *10 tips to beat insomnia*. Retrieved from www.nhs.uk/Livewell/insomnia/Pages/insomniatips.aspx

248. Ree, M., & Harvey, A. (2004). Insomnia. In J. Bennett-Levy, G. Butler, M. Fennell, A. Hackmann, M. Mueller and D. Westbrook. (Eds.). (2004). *Oxford guide to behavioural experiments in cognitive therapy*. (pp. 287-385). Oxford: Oxford University Press.

249. Sansone, R. A., & Sansone, L. A. (2010). Gratitude and well being. *Psychiatry MMC*, 7(11), 18-22.

250. Gander, F., Proyer, R. T., Ruch, W., & Wyss, T. (2012). Strength-based positive interventions: Further evidence for their potential in enhancing well-being and alleviating depression. *Journal of Happiness Studies, 14*(4), 1241-1259. doi: 10.1007/s10902-012-9380-0

251. Wood, A. M., Maltby, J., Gillett, R., Linley, P. A., & Joseph, S. (2008). The role of gratitude in the development of social support, stress, and depression: Two longitudinal studies. *Journal of Research in Personality, 42*(4), 854−871. doi: 10.1016/j.jrp.2007.11.003

252. Kendler, K. S., Liu, X. Q., Gardner, C. O., McCullough, M. E., Larson, D., & Prescott, C. A. (2003). Dimensions of religiosity and their relationship to lifetime psychiatric and substance use disorders. *American Journal of Psychiatry, 160*(3), 496−503. doi:10.1176/appi.ajp.160.3.496

253. Wood, A. M., Joseph, S., Lloyd, J., & Atkins, S. (2009). Gratitude influences sleep through the mechanism of pre-sleep cognitions. *Journal of Psychosomatic Research, 66*(1), 43-48. doi: 10.1016/j.jpsychores.2008.09.002

254. Algoe, S. B., Haidt, J., & Gable, S. L. (2008). Beyond reciprocity: Gratitude and relationships in everyday life. *Emotion, 8*(3), 425−429. doi: 10.1037/1528-3542.8.3.425

References

255. Hill, P. L., Allemand, M., & Roberts, B. W. (2013). Examining the pathways between gratitude and self-rated physical health across adulthood. *Personality and Individual Differences, 54*(1), 92-96. doi: 10.1016/j.paid.2012.08.011

256. Wood, A. M., Froh, J. J., & Geraghty, A. W. A. (2010). Gratitude and well-being: A review and theoretical integration. *Clinical Psychology Review, 30*(7), 890-905. doi: 10.1016/j.cpr.2010.03.005

257. Conversano, C., Rotondo, A., Lensi, E., Vista, O. D., Arpone, F., & Reda, M. A. (2010). Optimism and its impact on mental and physical well-being. *Clinical Practice & Epidemiological in Mental Health, 6*, 25-29. doi: 10.2174/1745017901006010025

258. Nes, L. S., & Segerstrom, S. C. (2006). Dispositional optimism and coping: A meta-analytic review. *Personality and Social Psychology Review, 10*(3), 235-251. doi: 10.1207/s15327957pspr1003_3

259. Schiavon, C. C., Marchetti, E., Gurgel, L. G., Busnello, F. M., & Reppold, C. T. (2016). Optimism and hope in chronic disease: A systematic review. *Frontiers in Psychology, 7*, 2022. doi: 10.3389/fpsyg.2016.02022

260. Lyons, K. S., Stewart, B. J., Archbold, P. G., Carter, J. H., & Perrin, N. A. (2004). Pessimism and optimism as early warning signs for compromised health for caregivers of patients with Parkinson's disease. *Nursing Research, 53*(6), 354-362. doi: 10.1097/00006199-200411000-00002

261. Lyons, K. S., Stewart, B. J., Archbold, P. G., Carter, J. H., & Perrin, N. A. (2009). Optimism, pessimism, mutuality, and gender: predicting 10-year role strain in Parkinson's disease spouses. *Gerontologist, 49*(3), 378-387. doi: 10.1093/geront/gnp046

262. Shepperd, J. A., Waters, E. A., Weinstein, N. D., & Klein, W. M. P. (2015). A primer on unrealistic optimism. *Current Directions in Psychological Science, 24*(3), 232-237. doi: 10.1177/0963721414568341

263. Shepperd, J. A., Carroll, P., Grace, J., & Terry, M. (2002). Exploring the causes of comparative optimism. *Psychologica Belgica, 42*(1-2), 65-98.

