

Dementia and Psychotherapy Reconsidered

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Preface

Preface for the *Reconsidering Dementia* book series for *Dementia and Psychotherapy Reconsidered*

Series Editors: Dawn Brooker and Keith Oliver

The dementia field has developed rapidly in its scope and practice over the past 25 years. Many thousands of people are diagnosed with dementia each year. Worldwide, the trend is that people are being diagnosed at much earlier stages. In addition, families and friends increasingly provide support to those affected by dementia over a prolonged period. Many people, both those diagnosed with dementia and those who support them, have an appetite to understand their condition. Care professionals and civic society also need an in-depth and nuanced understanding of how to support people living with dementia within their communities over the long term.

The *Reconsidering Dementia* book series sets out to address this need. It takes its inspiration from the late Professor Tom Kitwood's seminal text *Dementia Reconsidered* published in 1997 which, at the time, revolutionized how dementia care was conceptualized. The book series editors worked together on the 2nd Edition of the book entitled *Dementia Reconsidered, Revisited: The Person Still Comes First*. This 2019 publication was a reprint of the original text by Tom Kitwood alongside contemporary commentaries for each chapter written by current experts. Many topics in the field of dementia care, however, were simply unheard of in Kitwood's lifetime. The subsequent titles in this series are cutting-edge scholarly texts that challenge and engage readers to think deeply. They draw on theoretical understandings, contemporary research and experience to critically reflect on their topic in great depth.

This does not mean, however, that they are not applicable to improving the care and support to those affected by dementia. As well as the scholarly text, all books have a 'So what?' thread that unpacks what this means for people living with dementia, their families, people working in dementia care, policy makers, professionals, community activists, and so on. Too many books either focus on an academic audience **or** a practitioner audience **or** a student audience **or** a lived experience audience. In this series, the aim is to try to address these perspectives in the round. The *Reconsidering Dementia* book series attempts to bring together the perspectives of professional practice, scholarship and the lived experience as they pertain to the key topics in the field of dementia studies.

The book series is jointly commissioned and edited by Professor Dawn Brooker MBE and by Dr Keith Oliver. Dawn has been active in the field of

dementia care since the 1980s as a clinician and an academic. She draws on her experience and international networks to bring together a series of books on the most pertinent issues in the field. Keith is one of the foremost international advocates for those living with dementia. He also brings an insightful perspective of his own and others' experience of what it means to live with dementia gained since his diagnosis of Alzheimer's disease in 2010.

One of the first titles Dawn and Keith wanted to commission was this book on *Dementia and Psychotherapy Reconsidered*. Kitwood himself was a psychotherapist and he articulated a psychological model of the experience of dementia. However, in Kitwood's lifetime the idea that people experiencing dementia could engage directly with talking therapies was unheard of. Rik Cheston was one of the pioneers of talking therapies in the field of dementia care in the UK and this book bears testament to Rik's vast experience within this field. This is a ground-breaking book that brings together know-how, scholarship and humanity in equal measure for all those engaged in talking with people about the experience of living with dementia.

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Additional Thoughts from Keith Oliver

It has been an honour and a privilege for me as a person living with dementia to fulfil the role of co-editor for Rik Cheston's book, and from page one I was drawn in and hooked by Rik's wisdom, experience and style of writing. Since sharing my brain with Alzheimer's disease I have had many good days and weeks, but frustration and challenge is never far away, lurking in what I describe as the fog of my dementia. What Rik does is offer a pathway out of the fog into a sunnier place, one which I do know works. For half of the period since being diagnosed I have received therapy – either on the NHS or sourcing it myself privately – which has included psychotherapy, behaviour support therapy, and the two which worked best in a person-centred approach for me, which were narrative therapy and compassion-focused therapy. My sincere, heartfelt wish is that this book serves as a driving force to ensure more people with dementia are able to access good quality, person-centred therapy. It does work – I am living proof of this!

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Introduction

'What I'm asserting may at first seem to be surprising, paradoxical, counterintuitive. Psychotherapy with dementing persons? What an absurd and impractical idea! A bit of behaviour modification – yes, by all means. Some reality orientation, of course. But these, as we all know, are not 'real' psychotherapy, which aims at bringing about profound and enduring changes within persons. 'Real' psychotherapy with demented persons? That surely is a contradiction in terms. For doesn't dementia, by definition, mean a permanent loss of mind, which is roughly equivalent to saying 'out of psychotherapeutic reach?'

