The informal Dementia Carer — who cares?

Rex W Last

Lochee Publications

‘Carers are indeed the "invisible second patients" whose unseen problems are genuine, and their challenges do not suddenly come to a conclusion when their loved ones go into care…’

The Informal Dementia Carer — who cares?

by

Rex W Last

For Oksana
(1950-2023)

Lochee Publications

First published in 2023 by Lochee Publications

Oak Villa
New Alyth
Perthshire
PH11 8NN

ISBN 9798397227797

Printed by Amazon UK.

For further information on Lochee Publications please go to our website at www.locheeesoft.com

Author's note

First, a word of gratitude to my beta testers, who once again have done a splendid job on my scribblings. Particular thanks go to Liz Gordon and Margaret Holman. All errors which remain are mine. Under the pseudonym Bill King, I have written two previous books on subjects which relate to my present effort. They had limited circulation, and I donated most of them to local charities, organisations and individuals involved in the care of loved ones with dementia. It was therapeutic for me and also allowed me to give something back to those who had helped me. I was glad to offer advice, encouragement and support for the many people in the locality going through the same experiences. Chapter Two of this book is a revised and updated version of material which first appeared in *Parkinsons — the slippery slope to dementia* (see the Bibliography at the end of this book).

Why then have I written this third book when Amazon's electronic shelves are groaning with the weight of ever more guides to dementia? I am presenting here a serious wake-up call for society to listen to the one key player in the care of dementia who has been largely ignored by the medical profession and the government: the informal carer, thrust into the role without proper advice or training in how to cope with a loved one becoming victim to this terrible disease, and when the loved one finally enters a care home, that carer is unprepared for the huge shock of being left to their own devices without any proper support and guidance on how to cope with a lost love, a broken life, and an uncertain future.

I am trying to walk a difficult tightrope. Everything written here is based on personal—at times very personal—experience, which is intended to evolve into more general advice and encouragement to other carers and a serious challenge to the medical and political establishments. That is why, although my wife's name appears in the dedication, I do not refer to her by name in the body of the text. (She died in her sleep as I was completing work on this book.) I wanted to transcend the personal into an account representative of the decline and fall of so many other human beings struck down by Parkinson's and dementia and the consequent trials and tribulations of their carers. I suppose what I have sought to do is to take 'our' story and somehow, out of our own tragic and sometimes bitter experiences, to make some sense of what has happened and create out of it all something generally worthwhile, which can be positive and valuable to others.

I begin and end the book with some of the quotations which I have come across whilst putting this manuscript together. Most of them are helpful, some are not, but they do act as thoughtful and at times amusing bookends to a challenging and often tearful narrative. I must remember to buy shares in Kleenex. All proceeds from this book go to dementia causes.

I had intended to publish this book in the conventional way, but I decided to do so under my own imprint for three reasons: (1) it takes an absolute age for a publisher to come back with a rejection, (2) this is an urgent matter which needs to be aired now, not years hence, (3) being 83 years old I don't have long on this planet and want to see if my views can make even the tiniest dent on the entrenched positions of the medical and political establishment.

For more information please go to my website at www.locheesoft.com and click on the link to dementia YouTube videos.

Cover image: the statuette was Oksana's favourite, called Devotion, which we found in a shop in Crete many years ago.

About the author

Rex W Last was Professor of Modern Languages in the University of Dundee from 1981-1991 after nearly two decades in the German Department of Hull University. He has written books on topics from Hans Arp, Dadaism, Erich Maria Remarque and Erich Kästner to artificial intelligence and computer-assisted instruction for the language teacher. He was also the editorial director of a London publishing company specialising in German literature and culture.

He edited the pioneering computerised *Arthurian Bibliography* and has translated a number of books including Willy Brandt's wartime memoirs, a study of Max Ernst, a biography of the early peace campaigner Bertha von Suttner, and an account of West German President Gustav Heinemann. For most of its existence, he was editor of *PCW User*, the official magazine of the late lamented Amstrad PCW computer and word processor. Now retired as Professor Emeritus, he cared for his wife who has now died with dementia, writes computer programs, adventure novels set in Nazi Germany, designs websites and has written countless articles for a number of computer magazines. Three of his novels are published this year.

Visit his web pages at www.locheesoft.com for full details of his books and YouTube presentations.

Table of Contents

Opening quotes

Father, give us courage to change what must be altered, serenity to accept what cannot be helped, and the insight to know the one from the other.
(Reinhold Niebuhr, from the prayer he wrote)

Happy families are all alike; every unhappy family is unhappy in its own way.
(Leo Tolstoy, *Anna Karennina*)

Until you've had therapy, you don't know what's wrong with you.
(Danny Dyer, actor)

Life is what happens while you are busy making other plans.
(John Lennon)

Yesterday's the past, tomorrow's the future, but today is a gift. That's why it's called the present.
(Bill Keane)

Life is full of misery, loneliness, and suffering - and it's all over much too soon.
(Woody Allen)

You live and learn. At any rate, you live.
(Douglas Adams)

We must be willing to let go of the life we planned, so as to have the life that is waiting for us.
(E M Forster)

Why don’t they see every patient as an individual person instead of a diagnosis, when they walk in the door? Why does the medical profession rely on clichés and stereotypes, and as a result, so often gets it wrong?
(Wendy Mitchell, *What I wish People knew about Dementia*)

Nostalgia isn’t what it used to be.
(Peter de Vries)

So there is no ‘getting used to it’. My knowledge that ‘it’s not the real Nick’, it’s not going to make me feel any better. I am on a journey where the destination and every stop is grief. That is the adjustment a carer makes.
(Katherine Schopflin)

Carers do not realise what will be required of us, how many hours will be involved, or how many years of our lives will be devoted to someone whose needs we will put above our own.
(Richard Bates)

Sorry, Julia, but there's no point in crying. You’ve got to stop. Self-pity is understandable, but completely useless. You’ve got to toughen up and get on and deal with it.
(Julia Williams, quoting a therapist)

I have allowed myself to lead this little life, when inside me there was so much more. And it’s all gone unused. And now it never will be. Why do we get all this life if we don’t ever use it? Why do we get all these feelings and dreams and hopes if we don’t ever use them?
(Willy Russell, in *Shirley Valentine)*

Chapter One — Stating the problem

Let me transport you back to the year 2008. It’s late afternoon in the local teaching hospital and the Neurology department waiting area is almost empty. Like much of the main building’s interior, it’s an uninviting windowless space with notice boards groaning with health-related posters and advice on support groups for all manner of unpronounceable ailments. The seating is tired and uncomfortable-looking. The walls are drably painted the colour of institutional custard, and in one corner the brown reception desk shutters have long since clattered down for the night. The sole person present is a woman hunched in a chair looking lost and despondent. In the distance, you can hear the buzz of a vacuum cleaner and voices wishing one another good night. Time passes with aching slowness. Then a specialist nurse appears, hastens across to the woman, sits down, places her arm round her shoulder in a gesture of comfort and commiseration and starts to speak to her in hushed tones.

To my eternal regret, work commitments had prevented me from accompanying my wife to this consultation from which she had emerged, shocked and dismayed, half an hour previously. She had been asked to return to the waiting area and ‘someone would see her’. We had been given to believe that this appointment was nothing more than a check-up on a relatively unthreatening issue she had been complaining about for a year and more, but things had turned out very differently.

That is how my wife first came to meet the nurse who would play a significant role in our future lives, and who was now busily explaining to her the short-term implications of her diagnosis from the consultant: Parkinson’s. That was how our nightmare began, one shared by countless thousands of other people and their loved ones, and one which persists for me today, after my wife died during her second year in a nearby care home. I devote much of my time to writing, some of it about our experiences together and the simple, unvarnished fact that much of what transpired need not have been anywhere near as unpleasant as it turned out to be — and still is.

This is a very personal story, but it is one which I have sought to expand in more general terms, to demonstrate that our National Health Service has exacerbated the suffering of the carer by failing to recognise and mitigate their plight and take the necessary preventative steps to improve the quality of what is left of their lives. I am not intending to point a finger in any particular direction, simply to achieve two objectives: first, to set out how carers are disregarded and undervalued before and throughout the caring process and, more grievously, beyond.

I do not intend to just sit here at my computer complaining about the cruelty of fate, though, I also seek in these pages to try and fill in the huge gaps in carer's support by offering positive encouragement and information which should in an ideal world be routinely provided for all carers such as myself.

Before we go any further, I should stress that I am not a trained medic, although I was a Professor and Head of Department in a university with a medical school, but that fact does not in any way disqualify me from putting forward my views and seeking remedies for the current deplorable situation. Carers are experts too, but in a quite different way from that of the medical professional, and their voices deserve to be heard. I know I am speaking from the knowledge of just one individual caring for another, but what I'm struggling to express is that the general trajectory of the illness is not so different from one person to the next, and the emotional and psychological sufferings of carers generally are pretty much the same.

There is a world of difference between knowing a situation as a set of facts, like a clinician with years of acquired knowledge who will be able to identify and recommend treatment for neurological disorders, and on the other hand the accumulated life experiences of someone who has lived with and cared for a loved one on a daily basis for years on end, more or less making it up as they go along, and then being thrown on the scrap heap as soon as the loved one is finally transferred to the care home, with scant regard for the long-term effects of that decision on the mental well-being of the carer themselves. I cared for my wife at home for fifteen years before she became far too unwell to remain in our domestic environment, and much of what follows is based not just on what I learned and experienced during that time, but also on the enduring painful feelings and emotions of an ex-carer struggling to come to terms with a different and lesser kind of life. Having a loved one in a care home is akin to grief for a death, when no death has as yet occurred, nor any genuine 'closure' achieved. There will be much about 'anticipatory grief', as it is called, in the pages that follow, but here is a brief taster:

> Caregivers'…experience of loss was ongoing, the losses were cumulative and there was no knowable end in sight. (Bates p 187)

I tried a small unscientific experiment. As part of the preparatory work for this project, I had bought a pile of books on dementia and caring for loved ones with the illness for research and background reading purposes. I checked through them all to find out at what point they concluded, and, almost without exception, that came at the moment when the loved one enters a care home. You could almost see the words 'The End' coming up on screen and the plush curtains closing. Job done.

However, there does exist a thin scattering of lone voices in the medical literature pointing out that carers are indeed the 'invisible second patients' whose unseen problems are genuine, and their challenges do not suddenly come to a conclusion at that juncture. I have spoken to many nurses, care managers, and medics who do indeed recognise that the explosion in mental disorders like dementia is not being properly managed as far as the carer is concerned, but they regret that current circumstances are not conducive to acting upon my concerns. What I think they are saying is that the world isn't anywhere near ready to deal with the current and future explosion of sufferers from dementia, leaving the plight of carers a very poor also ran in that particular race. Dementia has also become the new number one taboo subject in succession to cancer and HIV.

Let me remind you of the numbers. According to the Alzheimer's Society website:

> There are 55 million people living with dementia around the globe. It is estimated that this number will rise to 139 million by 2050.

And the rider to that, which is not calculated here, is that there must be a pretty hefty number of carers, too. The next little fact from that website is the amount of money which these untutored and unwaged carers save the UK economy: £14.6 billion, rising to nearly £35.7 billion by 2040.

This book falls, like all Gaul, as my old Latin teacher used to tell me, into three parts. I first set out the urgent necessity for the carer to be forewarned and prepared as a matter of gold standard good practice on what to expect with a loved one diagnosed with dementia and vitally also how to cope with situations before they arise, rather than having to pick up the pieces after the event. When I spoke in those terms to one NHS mental health worker, the response was that you shouldn't overburden the carer with stuff they do not need to know, as it might frighten them or cause them distress.

That is the insulting language of an autocratic system which perceives the doctor to patient relationship as something on the lines of master and servant, and the role of the carer as an inconvenience at best and non-existent at worst. Do not confuse the poor things with knowledge, as they cannot cope with it. This is emphatically a wrong-headed approach to the care of people with conditions like dementia and, most significantly, to their carers. Of course, not every carer is capable of coping with the details of such information, but to allow a minority tail to wag the collective dog as an excuse for an information blackout is less than satisfactory.

Next, I deal with what should happen during the time the loved one is still in the family home. Third, and most importantly, I explore in depth the deplorable fact that the carer is left twisting in the wind when the loved one goes into a care or nursing home, again without any standard good practice determining if or how that carer should be supported and treated in their plight, and I offer what information and encouragement I can to supplement that cruel omission, based on my own experiences. Before

Parkinson’s and dementia intruded in our lives, I had witnessed serious illness with a mental health component mainly in much older members of the family, my father and mother-in-law being two particularly sad examples. But I had been spared the shock of knowing close up and personal someone dealt a vicious blow in the middle years of a high profile, successful and happy life until my wife’s diagnosis suddenly presented itself when she was in her early sixties.

I begin by telling you now our own story, partly to demonstrate that I am not writing from high up in a remote academic ivory tower, but mainly to set the scene, to demonstrate how deeply personal the experiences have been which have led to me putting fingers to keyboard and expressing my views so publicly. I intend to inject our own time together into the narrative and the debate that accompanies it. I hope also it may encourage you to speak out too, if like me you feel strongly that the carer is sorely neglected and that their case has yet to be listened to — by anyone who matters.

Chapter Two — A personal tragedy

It started with a twitch. An invisible twitch. For many months, neither of us thought much about it but it bugged my wife a great deal, and she kept on nagging our GPs until one fine day one of the doctors in our Health Centre referred her to the Neurology department in the local University hospital. Maybe, I guess, in the hope that they could make it — and possibly her, too — go away. However, things didn't quite work out like that. Then it was that the twitch became something far more sinister, and the whole direction of our lives together was irrevocably altered. A tipping point, if ever there was one. By the way, if you detect that the first sentence in this chapter strikes a vaguely familiar note, you are right. It's an oblique nod in the direction of that popular singing combo of yore Hot Chocolate and their number containing the words: 'It started with a kiss...Never thought it would come to this.' The first part of the quote is a fond memory of the past, and the second could be taken as a bitter-sweet reflection on the trials and tribulations of Parkinson's and dementia as they unfold.

Our relationship had started out so well, too, and it came about in a completely unexpected manner for both of us. I was on my merry way to Norway to address a conference of language laboratory experts at the Tandberg factory in Oslo, and the delegates met up at one of those bland hotels lining the outer edge of Heathrow airport, heavily insulated against the raucous din of constant take offs and landings. It was an annual event, and I'd been working as a freelance consultant for this company for some time, mainly programming their groundbreaking computerised audio visual equipment, and amongst other things giving a talk at each of their shindigs. So far, everything seemed normal.

I met some old friends and colleagues and quite a few new ones. Most of the attendees would be keen to listen and learn, but I knew that there was a small band of trainee alcoholics amongst the language laboratory technicians determined not to draw sober breath until they were back on the plane home. All went according to plan until, that is, my turn came to sign in officially for the trip with the new PA to the Managing Director of the company's English offshoot, whom I had only met thus far on the phone. OK, so most of us turn our pretty noses up at the very idea of love at first sight, and buy into all the grown-up stuff about getting to know someone gradually and developing a wholesome deeper relationship over a longish period. Taking it steadily and all that, one button at a time, as I might say flippantly. Don't believe a word of it.

I toddled up to the PA to the MD, and gave her my name, rank and number for the flight the following morning. She signed me in and then for some reason she reached out, touched me on the arm, held on to it gently for a moment and looked up at me. I returned the look, and from that moment I was a lost cause. At the time I was in an OK marriage which was getting much less OK by the week, but that wasn't the reason. I hadn't even recognised that I was becoming semi-detached and that a better kind of tipping point for me was just round the corner, to mix a metaphor. I rationalised it as falling for her gorgeous face with an amazing smile and a hint of Eastern Europe in her features.

Only later did I actually get to know that she was in fact second generation Ukrainian, a daughter of immigrants who came over shortly after the Second World War to start a new life away from the devastation of Europe and years of forced labour on a farm in Germany. Hence her unusual name. But it wasn't her face that did it. Nor was it that I 'fancied' her physically. So unlike me, but it never even occurred to me in that moment. It was (don't laugh) as if I had somehow recognised in that brief fragment of time that she was the woman I wanted to spend the rest of my life with. At first, I didn't even know if she was married or single, childless or a mother of ten, but I had by some mysterious process hoovered up from her simple glance everything I needed to know. Go on, mock if you will, but hands up all those who have ever found yourselves in a similar gobsmacking situation. Hmm, I thought so, quite a few of you.

I was told once that an uncle of mine, until then a shy confirmed bachelor, turning up for his first working day in the city of Hull in his newly promoted position in the insurance business, was walking through the main office when his eye was drawn to one of the typists. Instantly, he said to himself, ‘That’s the girl I’m going to marry.’ Maybe this propensity does indeed run in our family, but I’m not prepared to arrange a YouGov poll on the topic. Oh, and by the way, he did marry the girl.

Oslo was cold, really cold. Minus ten or fifteen. But it was dry rather than unpleasantly damp unlike the snow in the UK, usually the wrong kind of snow for the railways just as they are recuperating from the wrong kind of leaves in autumn. Over in Norway, instead of fighting the conditions or regarding them with bemused puzzlement, the locals embrace them and just get on with their lives. A year or two earlier when the conference delegates all stayed in an old-fashioned hotel in the city centre, my room looked out on a side street and I could observe the taxis returning to join the queue for new fares, hurtling in their snow tyres down the roadway and performing sudden U-turns into the taxi stand with the grace of swans in the ballet. Do not try that at home.