264. Seligman, M. (2006). *Learned optimism: How to change your mind and your life*. New York: Vintage Press.

References

265. Blackwell, S. E., Rius-Ottenheim, N., Schulte-van Maaren, Y. W. M., Carlier, I. V. E., Middelkoop, V. D., Zitman, F. G., Spinhoven, P., Holmes, E. A., & Giltay, E. J. (2013). Optimism and mental imagery: A possible cognitive marker to promote well-being? *Psychiatry Research, 1*(3), 56-61. doi: 10.1016/j.psychres.2012.09.047

266. Meevissen, Y. M. C., Peters, M. L., & Alberts, H. J. E. M. (2011). Become more optimistic by imagining a best possible self: Effects of a two week intervention. *Journal of Behavior Therapy and Experimental Psychiatry, 42*(3), 371-378. doi: 10.1016/j.jbtep.2011.02.012

267. Renner, F., Schwarz, P., Peters, M. L., & Huibers, M, J. H. (2014). Effects of a best-possible-self mental imagery exercise on mood and dysfunctional attitudes. *Psychiatry Research, 215*(1), 105-110. doi: 10.1016/j.psychres.2013.10.033

268. Hayes, S. & Smith, S. (2005). *Get out of your mind & into your life*. Oakland: New Harbinger.

269. Kashdan, T., & Biswas-Diener. R. (2014). *The upside of your dark side*. Plume.

270. Calvo, M. G., Gutierrez-Garcia, A. (2016). Cognition and stress. In G. Fink (Ed.), *Stress: Concepts, cognition, emotion, and behaviour* (pp. 139-144). San Diego, CA: Elsevier Academic Press.

271. Sandi, C. (2013). Stress and cognition. *Wiley interdisciplinary reviews: Cognitive Science, 4*(3), 245-261. doi: 10.1002/wcs.1222

272. Crane, R. (2009). *Mindfulness-based cognitive therapy: Distinctive features*. London: Routledge.

273. Gillanders, D. T., Bolderston, H., Bond, F. W., Dempster, M., Flaxman, P. E., Campbell, L., Kerr, S., (2014). The development and initial validation of the cognitive fusion questionnaire. *Behavior Therapy, 45*(1), 83-101. doi: 10.1016/j.beth.2013.09.001

274. Harris, R. (2008). *The happiness trap*. London: Constable & Robinson.

275. Alidina, S. (2015). *Mindfulness for dummies*. Chichester: John Wiley & Sons Ltd.

References

276. Mindful (2017). Jon Kabat-Zinn: Defining mindfulness. Retrieved from https://www.mindful.org/jon-kabat-zinn-defining-mindfulness/

277. Camilleri, G. M., Mejean, C., Bellisle, F., Hercberg, S., & Peneau, S. (2016). Mind-body practice and body weight status in a large population-based sample of adults. *American Journal of Preventative Medicine, 50*(4), e101-e109. doi: 10.1016/j.amepre.2015.10.005

278. Yau, Y. H. C., & Potenza, M. N. (2013). Stress and eating behaviors. *Minerva Endocrinology, 38*(3), 255-267.

279. Brown, K W., & Ryan, R. M. (2003). The benefits of being present: Mindfulness and its role in psychological well-being. *Journal of Personality and Social Psychology, 84*(4), 822-848. doi: 10.1037/0022-3514.84.4.822

280. David, D. (2014). Some concerns about the psychological implications of mindfulness: A critical analysis. *Journal of Rational-Emotive & Cognitive-Behavior Therapy, 32*(4), 313-324. doi: 10.1007/s10942-014-0198-z

281. Howell, R. T. (2012). Finding 'flow' this week. *Psychology Today*, 25/02/12. Retrieved from www.psychologytoday.com/blog/cant-buy-happiness/201202/finding-flow-week

282. Csikszentmihalyi, M. (2002). *Flow: The classic work on how to achieve happiness* (Revised Ed.). London: Rider.

283. Bryant, F. B., & Veroff, J. (2007). *Savoring: A new model of positive experience.* New Jersey: Lawrence Erlbaum Associates.