Tom Kitwood, 1990, p. 42

The title of this book reflects its origins in the 2019 republication of Tom Kitwood's landmark publication *Dementia Reconsidered: The Person Comes First*. The new book, edited by Professor Dawn Brooker was titled *Dementia Reconsidered, Revisited: The Person Still Comes First* and in it each of the nine chapters from the original book were republished alongside a commentary (Kitwood and Brooker, 2019). For eight of these chapters, the commentary was written by a contemporary dementia researcher and reviewed the progress that had been made in that area in the 20+ years since the publication of the original book. In keeping with the underlying principles of person-centred dementia care that Tom Kitwood had done so much to advocate, the ninth and remaining chapter was accompanied by a commentary written jointly by Keith Oliver (a man living with dementia) and Reinhard Guss (a clinical psychologist). Additionally, both a foreword and afterword were also written by two women living with dementia: Christine Bryden and Kate Swaffer.

I was lucky enough to meet Tom Kitwood at the start of my career in the early 1990s. Throughout my career, my own clinical and research work has, like so many others, continued to draw inspiration from Tom's writings. However, when I started working with people with dementia, as a newly qualified clinical psychologist, I had no great interest in working with older people, let alone people living with dementia. I had applied for a post in this area largely for personal rather than professional reasons as I wanted to live near Bath, and this was the only job I could find. While I had ambitions to develop as a psychotherapist, there seemed little opportunity to do this, as the work of clinical psychologists with people living with dementia seemed to be confined to three areas: the assessment of people with memory problems; the provision of support to their families; and the delivery of training for the staff caring for them.

One of the important turning points for me at this stage was when my first Older Adult Psychology manager, Jane Fossey, lent me a copy of a 1990 article that Tom had written in the Newsletter of the Psychotherapy Section of the *British Psychological Society*. The extract above comes from this article. Compared to his other publications at this time, in *Ageing and Society* – the journal

of the British Society of Gerontology – this was a small, almost incidental article in a relatively obscure newsletter. However, what I read helped me to see possibilities in my work that I had previously not been aware of. By this time, I was aware of Tom's espousal of person-centred care, but I had assumed this was confined to institutional care – so to come across not only arguments that it might be possible to use psychotherapy with people living with dementia, but also that there might be a moral imperative to do so was something of a revelation.

However, while Tom's work fired me with a belief that psychotherapy might be possible, I still did not know how to do so. I am now approaching the end of my professional career and have spent much of the time since then trying to work out the answer to this question. This book is my attempt to record some of what I have learnt.

This book is divided into four sections. In common with the other books in this series, at the end of each section I have provided a brief summary of the most salient points, together with an outline of the main implications for people living with dementia, family carers, therapists and dementia care workers.

In Part 1, I set out an overview of what is meant by the term dementia. Chapter 1 provides a summary of the syndrome of dementia, its prevalence and impact on families and society.

Chapter 2 continues to look at the impact of dementia, but extends this to frame dementia as a psychological threat. This chapter draws on the work I have carried out with colleagues at the University of the West of England in Bristol and Constantine Sedikides and Tim Wildschut who are social and personality psychologists from the Centre for Research and Identity at the University of Southampton. In this collaboration we have begun to translate a major paradigm from social psychology, the Terror Management Theory (Solomon et al., 2015), into dementia research. In so doing, we have tested a series of hypotheses around how people defend themselves against threatening information. Although our early research was largely laboratory based, we have recently begun to take the first steps towards translating our ideas into clinical interventions – a process we hope to continue in the next few years.

Chapter 3 argues that people living with dementia have all too often been left to respond to this threat on their own, as for many the sheer awfulness of dementia has been ignored. Instead, this chapter makes the case that we need to find a way to talk about their dementia with people – and that psychotherapy has an important role to play in this.

Part 2 also consists of three chapters and examines how individual therapy (Chapter 4), couples therapy (Chapter 5) and group therapy (Chapter 6) can be used with this client group. Each of these chapters presents some of the relevant research base but also draws on my own experiences as a clinician providing psychotherapy and as an active researcher. In order to illustrate the potential for psychotherapy I have included in each chapter one or more clinical cases drawn from my own practice. In order to protect the anonymity of my clients I have taken two measures: first by using pseudonyms and changing all

personal details; and secondly by ensuring that each case study is a composite of two or sometimes more pieces of clinical work.

Part 3 consists of four chapters that look at an issue that has been missing from many psychotherapeutic accounts – that is to say, how we talk about dementia with people who are living with dementia. In my work I have come to see a capacity to talk about dementia as synonymous with adjustment – both in the sense of people finding the words to describe their dementia to themselves and within therapy, but also in their being able to tell other people.