On this particular occasion, though, we were in one of the poshest hotels in Norway, the Holmenkollen Park, in the hills above the capital city not far from the ski jump where the local team had triumphed in the 1952 winter Olympics. The whole atmosphere was laid back and unfussy. In fact, I happened to be in the main entrance hall late one afternoon when the King turned up for an evening meal and was greeting fellow guests. No big deal. It was so informal, so human in scale and no one made a song and dance about royalty in our presence. Just another pleasant and unexceptional evening in frozen Norway.

After breakfast the next morning, I wandered out with the PA on to the packed snow outside the main portico as a reddish sun struggled to light the clear blue sky and a Scandinavian Airlines plane rose in the air, soared round in a half circle, and headed for Heathrow or other points west. It was a magical spectacle. I turned to her and said, ‘I find you totally fascinating.’ Yeuch. I was always the one for the inept chat-up line. But that was the best I could accomplish with my tongue tied. Fortunately she managed not to have a fit of the giggles, and we arranged to meet up as soon as possible after our return to the UK. And, in case those among you with a prurient curiosity are craving to know, during the brief three-day stay Nothing Happened. Whether or not it was for want of trying, I am going to draw a veil over that and let you guess. Put yourself in my shoes.

Later, it turned out that there were a couple of less than minor obstacles to overcome. I was, as I said, already married. She was, I soon discovered, also married but getting divorced and had two children. She lived and worked in a city in northern England, I worked many miles away in Scotland, so that was when things got a bit complicated. We managed to communicate early most mornings by phone. I was usually up and away at first sparrow fart (as some folk delicately put it), to get some real work done in my office at the university before the great unwashed turned up and demanded education, and in that time we were able to talk together. I still knew little about her, whether she lived in a squat or a mansion. And she didn't know a great deal about me, either.

The scene now shifts to the first floor dining room of the city centre hotel next door to my department in Scotland. It was lunchtime, and liquid refreshment and snacks littered the table between us. My colleague and good friend the Professor of English sat opposite me. He became, for better or worse, my confidant, my agony aunt. I poured out the whole tale to him and he listened quietly. You could almost hear the cogs whirring away in his head, as this fine medieval scholar finally harrumphed and said, 'Well, young man, you have a choice. Either Plan A or Plan B.'

I could hear them coming, tough words of wisdom from a crusty old scholar seared by years of cynicism being passed on to a brand new professor still very damp behind the ears. 'Plan A is to keep her as a mistress, Plan B is to go the whole hog, confess to your wife what is going on, and opt to marry the girl and live happily ever after.' Or not, I could hear in his voice. Of his own marriage, the less said the better, but drink was involved. A lot of it. At least I had found someone to talk to in that time of self-doubt and confusion. He and I occasionally used to chatter the afternoon away in the sitting room at his home, me perched on an uncomfortable antique chaise longue, he leaning back in an ancient wing chair, looking out on a splendid view of the Tay estuary through the bay windows.

On one occasion, he had passed me a wine glass which looked unusually chunky. It had a crest of some kind on it, with the letter ‘N’ engraved underneath. I asked what it signified and he replied nonchalantly that he had found and purchased a few of them in an antique shop for a song. They were, he added, Napoleon’s military campaign glasses. Hence the solid build quality. That was hardly the sort of thing to tell someone downing their third or fourth glass of expensive Chardonnay. I clutched on to it for dear life during the rest of that afternoon.

A few weeks later she and I finally met again in a hotel down in England one wet and wintry evening. I had persuaded my wife and the world at large that I was just having another Important Meeting with the manager of the company I freelanced for as a computer consultant, and I took the one direct rail service per day and duly turned up. I can assure you that this was not the kind of situation I was accustomed to, walking a high wire without a safety net and not knowing what was at the end of the journey, if anything. Plan B was well underway. Faint heart never won fair lady, but in my case it was a seriously clumsy ticker that somehow did the trick. I clicked open my posh Samsonite attaché case and presented her with the largest box of chocolates I could fit into its black leather interior. Not a good move.

She took it, then told me blushingly that she was on a diet, but that didn’t stop her from setting it carefully on one side. Then I handed her a photograph which I had taken of a red rose. OK, not the grandest gesture, I’ll admit, but you’ll find that fresh flowers inside a stuffy briefcase for hours on the long train journey down to England is not a good idea either. My excuse is that those were the days before every main railway station had been turned into a shopping mall. These offerings seemed to work, and despite my clodhopping efforts, things went rather well after that. Fade to black, as they used to do before Netflix insisted on showing us (nearly) every gory detail. Later, I told her I had two adopted children from a previous marriage and that things were not too bright for me in my current relationship. Sorry to be a bit vague at this point, but I have to avoid treading on some rather sore toes.

I was overwhelmed by her genuineness, her confident tone, her distinctive voice, her warmth and – how long have you got? I was well and truly a prisoner of love, to quote Perry Como, a songster from the early days of those American TV shows which were imported over here to fill up the programme schedules. We went down to the hotel carvery, bright lights, the clatter of plates and cutlery and a babble of loud conversation covering our tentative exchanges. She had just signed divorce papers and lived in a terraced council house. Juggling work at Tandberg with child care was a real challenge, and her greatest blessing was that she lived directly opposite a fish and chip shop, in a city which was a pretty good place to enjoy such delicacies. No Scottish gourmet affectations like deep fried Mars bars, simply the signature dish of cod battered golden and cooked until it curled up like those images of salmon leaping up a fish ladder. Her very well-fed children were a girl, eleven, and a boy, nine.

The time after that when we met again, believe it or not, we were organising her move up to the frozen north with the two children and all her possessions. (Plus a guinea pig, but that doesn't even merit a cameo role in this tale.) You may think this was totally crazy on our part, which I suppose it was, but there was an overwhelming sense of inevitability and happy anticipation about the whole business which caught both of us by surprise. Mother-in-law to be, though, was at first not amused. Fast forward several happy years with just the usual teenage screams and tantrums. Not from us two, I hasten to add.

The children were at last off to college and now, we thought, life would become easier. Then a family member suddenly fell victim to a severe mental health episode. Someone rang to tell us that he was currently in the psychiatric ward of a local hospital. That led to many years of problems and heartache, but our love for each other was strong enough to carry us through. Corny, but true. I recall the father of a young man in similar circumstances telling me gloomily, ‘This will affect your marriage.’ By which he meant it will totally screw things up if the mother became utterly obsessed with caring for her wayward son and left the fractious hubby on the sidelines, as had evidently happened in his case. Fortunately, that did not happen to us.

So life bumped along, and then for a while mother-in-law came to stay. We had agreed to care for her, as she could no longer manage life in her own home. I won’t bore you with the details, but there she was ‘one fine day’, as the lady in *Madama Butterfly* sings. She was an archetypal Ukrainian matriarch, with a fixed glare that could kill at twenty paces. Her problem was that she wasn’t in control of our house. My wife and I would not tolerate it. So there was the odd bruising encounter, but it sort of worked out. They chattered happily away in quick-fire Ukrainian most of the time, so I wasn’t particularly sure what was going on. I was gradually making sense of bits of the language, as it is fairly close to Russian, which I had started to attempt to master many years before. After a few months, mother-in-law had to move full-time into a care home as her health declined. That was our first and—I hoped—only taste of dealing with local authority workers and moving someone into residential care.

We had continued to struggle to cope with our other relative’s mental issues for so long it seemed like normal, but someone please tell me what normal is really like and can I have some. Those issues became just noises off, as they say in the theatre, so let’s focus on my wife and her cruel date with destiny and that twitch, which came to us all as a complete surprise. I’d just taken early retirement and we were enjoying ‘proper’ holidays for the first time, our destination of choice being the Canary Islands, especially Fuerteventura.

The situation with the mentally ill relative had begun to stabilise and we were able to travel and enjoy our time together, even though I was busily editing a national computing magazine from home, communicating with the editorial office and the printer by fax, that ghastly invention that has since deservedly died but apparently still lives on to this day in the NHS and elsewhere. Get a grip, people, and join the twenty-first century.

Just when it seemed all was going well for a change, along came that fateful afternoon when she drove off in her car to the hospital to discuss her ‘twitch’ at the neurology appointment. We didn’t think there was much cause for concern, and, as I’ve told you, to my later great regret I couldn’t accompany her, as I had a key committee meeting which I couldn’t squirm out of as I was chairing it and a few heads badly needed knocking together. So the afternoon droned on and I came back home to the former jute mill owner’s house we had purchased from a local doctor. It was in need of some TLC, but we were instantly won over by the airy high-ceilinged rooms (except in the maid’s bedchamber upstairs, of course) and the splendid Norwegian pine broad staircase with a stained glass window on the half landing depicting the Hermitage, a local beauty spot.

In those days, no one had yet come up with the smart phone, so I waited to see if she could find a phone booth (one of those red boxes with a pay telephone in it – remember them?) to call me. She did, and the news was not great. In fact, it was pretty terrible. The twitch that no one could observe because, as she said repeatedly, it was ‘inside her arm’, was not as innocuous as we thought, it was actually an early symptom of Parkinson’s. Ouch. No wonder the poor lass was upset, even though we hadn’t at that time got a clue about the full implications of what Parkinson’s was and how it was going to affect her over time.

Google was but a babe in arms, and all we had was the Concise Oxford dictionary and other works of reference. I experienced an unpleasant flashback to a telly documentary I had seen in the days of flickering black and white 405 lines, or maybe it was BBC2 with its massive 625 lines resolution. It had depicted some poor chap with the disease, struggling to cope with wild uncontrollable movements which could not at the time be managed because of the lack of the modern medication which had mercifully come on stream by the time my wife was diagnosed. The shock of witnessing some stranger cut down in their prime by this awful condition had for some reason stuck in my mind and it suddenly rose up again now to haunt me. My dear departed mother used to say, with that know-it-all nod and a wink beloved of the matriarchs of her generation, ‘Some things are meant to be, my dear.’ Oh, really. Do you think you could have a word with whoever it is makes this stuff up for us?

I must have still been tucked up in my mother’s womb when the Phoney War occurred at the start of World War Two, so I don’t remember what was later well described as the quiet before the storm. Some quiet, some storm, as Churchill might have said. We lived more or less happily through our own Phoney War of Parkinson's which lasted for some considerable time, three or four years in fact, and only gradually did the real symptoms begin to manifest themselves. And even then, they didn’t seem too bad, just an occasional shaky leg and a bit more besides. I recall one of her consultants saying that for someone with Parkinson’s she seemed to be one of the lucky few whose illness progressed at a relatively slow pace.

And so it did, until we came to the first of a number of bumps in the road. In the middle of the night, she woke up yelling with pain and quite inconsolable. It was pretty clear that something other than Parkinson's was behind this sudden bolt from the blue. The out-of-hours doctor turned up at the witching hour, produced an evil-looking syringe-full of analgesic and plunged it into her lower back. That seemed to do the trick. A painful trip to the hospital X-ray department came soon after, and there it was confirmed that she had three crushed lumbar vertebrae which were causing her a spot of bother. It never rains, but it pours. That didn’t help to hold back the onward march of Parkinson’s one little bit, and from then on she went about with a curvature of the spine which became progressively more pronounced as the weeks and months went by.

One of the things medics like to do to patients is to give them a drip feed, but unfortunately they also tend to extend that practice to the patient’s carer. We get information drip fed to us, a stage at a time, most often after the event, and we are not told about the whole story of the illness at the outset, so we don’t know what we are letting ourselves in for. It’s a case of ‘You know we said this stage is as bad as it gets’, but don’t get told that the next one is worse still until it turns up out unannounced. Why don't the professionals just come out and tell us what the destination can be of a long-term disease like Parkinson's? Because I suppose no one wants to mention that dreaded D-word until the last possible moment (when it's too late to readily adjust to the idea). Gradually matters went downhill, accelerating down the slippery slope, heading helter-skelter towards that D-word, dementia.

When her dementia set in, the worst moment on that journey was a severe psychotic episode, another unsignposted stopping point on her travels to God knows where, which caused her to lose complete touch with reality, and it was apparently not uncommon with Parkinson's-related dementia. The diagnosis was delirium, which sounds like some Victorian affliction to be managed by laudanum, but which is a genuine medical term characterised by a clutch of unpleasant symptoms. You can guess I was told that after the event too. A classic manifestation of Parkinson's, I was glibly informed. More of that little word classic later. I really don't want to mention this next bit, but I feel I must do so in order to demonstrate what a seriously disturbed individual can do and the potential harm that can occur, not least to the carer who hasn't got a clue of how to manage the situation because no one has enlightened them as to what is taking place, and why.

Somehow, she had got hold of one of the extensions to the house phone. She called 999 to scream at the police that at that very moment I was beating the living daylights out of her. You can imagine the pretty unpleasant thoughts that skittered through my mind, which was half shredded into mush by the situation anyway, having to cope with this on top of her crisis, summoning the doctor urgently and all the palaver that goes along with that. Quite soon after, a blue and white patrol car, lights flashing, charged up our driveway, and I thank my lucky stars that the two young policemen on board, bless them, actually listened to me, and when they saw her screaming and yelling they recognised that I was no wife beater. But an accusation like that can be as bad as being condemned as a paedophile. It could be entirely untrue, but the mud sticks and there's no smoke without fire, as the wise-asses say. I'll be referring to this incident again later.

So she ended up in a locked ward in the local psychiatric hospital, ironically the same institution in which our relative had spent a long time years before. The whole process was exacerbated by the fact that this all took place during the Covid-19 lockdown period. Visiting was a nightmare, as she would repeatedly tell me with all the venom at her command that I was deceiving her, bedding half the women in the local town and generally acting the playboy. That apparently is another classic response by a Parkinson's victim in that situation. But have you seen half the women in the local town? I wondered.

Gradually she improved when she came back home, suffered two further less severe episodes as a result of UTIs (Urinary Tract Infections), after I'd been her carer for what seemed like for ever, since Big Ben was a wristwatch, as they say. One of the unwritten laws of mental health crises is that they almost always get under way at around 5pm on a Friday afternoon, when all the social work departments, health centres and the like have closed for the weekend. I was given a spare course of medication to give my wife whenever her symptoms reappeared, which they did a couple of times, like clockwork, on late Friday afternoons.

At this point, I had also learned my first really harsh lesson as an unpaid carer 24/7, which you too will almost certainly have to come to terms with. It goes something like this: the closer you are to the person you're caring for, the more opprobrium is heaped upon you from a variety of sources. And between you and me, highest in order of unpleasantness after the lambasting you may receive from relatives, the chief carer really can get it in the neck from the very person you're caring for too. I know, I have been there, got the bloodied T-shirt and the film rights to go along with it.

I experienced some months of increasingly challenging challenges with my wife, until, having been seriously leaned on by the GP, social workers and members of the CMHT (Community Mental Health Team), I was metaphorically pinned down by them all and told that I was breaking up under the stress, that if something wasn't done about it, I might well be the next guest of the local psychiatric hospital after her. A consummation devoutly to be avoided. What choices did I face? The name Hobson came to mind.

Before answering that, though, I must tell you how I arrived at this particular tipping point. The answer, oddly, is very gradually, and this can easily happen to anyone in a similar position. Let me explain it this way. If you have grandparents who visit their grandson every six months, their first words on greeting him may well be, 'Hasn't he grown a lot and changed?' And you say to yourself, No, not really. And then you recognise it's all been caused by that four-letter word 'time'. Small incremental changes day by day add up to a huge transformation after six months. And that is what happened in my journey as a carer.

To lighten the tone for a moment, it reminds me of the doting grandparent who allegedly proclaimed, 'You wouldn't recognise little Johnny, he's grown another foot.' (Joke alert.) That is precisely what happened to me, when I realised how far things had developed. I don't mean I ended up like little Johnny and the three-legged design on the Isle of Man flag, but I had travelled from point A to point B without realising how the gradually increasing pressure of a worsening disease plus the passage of time had impacted on me, turning me into a knackered carer who would end up going to hell in a handcart, if he or she isn't brought up short and forced to recognise that things cannot go on like this.

All of which leads me to the most painful decision I've ever had to make in a long lifetime. They—social workers plus Parkinson's nurse plus CMHT specialist nurses, etc—told me she had to go into respite care for a fortnight to give me an essential break from caring. Either that, or I would end up as one of their customers too. No way will I agree, I responded. I fought like a cat trying to struggle its way out of a ball of wool it had itself rearranged into a tangled cat's cradle. But my resolve, such as it was, was weakening. Still, I had to be told. Forcefully. And so, too, did my wife have to be informed of where she was heading, and you can imagine how awful it was not just to tell her, nor just to cope with her reactions, but to live through a painful transitional period until she finally settled down in the care home.

At this point I had again been drip-fed the information: first, I was persuaded to let her have a taster of respite care for a while, and only then was I informed that a nursing home was clearly the appropriate place for her to remain for the foreseeable future and that the relevant booking had already been arranged. That was a real body blow for me. At least, I did not have to go on a trip round the local care homes to make my selection, and by good fortune my wife had a place allocated to her in an establishment just fifteen minutes away by car which had been rated as amongst the top twenty in Scotland. And that reward certainly turned out to be well merited.