284. Ford, J., Klibert, J. J., Tarantino, N., & Lamis, D. A. (2017). Savouring and self-compassion as protective factors for depression. *Stress & Health, 33*(2), 119-128. doi: 10.1002/smi.2687

285. Jose, P. E., Lim, B. T., Bryant, F. B. (2012). Does savoring increase happiness? A daily diary study. *The Journal of Positive Psychology, 7*(3), 176-187. doi: 10.1080/17439760.2012.671345

286. Smith, J. L., & Hollinger-Smith, L. (2015). Savoring, resilience, and psychological well-being in older adults. *Aging & Mental Health, 19*(3), 192-200. doi: 10.1080/13607863.2014.986647

References

287. Greenberger, D., & Padesky, C. A. (2016). *Mind over mood: change how you feel by changing the way you think* (2nd ed.). New York, NY: The Guilford Press.

288. Ford, B. Q., Lam. P., John, O.P., & Mauss, I. B. (2017). The psychological health benefits of accepting negative emotions and thoughts: Laboratory, diary, and longitudinal evidence. *Journal of Personality and Social Psychology*. Advance online publication. doi: 10.1037/pspp0000157

289. Family Caregiver Alliance. (2014). Emotional side of caregiving. Retrieved from https://www.caregiver. org/emotional-side-caregiving

290. Adam, Y., Meinlschmidt, G., Gloster, A. T., & Lieb, R. (2012). Obsessive-compulsive disorder in the community: 12-month prevalence, comorbidity and impairment. *Social Psychiatry and Psychiatric Epidemiology, 47*(3), 339-349. doi: 10.1007/s00127-010-0337-5

291. Fullana, M. A., Mataix-Cols, D., Caspi, A., Harrington, H., Grishman, J. R., Moffitt, T. E., & Poulton, R. (2009). Obsessions and compulsions in the community: Prevalence, interference, help-seeking, developmental stability, and co-occurring psychiatric conditions. *American Journal of Psychiatry, 166*(3), 329-336. doi: 10.1176/appi.ajp.2008.08071006

292. Srivastava, S., Tamir, M., McGonigal, K. M., John, O. P., & Gross James. J. (2009). The social costs of emotional suppression: A prospective study of the transition to college. *Journal of Personality and Social Psychology, 96*(4), 883-897. doi: 10.1037/a0014755

293. Brockman, R., Ciarrochi, J., Parker, P., & Kashdan, T. (2016). Emotion regulation strategies in daily life: Mindfulness, cognitive reappraisal and emotion suppression. *Cognitive Behaviour Therapy, 46*(2), 91-113. doi: 10.1080/16506073.2016.1218926

294. McKay, M., & West, A. (2016). *Emotion efficacy therapy*. New Harbinger.

295. Cameron, K., Ogrodniczuk, J., Hadjipavlou, G. (2014). Changes in alexithymia following psychological intervention: A review. *Harvard Review of Psychiatry, 22*(3), 162-178. doi: 10.1097/HRP.0000000000000036

296. Katsifaraki, M,. & Wood, R. L. (2014). The impact of alexithymia on burnout amongst relatives of people who suffer from traumatic brain

injury. *Brain Injury, 28*(11), 1389-1395, doi: 10.3109/02699052.2014.919538

297. Lai, C., Luciani, M., & Morelli, E. (2013). Predictive role of different dimensions of burden for risk of complicated grief in caregivers of terminally ill patients. *American Journal of Hospice and Palliative Medicine, 31*(2), 189-193. doi: 10.1177/1049909113490227

298. Di Fabio, A., & Kenny, M. E. (2016). Promoting well-being: The contribution of emotional intelligence. *Frontiers of Psychology, 7*, 1182. doi: 10.3389/fpsyg.2016.01182

299. Plutchik, R. (1991). *The emotions* (Revised Ed.). Lanham: University Press of America.

300. Gilbert, P. (2009). *The compassionate mind.* London: Constable & Robinson.

301. Neff, K. (2011). *Self compassion.* New York: HarperCollins.

302. Linehan, M. M. (1993). *Skills training manual for treating borderline personality disorder: Diagnosis and treatment of mental disorders.* New York: Guilford.