Chapter 7 sets out how, in the absence of a psychological model that could describe this process of talking and adjusting, I have adapted a framework developed by Bill Stiles, who is Professor Emeritus in the Department of Psychology at Miami University in Ohio. In contrast to many of the theoretical frameworks that have been applied to studies of awareness in dementia care, Bill's assimilation model represents a person's ability to process threatening or problematic material as involving both cognitive and emotional factors. I have found this adapted assimilation model to be a useful research tool, and an invaluable clinical aid.

Chapter 8 then examines the initial stages of this process of assimilation, stages in which the difficult, problematic nature of dementia is at first pushed away before emerging in a disguised form, progressively heightening the person's emotional response. The task of the person with dementia is to put a name to their dementia without being emotionally overwhelmed by this.

Chapter 9 continues to chart the process of adjustment as the individual strives to find some distance and perspective from their dementia, for instance by exploring how its impact resonates with other aspects of their life.

The final chapter in this section of the book (Chapter 10) looks at instances of how some people living with dementia have been able to incorporate their dementia into their existing identity and to find ways of balancing living their lives well with being mindful of their diagnosis.

In the final section, Part 4, I turn to factors which can complicate the application of psychotherapeutic skills. For the first time, in Chapter 11, I will foreground the direct consequences of the neurological damage inherent in dementia, and how the resulting cognitive impairment impacts on the therapeutic process. In Chapter 12 I will examine the need for therapists to take into account both social and personal frailty in assessing whether, and if so then how, to offer psychotherapeutic work. Finally, Chapter 13 returns to a central theme in Kitwood's 1990 paper – that of the importance of being therapeutic in dementia care as well as doing therapy.

In writing this book, I have made some assumptions about who might be likely to read it. First, I have assumed that readers will have at least a passing familiarity with dementia – for instance either from working in dementia care themselves or witnessing someone close to them experience a form of dementia. Similarly, I have also assumed that the majority of readers will have a background in the psychological, psychotherapeutic or counselling professions. This is not so much a book about how to do psychotherapy, as a book about how to adapt psychotherapeutic practice to accommodate the differing

demands of working with people who are living with dementia and their families.

This book also reflects at least two of my own beliefs about therapy, or perhaps it might be more accurate to say, my own biases about therapy.

Firstly, while I appreciate that there are distinctions to be drawn between terms such as 'psychotherapy', 'counselling' and 'psychological therapy', to my mind there are far more similarities between all of these than there are differences. As novelists and dramatists have known for millennia, we are all capable of changing ourselves, of seeing the world in a new way, of gaining perspective and distance from trauma. There is no reason, then, to see the work that is done within psychotherapy as being different in its entirety from that which occurs within other settings. Nevertheless, I can appreciate that for many, this blurring of distinctions may feel at best imprecise, and at worst positively careless.

Secondly, just as my own therapeutic practice is unashamedly eclectic, so is this book; I have not sought to privilege any single therapeutic modality. Thus, in common with many clinical psychologists, as part of my own professional development I have trained as a CBT therapist and also spent a year on an experiential group analytic psychotherapy course. Again, I know there will be many whose own practice is much more focused, and for whom there is little if anything to be gained from studying other ways of working. If this is the case for you, then I can only hope that you will find enough of substance here to help you to use your own skills in working with people with dementia. Ultimately, perhaps the best way to learn is to make your own mistakes.

The genesis of this book is firmly within person-centred care. Accordingly, the focal question that I seek to answer is one that is central to person-centred dementia care, but one that has been, I believe, all too often neglected: *'How can we help people living with dementia to talk about what is happening to them?'* After all, being able to put a name to the challenges that someone faces should, one would imagine, be essential to any truly person-centred encounter. However, in my experience, it is striking how often this very basic discussion is missing from what are otherwise excellent forms of service provision. Perhaps even more surprisingly, finding a way to talk about their dementia with clients is also all too often missing from accounts of psychotherapy and counselling in this area.

The reasons why this neglect of dementia is so widespread is something that I will engage with throughout this book. Put simply, however, the reason may be obvious: dementia is just too big and too frightening a topic to touch upon lightly. I suspect that for many healthcare professionals it is, frankly, something of a conversation stopper. They avoid raising the subject, because they don't want to upset their clients and because they fear they wouldn't know what to say if this happens. If I am correct, and this is how many experienced clinicians feel, then this conversational dilemma is likely to be even stronger for the

families of the person with dementia. Indeed, I know from talking with many people who have been diagnosed with dementia, that they too are very aware of the difficulties associated with talking about their diagnosis.