To make the situation slightly less chaotic, my wife and I had drawn up mutual Power of Attorney agreements some time before when she was still compos mentis, and now I had to exercise full POA for her, as she was now deemed incompetent by the medics. I hate POAs. I had held a POA for my mother and had then felt the full force of bureaucracy bearing down upon me until I nearly screamed for mercy. Apart, that is, from the huge responsibility of being in sole charge of someone else’s affairs and finances.

But I did finally have to admit that I had run out of road. I was exhausted, tearful and heading for depression. When one of the splendid nurses from the community mental health team asked me how I felt, I answered, to my own amazement, ‘I am broken.’ Those three little words just slipped out unawares to my great surprise and embarrassment. No stiff upper lipped Briton cares to admit to that degree of helplessness, especially not a bloke, but if you ever feel so utterly drained, you are not alone. Admit it. As I put it in retrospect, I wasn’t at the end of my tether, I was witnessing my tether rapidly disappearing way into the distance and had no means, it seems, of grasping towards it and getting back up on my feet.

Asking for help when you can manage no more, that’s the first positive step in beginning to cope with a new and scary situation which for the former full-time carer can be even more daunting. I thought ironically back to a poster I once saw pinned to the wall of one of those gloomy, dusty, old-fashioned hardware stores: ‘I walked alone under a dark cloud and a voice in the cloud said to me, “Look up. Things could get worse.” So I looked up, and lo, things did get worse.’

How do you tell the love of your life that she is to go into a nursing home, with you heavily involved in the decision-making process? I had sincerely sworn to her repeatedly that she would do that over my dead body (which, I now suspect, could have been arranged), but I had not expected that this extraordinarily painful turn of events would ever confront us. I had envisaged myself bumbling along and continuing to manage things indefinitely as I had for the past decade and more. I recalled that, some while before, she had come up to me and asked quietly, ‘Are you going to put me into a home?’ My innocent reply was, ‘Certainly not. You *are* in a home, love. Now. Yours.’ But, as some wise man must have said, the one thing you can’t predict is the future. You should be prepared, however reluctantly, to revise much of what you may have promised in the past in the light of your loved one’s increasingly severe dementia.

In many ways, I suspect it’s a blessing we cannot spy into the future, as most of us would run screaming in the opposite direction if we had a crystal ball. As Woody Allen once said, ‘I don’t mind dying one day, I just don’t want to be there when it happens.’ So, having laid out our personal background for you, let me dive straight in to the vexed question of what a carer is and does.

Chapter Three —The role of the ‘informal carer’

First things first. What do I mean by ‘a carer’? In the present context, he or she is an adult who is largely unpaid and ‘unqualified’ in the formal sense, and who is looking after another adult, most often a partner, a parent, or close relative suffering from one of the many variations of dementia. Somehow the term ‘informal carer’ has crept into the vocabulary, presumably in contrast to the ‘formal’, paid carer who probably has at least a modicum of training for the role. I was tempted to use the term ‘unpaid’ instead, but it isn’t the money which is the key issue here, it’s the supposed ‘amateur’ versus ‘professional’ split which is at the heart of the issue.

There are two key points which should be borne in mind at this point, especially by healthcare professionals, namely, that there is—or rather, should be— a trade-off taking place. The trained doctor or consultant dealing with your loved one’s condition is seeing a patient who presents with symptoms they have been observing for many years, whereas for the informal carer everything is happening for the first time. So the situation for the carer is radically different: this is new ground we are breaking, on top of all the emotional, financial, legal and other problems which have landed unannounced in our laps.

But that’s just part of the story. There is another element of the trade-off, and it is a matter which my wife and I in the days long before dementia struck her were constantly battling the professionals over. We were then dealing with our relative with a diagnosis of schizophrenia and the case which we kept on pressing is that the professionals may have all the knowledge which goes with years of study of the medical condition, but we are also ‘professionals’ in knowing and managing the individual who has received the diagnosis. Let me put it this way: they may know the patient from the outside in, as it were, but we know the patient from the inside out.

We too can bring a wealth of knowledge to the table, mostly not medical, but all of it highly relevant to the current condition and future treatment of the patient. It emphatically is not a case of the medical professionals with their greater knowledge being in any way superior to Joe Public and his or her loved one. We are — or should be — approaching the situation as different kinds of equals interpreting it from radically distinct perspectives, and it is in my view essential that the mentally ill patient should be viewed from both directions, as it were, if they are to derive the greatest benefit from those around them who are handling their case.

Time and again my wife and I were made to feel as if we were the poor relatives turning up to a posh occasion at a wealthy relative's house and being asked to kindly remove our footwear so as not to damage the expensive Persian carpeting with our soiled wellies. So that little word 'informal' covers a wider number of key issues which we as a society really haven't begun to come to terms with. First, the informal carer is undervalued simply because they have not taken on their role as a result of any relevant skills or education they may have received. No one wakes up one fine morning, saying, 'Hey. Today I am going start being a carer, unsupported, unregarded, unwaged, for my loved one — possibly for the rest of their life. Bring it on.'

The newly-minted carer has been dealt a particularly grim hand of cards out of a clear blue sky and has bravely undertaken to accept the situation and perform an open-ended role with unknown and increasingly severe challenges lying ahead. In the words of Richard Bates in his excellent study of the informal carer's situation:

> When we undertake a caring role, we often do not even recognise ourselves as a carer. We may not have a nursing, financial, legal, or medical qualification… Carers taken on an open-ended commitment. Only when carers perceive that no one else is willing or able to help, do they realise that they are providing an unpaid service for which someone else would be paid. (Bates, viii)

The medical profession still operates a strictly hierarchical structure which to my untutored eyes is almost medieval in its rigidity, with a pecking order of medical and social care staff, and in all of that the informal carer comes last, way off the bottom of the list. There are two barriers to overcome here, neither of which is appropriate in a society where the need for the caring role is increasing at a phenomenal rate due to our ageing population. The first is that 'caring' itself is perceived in the medical world as (a) different from and (b) inferior to nursing and medical treatment.

One direct result of that outdated perspective is the low level of remuneration for care workers, bringing with it recruitment and retention issues in the social care sector, most notably in the residential homes of the UK. The lower status of the professional carer lies at the heart of the crisis in the caring professions which bedevils any attempts at a rapprochement between 'treatment' and 'care'. There is also the mystique of the medical profession to overcome, which determines that certain roles can 'only' be performed by a fully trained nurse or doctor.

Anyone tempted to undermine non-medical staff on purely educational grounds should watch, as I have done on a regular basis, a trained carer assisting an old lady or gentleman to eat their lunch, quietly talking to them, encouraging them to take one more mouthful and generally being gently supportive, and then wiping their hands and face, taking them across the corridor to the toilet, constantly maintaining communication with them and ensuring that their dignity is upheld. Put a price on that. Now you try doing that, day in and day out for the kind of wages on offer.

This class system in education and society generally is a very British flaw. We admire academic stuff and sniff disapprovingly at apprenticeships. Brains good, hands bad. It was a fault-line in our culture which was identified by the scientist and novelist CP Snow at the end of the 1950s, when he deplored the perceived gulf between arts and sciences and the detrimental impact that it was exercising on the development of society as a whole. I was in my early enthusiastic days as a lecturer around that time, and I recall vividly the condemnatory scorn of the old guard when I was venturing to explore the synergy, the beneficial interactions if you like, between literature and language on the one hand, and the burgeoning power and potential of the electronic computer on the other. How dare I bruise the delicate flower of literature with the raw brute force of a dumb machine? Time and again real breakthroughs flourish, not within an individual discipline, but between two disciplines sometimes far apart on the academic spectrum. Do not obsess with the cutting edge of your particular subject, look for inspiration wherever it offers the possibility for the advancement of your discipline.

This supposed division between brain and brawn in particular is damaging at every level. A quick anecdote: I was talking to our joiner a while back, and he asked me what it was like to be a professor. My response was that he could not do my job, but I certainly could not do his job. We complement each other, we are all interdependent, and we all matter. We should never accept a situation like that devastating quote in George Orwell's *Animal Farm*: 'All animals are equal, but some animals are more equal than others.' In the case of dementia, there is a further aspect which I find lurking in the literature and which is, in my view, one of the elephants in the room which the professionals pretend isn't there. (I am tempted to add that it isn't just a matter of ignoring the elephant in the room, some professionals seem to think that there isn't even a room.) I have read and experienced time and again the view being expressed that because dementia cannot be 'treated', any interaction between professional and patient is merely one of managing decline and therefore becomes relegated to a purely 'care' situation rather than handled in 'treatment' mode.

Instead of splitting hairs over such theoretical approaches as the diagnosis and prognosis models of patient treatment (don't ask), it would be far more beneficial if a less rigid pattern of interaction could be envisaged. It has been my experience that this box-ticking approach has been unhelpful for the patient with dementia and plain disastrous for the carer, and that latter issue is one which I'll be examining in depth in the course of this book. The onward march of patient-centred medicine is all well and good, but I get the distinct impression that there should be strict limitations on how far and how fast that march should occur without bringing the informal carer into the equation.

It is unhelpful for the patient, because there is no chemical bullet available (yet) to produce beneficial ameliorative outcomes for a person with dementia. And it is far more unhelpful for the carer, to put it mildly, because the profession hasn't come up with a diagnostic profile for the issues confronting them. What I mean by that is that, due to the strains and stresses of being an informal carer, their health condition will increasingly be one demanding medical attention. However, it doesn't have a medical name, so it doesn't appear to exist. Given that gap, as it were, I have come up with the diagnosis name 'careritis' to describe the condition. There is one further important matter which relates to interactions between the three parties involved here — clinician, patient and carers — which in the past caused my wife and myself all kinds of bother in seeking to care for our weekend visitor with schizophrenia all those years ago.

Let me take you back to the early 1990s, when old attitudes flourished and our relative fell ill with schizophrenia. My wife and I found ourselves in the undervalued role of part-time carers. This all happened well over thirty years ago, and I recall our being summoned like naughty schoolchildren to the presence of our relative's consultant, who sternly rebuked us for daring to challenge his approach to the patient. We were thoroughly hauled over the coals by the man. That phrase, by the way, refers to a torture meted out to medieval heretics, literally being dragged over red-hot coals. We knew how those poor old heretics must have felt, but we defended our corner vigorously and we persevered, as we knew that there was a serious injustice being done here which we were determined to rectify.

Our relative was in a long-term hospital ward and had been considered sufficiently stable to spend the weekends at home with us. We obviously had a number of questions to ask, which in our innocence we thought were quite reasonable: What medication is he on? How do we ensure he takes it? What happens if a crisis blows up and who do we call? Those are representative of the concerns that were swirling around in our heads. Here was someone with a severe and enduring illness coming into our home without our being given the tools to make his stay as stable and profitable as possible, without risk to himself or to ourselves. You are probably way ahead of me as far as the consultant's automatic response to those questions is concerned: 'Patient confidentiality does not permit us to inform you of these matters.' This knee-jerk reaction was our first taste of a bizarre and potentially dangerous Catch-22 situation in which we were handed responsibility for a patient with severe and enduring mental health issues, but without any of the tools essential to managing them properly (or at all). That has for far too long been a barrier to proper care for people with mental illness, and is compounded when patients themselves insist that others should not be aware of the nature of their condition. This reluctance, ironically, is a well-known symptom of their illness, but round and round the circle we go.

To my mind, it beggars belief that, in a situation where the patient is suffering from a mental health condition which distorts their world view to the point at which their claim of confidentiality becomes a severe impediment to their treatment, we still cannot access reasonable information. We found ourselves facing the same logical conundrum as Buridan's ass, which would be laughable if it were not so desperately tragic. The said animal represents a philosophical conundrum in which the creature is equally hungry and thirsty and is placed halfway between a pile of hay and a pail of water. In its anguished indecisiveness, the poor creature expires of both hunger and thirst. This misappropriation of patient confidentiality can and does cause untold damage.

To cut a long and painful story short, that was the key trigger for many years of campaigning on our part in which my wife took a leading role, becoming a Board member of NSF (Scotland) and a trustee of the National Schizophrenia Fellowship nationally, as it was then called. The London organisation was later re-badged as Rethink in pursuit of the current fashion of taking perfectly good descriptive names and dressing them up in meaningless words and phrases which are allegedly more user-cuddly and neatly skate round the uncomfortable subjects they cover. She also became a key member of EUFAMI, the European Federation of Families of People with Mental Illness, speaking at conferences across Europe, notably a WHO convention in Athens, and her campaigning played a central part in bringing about a transformation in the awareness of the role of families and informal carers in the care of severe and enduring mental health issues and the role which they can and should play in its management and mitigation. It is sadly ironic that she spent her last years in a residential home as a ‘customer’ of mental health services herself with me as her erstwhile carer, and she was still on the receiving end of some of the attitudes and practices which should have been dead and buried years ago. Mercifully those practices did not apply in her own care home.

The narrow interpretation of patient confidentiality must be allowed to expand to embrace the immediate circle of informal carers and serve to help break down the vertical and horizontal barriers within the medical profession in the treatment of mental health. If you as a carer have the appropriate Power of Attorney and your loved one has been determined to be mentally incompetent, some of these confidentiality issues go away, but not all. Trying to comprehend the fact that the old attitudes are still deeply ingrained in parts of the NHS was pretty depressing, reminiscent of that French phrase, ‘Plus ça change, plus c’est la même chose’, in other words, the more it changes, the more it stays the same.

The ‘informal’ carer of a loved one with dementia has a particularly raw deal. That might sound like an extraordinary statement, but it is a key purpose of this book to demonstrate that this is indeed the case, but I also explore ways in which the informal carer can put themselves back together again and aspire to the prospect of not working in the dark in the absence of set of standard outside support systems. Ask yourself these questions: Did you know what you were letting yourself in for when you took on a caring role? Did any of the professionals take you on one side and give you even a general overview of what was likely to happen and how bad it would become? Did anyone offer you support and information when you ceased to be a full-time carer?

Do not be blindsided by assertions that ‘of course’ the carer is being swamped with advice and support. It is largely limited to practical matters and self help groups and the like. They are admirable but they are not nationally coordinated initiatives, nor do they strike at the heart of the matter, namely, their knowledge of the mental health condition of the carer, why it is so limited, and how it can be ameliorated across the patch as a matter of 'gold standard best practice', a medical watchword which is far more often honoured in the breach than in the observance.

There is also a strange disconnect between my experience of discussing these issues with professionals and the lack of a national debate on what is an exponentially growing population of informal carers. The most positive response to my lamentations on the subject has been that, of course, the time has long since passed when such matters should be somehow dealt with, but how? And how can you reprogram the groupthink of politicians whose life cycle is reckoned in the four or five years between general elections rather than planning decades into the future?

In the absence of any formal manual for informal carers (pun intended), this book covers in some detail the practical ways in which you can prepare yourself for dealing with the growing and shifting demands of your loved one as you look after them in the family home, and also, and perhaps even more importantly, how to manage and cope with the serious mental health challenges you face when your loved one goes into a care home. If you are not yet in that situation and are given to believe that at that point it's just a question of 'game over', and now you can get on with your life without a care in the world, just think again.

I have been very fortunate in two regards: as a retired senior academic, I am quite accustomed to getting up on my hind legs in public and expressing my opinions, popular or otherwise, and also in dealing with people at every level of society. Secondly, I have nothing but praise for the quality and opportunities for targeted support and encouragement in this corner of rural Perthshire in Scotland, but I fear that many of the facilities I have been able to draw on depend crucially on two factors: whether such benefits happen to exist in your area and, even more importantly, the knowledge and awareness needed to seek them out. Again, this is an issue tied to the fact that the caring role has come upon you unawares, without a set of instructions of any kind. It's also a postcode lottery in two senses. You may have to have the good fortune to live in the right place, but you also need to be in a position to know what it is you require in matters of support and how to go about obtaining it. Also, of course, you need to be computer literate enough to go in search of help online. Of the many websites offering advice and information, I hold the Alzheimer's Society information pages in high regard as well as their one-to-one consultation services, and I deplore the fact that it always seems to be the charity sector, ever playing a Cinderella role in health care, which offers the greatest awareness of the needs of the carer and provides positive initiatives in their support without gaining the level of recognition—and funding—it deserves. I know, I was volunteer Chairman of a local mental health charity at a time of severe financial restraints, and had to challenge the incredulity of the high heidyins in the local Health Board when I asked the Oliver Twist question for more money to help support the services that they actually demanded of us, or the organisation would fold before the week was out.

There is a paradox at the heart of all caring for dementia, and that is (and I am not being flippant here) that everyone's story is quite different, but everyone's experience is the same. In other words, the common factors outnumber the variations and that will, I earnestly hope, allow you to draw benefit from what I have put down in these pages. I turn now to examine the information which the carer should have upfront in relation to the role of the family home in looking after a loved one with dementia.