303. National Centre for Complementary and Integrative Health (2017). Relaxation techniques for health. Retrieved from https://nccih.nih.gov/health /stress/relaxation .htm#hed1

304. Francesco, P., Mauro, M. G., Gianluca, C., & Enrico, M. (2010). The efficacy of relaxation training in treating anxiety. *International Journal of Behavioral Consultation and Therapy, 5*(3-4), 264-269. doi: 10.1037/h0100887

305. Manzoni, G. M., Pagnini, F., Castelnuovo, G., & Molinari, E. (2008). Relaxation training for anxiety: a ten-years systematic review with meta-analysis. *BMC Psychiatry, 8*, 41. doi: 10.1186/1471-244X-8-41

306. Jorm, A. F., Morgan, A. J., Hetrick, S. E. (2008). Relaxation for depression. *Cochrane Database of Systematic Reviews, 4*. Art. No.: CD007142. doi: 10.1002/14651858.CD007142.pub2

307. Payne, R. M. (2005). *Relaxation techniques: A practical handbook for the health care professional* (3rd Ed.). Edinburgh: Elsevier.

References

308. Choi, Y. K. (2010). The effect of music and progressive muscle relaxation on anxiety, fatigue, and quality of life in family caregivers of hospice patients. *Journal of Music Therapy, 47*(1), 53069. doi: 10.1093/jmt/47.1.53

309. McCallie, M. S., Blum, C. M., & Hood, C. J. (2006). Progressive muscle relaxation. *Journal of Human Behavior in the Social Environment, 13*(3), 51-66. doi: 10.1300/J137v13n03_04

310. Pelekasis, P., Matsouka, I., & Koumarianou, A. (2017). Progressive muscle relaxation as a supportive intervention for cancer patients undergoing chemotherapy: A systematic review. *Palliative & Supportive Care, 15*(4), 465-473. doi: 10.1017/S1478951516000870

311. Vancampfort, D., Correll, C. U., Scheewe, T. W., Probst, M., De Herdt, A., Knapen, J., & De Hert, M. (2013). Progressive muscle relaxation in persons with schizophrenia: a systematic review of randomized controlled trials. *Clinical Rehabilitation, 27*(4), 291-298. doi: 10.1177/0269215512455531

312. Tusek, D. L., Church, J. M., Strong, S. A., Grass, J. A., & Fazio, V. W. (1997). Guided imagery. *Diseases of the Colon & Rectum, 40*(2), 172-178.

313. Ackerman, C. J., Turkoski, B. (2000). Using guided imagery to reduce pain and anxiety. *Home Healthcare Nurse, 18*(8), 524-530.

314. Roffe, L., Schmidt, K., & Ernst, E. (2005). A systematic review of guided imagery as an adjuvant cancer therapy. *Psycho-Oncology, 14*(8), 607-617., doi: 10.1002/pon.889

315. Posadzki, P., & Ernst, E. (2011). Guided imagery for musculoskeletal pain: A systematic review. The *Clinical Journal of Pain, 27*(7), 548-653. doi: 10.1097/AJP.0b013e31821124a5

316. Kosciulek, J. F. (2007). The social context of coping. In E. Martz and L. Hanoch (Eds.). *Coping with chronic illness and disability: Theoretical, empirical and clinical aspects* (pp. 73-88). New York: Springer.

317. Wells, J. D., Hobfoll, S. E., & Lavin, J. (1997). Resource loss, resource gain, and communal coping during pregnancy among women with multiple roles. *Psychology of Women Quarterly, 21* (4), 645-662.

References

318. Berg, C. A., Meegan, S. P., & Deviney, F. P. (1998). A social contextual model of coping with everyday problems across the lifespan. *International Journal of Behavioral Development, 22*(2), 239-261. doi: 10.1080/016502598384360

319. Thoits, P. (1986). Social support as coping assistance. *Journal of Consulting & Clinical Psychology, 60*(3), 12-20.