If finding a way to bring dementia into the conversational room can be problematic, this does not mean that we should not find a way to do so. There are many good reasons for doing just this – not least because it is much harder to adjust to an illness, if the condition itself cannot be mentioned. At the same time, there may also be very good reasons for not putting a name to what the science fiction author Terry Pratchett referred to as the ‘demon’ of dementia (Pratchett, 2015). Consequently, throughout this book I will explore the reasons why we should, and sometimes why we should not, talk about dementia. By focusing on this issue, I am aware that while I am doing so primarily within the context of psychotherapy, it is also relevant to many, if not all other areas of dementia care. Whether a health or social care professional works in a memory clinic, an Alzheimer’s café or in residential care, they will often need to find a way to bring some aspects of dementia into the conversation. Not only will almost everyone who works with people with dementia benefit from understanding how people adjust to or respond to their dementia, but I also believe that much of this book will also be relevant to many family caregivers and indeed for some people living with dementia themselves. Many of the skills and issues I outline in this book are applicable to contexts outside psychotherapy or counselling. You don’t have to be a therapist or counsellor to talk with someone about their dementia.

I will finish by recounting another story from my early years as a clinical psychologist struggling to understand both what I could do with people with dementia and what I should try to do. I attended two training sessions on what was at that time a novel, and somewhat controversial, therapeutic intervention: validation therapy (which I will briefly describe in Chapter 11). The first training session was in London and was led by Naomi Feil – the creator of this approach. Although I was intrigued by the possibility that talking to people with dementia and making an imaginative leap into their world might be helpful, I was also left somewhat bemused by much of the unfamiliarity of her approach.

Some months later I then attended another training session, also on Validation Therapy, led by the British clinical psychologist Bob Woods. After outlining the essence of Feil’s approach, Bob seemed to sense the uncertainty in the room. He summarized his thoughts (and here I paraphrase these) by saying that the important thing was not whether or not people used validation therapy in the way Feil intended. Rather, the important thing was to try to do something therapeutic. If your preferred way of working was through cognitive therapy, then use that. If you used psychoanalytic principles, then use those. If you were a family or group therapist, well just get on and implement these. It was not as important to do a particular type of therapy, but rather that we just got on and

did *something*. Use the techniques and concepts that you would normally use – and find ways of adapting these.

Almost 30 years later, I am still trying to live up to this call to action. It is one that I am sure Tom Kitwood would have agreed with – it doesn't matter what sort of psychotherapy we practice, just so long as we don't think that dementia, by definition, means that someone is '*out of psychotherapeutic reach*'.

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We need to talk about dementia

Until the start of the Covid-19 pandemic in the spring of 2020, I worked for seven years at the memory clinic run by RICE (or the Research Centre for the Care of Older people) in Bath, a city in the South West of England. The memory clinic's main function was to assess people who had concerns about their cognitive functioning, and to determine whether they met the diagnostic criteria for one of the many different types of dementia. My role was to provide a psychotherapy clinic each week to people who had been assessed and diagnosed as having an illness such as Alzheimer's disease. Typically, I would offer people time to talk over with me how their dementia was impacting their lives. Often, I would meet couples – where one of the partners in the couple had been diagnosed with a form of dementia – and encourage them to talk to each other about their thoughts, their fears and their hopes. Appointments lasted for fifty minutes and occurred once a month or sometimes once every three months. I have included anonymized descriptions of some of this work in this book.

On occasion I met people who, from the start of our work, talked openly about their dementia and reflected poignantly on the most upsetting aspects of their condition. However, more often, the people I met found it hard to talk about their illness, either forgetting important details or being greatly distressed when they recalled them. Sometimes my clients might forget that they had been told about their diagnosis, or they might insist that they could still do everything they had always done even when being contradicted by their partner. These memory lapses seemed to me to be very similar to the recall errors I have described in Chapter 2 and I tended to think that they functioned in the same way by protecting the people in the clinic against the threat of dementia. As our work progressed, however, most of my clients would begin to feel safe enough to explore their illness with me – and as they did so, they became more able to talk about what was happening to them and more at ease with themselves.

There were many different reasons why individuals and couples found it hard to talk openly about dementia. For some, the reasons paralleled the evidence my colleagues and I had gathered in our 'laboratory-based' experiments around the MNE that I described in the last chapter. For these clients, the thought of progressively deteriorating over time, losing aspects of themselves that were so precious to them was devastating. For others, it was their fear about what others (often including their partners) would think about them. In

these cases, it was the social stigma that surrounds dementia that made it hard for people to address the changes that they were experiencing.

The process of talking about dementia is, however, not straightforward. Often it is a conversation that healthcare professionals either routinely avoid or simply do not see as part of their remit or within their skill set. In this chapter I will argue that while we should not assume that people want to talk about their dementia or that doing so will always be helpful, nevertheless I believe that for many people who have dementia it is important to have an opportunity to talk about what is happening.