Chapter Four — A dementia-friendly home

I was working away on the computer in the upstairs office one day when I became suddenly aware of something which smelled remarkably like burning. Living in a rural area, the first thing I did was to peer outside to see if someone had lit a bonfire. No. So I sped downstairs and into the kitchen, where my wife was standing looking in a puzzled way at the ceramic oven hob, from one corner of which smoke and flames were beginning to issue. It took me a couple of seconds to realise what was happening. She had evidently mistaken the hob for the microwave and was trying to roast a packet of cashew nuts directly on the heating element, which is not exactly designed for that purpose. I did not realise until that moment that she was now needing to be watched far more closely and just about all the time.

One of the points which I will keep on holding forth about in caring for someone with dementia, and one which has a general relevance for a loved one with a disability or illness of any kind, is that prevention is better than cure. I know, there is so much other stuff going on around you when a diagnosis has taken place, and in many cases you will at first be asking yourself if you need to be prepared for anything at all, because your loved one hasn't suddenly changed overnight. Again, every situation is different, and what follows is based on my own experience in our home, and also in coping with my mother in hers. Her house was a typical semi, built immediately after World War Two, with a small extension later added on at the rear including a downstairs toilet. Our own home is a country cottage two hundred years old, with two extensions: three additional bedrooms downstairs plus a shower and toilet room, and upstairs a large room, with an en suite toilet, which has variously been a lounge, a bedroom and office space for both of us, and there is also a balcony for when the sun decides to make an appearance.

One important piece of advice must be shoe-horned in at this point, and that is that the local authority and the NHS have lots of equipment which can be loaned out to you to assist in creating a dementia-friendly home, so don't go rushing out to the nearest specialist store or online, as the prices can be pretty eye-watering for some of the products on offer. Ask social work for a needs assessment or your local health centre for information in this regard. I have also widely researched the issue of preparing for the coming changes in your loved one both in the literature and online, but I cannot hope to have explored every possibility, so I apologise in advance to longboat dwellers and horse-drawn caravaners, and others I may have overlooked. My aim is to provide a general framework and context, to offer you examples of broad principles involved in the task of making your home dementia-friendly. There are so many different aspects of adapting accommodation to suit a loved one with dementia all struggling to gain attention, so I am going to try and discuss just the most significant of them. First of all, though, let me address a common human failing encapsulated in that little phrase: 'It cannot happen to me.' Like the smell of burning from the kitchen, that won't happen to you—will it? Such a mindset is a positive discouragement to making sensible arrangements for the dementia-friendliness of your home.

Accidents will happen

If I look back over the forty years or so since we first bought this cottage in the country, we have only had the fire brigade up the drive once to help deal with a serious electrical fault which filled the house with smoke and did some damage, but we have had far less good fortune with water-related incidents, the most serious of which was the discovery by a workman that there was a slight problem with the bath which was in the process of being removed to make space for an extended shower basin.

The rocket scientist who had fitted this bath some years before on contract to the local authority, when mother-in-law was in residence with us, had omitted to connect the output from the bath to the waste water system, causing used bathwater to cascade all over the floor beneath. Fortunately, we hardly ever used the bath, but over time the floor under the bath had rotted to the point that the whole area was about to collapse, which might have been pretty disastrous if my wife had decided to have a soak one day. Visions of her drifting unclothed in the bathtub down the drive on a tide of soapy water haunted me for some time after. Titian would have made a fine painting of that, a sequel to Venus rising from the Sea.

What I am stressing here is, oh yes, accidents do indeed happen. That's why they are called accidents, and believe me, if you have charge of a loved one with dementia you will find that the incidence of such occurrences can increase substantially over time. So what you need to do, long before it becomes necessary, is to undertake an audit of your house or flat or whatever your living accommodation looks like, and determine what kind of changes are going to be needed to transform it into a dementia-friendly place, and to avoid accidents where possible. It is foolish, but all too common, for you to wait until a need arises and only then consider how to manage it. One of the most frequent issues is that of accommodation on more than one level, and we shall be exploring that in a moment.

Do bear in mind that money may well have to be found or allocated, and also that it takes a certain amount of time to organise and arrange for the electrician, plumber, joiner and other workers to undertake any alterations. Some building works will need planning permission or a building warrant of some kind, and those can take a while to be put in place. The moral of the tale is that, if you find yourself saying that a particular change isn't needed for a few months, then now is the moment at which you really need to get that change under way.

On the level

If you live on more than one level, in which the arrangements usually are that the bedrooms are upstairs and the living rooms and cooking facilities are downstairs, you already have the beginnings of a problem. Put bluntly, the time may well come when your loved one cannot manage the stairs any more. What do you do when that situation arises? A quick and easy response is to ensure that they live exclusively on the lower level, and that the bedroom and dressing room facilities are brought downstairs. Hang on a moment, though: many houses have toilets and bathrooms upstairs only, and anyway I am not convinced that it is good practice to exclude your loved one from half the building just because it's awkward. Time for the thinking cap. The newspapers and magazines are full of advertisements for stair lifts and 'proper' lifts, for all kinds of bathroom facilities and the rest. Two problems instantly arise: cost and space. If you install a toilet and/or shower, you will need to locate a suitable place for it, or even build an additional room to accommodate it.

Leaving aside the toilet problem for a moment, one option may be a lift of some kind to allow the loved one to continue using the upstairs rooms for as long as is practicable. A standard staircase of the appropriate width should have enough space for an installation. A word of warning, though: my mother's house had a stair lift, and there was a right-angle turn three steps from the top, which meant that she in her nineties had to leave the lift, lower a wooden flap, and navigate across to those final steps, with the possibility of a pretty nasty tumble down the main flight if she lost her balance or was unable to hold on to the stair rail.

Our own staircase was too narrow to accommodate a stairlift, and also it was split into two distinct parts with a hundred and eighty degree turn near the top. That meant it was entirely unsuitable for that piece of equipment, so the next option was a real lift, which we did eventually have installed. The first point to bear in mind is the fairly substantial cost. Check carefully what the initial expenditure will be, and also the annual service or maintenance contract. To employ the delightful Scottish phrase, you will probably need to 'go out singing' to acquire the funds, and you'll have to sing pretty well, too (and frequently). Until the recent lifting of requirements for a face mask, Covid-19 regulations might have made that even more of a challenge.

Point number two is that it can take a long time to install, for two reasons. The local authority needs to be involved with planning permission or a building warrant. And do check that the company you deal with will cover the cost and arrangements of all aspects of construction. We discovered by pure chance that the firm we had bought the lift from had omitted to ensure that the work had been given a completion certificate, and the local authority were on the point of cancelling it. All without informing yours truly, of course.

The lift itself may require extra strengthening of the floor on one or both levels, and it takes up a certain amount of space, but it is designed to be as inconspicuous as possible. If there are young children around, do ensure that they are not allowed to play with the lift unaccompanied (or at all), as that can have unpleasant consequences. Also, when our lift was first installed, our cleaner, bless her, left a stool upstairs on the floor just where the lift rises up, causing me to be jammed halfway between floors. The lift does have an emergency phone, but that isn't much use if no one else is in the house, or your loved one is using the lift at the time and is too confused to know how to act in an emergency. I was in fact contemplating erecting a wooden fence-type arrangement round the upstairs and downstairs access points for the lift, with a little gate to prevent such accidents occurring again, but now that I am alone in the house, that is not — I hope — necessary.

The lift will come with a couple of remote controls so that you can summon it from wherever you require, or use it as a service lift for moving stuff up and down stairs. None of that, however, fully overcomes the toilet problem, because when a loved one with dementia needs to go, they need to go now, not in the 30 seconds or so it takes the lift to go up or down. And as for incontinence, that is quite a different issue altogether. I deal with toilets in the 'going potty' section a little later on. Depending on the level of your loved one's disabilities, present and future, you may also have to consider the issue of two-floor accommodation from the viewpoint of wheelchairs. If your loved one needs to be in a wheelchair or other form of support all the time, you have two choices here. First, you could have an additional wheelchair or Zimmer frame for upstairs use, or you can opt for a bigger (and more expensive) lift which is large enough to accommodate a wheelchair.

Access to the building

Go to your front door and open it. Now work out how you would manage if you had your loved one with you and they were either using a walking stick, a Zimmer frame or some kind of wheelchair. In our case, the answer was: not very well. An old country cottage was not exactly designed with modern requirements for folk with disabilities at the forefront of the builder's mind.

Our main problem was that there was a pretty substantial outside doorstep which the loved one would sooner or later find to be far too challenging to cope with. The solution we came up with was to have a builder construct a sloping concrete incline up to the entrance, with a handrail on one side. If my failing memory serves me correctly, some of that access can be funded by the social work department, so check that possibility before reaching for your wallet. Again be aware that such arrangements do take time, so make sure you plan well in advance of need. To round things off, I also arranged for half a dozen paving stones to be placed at the base of the slope, so that we could reverse the car up near to the door and my wife could manage the smooth surface more easily than the gravel surrounding it. Whilst you are looking round outside the house, think also of accessibility by wheelchair to various parts of the garden. In our case, we have a large area which is gravelled over, as it is no longer used for vegetable growing and needed to be as maintenance free as possible, and at the far end, in one corner, a summer house (don't ask why in Scotland we have a summer house) perched on wooden decking.

Gravel does not like wheelchairs with little wheels, and our chair designed for indoor use simply sat there spitting out pebbles and refusing to budge. Fortunately, we had another electrically-propelled machine which we had purchased for trips into the nearby town, and the wheels were fat enough to cope with the surface. Then there was the issue of access to the summerhouse itself. All kinds of metal ramps can be purchased, although the prices of some of them make one wonder if they are constructed of 24 carat gold. Do ensure that the degree of slope you decide on is very gentle because wheelchairs and similar devices do not take kindly to steep ramps, not least because they tend to have low ground clearance.

Let me return for a moment to the front door. Please be aware that going walkabout is a failing of many people with dementia, and they must be protected from this eventuality. Keep the outer doors locked. A badge round the neck with name, address and phone number will help if they do manage to get outside. If you have a garden with a secure wall or fence, you could allow the loved one access to it, but that would mean locking the front gate, and you would then have to put a note out or make some other arrangements when the courier from Amazon calls, or the postie turns up. An intercom system might work well in such a case.

From room to room

It may well happen that your loved one becomes unable to walk easily from one part of the house to another, and there are a number of issues to bear in mind here. Let's begin with doors and flooring and move on to other related items which will make life easier for you, again based on a subtle blend of my own experience and reading through the literature.

Doors

Imagine you are in the porch, seated on the brand new powered wheelchair that arrived earlier in the day, with its battery now fully charged. Time to give it a test drive. This toggle control looks a little oversensitive. It is. There is a sudden jolt as I crash backwards into the coat rack. This was supposed to be easy—that's what the salesman told us in the shop, but it's reminding me of the time I first started learning to drive, with everything to remember at once. After a while I pluck up courage and decide to venture out into the hall.

After an inelegant three-point turn (make that four), I come face to face with the main house door, which opens towards me. I reach forward, pull. No joy, the door simply gets stuck as it collides with the footrest of the chair. So I ease back a little, and try again. After a long struggle, during which I nearly fall off the chair altogether, I persuade the door to open. I edge the toggle forward to enter the hallway, but then I am brought to a sudden halt by another obstacle. More of that one in a moment.

You may be tempted to ask what the humble door is doing in a chapter on making a home more dementia-friendly, but I hope I have just demonstrated that one of the issues which you have to confront as a carer is that of recognising that a particular feature of a building may be very convenient for able-bodied people to use, but it can present insuperable obstacles to those with mental and/or physical disabilities. If you are not inclined to believe me and you have a wheelchair for use inside the home, try the following. Sit in the chair and propel yourself to any door in the house which opens towards you. Now try and pull it open like I did.

Without labouring the point, you'll see that it is not exactly easy to lean forward, grab hold of the door handle, then pull it towards you with the wheelchair blocking your path, and so it goes on. And that brings me to what is called 'low level assistive technology'. Nowadays, it seems that nothing can properly exist without a fancy mouthful of a name tagged on to it. Basically, you should look for the simplest, cheapest and most readily available way of resolving a problem, rather than going down the expensive path, which I have also tried, with less than stunning results. More of that in a moment.

Back to the door, which by the way can also be just as awkward if your loved one is using a Zimmer frame or a walking stick. There are a number of possibilities, most of which I have tried with varying success. The first is to remove the door altogether, which is not such a bright idea for a bathroom or bedroom, for example. Plan B is to purchase a pack of those little anti-skid rubber door stoppers, the grey versions of which look like extremely old wedges of cheese. Keep the doors open during the daytime when the loved one needs to pass through them.

Next up the technological ladder is a sliding door, which requires space to one side for the door to slide to when open. Unless you are pretty good at DIY, I suggest you get a professional to fit the door for you. I tried it once many moons ago and it was only an intermittent success.

Right at the top of the scale is a door which operates with an electric motor as it swings open and closed at the press of a button or a remote, the expensive path I referred to just now. These are at the Rolls Royce end of the market (price-wise, too). A local tradesman fitted one of those contraptions in our home, leading to the bedroom, but it got little use, because by the time it was delivered and fitted my wife was on the point of departure to the care home, and, I realised, getting to the stage where any simple piece of technology for controlling stuff, from a TV remote to lift buttons and door opening controls was beyond her capabilities. The speed with which her ability to use simple electronic gadgets degraded and then disappeared altogether caught me completely unawares. It's another feature of dementia which I learned about the hard way. You could also try a door which you can push open, like the entrance and exit doors of a restaurant kitchen, which are sprung so they close on their own, but I did not have an opportunity to explore that particular route.

Now for another issue relating to doors, which halted me in my tracks when I went for the first test drive with the new chair, as I described a little while back. I had no idea would be a problem until my wife sallied forth on her maiden voyage in an electrically powered wheelchair (electric chair doesn't quite have the right kind of ring to it) and tried to cross from the dining room into the kitchen. She came to a sudden stop, and was nearly tipped over in an undignified heap into the kitchen, with its solid stone floor. Incidentally, I might as well mention here that if your loved one is rather doddery, you should ensure that their chair seat belts are always in position and properly locked to minimise the chance of their falling out.

What I had completely overlooked was the fact that most doors inside a house have what's known as a threshold, a strip of wood or metal which serves to make a neat edging for the flooring material, and also to help draught-proofing. Able-bodied folk don't even notice them, but even a very modest wood strip can present a really stiff challenge to a wheelchair, particularly one with small wheels. The solution is not hard to find. Either shave the edges of the wood to make for a smoother passage of wheels, buy a shaped wooden threshold, or go for a metal threshold with smooth sides. When two adjoining rooms were having wood block flooring installed at the same time, I managed to overcome one such problem by having the flooring run seamlessly from one room to the next without a threshold.

Flooring

That brings me neatly to the broader question of what to do about the floors. Here we face a real challenge of design versus function. Do you go for fitted carpets or wood/laminate flooring? Or tiles or anything else for that matter? There are a number of factors to bear in mind here. On a purely practical daily maintenance level, you will have to contend with food and other less savoury spills on to the floor, and for that reason alone, we changed all the flooring in the house to oak blocks (laminate will do perfectly well), with a couple of exceptions, and there were two immediate benefits.

The first was that a mop and bucket make light work of a little unwanted splash on the floor (to put it coyly), but by contrast the damage to a carpet can be much more of an issue. If you do have carpeting, a strategically placed mat, the kind you buy for use in a bathroom, can capture any embarrassing drips and it can simply be thrown into the washing machine when the need arises. The second benefit is that wheelchair access is easier and less hassle with a plain floor. An unpowered wheelchair and a carpet with a chunky pile simply do not go together. You are welcome to try that if you like. Our electrically-operated wheelchair happily took her all round the house, and the bedroom carpets are of the flat pile variety so they did not present too much of a challenge.

I referred a while back to a couple of exceptions: the kitchen, shower room, bathroom and toilets were tiled, and the bedrooms carpeted for general comfort (walking barefoot, for example) and a cosier feel than plain wood or laminate. Now for an issue which often gets completely overlooked, but which is of vital support for the loved one.

Handling the situation

This topic is relevant to any room in the house and also outside and is particularly significant in relation to any shower or bathroom you may have. It soon became apparent that my wife needed additional support when moving around the house and inside various rooms. She was still able to use the stairs in the weeks of what I have called the Phoney War of Parkinson's, when no marked mental deterioration seemed to be taking place but mobility was becoming something of a struggle, so I had a rounded rail fitted up the staircase, which was much easier to grasp. It had previously been a plain wooden panel, which had been placed there more for decoration than support.

Next in line came the toilets. She was beginning to need help in steadying herself as she sat down and raised herself up, and so I fitted handrails around 40cm in length. At this point, do involve the loved one, because you need to get the height correct and also the angle at which you affix the rail to the wall. She also required help and support in standing up and sitting down in the shower and bath. The rails must be fastened firmly to the wall as a forceful tug on one which is just screwed into plaster board can produce interesting but unintended results.

However well you prepare for what may happen in the future, there will always be additional problems that pop up unexpectedly and cause you to revise your plans. As my wife's mobility deteriorated, for example, it was clear that she soon would need a floor-standing support on the other side of the toilet as well, so that she could raise herself up with both hands. However, the door to the toilet and shower room opened, as they do, inwards, which meant that fitting an additional support rail would make a major undertaking out of getting into the room, closing the toilet door and manoeuvring her into position to use the toilet. Do not underestimate the challenge of persuading someone who is dodgy on their pins to shuffle sideways and then backwards. Several times a day, too.