320. Woodward, A. (2017, May 1). With a little help from my friends. *Scientific American.* Retrieved from https://www.scientificamerican.com /article/with-a-little-help-from-my-friends/

321. Edelstein, H., Schippke, J., Sheffe, S., & Kingsnorth, S. (2017). Children with medical complexity: a scoping review of interventions to support caregiver stress. *Child Care Health Development, 43*(3), 323-333. doi: 10.1111/cch.12430

322. Vandepitte, S., Van Den Noortgate, N., Putman, K., Verhaeghe, S., Verdonck, C., & Annemans, L. (2016). Effectiveness of respite care in supporting informal caregivers of persons with dementia: a systematic review. *International Journal of Geriatric Psychiatry, 31*(12), 1277-1288. doi: 10.1002/gps.4504

323. Whitmore, K. E. (2016). Respite care and stress among caregivers of children with autism spectrum disorder: An integrative review. *Journal of Pediatric Nursing, 31*(6), 630-652. doi: 10.1016/j.pedn.2016.07.009

324. Strang, V. R. (2000). Caregiver respite: Coming back after being away. *Perspectives, 24*(4), 10-20.

325. Egeci, I. S., & Gencoz, T. (2006). Factors associated with relationship satisfaction: Importance of communication skills. *Contemporary Family Therapy, 28*(3), 383-391. doi: 10.1007/s10591-006-9010-2

326. Hamm, M. P., Chisholm, A., Shulham, J., Milne, A., Scott, S. D., Given, L. M., & Hartling, L. (2013). Social media use among patients and caregivers: A scoping review. *BMJ Open, 3*(5), 1376-1383. doi: 10.1136/bmjopen-2013-002819

327. Gage-Bouchard, E. A., LaValley, S., Mollica, M., & Beaupin, L. K. (2017). Facebook for cancer-related communication. *Cancer Nursing, 40*(4), 332-338. doi: 10.1097/NCC.0000000000000418

References

328. Ellison, N. B., Steinfield, C., & Lampe, C. (2007). The benefits of Facebook "friends": Social capital and college students' use of online social network sites. *Journal of Computer-Mediated Communication, 12*(4), 1143-1168. doi: 10.1111/j.1083-6101.2007.00367.x

329. Ledbetter, A. M. (2017). Friendship and social media. In M. Hojjat and A. Moyer (Eds.). *The psychology of friendship* (pp. 93-108). New York: Oxford University Press

330. Chan, D., Livingston, G., Jones, L., & Sampson, E. L. (2013). Grief reactions in dementia carers: A systematic review. *International Journal of Geriatric Psychiatry, 28*(1), 1-17. doi: 10.1002/gps.3795

331. Schulz, R., Mendelsohn, A. B., Haley, W. E., Mahoney, D., Allen, R. S., Zhang, S., Thompson, L., & Belle, S. H. (2003). End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *New England Journal of Medicine, 349*(20), 1936-1942. doi: 10.1056/NEJMsa035373

332. Caserta, M., Utz, R., Lund, D., Supiano, K., & Donaldson, G. (2017). Cancer caregivers' preparedness for loss and bereavement outcomes: Do preloss caregiver attributes matter? OMEGA- *Journal of Death and Dying*, Epub ahead of print. doi: 10.1177/0030222817729610

333. Allen, J. Y., Haley, W. E., Small, B. J., Schonwetter, R. S., & McMillan, S. C. (2013). Bereavement among Hospice Caregivers of Cancer Patients One Year following Loss: Predictors of Grief, Complicated Grief, and Symptoms of Depression. *Journal of Palliative Medicine, 16*(7), 745-751. doi: 10.1089/jpm.2012.0450

334. Kelly, B., Edwards, P., Synott, R., Neil, C., Baillie, R., & Battistutta, D. (1999). Predictors of bereavement outcome for family carers of cancer patients. *Psycho-Oncology, 8*(3), 237-249. doi: 10.1002/(SICI)1099-1611(199905/06)8:3<237::AID-PON375>3.0.CO;2-C

335. Burns, E., Prigerson, H. G., & Quinn, S. J., Abernethy, A. P., & Currow, D. C. (2018). Moving on: Factors associated with caregivers' bereavement adjustment using a random population-based face-to-face survey. *Palliative Medicine, 32*(1), 257-267. doi: 10.1177/02692163177 17370

336. Thomas, K., Hudson, P., Trauer, T., Remedios, C., & Clarke, D. (2014). Risk factors for developing prolonged greif during bereavement

References

in family carers of cancer patients in palliative care: A longitudinal study. *Journal of Pain and Symptom Management, 47*(3), 531-541. doi: 10.1016/j.jpainsymman.2013.05.022