Should healthcare professionals talk about dementia?

I have been fortunate over the course of my career that the majority of doctors I worked alongside found compassionate ways to disclose a diagnosis of dementia to their patients and their families. However, this is not always the case. Indeed, until relatively recently, many clinicians were reluctant either to give the diagnosis or even in some cases to make a diagnosis at all. Thankfully this silence around diagnosing dementia is much rarer now. However, even today, many healthcare professionals are often reluctant to have a conversation with the people they work with about their dementia, out of a concern that this will be too upsetting. While I recognize that not everybody who has dementia either wants to talk about it or would benefit from doing so (topics I will return to later in this chapter and in Part 4), many others will benefit from these discussions. If we, as healthcare professionals, can't talk about dementia with the people that we diagnose then there is a risk that we will be collectively entering into a conspiracy of silence about dementia. One of the facilitators in a LivDem group (see Chapter 6) fed back to me about a conversation she had with her supervisor, who suggested to her that *'if the professionals can't say the word dementia, well how are they [her clients living with dementia] going to accept their diagnosis and move forward? And that really, you know, made sense to me. You know, really made me think, "Oh my word, I've never thought of it like that"'*.

The skills most associated with having these sorts of open conversations are sometimes referred to as 'active listening skills'. They include the listener paying attention to what they are being told, showing that they are listening and responding appropriately in a non-judgemental way. Good listening skills are integral components for all forms of talking therapies, from person-centred counselling to cognitive behaviour therapy and other forms of psychotherapy (issues that I will return to in later sections of this book). Talking to someone who is a 'good listener' helps us to feel that we are being taken seriously and encourages us to explore and understand problems that we may be facing. At the same time, active listening does not just take place within psychotherapy or counselling sessions – many people use these skills instinctively as part of

encounters in their everyday life. However, for some people, active listening skills need to be practiced and developed.

Perhaps surprisingly, many healthcare professionals do not routinely learn active listening or counselling skills during training. However, when they are taught, and clinicians feel more confident in using them, then the results can be surprising. In one study, community psychiatric nurses (CPNs) were taught to use counselling skills in their work with people who had dementia (Weaks et al., 2009). As a result, their clients felt listened to and treated as a person, while the nurses developed skills themselves that they were able to use elsewhere in their professional lives. This study showed that CPNs potentially had an important role in offering emotional and practical support to people with dementia and their families who have been recently diagnosed with the counselling skills enabling the CPNs to address the psychosocial needs arising from their diagnosis more effectively.

Do people living with dementia want to know about their diagnosis?

In a UK study of 50 people with mild levels of impairment caused by their dementia and their family carers, all but one of the participants said that they would want to know if they were diagnosed with cancer – with only slightly fewer (92 per cent) also wanting to be informed about their diagnosis of dementia (Pinner and Bouman, 2003). Similar levels of carers said that they would want to be told if they were to develop either dementia or cancer. More recent research paints a similar picture – namely that the vast majority of people with probable dementia want to be informed about their diagnosis (Robinson et al., 2011). At the same time studies also consistently suggest that some people (in some cases as many as one third of people interviewed) do not want to know what is wrong and that their wishes also need to be respected (Marzanski, 2000). Nevertheless, over the years a shift has taken place, so that nowadays, in the UK at least, the default position tends to be that a person with probable dementia has the right to know about their diagnosis, should they wish to do so, and that for many knowing about their dementia may also be empowering (Bamford et al., 2004; Bortolotti and Widdows, 2011).

How do people react to being told their diagnosis?

Studies consistently show that people with dementia experience a wide range of emotions on receiving their diagnosis and that they react to the disclosure in different ways. While some people are shocked and react with disbelief and anger (Byszewski et al., 2007), others say that it had confirmed their suspicions (Derksen et al., 2006) and that they are relieved that their symptoms have an

explanation (Pratt and Wilkinson, 2003). For many people their most immediate worries after receiving a diagnosis relate to a fear of the unknown and an unfolding sense of loss. In particular, the social stigma of receiving a diagnosis of dementia is often a key issue (Husband, 2000), with many people being concerned that others will find out and that they may be socially embarrassed by their poor memory or another type of cognitive failure. Consequently, as I described in the last chapter, some people with dementia are hyper-vigilant, watching for evidence of a memory slip, and when these occur then attempting to 'cover up' or minimize their difficulties (Bahro et al., 1995; Husband, 2000).