So I pondered a while. It called to mind a cartoon I saw once of a posh office with a sign on the wall bearing the word ‘THINK’. Some comedian had added underneath ‘OR THWIM’. I was in that kind of mode, puzzling for a while what to do, then it occurred to me that a sliding door to the bathroom might solve the problem. But (and in this kind of planning there is at least one but) there was no space inside the bathroom for a door to slide, and next to the toilet door in the outside corridor someone had installed a radiator, part of the house’s heating system. Building a sliding door would involve moving the radiator, sourcing a sliding mechanism, and so on. I was about to bite the bullet and carry out the necessary preliminaries, when the fateful day arrived and she had to enter the care home. Problem solved, but don’t expect everything to resolve itself so easily. It didn’t in the case of that electrically operated door I referred to a while back, which hardly got any use.

Now I am going to put my neck in the noose and state that I do not like most of the rails on the market, for one very simple reason. Soap products and their fancy variations for hair washing, body pampering and other functions are all very slippery, and a shiny metal rail is the last thing you need to get hold of, especially if your grasp is becoming weaker as the illness progresses. So I looked around and came across one product (there may be more, but I won’t name names) which has neat non-slip rings at intervals on the rail, and they offer much firmer support, so I urge you to look out for that kind of additional feature.

Plugs and sockets

Some of the most useful changes you can make can cost very little, and electric plugs and sockets certainly fall into that category. Most houses and other accommodation have sockets located above or actually on the skirting board, which can be pretty inconvenient even for the most able among us, but if you are in a wheelchair and want to charge your iPad or whatever, it will be impossible to do so without assistance. With all these aids to make life more user friendly for the loved one, it is important, wherever it is practical, to provide them, in order to give your loved one as much independence as possible for as long as you can. With sockets, don’t go rushing to the nearest electrician, unless your money is burning a hole in your pocket, just seek out the local hardware store or go online and purchase a four-gang trailing block with individual switches for each of the four sockets, if possible. They cost around £10-£15 at today’s prices. You may prefer less than four outlets, but that is up to you entirely. The important point is to buy one with just a short length of cable attached — one metre is fine.

All you need now are the usual DIY items for fixing two countersunk screws into the wall to take the trailing block, and the height which I have found works well is around 80cm above floor level. Now affix the socket to the wall immediately above the existing floor-level socket, secure the cable with electric cable pin clips, and you have an instant relocated socket with additional outlets at a height which your loved one will cope with far more easily, and, let’s be frank, so will you. Look out for 13A plugs with handles to make it easier to push them into place and pull out.

One similarly helpful electrical product to be aware of is a variation on the standard table lamp which works by touch, usually giving you three or four choices: off, dim, medium, bright, for example, and they make life a lot easier for your loved one.

Going potty

Inevitably, your loved one will at some stage need the convenience (I choose my words with care) of a commode chair, which is one of the items which the local authority and others seem anxious to provide. There appear to be broadly three kinds of such pieces of furniture: a white-painted metal tubular construction which tends to look as if it spent its better years rusting away in a hospital storeroom; a wheelchair with a built-in commode; and finally what looks like a normal chair which has a commode concealed within. We used the wheelchair lookalike for some time, as it had the obvious ability to be moved around the house as needed. (By the way, that’s another good reason for not having bumpy thresholds between rooms.) A metal tubular commode was squeezed in neatly by the bedside and was a nighttime blessing. Note that you should acquire disinfectant and set aside a small amount of time each day for what used to be called ‘gardeyloo’ in the lavatorially challenged days of old Edinburgh city. It was a corruption of ‘gardez l’eau’, which meant ‘watch out for the water’ and gently signified that it wasn’t necessarily just yellowish liquid being cascaded from an upper window. Solids may also be involved.

Now for the delicate subject of the toilet. You may be aware of the fact that a variation on the simple loo does exist which assists the user who has difficulty in moving and reaching certain anatomical areas by providing a wash and dry service as part of the process. Our local authority assisted in the purchase of this hugely expensive machine, for which we were eternally grateful, as it was of great assistance to my wife. And yes, in case you were wondering, the water used for washing is warmed, as is the blast of air in the drying part of the process.

When the time came for it to be inaugurated, as it were, a small crowd of admirers from social work and elsewhere solemnly gathered around the aforesaid pedestal and they hung on to every word from the gentleman salesman representing the product company. He was all eagerness to demonstrate the device, for which purpose a transparent plastic cover was provided which fitted under the seat whilst the extremely vigorous wash cycle was under way. Unfortunately, in his enthusiasm the salesman had failed to fix the plastic cover correctly, and when he depressed the electrically-operated button to initiate the proceedings, the toilet first flushed and then a chrome-covered tube with holes therein emerged from the back and the power wash phase commenced. On this occasion, the plastic cover toppled to the ground and the salesman, who was — how shall I put it? — looking into the problem was thoroughly anointed with a cascade of (warm) water, much to the merriment of nearly everyone present. At that moment, gardeyloo acquired a whole new meaning. A second or two of panic, then someone had the presence of mind to rush out in search of a large towel.

Next, the tube retreated and a more innocuous twin tube, the air dryer, appeared, but I believe on this occasion most people's vision was still blurred with mirth and the sight went somewhat unregarded. The toilet was thereafter an unqualified success, but you do have to inform those visitors to your home unfamiliar with the device that if they press to flush whilst still seated, they are about to be mechanically washed and dried without further warning.

Over the course of time, your loved one may well become incontinent, and when that reaches the level of double incontinence, that is one of the good reasons for them entering a care home. As the problem progresses, you should consider purchasing packs of disposable absorbent underwear to catch any unfortunate leaks. The incontinence pull-up pants are particularly invaluable for night-time use.

Shower time

You may be able to claim financial support for upgrading your shower pan and other parts of the facility. It should, if space allows, be big enough for a plastic-covered metal chair (possibly provided by the NHS) to seat your loved one and room too for a carer to help with the shower, either yourself or a paid carer. Also, ensure that there are handles aplenty to help your loved one move about safely inside. One shower is very much like another, but one bolt-on goodie which we attached to ours was I believe an American product, looking like a thick vertical white tube with holes at intervals running from the floor to near the ceiling, where dwelt a box with a motor inside, which produced a powerful hot air blast in three levels of intensity to assist in drying the loved one. A quick look online, and there seem to be two kinds available, a floor standing device for about £500, and one wall-mounted like ours, for which you might have to arrange a second mortgage.

Sitting down

There are a couple of points to bear in mind when considering what to do about seating arrangements for your loved one. Surely, you will say, there's enough tiresome stuff to consider without worrying about chairs and the like. Not true. And that's especially so if, like us, we had a couple of large comfortable chairs which were part of a suite we acquired ages before. It is very pleasant, luxurious even, to sink into one of them after a hard day's graft, and let the TV take the strain.

But you have now to bear in mind that your loved one is going to become more and more debilitated as time goes by, and a chair like the one I have described may be fine to flop down on, but you try persuading your loved one to rise up from its soft low seat and you might be persuaded to change your mind. I have a couple of suggestions to offer. First, a simpler and cheaper purchase: we bought a couple of upholstered chairs which, while comfortable, were firmer and more upright, and they made it much better for my wife to manoeuvre in and out of under her own steam.

As she continued to worsen, though, the difficulty of getting up from a chair became more and more acute, so we explored riser recliner chairs, as they are called. Prepare to cause pain to your piggy bank, because they start at around £600 and keep increasing to well over four figures. There are two valuable features of these electrically operated gadgets. First, a press of the button will tilt the chair into an increasingly laid back position, and that means they can be used for a daytime rest without involving the major upheaval of a move to the bedroom. Secondly, and much more importantly for us, the opposite feature tips the chair up and forward, easing the occupant to a standing position. It was one of our better purchases.

Time for bed

A key question to consider with your loved one, if they are your partner too, is what to do about current sleeping arrangements. We were fortunate in that my wife had been finding it difficult to be comfortable in bed long before her diagnosis, so we had invested in one of those all-singing, all-dancing electric double beds which tilt head and foot (very useful) and also vibrate (no comment).

This meant that we had in effect two single beds fastened together, each with its own powered features and mattresses, operated by remote controls. A side effect of that arrangement is that if your loved one has a serious accident in the night, you only have one smallish set of bedding to deal with. I hope you will by then also have a waterproof mattress cover in place (and one on your side, too, in case of advancing years). Sleeping in the same room also helps when the loved one has a sudden desire to use the toilet during the night, for which we had a commode located by her side of the bed, and it ensures that you are on hand to deal with that and other emergencies. And it's important, if you can, not to lose that togetherness of a relationship, unless snoring and other intrusive kinds of sleeplessness make it too much of a challenge for the practice to continue.

A word of advice about these beds, which is entirely my own opinion and can be disregarded as you wish: buy one with care, and do see if you can purchase an end of line product at a much lower price than the ridiculous amounts some of these pieces of furniture cost. We found one at a pretty substantial discount in a local department store which was having one of their end of season events.

I have one additional piece of advice if you purchase one of these beds. If they are still employing the same clunky black boxes and wiring that ours does, you may find that one fine day one or both of the remote controls may seem to stop working. This happened to me, and it took me ages to work out what had happened. Someone had been tidying up under the bed and in the process had moved one of the black boxes underneath the bed towards the middle. To cut a long story short, that was the receiver for the remote control and in its changed location it could no longer pick up a signal. So I pulled it out to the side of the bed and attached it there firmly. Problem solved, but I suggest you ensure from the outset that the sensor for picking up the signal is in a good place, so to speak, to avoid that kind of baffling problem arising.

Wherever your loved one is sleeping, the following improvements should be considered. First, difficulties in getting in and out of bed can be mitigated by acquiring a low raised step which acts as a way of easing the person on to the bed. That should be available from social services. Second, we came across a couple of odd-looking blocks with handles, looking rather like the paddles used with a defibrillator, which my wife used to grasp, one in each hand, to help drag herself into position in the bed. Sounds odd, but keep an eye open for them, as they do work pretty well. The manufacturer we purchased them from calls them 'bed blocks hand supports'.

Most important of all, you should consider what you can purchase to prevent, as far as is possible, your loved one from inadvertently falling out of bed once they are settled in. Believe me, it does happen. Strictly between us, it can also happen to an exhausted carer, too. There are all kinds of supports which also serve as additional grab handles when getting in and out of bed, but there are a couple of points to bear in mind. My advice is not to buy one which just slips under the mattress, as it is not strong nor stable enough when a problem arises.

I acquired one very heavy and solid support which stands by the bed and is held in place by brackets that fit underneath the side of the bed. Two prongs a bit like the stunted tines of a fork lift truck are shoved under the mattress, and it's extremely sturdy. The other kind is a simple vertical bar with a looped top with screw-holes to allow it to be firmly affixed to the wooden side of the bed, which also does the job pretty well. If you can, use nuts and bolts with washers rather than screws. Bear in mind that you also have to ensure that the supports may have to cope with the location of the fitted drawers in the base of the bed, and that some kinds of support are quite unsuited to beds with electrically operated tops and bottoms which rise and fall.

Alexa (and friends)

Now for a piece of technology which can be transformative. You may need Wi-Fi availability in your home for this to function, and you may require something like the Alexa Echo Dot or a similar product costing around £50, incorporating a built-in speaker. However, do be aware of the fact that Alexa and Siri, for example, can be accessed from your mobile phone or iPad or computer for zero extra charge. All you need is to download an app. Once you have your hands on Alexa, one way or another, the world is your oyster. The number of uses to which you can put this little device are legion, and they seem to keep mushrooming every day. If you are not familiar with this technology, here is a swift rundown of just how easy it is.

Basically you are dealing with a microphone which listens for your commands or requests, processes them on a remote computer and acts on them. With Alexa, which is the product I am familiar with, you simply use the wake-up word ‘Alexa’ followed by a command of some kind. You can speak to an Alexa station from anywhere in a normal-sized house room. Imagine you are a loved one entering a dark room and need to have some illumination. Just say ‘Alexa turn on all lights’ and if you have the appropriate smart lightbulbs (the price of which is quite reasonable nowadays) set up using an app, it will turn on all the lights which it is aware of. I was tempted to say ‘she’, but let’s not go down the route of questioning pronouns. Life nowadays is complicated enough as it is. The only problem is training your cleaner or carers who come in to help with feeding and washing and so on how to use Alexa, otherwise light switches keep getting closed or opened and Alexa can’t — yet — reach out and reset them. That, though, is just the beginning. Given the right sort of bulb, you can dim them or change colour, or switch them on and off individually. All I suggest is that you speak clearly with a slight gap between each word, to avoid misunderstandings.

So you want to listen to the radio? Just say ‘Alexa, Play Classic FM’, or whatever station you want. Or you can ask for a particular kind of music. Again, if you want to know whether it’s going to rain, ask ‘Alexa, what’s the weather like today?’ If you really must, you can ask what the weather is up to anywhere on the planet. And, if Alexa gets confused and starts rabbiting on about how tough it is being an electronic servant, the phrase ‘Alexa, stop’ can be invaluable.

I could go on for ever telling you about the abilities of these little devices, but I recommend that you first of all go online and search for a Quick Start Guide to your favoured device. Also, download the app on to your phone or other equipment. You will find that your loved one will delight in having such a companion in the room. Do you want to know how to spell a word, or what it means, or what the French for bicycle is, or who Eisenhower was? The list of possibilities is endless.

One of the most valuable functions is that of security, especially if you have a system with a screen which can show you who is at the front door, and a remote to operate that door if you wish to let the caller come in. And believe me, you may be swamped with callers as the years go by, professional carers helping with feeding, washing, showering, and so forth. That is far more secure than a key box operated by a combination lock outside the front door. The list of options for these devices is pretty well endless, and it is growing all the time. This is truly one of the great positive benefits of modern computer technology for the able and for those with a range of physical or mental challenges to contend with.

Tick tock

No, I am not referring to one of those dubious networking services in the social media business, although I am tempted at times to call them the anti-social media. I'm drawing attention to the fact that pretty high on your loved one's list of challenges which grow day by day is disorientation in time and space. Anything we can to do mitigate those potential causes of distress is to be welcomed. As far as time is concerned, I have come across a collection of clocks which are delicately referred to as 'dementia clocks'. That is about as tactful as that soothing balm for sore bottoms on the market called Anusol.

These clocks, which cost around £40 at today's prices, display the hour, time of day, date, day of week and other nuggets of information. Check carefully through the list of features before opting to buy. My own preference for my wife was a clock which offers a digital and analogue display side by side. She seemed to like that option. You can also purchase one which connects to the mains electricity or is battery-powered. Mentioning batteries reminds me to tell you that if you use up lots of them, opt for rechargeable AA or AAA batteries and a little machine that will do the charging when they become drained. Be careful not to let your loved one get access to the batteries, because my wife was always throwing the discharged batteries away regardless of whether they were rechargeable or not.

One of the parts of the day which comes up on these clocks is ‘Pre Dawn’, and I wonder how they manage north of the Arctic circle in the depths of winter with that expression? Also available are displays in different colours, and the clocks can sometimes also be used as colour photo galleries. And, of course, you can also ask Alexa, who is pretty well clued up about time zones and summer and winter time changes.

I turn now to other less tangible aspects of making your home environment user-friendly.

Problems with the senses

As your loved one deteriorates, their senses and their awareness of colour and space changes. This is a pretty huge subject, and I will attempt to do no more than offer a broad outline of what you might expect to happen. I can do no better than offer you my take on the problems of sensory challenges from my *Dementia—what every Carer needs to know* book (see Bibliography under Bill King).

It’s almost inevitable that the senses will be negatively impacted by dementia. Again, this is something which affects people very differently, and what follows is a mix of my experiences with my wife and hoovering information from the internet. Do be aware of the fact that as we become older, all our senses deteriorate, as do our means of processing what the senses are telling us. Having dementia intensifies, amplifies and accelerates such changes.

Smell

This sense is not readily lost but olfactory hallucinations can be a very troubling phenomenon. My wife was often plagued by her perceived smell of burning, almost to the point of calling the fire brigade. Smell can also be affected in a similar way to the impact it has on victims of Covid-19, where it can become almost completely wiped out. As smell and taste go hand in hand, so to speak, it's not surprising that it can then be one of the causes of eating problems for the loved one.

Hearing

If you have tried recording an interview in a relatively noisy environment, you will be surprised at how much of the unwanted ambient sound intrudes upon your recording. The reason for this is that our minds can filter out many sounds when focussing on a particular voice or voices, whereas the dumb machinery just reproduces everything within its audio range. There is evidence that this kind of indiscriminate audio intrusion is often to be found amongst people living with dementia, and loud noises can be particularly disturbing for them. Also, you may find that your sufferer's voice becomes quieter and quieter, and when they are asked to speak up, they protest that they are speaking at normal volume. Hearing loss can cause isolation for the loved one. If you see signs of this occurring, take steps to arrange a hearing test; and also ask for a nurse to clear any ear wax, as this tends to accumulate in dementia. When I suggested flossing her ears, one nurse was far from amused. Some medics have no sense of humour.