Two research studies shed some light on whether, in retrospect, people believe that receiving the diagnosis had been helpful to them – while both of these studies took place over 20 years ago, nevertheless their results are still likely to be relevant now. Bachman et al., (2000) interviewed 35 consecutive referrals to a memory clinic between three and twelve months after they had been given a diagnosis of Alzheimer's disease. Over two thirds (69 per cent) of family carers thought it was a good idea to tell the patient the diagnosis, with almost three quarters (74 per cent) saying that it had not been too upsetting. Even where the person with dementia was judged to have been 'very upset', their carers still thought that the honest discussion of the diagnosis had been helpful. The second study (Smith et al., 1998) produced very similar results with almost all family carers reporting that they found it helpful both for themselves (98 per cent) and for their relative (84 per cent). These two studies, then, suggest that although there may be short-term distress, most carers report that receiving the diagnosis had been helpful. Indeed, a review of the literature carried out 10 years ago concluded similarly that although there may be short-term distress, the majority of people with dementia did not experience long-term negative effects after receiving their diagnosis (Robinson et al., 2011).

What impact does knowing about a diagnosis have?

One area of post-diagnostic adaptation to the diagnosis of dementia that has been studied in some depth relates to whether people who seem to be more aware of their diagnosis have worse outcomes in terms of a poorer quality of life, or a higher presence of psychiatric symptoms. The results of these studies paint a rather confused picture. Thus, some studies do show a relationship between low levels of awareness about a diagnosis and poorer outcome, such as challenging behaviour and higher levels of family caregiver burden (Clare et al., 2004). At the same time, there is also evidence that higher levels of awareness may also be problematic and aggravate changes in mood including depression and anxiety (Aalten et al., 2005; 2006).

One of the largest and best funded studies to explore this area is the Improving the experience of Dementia and Enhancing Active Life, or IDEAL, study in the UK. Alexander et al. (2021) reported the relationship between awareness and self-reported quality of life, well-being and life satisfaction ('living well'), and caregiver stress using cross-sectional data from over 900 people with

mild-to-moderate levels of dementia and family carers. Of the people that they interviewed, 83 were classified as having 'low awareness', 731 people with 'some awareness', and 103 people with a 'high awareness' of their condition and diagnosis. Their results showed that psychosocial factors such as lower levels of mood, optimism and self-esteem were stronger predictors of awareness than were cognitive and functional ability. People with higher levels of awareness reported lower levels of mood and scored less well on measures of living well, optimism and self-esteem.

Awareness is, however, a deceptively tricky area to study as it presents a number of methodological challenges. Some of the challenges of carrying out this type of research can be illustrated by a series of conversations that I had with a couple in my clinic who I will call Anna and Philip. I had known and worked with this couple for several years (Cheston, 2021). In all of that time Anna refused to acknowledge her diagnosis of Alzheimer's disease. She was a complex woman, who was capable of being charming and engaging, yet also angry and dismissive of her husband whenever he challenged her. Throughout my work with them, Anna maintained that she had not changed at all – that she was just the same person as she had always been, and that while her body may have slowed down, she still did all of the things that she valued, such as sewing, seeing friends and relatives. Whenever she lost or forgot anything then she either refused to accept that this had happened, or blamed her husband, at first in a semi-humorous way, and then more forcefully. Philip, for his part, struck me as a patient, caring and sympathetic man who was constantly on the lookout to avoid situations that Anna would find challenging and willing, for the most part, to contain the anger that his wife directed at him without responding in a way that provoked her further.

My impression, from all that they told me over the years, was that Anna displayed many features of narcissism – an area that I will explore in more depth in Chapter 12. In essence, people with narcissistic traits have a fragile sense of identity that they protect by maintaining a high level of external self-esteem. Anna needed to maintain the illusion that she was unchanged because to admit to even a simple failing would have been overwhelming for her. Consequently, everything in her life was devoted to maintaining the illusion that she was unaffected and unchanged.

Patients at RICE were often offered the opportunity to take part in large research studies, and Philip and Anna took part in the study reported by Alexander and her colleagues. During one of my sessions with them, while Anna was in the toilet, Philip wistfully described to me their recent participation in this study which he felt encapsulated something of his relationship with Anna. He recounted how Anna had told the researcher that her life was wonderful – that she was still busy and active and could do all the things that she wanted to. He knew that what she had told them wasn't true, but they didn't seem particularly interested in what he had to tell them. From my knowledge of Anna, I think it is highly likely that she would have both been placed in the low awareness category, and yet also scored at a high level for self-reported quality of life. Yet, in reality, Anna's life was circumscribed and limited. She was in some regards an unreliable narrator on both her dementia and her life. Her

narcissistic traits meant that she needed to maintain a position in which nothing had changed in her life – neither her cognitive abilities, nor her social life. By contrast, many of the people that I met at RICE who were able to talk meaningfully about their dementia would have been more cautious in their assessment of their quality of life.

Adjusting to dementia – responding to fear and loss

The evidence, then, suggests that most people want to be told about their dementia and that, although painful at first, this disclosure generally does not lead to serious, long-term reactions. However, all too often, once people have been told their diagnosis, there are few opportunities for them to continue to discuss its impact on their life. Disclosure becomes a one-off event, rather than a process of discussion. The important people in their life – their family and partner – may not know how to go about talking about the dementia and may avoid doing so because they know talking about it may be upsetting. All too often, health and social care professionals are either not available or avoid talking about the dementia. However, without opportunities to discuss the dementia people have a reduced chance to adjust to what is happening – in effect after being initially raised, the subject of dementia subsequently becomes something of a taboo.

The consequences of this silence about dementia are that the emotions associated with it, including peoples' fears about it, are often not addressed. In the absence of a place to talk about and to work through their distress, so the person with dementia may be more likely to avoid situations in which their difficulties are exposed. One recent study supports the possibility that fears about memory dysfunction led to both a lower quality of life and also to more actual memory failures among older people (Farina et al., 2020). The researchers asked 67 people aged between 59 and 81 to complete a self-report scale designed to capture different aspects of their fear of memory loss. They also asked participants to complete scales to assess their perceived memory failures, their quality of life, scales to assess their mood and an objective measure of memory performance. After adjusting their results to take into account the person's objective memory performance and their anxiety levels, they found that the more frightened the participants were about their memory lapses, the more they avoided situations because of this, then the lower their quality of life was, and the more likely they were to perceive themselves as having a poor memory. The authors suggested that the best way to make sense of these findings was that people who are frightened by their memory lapses begin to withdraw from activities as a way of coping with these failures and that, over time, this combination of fear and avoidance begins to impact negatively on their everyday functioning.

While the study by Francesca Farina and her colleagues was with older people without dementia, my clinical experience is of similar processes occurring among people who have dementia in which fear and avoidance lead to a worse quality of life. More specifically, the dysfunctional patterns of fear and

avoidance that Farina's study identified are processes that can potentially be prevented and treated through psychological interventions, including psycho-education and psychotherapy (Fratiglioni et al., 2020).

Any process of adjustment, then, must focus on the emotional responses that people have to their dementia, including their fear, guilt and distress. In order to glimpse something of what this process might involve, we need to take an empathic leap and to think back into our own lives about the powerful emotions that even a minor, temporary lapse of memory can set off.

Adjusting to dementia

I am extremely grateful, that for now at least, I do not have a personal or immediate knowledge of the challenges of adjusting to dementia. Consequently, I have to imagine something of what must be involved.

One way to enter this imaginary space for me is to remember a recent occasion when I became angry and frustrated with myself. Early one evening I had been working on my laptop and at the same time using my phone to pay for online shopping. At the point when I prepared to go to bed, I realized that I couldn't find my wallet and mobile phone. As I hunted for them, I became progressively more and more frustrated that I couldn't find them, searching high and low. I wanted to go to bed but I couldn't do so because I needed to find my wallet and phone for the train journey to work the next day. In desperation I tried using another phone to call my mobile, hoping that I would hear it ring, but even this didn't work.

My family kindly tried to help me, but I snapped back at them, which also made me feel guilty as I had only recently told my son off for behaving just like this. I was aware that I should be coping better and was annoyed at myself for not taking more care with my possessions but thinking about this made things worse.

Finally, success! I realized that I absent-mindedly put the phone and wallet away with my laptop. I thought what an idiot I had been not to have looked there earlier. I became aware that the upset of not knowing where my phone and wallet were, and the inconvenience of looking for them had been multiplied by anger, guilt and shame – all of which make me use inefficient search strategies.

Episodes like this, are, I suspect, common to many people. While they may provide only a partial analogy of the experiences of people with dementia, they point to how difficult it must be for people to adjust to these changes. Just this one, simple, mundane episode of forgetfulness generated frustration leading to conflict and distress intensified by feelings of guilt (at being upset) and shame (at having this flaw in my personality).

Even worse, this may bring up thoughts about the future – that if this is the start of an illness, then things may get even worse. Often the people I have spoken with in my clinic told me that they found it too hard to go to this place in their minds, and consequently they tended to shut off thinking about that part of themselves and their life. For them the temptation was to try and pretend that there was nothing wrong.