Hearing aids can be very beneficial, but like all equipment they present problems of understanding, care and operation for the loved one. They can also so easily become lost, and do let me know if anyone has managed to change a hearing aid battery without causing it to roll under the nearest sofa and disappear. The latest hearing aids do have built-in rechargeable batteries which overcome that issue, and they are far easier to use—and also program, using an app. I know, I am wearing mine as I type.

Touch

Do continue to hug and touch your loved one, but try not to upset them in the process. Respond rather than taking the initiative. The loved one needs to feel loved, wanted and respected.

Taste

Reduction in tasting ability can cause the loved one to change their food likes and dislikes.

Vision

This can be very problematic, but I have not personally encountered distortions of vision in my wife. She has suffered from visual hallucinations, but that is a different issue from eyesight deterioration. More on them in a moment. My wife has been particularly keen to point out patterns in, say, wallpaper or carpets, claiming she can see shapes (people and animals) where I could not perceive any. I did not give it a second thought until I read somewhere that this too could be a sign of Alzheimer's or dementia.

At the time I was completely unaware of the fact that a decline in vision was a warning sign of future deterioration. It is common generally amongst those with dementia to over-interpret what their eyes are telling them, and this is an information processing issue which requires sensitive handling. Ensure that the loved one has spectacles to suit their condition, with back-ups in case of loss or damage. My wife would purchase additional reading glasses at knockdown prices from local shops.

Colour

Another aspect of vision which can have a negative impact on the loved one with dementia is colour. The general view is that strong, simple colours are good, complicated patterns are confusing, and some colours have a negative impact. Above all else, use bright lighting as that helps the more elderly amongst us, me included, to see better. The jury appears to be still out on the importance of colour and light for dementia patients. However, I have managed to distil a couple of general points. Blue is regarded as restful and blue food plates offer a clear colour contrast to food. Red also offers a positive choice for food plates, but it is more of an attention-grabbing colour than blue. Green, by contrast, is very restful and is a good choice for decorating walls.

Pink apparently reduces aggression and that could also be useful for wall covering. Black is contentious, as it can cause the loved one to see it as a dark hole, so black floor mats are out. Advice abounds, such as painting the doors of rooms contrasting colours (as well as putting an image and name plate to indicate their purpose), but this is an area which in general appears to me to be work in progress with few definitive conclusions from the experts.

Hallucinations

These can be very real to the loved one with dementia, and distressing, too. It is therefore important to treat them with sensitivity and direct the attention away from them. They tend to take one of two forms — visual and auditory — although hallucination of the other senses can occur.

My wife often ‘sees’ her mother and sister, and has heard sounds like the siren of a police car or people moving about the house, and it was clear, in the early stages of illness, that she had enough self-awareness to be very upset by the clear disconnect between reality and what her eyes and ears seemed to be falsely telling her. The hallucinations were very compelling and powerful, and she could not make sense of the fact that she ‘knew’ that what she supposedly saw or heard was not true. As I stated earlier, she was also troubled with hallucinations relating to smell.

I’m not sure whether this comes under hallucinations, but I’ll shoehorn it in here, as distorted vision of a kind is involved. You may well find that your loved one loses a sense of proportion or perspective, and with my wife nowhere is this more apparent than in the situation where she is watching the news on TV, and confuses a wild fire in Australia with a local incident nearer home. The same can happen with family and national events, so keep an eye open for this issue, console your loved one and carefully divert them away from the subject. In managing these distortions of reality, your response can be of great significance. Do not mock the loved one, do not tell them they are mistaken. Simply go along with them for a moment, then distract them and turn the attention elsewhere. Hallucinations can also simply be due to the ‘wiring’ of the brain not functioning properly. That leads me towards a different jargon word to play with, and here it comes.

Confabulation

This rather splendid-sounding term hints at its meaning in the Latin term ‘fabula’ in the middle, which stands for play or story. That’s the word which gives us the term ‘fable’. It refers to the situation in which a person with a mind clouded by dementia, discovering that there is a gap in their memory, fills it with an invented story. This is what happens when my wife used to tell me, before her speech deteriorated too far, that she saw her mother the day before in the corridor.

And how should you respond? Not at all. Simply acknowledge that she has referred to her mother by responding along these lines: ‘She was a very special person’, and then divert the conversation away to another topic, such as, ‘What did you have for lunch today?’ Above all, do not correct your loved one, especially if they have ‘seen’ or ‘heard’ a relative or friend whose current address is the local cemetery.

That is best practice in a lot of similar situations when difficulties arise. Listen patiently, agree to some extent with your loved one, and gently change the topic of conversation. They will have forgotten the incident in no time at all. It is completely wrong to try and correct them by asserting, ‘Don’t be daft, she died years ago, you silly thing.’ That only causes further confusion in a brain which is already seriously challenged. In so many situations like this the best advice when you ask yourself how to react, the answer is: Not at all. Do not confront: deflect, rather like the magician practising misdirection. I know — it’s counter-intuitive and not spontaneous, but you are sadly not dealing with a normal interaction, but seeking to dispel the confusions and fears of a loved one trying to make sense of a strange and shrinking world view. It’s yet one more challenge we as carers just have to face.

Try to be compassionate with your loved one as their world closes in on them and becomes more confusing and makes less and less sense to them. As you watch them move away from the person they used to be, it can be extremely painful, but you might find consolation in these words by Jane Mullins:

> If you can understand what is happening in the present moment and keep an open mind to what keeps them content, you can learn to connect together and help them to feel calmer.

The positive spin-off from that advice is that if the loved one is calmer, then so are you.

But to my mind, the hardest advice of all is: Do not take it personally. What else have we been doing all those years before, when our loved one was well? Of course, interactions in a normal relationship are very personal, that's how relationships evolve and flourish, and here I am telling you to do the exact opposite. There is a deal of frustration hidden in your suppressed reactions, and here is another anecdote which underlines what I believe you may be feeling.

I have been a member of the Institute of Advanced Motorists for over fifty years, and even have a framed certificate and a gold colour windscreen sticker to prove it. One of the basic approaches I was taught when training for the IAM extended driving test was 'defensive driving'. Basically, it means holding back when there is any sign of bad driving by other road users, possibly leading to danger. All those years ago, the chairman of IAM was filmed driving from A to B in a short film entitled *Journey without Incident* (which is actually still around somewhere on YouTube if you care to search for it), in order to demonstrate this technique and it was duly trotted out for us to watch. The positive outcome from this approach is that your chances of survival are much greater, but there is a psychologically negative side, and that is that the bad driver you have just avoided has learned nothing, and continues on his or her merry way oblivious to your defensive reaction. If anything, their bad conduct may even have been reinforced by your submissive response.

That particular aspect is hard to swallow, but it is very similar to the feelings you will experience when your loved one behaves in a way which is challenging or difficult. React negatively, and you are doing two things: you are reinforcing their poor conduct and you are building up tensions between yourself and the loved one. Try and bear in mind the simple fact that your loved one is only trying to make sense of a world which from their perspective is broken, frightening and strange. There's a story about the little child who was told that in the Bible, when you are attacked, you should turn the other cheek and not respond violently. One day the child comes home and says, 'Mummy, today I turned both cheeks. What do I do when I run out of cheeks?' You'll find that as the carer of a loved one with dementia you will have asked yourself that question privately on a pretty regular basis.

Money and the law

I am going to do no more than outline advice of a financial and legal nature, as everyone's circumstances are different and there is an abundance of help and support out there. Try your local authority website and also the local and national charities dealing with dementia.

It is important to ensure that you have all the benefits due to your loved one, from PIP to pensions and extra pensions payments. In addition, if your loved one is on the highest level mobility, they can apply for a Motability vehicle to ensure that they can still get out and about. We had a series of such vehicles, the most recent one before my wife went into care having an electrically operated wheelchair lift in the back which was invaluable. You will presumably have a needs assessment from the local authority, and do also take advantage of offers of support in washing, feeding, and other practical help. Equipment needs can also be met and additional installations of various kinds can be arranged. Legally, it is vital that you and your loved one draw up mutual Powers of Attorney as soon as possible with appropriate functions to permit you to take over the necessary roles when the loved one is no longer competent to do so. Make it clear to family members what a POA entails and what the powers are, as it caused quite a spot of bother in our family. You should also draw up wills, without which it can be a real nightmare when the loved one dies.

Money can also be a serious bone of contention and can bring all manner of friends and relations out of the woodwork to see what's happening, and, sadly sometimes, what's in it for them. I can only strongly advise you to be cautious in all your financial dealings and to ensure that everything is put down in writing. In caring for my mother, I had the misfortune to acquire the services at one stage of two supposedly professional carers, who came highly recommended but who turned out to be more concerned with their own interests than hers.

At this point, there is one more financial issue which I should like to raise, but it is a little tricky as I must avoid recommending action to deprive yourself deliberately of some funds. Perish the thought. I am simply going to tell you what the situation is, and what you do about it is entirely in your hands. If and when your loved one goes into a care home, there are serious financial considerations which must be faced. Social services make an assessment of your loved one's financial situation, particularly in regard to savings. If they hold less than a specified sum, then they do not suffer any penalty as far as savings is concerned. However, if they have more than that, there is a financial penalty which increases to a certain point, at which you are deemed to be entirely self-supporting. Care homes can cost—wait for it—from £1000 to £2000 per week. Getting detailed information online is like pulling teeth, but those seem to be the ballpark figures.

I need to put some more flesh on these bones, so to speak, and I will take figures from my local authority website for 2023 by way of illustration. If you have savings of £18,500 or less, you will pay only (!) most of your state pension and other benefits, leaving you a whopping £31.00 for personal expenses. With a daily copy of *The Times* at retail prices that eats up two thirds of the money already. Now it gets unpleasant. For every £250 over that amount, you pay £1 extra per week up to a total of £29,750, at which level you are deemed to be self-funding. I referred to 'savings' just now. This includes capital and investments and, it seems, any income. Joint holdings are dealt with pro rata. If your home is in your loved one's name or joint names, you should take advice about the implications of that situation.

If you are still with me, I could go on about this subject for quite a while, but I hope you get the point that if you have reasonable savings, you should consider carefully how you should proceed. Get expert advice if you think you might need it. Do keep a record of expenditure, because the team assessing you will want bank statements going back a couple of years. And do make a note of upcoming expenditure. For example, if you have a Motability vehicle, that will cease when your loved one goes into a home, and I nearly fell off my perch when I discovered the price of cars nowadays. My urgent advice to you is to act now, even if it seems a very long time in the future before your loved one might go into care.

That legal and financial section concludes my tour of items of various kinds designed to enable you to plan for the future and make living at home less troublesome for yourself and the person you are caring for. Now for a chapter on dodging the bullets when problems arise.

Chapter Five—When things do go wrong

It was one of those long meetings with all the interested agencies present, plus me as the informal carer. My wife's situation in the locked ward of the local mental health hospital was the topic up for discussion, and it was pretty clear that the general consensus was that the psychotic episode which was besetting her should be allowed to subside whilst the medical team assessed the appropriate medication to manage and control her symptoms. The consultant psychiatrist, a man whose judgment I respect and who clearly understood and felt genuine sympathy for the patients under his care, then said something which for me was one of the really shocking light-bulb moments of all the years of caring for my wife. I paraphrase, as I was too stunned to note down his exact words: 'Her psychotic episode is classic Parkinson's.' This was before her dementia really came to the fore.

You may wonder what is so earth-shattering about those few simple words. In fact, they go to the very heart of the key theme of this book, and they were one of the trigger points which first set me writing and campaigning about the role of the informal carer in dementia. If you are still puzzling over why that statement had such a negative impact on me, let me turn the clock back a few weeks to the day when that psychotic episode itself first broke out. I was struggling to come to terms with the increasingly bizarre and compulsive behaviour of my wife, which had been getting progressively worse in recent days and was now completely off the scale. As I have already described, this was the occasion when she had even grabbed hold of a phone, dialled 999 and told the police that I was attacking her.

So I called our local health centre, and the doctor arrived within half an hour or so. He examined her for a few moments and told me that she would have to be admitted to hospital right away, and that her mental capacity was so severely impacted that she could no longer make reasonable decisions for herself and her welfare. I drove her to the hospital and arrangements for visits were drawn up: none for a few days, to allow her to settle in, and then twice a week with only myself permitted to attend. This was in the midst of the Covid-19 lockdown, by the way.

In the interval between her admission and the meeting I referred to at the start of this chapter, my battered brain began to ask itself questions, as I gradually strove to come to terms with what had happened. I knew that there had been a step change deterioration in her behaviour which was getting more severe, but I had no idea where it was leading to. There was, as you can imagine, a painful sense of unreality about the entire situation. A long time before, I had witnessed someone in the throes of a florid episode of schizophrenia, but that was entirely different, and the dramatic changes she underwent in her psychotic episode were almost impossible to reconcile with the person I knew and loved. Schizophrenia seemed to direct the patient's thoughts and actions inward, whereas my wife's psychosis did the opposite, as her confusion and distress were directed venomously outwards, mainly against myself.

That, however, wasn't the nub of my problem with what had occurred. The world view of the consultant was a million miles from my own in this situation. He spoke with the professional experience of caring for countless other patients who had undergone similar episodes over many years. By contrast, I was going through all this for the first time without any means of managing or properly understanding what was happening, let alone acquiring any coping skills to help interact with my wife to assist her on her path back to what passed for her current state of normality. In the well-known phrase or saying, I felt like I was bringing a knife to a gunfight.

Then I started matching this experience with other, very different, behavioural issues which had manifested themselves in my wife in the past, and which the very caring and skilled team supporting her informed me were precisely what was to be expected of someone with Parkinson's heading towards dementia. The penny dropped. I realised that I was constantly being informed (a) after the event and (b) how to go about firefighting the issue concerned rather than offering me advanced warning of what might happen and being given the appropriate tools to cope with it. There was never any attempt to prepare me for issues which were yet to raise their ugly heads, and — I must add this point — I felt that this pattern was being followed for the best of all reasons, namely, not to present the carer with theoretical challenges when there are enough actual ones taking place on a daily basis.

If you work through this issue logically, you will recognise that this situation is not just regrettable, it can be plain dangerous. Take the current pattern of events: (1) a problem, large or small arises; (2) the carer has no idea that it was coming nor how to handle it; (3) we all muddle through until the problem is resolved; (4) the next time it happens, we have a rough idea of what to do now. Only on subsequent occasions when the problem swims into view do we begin to have a rough idea of how to react and what to do, and by then, if the first occurrence has gone badly, we recognise that a serious mistake has been needlessly made by not informing us, the carer, in advance of what might happen with certain well-recognised behavioural patterns and how to cope with them.

This is a false economy on so many levels: no one had factored into my situation (and, by extension, that of legions of other carers in a similar plight) the enormous negative impact of being confronted with a potentially dangerous situation in the behaviour of a loved one without understanding what was happening and no means of coping appropriately with the crisis. It may be classic Parkinson’s or dementia to the medically-trained expert, but it was for me also classic in its attitude to the informal carer who, poor soul, is not blessed with a medical degree but is simply doing an impossible job with both hands tied behind their back.

As you might gather from the past few paragraphs, that psychotic episode was not the only occasion such a shocking crisis arose with my wife. She underwent two further such episodes before she had to enter a care home, both of which cast a great deal of light on the lack of information which we, as carers, are given in relation to the tasks that lie before us. In the subsequent episodes, I was able to explain to the doctor what was happening before the situation became unmanageable and he responded instantly and appropriately by seeking a urine test and declaring that this was another (wait for it) classic response of someone with her condition, in this case triggered by a UTI (urinary tract infection). A strip of pills later, she was completely recovered, and when the next episode was threatening to become serious, I had a stock of pills in the medicine cupboard and began administering them right away. That was extremely helpful, as medical issues with dementia (as I've already pointed out) seem to occur, like all mental health crises, at around 5pm on a Friday, when everyone is off for the weekend and there is no one to communicate with readily who can help sort the problem out.

So, with subsequent crises I was able to build on the experience of the first episode and modify my own behaviour accordingly, meaning that I was reacting in a more informed and positive manner. But that is hardly the right way for a carer to have to learn what to do in such a crisis situation. You shouldn't have to conduct experiments on the person you are caring for. This is why I am constantly harping on about the need for the desperate carer to be informed in advance as well as just bumbling along without any reference points for acting correctly. The carer of a loved one with dementia faces a significant range of difficult challenges, and they are not made any easier if he or she is not given the tools to do the job. It is all very well to state that one should listen, learn and apply. But if, as is the case now, there is no one to listen to, to train you how in general terms to respond, you can cause all kinds of issues with your loved one if you unintentionally damage your relationship with them.

It reminds me of the tale of the posh young man in his natty sports car, British racing green, of course, out for a spin in the country. He finds himself lost and, espying an elderly yokel sitting on a milestone by the roadside, he skids to a halt and calls out, 'I say, my man, can you tell me the way to the village of Much Piddlington?'

The old man chews thoughtfully on his pipe, then responds in an almost inscrutable accent, ‘If Oi wuz you zur, Oi wouldn’t start from ’ere.’

I discussed this general issue with a diehard NHS medic who stated that you really mustn’t upset the carers by telling them stuff they don’t need to know yet. That, apart from being pretty insulting, is light years away from the kind of approach that is desperately needed. It isn’t beyond the wit of man to create a graduated system of information, with everyone being given the main bullet points and more detailed information as and when appropriate.

And, as I try and point out in this book, it is far harder to make up for errors in dealing with loved ones than it is to avoid them in the first place. So let me now make some ‘informal’ attempts at plugging this information gap in situations which I experienced when, in the words of this chapter heading, things do go wrong.

A simple fall

Did I just write that subheading? With my wife, there was no such thing as a simple fall. When she was still well enough to communicate properly with me, I’d joke that one sneeze from her and I would have to call the air ambulance, which as it happened, was stationed a mere ten miles or so down the road in a building right next door to the old Control Tower of the local airport, where she worked for some years in the office as PA to her MSP boss (Member of the Scottish Parliament, in case that eludes you). In other words, she would make the most incredible song and dance about falling and called me all the names under the sun whilst she gradually calmed down and we began to face the interesting challenge of helping her up on her feet, with a combination of footstool, small step ladder and wheelchair.

One particular fall occurred in the kitchen just after a new care worker, a young lass who was being thrown in at the deep end because of staff shortages, arrived to help her with breakfast and morning pill taking. My wife put on an Oscar-winning performance of distress when she collapsed in a heap in the kitchen, during which I had to keep reassuring the tearful new arrival that my wife would gradually get over the event and return to whatever passed for normal at that time, and this again demonstrated to me forcefully the vital need for preparedness for such situations. It was one of those few odd occasions in which I was actually better informed about what was happening than the professional carer.

There was another very negative side-effect to that particular situation and here I have to tread carefully. Let's say a relative appeared later that day and my wife complained that I had made light of her serious fall. Following the usual pattern, the relative took her word against mine, generalising from a distorted snapshot of a situation, and accused me of trivialising her condition and lacking sympathy, and so once again the main carer gets it in the neck from the non-playing captains in the private tragedy of a carer's life.

My wife in the care home came to react to a fall quite passively, although she tumbled so often she was on what I suppose the care home would call 'fall watch', with an ingenious pressure pad on the floor near to her which is plugged into the mains and sets off an alarm if she should take a tumble on to it. She also became too advanced in her illness to respond to what was happening to her and just lay there passively waiting for staff to pick her up.

Falling is—dare I say it—classic for someone with Parkinson's/dementia and is usually caused by the loved one failing to estimate space and distance properly. Time and again, my wife would stretch out for support from a chair back or a door handle which would be well out of reach.

My appproach when she fell, once I got the hang of the situation, was to ride out the storm, pointing out to her that she really should not attempt to move around without the support of her rollator or Zimmer frame, but that was a counsel of perfection seldom attained. The reason for her excessively alarmist response was a nervous reaction, partly based on fear, to the fact that the world about her was not behaving in the way she had been used to managing before the illness struck. Hand-eye coordination was beginning to fall apart.

Knowing those two simple facts in advance, plus the necessary skills for easing someone back to their feet when the loved one quite often tends to go limp rather than support the carer in getting up, would have made my life just a little less fraught. Just a little, but enough when accompanied by consistent good advice across the whole range of her behaviours to make a substantial difference to my mental health as a carer. And I am sure that you too would benefit from such information.

Perhaps the greatest shock of all for me came some time before that when it became clear from her words and actions that something more than Parkinson's was impacting upon her. She displayed signs of compulsive behaviour and gaps in her cognitive abilities which had me worried until someone — I cannot recall who — told me that the shift towards dementia was yet another classic manifestation of Parkinson's. Another bombshell for which I was not exactly prepared.

Can't eat, won't eat

I don't want to clutter up the narrative here with too much detail on too many issues, and I believe I have drawn from what I have put down already enough general principles for you to get some idea of how to act when things go wrong, or, to put it another way, how to get your retaliation in first. However, there is one other problematic area which occurs so frequently and which demonstrates so many features of the situation of the loved one with dementia that I feel constrained to give it some prominence. That problem arises at mealtimes.

Point number one: remember, however difficult it may be, that your loved one is not acting maliciously or out of some kind of perverse challenge against you. It is overwhelmingly down to the relentless onward progress of the disease. Second point: many of the apparently wilful responses are a reflection of the radically different perceptions of the world the loved one is now inhabiting, and which at the same time are impacting on their short-term memory. The first on the following list of issues demonstrates this:

(1) forgetfulness — thinking the food has already been eaten.
(2) difficulty swallowing (a speech therapist may help here).
(3) the plate of food is confusing for some reason.
(4) the food is too hot or cold.
(5) sense of taste has faded.
(6) what's on the plate isn't really food.
(7) the colour of the plate is confusing.

That's just a selection of the reasons why your loved one might baulk at the prospect of eating what is in front of them. And, apart from dementia-related issues, do also bear in mind that the loved one may simply actually not like the food — they still have taste buds and likes and dislikes. Now how do you go about responding to this situation?

The general central point to remember is that it is not personal. I know, it's all very well and good stating that in a book, but when you are confronted with an actual situation with the loved one when you have sweated blood and tears cooking up a storm for them, it can be just a touch irritating when they turn their nose up at it.

The best advice in this and any potentially confrontational situation about responding is: Don't react. The experts tell us that this is not an equal relationship any more with the kind of high level interaction between the two of you that you were accustomed to experience in the past. See the section 'Anticipation beats reaction' below for some more guidance on avoiding mealtime problems.

Throw into the mix the fact that your loved one may well be confused, frightened even, by the changes taking place in their brains, and you will I hope recognise that the sensible response is to hold back, think for a moment, and determine how you might turn the situation around. Do, however, remember, that as in any negotiation, you may not succeed every time and the plate of food may end up in the bin or filling the stomachs of the local bird population in the garden.

Compulsive behaviour

One of the most challenging aspects of dementia is compulsive behaviour, and it was certainly a real difficulty with my wife. Take, for example, her concerns over medication. This had always been a contentious issue, not helped by family members holding forth about which pills she should or should not be taking, and for weeks on end she would fire up her computer and edit and re-edit her list of medication. It was as if she were somehow trying to make sense of it, why she needed so many separate items and when and how much exactly should be taken.

Another bone of contention arose when, in the days when she was still mobile and cognitively capable, our son called to drive her into town for shopping and lunch. It could literally take her an hour or more choose what to wear, and then to move from the bedroom across the house to the front door. Every step, she would pause, pick up a pen or a book or an item of her jewellery, examine it, then place it back down again. Then she would move with aching slowness on to the next item.

To admit that this caused a little friction would be the understatement of the century, but it is a component of the illness and should be gently worked around, not challenged head on. Once again my advice, having observed that behaviour and the responses to it time and again, is: do not react at all. Think of other ways to overcome or moderate such demeanour. For example, tell your loved one to get ready well in advance of the time when you want to leave. Also, I would attempt to tell my wife about the trip out when she was already near to the front door, to avoid the slow obstacle race across the entire building. Telling her to hurry up and not be keeping folk waiting is not exactly the correct approach.

A footnote: do check that your loved one is dressed properly and has picked up all the stuff required for a trip out, especially when medication needs to be taken during the expedition.

Retail therapy?

One of the many jokes doing the rounds about old age, some unkinder than others, is this question: What do a pair of cycle clips, a copy of *Puzzler* magazine and a nearly used tube of Glamour Girl lipstick have in common? Answer: They are all things my gran has accused me of stealing from her bedside drawer.

Loved ones with dementia and shopping are activities which do not necessarily go well together for similar reasons of forgetfulness. On one occasion when our son took her to the nearby town, she insisted on calling in at the jeweller's shop which we had bought stuff from on many occasions in the past. When she got there, she berated the owner for holding on to one of her rings which she claimed he had taken to have reduced in size. She had completely confused herself about the situation. Not unexpectedly, I was hugely embarrassed about this episode, and called in the next day to apologise on her behalf. The manager waved away my regrets, saying that he had come across similar situations more than once in the past. His awareness and compassionate response was a huge relief to me, because taking the loved one shopping can be a considerable challenge.

Let me try and break this issue down into three elements: the shop building itself, the staff, and your loved one's conduct on the sales floor. Of all the establishments in the town a few miles down the road from where we live, the charity shops are the most challenging, for a number of reasons. First and foremost, they are mainly recycled retail outlets which have lain unused for some time and don't come up to the latest standards of user-friendliness. The entrance will probably consist of one or more steps, which makes it impossible for wheelchairs to navigate them, and once inside, the layout of the premises can leave much to be desired. Narrow aisles, goods crammed together, hats and shoes on shelving even able-bodied customers struggle to reach, all make the whole place unfriendly.

Now for the staff: not all staff, especially volunteers, are as aware and sympathetic as our friend the jeweller, and in fact, I have more than once encountered hostility towards my wife and impatience at the slow pace of her progress round the goods on sale. And her own conduct contributes as well to the dysfunction of the whole experience. She is confused by the clutter and noise and other folk in the shop, she tends to pile her lap high with stuff she doesn't need or want, and if you don't keep a very close eye on her, she could leave without paying, because she thinks she already has.

In sum, if the loved one is only mildly affected by dementia, a shop visit can work reasonably well, if you have eyes like a hawk and can persuade them not to purchase everything in sight. However, once dementia really sets in the experience is not a happy one: not for the shop and its largely untrained staff in handling such customers, nor for the loved one either, as they can become disorientated and frightened in the retail environment.

So the next stage is to crank up the laptop and switch to making purchases online.

Calling the ambulance

I'd like to offer one more illustration of what can happen to a carer like myself who was, even at a relatively late stage when she was near the time for moving to a care home, still flying by the proverbial seat of my pants with no idea how to react in the particular crisis I'm about to relate to you. One day she was taking an afternoon rest in bed, and I was becoming concerned that she had been sleeping for such a long time. I sat by her on the bed and tried to waken her, but she did not respond. Her breathing was shallow and her pulse thin, and she was completely unresponsive. I am reminded at this point of the immortal words of Lance Corporal Jones in the TV golden classic sitcom *Dad's Army*: 'Don't panic!' Pause for a moment and ask yourself what you would do. I dialled 999 and spoke to the emergency operator. She asked me to give further details about her breathing and other functions and instantly sent an ambulance on its way to us.

When the crew arrived, they could not rouse her either, and, when they had undertaken all the usual tests and so forth, they were on the verge of deciding that she should be transported to hospital for further investigation. At that point, my wife opened her eyes and said, 'That will teach you to worry, then,' or words to that effect. I was too distressed to hear them properly. I told the crew that her actions were out of character, but that she seemed to be playing some kind of perverse game driven by her dementia.

The paramedics packed up their kit and melted away. I was left feeling foolish, and my wife was sitting up in bed as if nothing had happened. I had once more been blindsided by dementia and her unexpected conduct, which may even have been some strange game she thought she was playing, a discordant echo of her past self, but I had no way of knowing that there was actually no immediate medical emergency. However, I heard one of the paramedics saying (I presume he thought he was out of my hearing) that it was just a psychological thing, almost as if their time had been wasted. I spoke to other professionals afterwards, and they were not surprised by her actions. But once again I had all the responsibility and none of the knowledge. It was just another classic manifestation of dementia.

Anticipation beats reaction

A common problem with your loved one can be confusion as the world they are in becomes different from previous perceptions, and a great piece of advice I came across more than once is that you should try and prevent a situation arising by making the general context less challenging for your loved one. That’s a bit abstract, so let me give you an illustration.

When you sit your loved one down for a meal and put the cutlery in front of them, if you think they may be confused, tell them slowly and clearly that this is a fork, this a knife and so on. Then when you place the food in front of them, make sure that the various elements on the plate — for example, potato, meat, vegetables — are set out separately and you can introduce each of them to explain what they are. By the way, another trick of the trade is to ensure that the food is not difficult to eat, for example, the meat is cut up ready for them in chewable chunks.This kind of running commentary can be used in all manner of situations, and can help to put the loved one at their ease.

I hope that you can draw a couple of valuable broadly applicable techniques from that mealtime situation. The first is that

— once again — prevention is so much better than cure, and that depends on your having a modicum of knowledge in advance of a potentially challenging situation, professionals please note. Secondly, I have always found that you should not try and make a situation ‘perfect’ for the the loved one; in other words, if you can remove most of the potential problems, those remaining seem far less significant. If you get things over fifty per cent correct, you have done enough to sigh with relief and move on to the next challenge.

That does not in any way diminish the fact that you are living through a heartbreaking situation which will only get worse as time goes on, but if you can make life easier for your loved one, you will be doing the same valuable service for yourself, and your exasperation and hopelessness and all the other emotions that can boil to the surface from time to time will not seem so awful.

Sundowning

What, I hear you cry, is that term all about? That was exactly my reaction when I came across it in the literature on dementia. My first supposition was that it related to a person’s drinking habits, as my understanding was that a sundowner was mainly a reference to a tipple ingested at sundown, after a long day’s work. In dementia, however, it has come to mean something quite different.

In caring for my wife, I had often noted that she had good days and bad days, times when compulsive and disruptive behaviour slipped into the background, and other days when she was not exactly easy to be around. Also, I had recognised that her state of mind and general well-being varied according to the time of day. In her case, mornings were nearly always a challenge, and a mood change would come over her around lunch time and for the rest of the day.

Apparently, this pattern had a name, and that was sundowning — a behaviour pattern in which the loved one becomes distressed in the evening and disoriented. In our case, my wife reacted quite differently. Clearly she hadn’t read the memo — or this was just another case of dementia being such a shape-shifting creature that it can be impossible to pin down some behaviour patterns. So let's give them a name, and sundowning it is.

Around that time, I came across a teenager wearing a T-shirt with the legend 'Caution: next mood swing in ten minutes'. I was almost tempted to ask where they bought it from and acquire one to wear when trouble threatened at home.

Alarm

This is the point at which I tend to get into trouble with the Powers That Be (even more than elsewhere). It was more or less compulsory in our neck of the woods for a telephone-based monitored alarm system to be acquired, with a remote control around the loved one's neck to be pressed in the event of an emergency. The care staff from the outside company providing regular services for us would constantly check on whether my wife had the remote control dangling round her neck, and nine times out of ten she had mislaid it. They would search high and low for this button on a rope as if it were lost Inca gold and not rest until it was round her neck once more.

Again I return to the principle of employing the simplest possible level of technology to any given situation. Let me break down my objections to this creaky old technology: it won't work if your loved one falls and is in a room where she cannot speak to the base unit microphone which sits next to the phone socket in the sitting room; we live in the countryside miles away from the alarm service headquarters if a car is needed to come out to us (and no arrangements had been made about door keys); and if the power goes down, the main phone line ceases to function anyway.

Maybe this was the best — and only — option available many years ago but it certainly is not valid any more in the modern age of Alexa and friends. I broke the problem down into two parts: if both of us were in the house, what would be the best way of communicating distress? If my wife could not summon me, how then does she get help?

I got the idea for the first solution from a clip from one of my favourite films, *Genevieve*, a delightful comedy about two young couples engaging in friendly rivalry on the annual London to Brighton run of veteran cars which gets well out of hand. It was the sound of their old-fashioned car horns that reminded me that it might still be possible to purchase some of the smaller bicycle variety, and that I did. Now my wife had a horn fixed firmly to her rollator and others strategically placed round the house. It makes a strident din which carries throughout our rather large establishment.

And if I am not available? I have ensured that Alexa is present throughout the house, by having my wife carry her phone at all times, and by installing the device in different rooms. Alexa can also be trained to ring phone numbers and seek help.

Respite

One ever-popular mantra amongst the care professionals is respite. I am sorely tempted to say that surely the ‘p’ has been left off the end of the word mantra, but I will resist. As you might gather, I am not a great fan of the idea, but again I must be an oddity.

The general notion of taking a timeout is fine, and it is at times almost compulsory if you are to remain sane and level-headed. To misquote line three of the opening of Kipling’s famous poem ‘If’:

> If you can keep your head when all about you
> Are losing theirs and blaming it on you;
> Then you don’t get the gravity of the situation.

In other words, there are times when you really have to howl at the moon at the awfulness of it all, but there is a big question mark in my mind over what you should actually do about it. You may well be very different in your reactions and feel comfortable in some of the situations I am about to describe.

The lowest level of respite is taking a short while away from the loved one in order to press your ‘reset’ button after a particularly challenging time. Go out into the garden and chase the rooks away from the bird table. That’s fine, and I have done it more than once. In this case, it's not a matter of how long you are taking but how you use those few blessed minutes of relief to best advantage.

Level two, I suppose, is where I begin to part company from orthodoxy. Send your loved one off for a couple of hours or so to a day centre. We had never had the opportunity to try that personally, because of transport issues, but I suppose it can do no harm. If it's part of a routine to allow your loved one to mingle with other people in a similar situation, I have no difficulties with that. But it isn't respite proper. You cannot summon up respite need at regular intervals in reaction to a unpredictable moment of urgent need.

Many years ago, during a time which seemed to consist largely of a string of wall-to-wall committee meetings, I was dozing off during a discussion on the proposals for a new care in the community plan for mental health in our region, when someone piped up, 'Can't you offer cognitive therapy?'

The response came, 'Of course. We do. But there is a bit of a waiting list. Fifty-two weeks.'

Have you noticed how the NHS statisticians manage to make waiting lists seem shorter? Fifty-two weeks doesn't sound that bad; twelve months is a little less desirable; and one year is an eternity.