Final words

Looking back at my clinical work, my impression is that the people that I met who seemed to have adjusted to their dementia most effectively recognized both that while so much about them had changed there was much that had stayed the same; they saw themselves as being both the same person but also as being different.

If we are to help people to adjust to their dementia – to be the same but different – then we need to be able to enable them to find words that help to shape or form their internal world. This can be easier to achieve if we provide people with dementia with opportunities to meet others who share their diagnosis, so that they can listen to their experiences, share their own accounts without fear of being judged and learn that they are not alone. It can be easier for people with dementia to work their way through their guilt about the burden they fear they place on others if they can discuss this with someone they love. It can be easier for a client to forgive themselves for the things that they forget or can no longer do if they talk with a skilled therapist who helps them to feel compassion for themselves. These are all opportunities that can be available through psychotherapy – be this individual work, couples counselling or group therapy. It is to this subject of how psychotherapy in its different modalities can make a difference to the lives of people living with dementia that I will now turn.

Summary of Part 1: Loss, threat and change

Dementia is a profoundly human tragedy that affects almost a million families in the UK, and many more across the world. In whatever way people respond to their dementia, it impacts on the most fundamental aspects of their being – it is an existential threat. Consequently, thinking about dementia can be profoundly upsetting – even if many people try to ‘*put a brave face on*’. For those around the person who has dementia, whether this is their family or paid carers, then it can be tempting to go along with this. The danger, however, is that what emerges is an unspoken agreement not to talk about the dementia. For some people, the level and type of neurological change does indeed mean that it becomes almost impossible for them to think about their dementia, but for the majority of people at least some level of awareness is possible. At the same time a social resistance to thinking and talking about dementia can have the effect of limiting the opportunities available for people to talk about their experiences of living with dementia. This in turn is likely to make it harder for many people living with dementia to adjust to their condition.

Implications for people living with dementia

Everyone with dementia will respond to what is happening differently. There is no single, ‘best’ way of coping – each person living with dementia will find their own way through this condition. Many people living with dementia should think about the following points.

- They may well have questions about what is going to happen or need time and space to sort things out for themselves, or they may just want to be left alone and to get on with their life. However, if there are opportunities to talk to people about their illness, then they may find this helps. A problem shared is (sometimes) a problem halved.
- They may find it helpful to remember that dementia affects many people. There is much more awareness about dementia now, partly because of the many people who have been open about their illness. This has helped to change attitudes, and they may be surprised how accepting people are now. If there are opportunities to meet others who have been diagnosed with dementia, then this may help someone living with dementia to feel less on their own.

- Many people living with dementia have a good quality of life and live well. It is possible to adjust to the condition, even if they are overwhelmed at first.
- While there will be much about the person that changes, there will be more that stays the same.

Implications for family carers

People who are caring for someone with dementia should think about the following points.

- They should look after themselves. They will have their own sense of loss and change to make sense of.
- If there are opportunities to do so, then the person they are caring for may find it helpful to occasionally acknowledge that life has changed. This doesn't need to be a long conversation, but gently acknowledging how the situation has changed can help couples, families and friends to be closer to each other.
- It can be easier for people with dementia to work their way through their feelings about what is happening if they find a space to discuss this. For some, this is best done within their family or with friends. For others, talking is easier with a counsellor or therapist – either as an individual or as a couple.

Implications for therapists

Healthcare professionals whose jobs involve offering specific counselling or psychotherapy sessions should think about the following points.

- They should not be afraid or reluctant to offer psychotherapy sessions to people living with dementia.
- They should be aware that dementia represents a major public health challenge. For many people living with dementia, as well as their family carers, psychotherapy provides an important way to make sense of what is happening and to adjust to the changes that it brings.

Implications for professionals and workers in dementia care

Staff working in dementia care should think about the following points.

- They should not underestimate the psychological impact of dementia on the people they work with. People are good at putting on a brave face when we

met them. Often, the staff working with them need to go along with this – but there may be opportunities to be curious about how things *really* are.

- They should ensure that they feel confident using active listening skills – including receiving training in this. Staff teams need to be open in recognizing that having a space in their service to allow people to discuss how dementia is affecting them is important.
- They should listen out for instances where people acknowledge that their life has changed. The core skills of dementia care include active listening – paying attention to what people say and showing that you're listening and interested in what they have to say. If staff feel confident enough and have received training, then they can also consider using basic counselling skills to facilitate discussion.
- When a team member talks to someone about any aspects of their dementia, including disclosing the diagnosis, then they should record this in the person's notes. This includes recording what has been told, by whom, where and how. Other members of the team who then read the notes will know what has been discussed, which will facilitate future conversations.