My guesstimate for fulfilling an urgent cognitive therapy appointment timing would be: now, if at all possible, but if not, some time the same day. That is how I regard respite, I suppose. It isn't something that can be summoned up to suit the plans of others, nor an under-resourced option for which there is an interminable waiting list. To borrow a quote from the pop combo Queen, 'I want it all, and I want it now.' Imagine going to A and E and being told that, yes, you need an emergency abortion and we can oblige. We've got the waiting list down to 48 weeks (you do the maths).

A mental health issue demands a quick turn round, otherwise the problem will simply fester and increase in severity, in the end costing more in people and resources to make things right again further down the line. So that's my rant about respite. Let me quickly cover what it currently tends to signify.

You could attend meetings of carer groups, just so long as there is someone back at home to look after your loved one, or you can opt for a longer period of stay for the loved one in a temporary care home placement. I am no friend of group gatherings, but if that's something you enjoy, please go ahead and find out if anything is available locally. By the time I've written this, there will doubtless be Zoom groups available online as well. As for a longer period of respite, I was not happy with a temporary care home placement for my wife, and in any event I found myself just worrying about her for a fortnight, so the idea didn't work out for me too well. She was pretty unhappy there, too. I hope you have a better experience.

General principles

I'm sure you can take the specific ideas I have offered you and apply them to other situations. For example, if the loved one cannot recall where in the kitchen the coffee mugs are, put a note with an image on the cupboard door. The same applies if they do not know which room is which in the house any more.

Don't respond negatively if your loved one challenges you about food or medication, for example. Take a step back and try a gentle response. Fear and frustration are the key drivers here, and, as in other situations, 'the first rule in responding to aggressiveness is don't respond'. (Jan Hall)

Be kind, reassure them, keep calm and carry on (that might make a good slogan for a poster). No one said this was going to be easy, and it isn't. And it gets harder. But knowledge of how to cope is vital in your role as carer, and the inner strength to ride with the punches and come up smiling is there within you, even if in your darker moments you fear you may have lost that quality. And if indeed you have, you may well be approaching the time when the loved one has to go into a home, and that leads me neatly into the next chapter.

Chapter Six —They think it’s all over

Now I turn to that most challenging time of all, after your loved one has entered a residential home and all the fuss and bother surrounding their departure has settled down into an everyday routine. It’s a pattern sadly familiar in any crisis situation, whether it be a death, a divorce, a domestic fire, a vehicle accident, or whatever. The initial phase is one in which you are so preoccupied with the practicalities of the crisis that you have little time to sit and contemplate the nature of your radically changed personal circumstances, but then after a while life returns to its daily round, and the full awfulness of a loved one now transferred into a care home for good hits you full in the face.

In what follows, I explore in some depth a whole raft of negative feelings which may well overwhelm you in your newly-changed situation. This does not, however, mean that there is no way of seeking help or support in such matters. Those more positive issues will be dealt with later on, but it is important to clump all the unpleasantness together. Keep smiling.

Guilt trip

The first emotion to surface in my case was guilt. I had the Power of Attorney, I made the decision, she ended up in a home — and the immediate aftermath was pretty fraught, to put it mildly. Fortunately I was not accused by any relatives of ‘putting her away’ for my own convenience. That, I understand, can happen quite often, as relatives, particularly sons and daughters, are not notorious for their rationality in these situations.

My own sense of guilt was pretty irrational, too, now that I observe it from a respectable distance, because I was basically given no choice. I was at the time metaphorically pinned down and told in no uncertain terms by a combination of community mental health team members, social work, and sundry other professionals that I could not possibly continue caring for her and that she was becoming a real danger to herself without full-time professional attention. So I concurred. But I still felt the guilt. Rationality has nothing to do with that, just raw emotion in the face of a cruel loss. But there is more to come. Later, we will examine guilt again: where it comes from, what it is, and what can be done to mitigate it.

Inferiority feelings

Another irrational but equally powerful emotion which emerges is a compelling sense of inadequacy and self-questioning on the carer's part. Did I look after my loved one properly? If I had acted differently, maybe they could have stayed with me? Those and a nagging host of similar questions arise and it was here more than anywhere that I became aware of the fact that in seeking to cope with these emotional flare-ups, I was very much on my own. Whether or not you have a large circle of support, much of the challenge of being a carer and in particular an ex-carer lies in being able to work your own way through all the negative stuff by yourself.

A well-meaning friend or relative might well say, 'I know how you feel' or 'I feel your pain', but, no, sorry, you don't. You can begin to be aware of it, recognise it, sense it in me, but you cannot possibly grasp the personal all-consuming enormity of what I am going through. It's not just one aspect of myself that has been damaged by a particularly unpleasant situation, I have been completely torn apart by it. A significant chunk of my own sense of purpose, of self-esteem, call it what you will, has simply been thrown out of the window. Like some electronic piece of modern wizardry, I have been given a factory reset, but without any particular notion as to where to go from here, or even if it is worth attempting to find a way out of the situation.

In my days of political involvement, I would rapidly lose patience with folk who would bleat that 'they' should do something about a particular issue, from sewage seeping into our rivers to the plight of the Ukrainian people. My response then was: Don't expect 'them' to do anything, because *you* are them. Everyone has a co-responsibility for the society and community they live in. And in a similar vein, do not fall for the trap of believing that ‘someone’ could do something for you in relation to grief, guilt, self doubt and the rest. You have to step up to the plate and face the music (to mix a metaphor again). No one is going to do it for you. And that applies especially to the carer for someone with dementia.

Anticipatory grief

Worst of all, you will also find yourself suffering from what is known in the business as ‘anticipatory grief’, which I touched on right at the beginning. In sum, it means feeling grief for a loss which has not yet been fully completed. Your loved one has gone, but he or she is not physically dead, to put it bluntly. Or, to employ a term which I don’t particularly like but which clutters up the airwaves nowadays, you do not have ‘closure’. It’s not one of those situations which allows you to acquire a get out of jail card and all will be well. The term ‘closure’ is somewhat trite in this context as we never completely ‘get over’ what has happened to our loved one, our relationship with them, and the ending of our lives together in such a cruel manner. I was about to begin exploring this issue by stating that the worst thing about anticipatory grief is such and such, but I suddenly realised that there were actually at least two ‘worst things’ which closely relate one to the other, and probably a whole lot more. Here they come.

The first factor

Anticipatory grief is open-ended: unlike grief for a departed loved one, the pain will go on and continue to get worse as your loved one deteriorates further. The possibility of closure (that word again) simply does not exist, and the loss of your role as informal carer adds to the burden, as does the pain of seeing your loved one slip further and further away from you. A sense of isolation compounds the tragedy.

That is well enough known and commonly reported in the literature, but what is generally overlooked is another important feature of this enduring and increasing grief, namely, that it is not a smooth continuous turn of the mental thumbscrews as the weeks and months go past. What I am attempting to put into words is the fact that the loved one's decline is not a gentle one-way process, with each day imperceptibly getting worse by a tiny but measurable amount.

In the case of my wife — and I had been told by staff this is not an unusual occurrence — she had good days and bad days as part and parcel of the process. In other words, what I found so upsetting was the fact that I could never tell in advance what it would be like to visit her on any particular occasion, and what is even more disorientating is that the 'good days' tended to have a worse effect on me than the bad ones. It was then that she tended to ask when she could go home, or to speak of ordinary things in a relatively lucid manner. This rollercoaster effect added to the negative impact of her dementia, and the sense of not knowing precisely what was happening further exacerbated the carer's feelings of grief. Unpredictability on top of everything else can threaten to be a problem too far.

The second factor

There is, however, another highly significant additional feature of anticipatory grief which also tends to be completely overlooked by the medical establishment, and that is that you as a carer now find yourself sidelined and irrelevant, almost an embarrassment. I sensed sometimes, when I entered the care home to visit, that I was intruding upon a situation rather than enhancing it, even in a small way. I am not in any way criticising the care home here, nor am I claiming that such feelings are unworthy or unrealistic. The simple fact is that we will succumb to such assumptions from time to time, and they should be taken seriously.

The carer will find such states of mind further intensified if their loved one has been aggressive and confrontational in the final days and weeks at the family home, as those attitudes can tend to drop away when they enter a care home. It is hard at times not to feel resentful at the fact that your loved one seems now to be so content and unflustered by the environment of the care home, once the awkward transitional period has passed, and it is at this point that family members may well pipe up that the loved one should not have been placed there as it appears they are becoming institutionalised.

It is important that you should recognise that this is simply untrue. And do tell anyone who makes that assumption that they are plain wrong. After an initial challenging period of settling in, people with dementia will tend to settle into the comfortable routine of the care home in the company of others who are similarly ill, and without the stresses and strains of the final days in the family home, when nerves are shredded and tensions are running high. They are not being brain-washed by the institution, they are simply following the inevitable pathway of dementia alongside others suffering similarly from the illness.

Do remember, though, that it is the informal carer who always gets it in the neck, because family and others see only part of the picture, and most of them have a pretty heavy emotional burden to bear in the light of the tragic circumstances of dementia, to the point at which, in some cases, they cannot cope with the situation and either behave quite irrationally or seek to withdraw altogether — or both. Family members may well be feeling a sense of guilt for not visiting very often (or at all), but their misjudgments tend, I believe, to spring from a raw fear of what might happen to themselves and their own children as a result of this diagnosis. Will they ‘catch it’ too? And this, of course, is hardly a basis for logical thinking.

However, that does not prevent them from shouting from the bleachers, as our American cousins call them, complaining and accusing you as the main carer of mismanaging the whole process. In my own case, the greatest bone of contention was medication. It was almost constantly being asserted that their mother was on the wrong medication, and that pill A clashed with pill B, and anyway it says on Google that this or that anti-psychotic is potentially dangerous, addictive or lethal. This kind of confirmation bias, or whatever you choose to call it, is not uncommon in stressful situations, where an individual jumps to a conclusion and then looks for ways of confirming it, rather than taking a step back, suspending judgment and appreciating the wider picture. Relatives seem to have this inbuilt capacity to direct blame outwards to everyone else, particularly the main carer, rather than looking inward to their own imperfections.

There is an additional aspect of the attitude of relatives which can exacerbate already strained relations (in both senses of the word). In most medical situations, they are accustomed to yes or no answers to the questions they pose. Is his leg broken? That tends to have just one of two answers. However, in the case of mental issues, the response is quite different. Should we put the patient on pills A or pills B? It all depends. And that element of apparent ambivalence, which goes to the heart of the difficulties facing those seeking to identify and manage mental illnesses, is something which relatives find difficult to assimilate. The lead consultant in my wife's case said that much of his work involved judgment calls, not yes or no decisions, and he was simply telling things as they are. Do be aware of this issue, which can cause all manner of conflict within a family. The medic who is basically saying 'I'm not sure', is being honest and open in the context of his area of expertise, he or she is not displaying indecisiveness or incompetence. Certainty is what the relatives may demand, but in mental health circles it can be way beyond anyone's reach.

You may also feel that the medical profession now regard you as irrelevant, no longer involved in day-to-day decisions on medication and treatment. Since my wife entered the care home, I had no dealings at all with her new GP, but on the caring side, the home always contacted me by phone when she had a fall and kept me very well informed about her condition. They were also particularly sensitive to the fact that I was taking the situation pretty badly.

In the earlier stages, you may indeed have coped pretty well with the gradual deterioration of your loved one. The pace of change tends to be slow and its nature manageable. It is only when the time approaches for them to be transferred to a care home that the rate of deterioration seems to accelerate (in our case, at least). The fact that I was now separated from the loved one only exacerbated the situation, because I was no longer interacting with them on a daily basis, and in any event their ability to engage in meaningful conversations becomes more rapidly depleted. I have said elsewhere that dementia constitutes a moving target, and that is definitely still the case after the loved one goes into a home. They seem to recede more and more swiftly into the distance. No, correct that: they actually *do* recede more and more, becoming further and further out of reach and no longer resembling the person whom you had lived with before. In the words of a manager of the care home in which my wife was resident, 'She is no longer the woman you married.' That was a bitter pill to swallow. And that is not the kind of situation in which you expected to find yourself nor one which you are in a good position to cope with successfully.

Another challenge — visiting times

I thought that placing my wife into a care home was the hardest decision I had to make, but there were similar tough decisions to come when visiting times arrived. It was indeed pretty awful to begin with, especially since she was still fairly lucid most of the time and also somewhat disoriented in her new environment. The most challenging moments came at the end of a visit, when she would ask if I was going to take her home now. That left a long trail of distress within me, and I found myself taking most of the next day to recover from the experience.

I had settled on seeing her three times a week, but the emotional roller coaster of visits and the painfulness of leaving were becoming hard to bear. I was beginning to dread the next encounter as I drove the car up the driveway to the care home and wondered what her state of mind would be on this occasion. After a while, the situation somehow seemed to arrive at a plateau and she had indeed settled into the home, realising perhaps that this was now her permanent place of residence. Now and again, leaving her and saying goodbye would still be a challenge, but for a while a pattern established itself which I was, quite honestly, beginning to reluctantly settle for. However, as she gradually declined further, I realised that her interactions with me were becoming less and less meaningful, her world had shrunk, turned in on itself, and I was again beginning to find the situation less and less tolerable as the weeks went by.

One afternoon, I was sitting in the manager's office discussing her, when she asked me how I felt. Pretty horrible, actually. At a time like this, you have to be brutally honest with yourself and others, so I said that my problem was that, as my wife had become very unresponsive and indifferent towards me, visiting three times a week was now becoming too great an emotional burden. Every time I went to see her, it still took me a day to get over it, and it was wearing me down. There, I had said it. Not the conventional response one is supposed to have, but that was the plain fact. If you want it spelled out in simple terms, she was slipping away from me, so I had to be doing the same for myself and my own sanity. Love yourself first, and you'll find a little further on a section devoted to this phrase which sounds pretty counter-intuitive. And don't let the relatives tell you that you are letting the side down, because the best response to some of them is to ask when they last darkened the doors of the care home. So my harsh advice is: don't pretend all is well when it isn't, tell it like it is. Otherwise, your own mental state will suffer as a result.

So I had to make another choice, this time to reduce the visits from three per week to two, Mondays and Thursdays. I road-tested this on the manager and her response was sympathetic and understanding. I almost got the impression that visiting three times a week put the routine visiting patterns of most of the other carers to residents in the building in the shade, so to speak. But what really made me decide was the answer to the question I then put: 'Will she know that I am not visiting so often?'

'No.' was the sad reply from the manager. 'She won't.' The distressing implication from her words was that I could well be coming that often for my own sake rather than my wife's, and that's another tough fact to have to face up to.

I was on twice-weekly visits for some time, and it was a very sensible choice for all concerned. It seems in this business of informal caring that there are some pretty painful basic facts of everyday life you have to face up to, but once you have confronted them, it will be something of a relief for you. I'm still squirming a bit, though.

I'd like to pass on to you one other valuable lesson I have learned, for what it is worth. Do not do as I did now and then, occasionally treat your loved one as if nothing had changed mentally. It's a case of clutching at straws, which is quite understandable. You are making a mistake to interact with them as if they are just a slightly diminished version of their previous selves. Let me drag a whopper of a technical term into this: anthropomorphism. Here's a quote from a learned article which I found buried somewhere on the internet:

> Anthropomorphism refers to the practices in which humans attribute human emotional and behavioural features to non-human animals and objects. For some people, this represents a means to reinforce the human-animal connection, display empathy towards their companion animals, and show care and interest in their well-being.

Before you reach for your pen to dip it into vitriol, I am not, repeat not, referring to our loved ones as non-human. I am making a quite different point, which is that, although they may look like they did before dementia struck, something so destructive has impacted on their brains to the point at which previous normal reactions are no longer valid. Their world view is radically different from ours, and their reactions will therefore also be totally changed.

I was being guilty of not recognising this, of believing that a tear in her eye meant that I was causing unnecessary extended suffering to my wife. I could not be more wrong. A further part of the manager's response to my concerns was that my wife would forget in no time at all that I had even been present with her for a visit. And that leads back to that phrase which has been drilled into me time and again: Do not take it personally. Do not beat yourself up out of a well-meaning desire to be as kind and thoughtful as you were in the past and expecting the former responses to function as they did in the good old days.

Love lost

Parting is such sweet sorrow. Oh no, it isn't. It's pretty grim. I recall a little while ago I met an acquaintance I had not seen for some time and told him about my wife. He expressed shock and surprise, and then he said something quite unexpected, 'You've lost the love of your life.' Odd in the sense that you would not expect anyone except a close long-term friend to express words like that. The fact that he suddenly blurted them out told me that he too must have followed a similar tragic path, but I did not question him. He'll tell me when he is able to, which may not ever happen. In sum, anticipatory grief and its various components can make you feel as if your very self has been undermined. Everything which has taken place in the past, especially the exhausting challenge of caring, has lost its significance and relevance. You are no longer part of the picture, you are out of the picture altogether, with the possible exception of the folk who run the care home and look after your loved one.

At this point, I must interpose something about a loss of intimacy, and I am not just referring to a sexual relationship in the case of carers for partners. For more information on that topic, go to the Alzheimer's Society website and enter the word 'intimacy' into their search box. Equally significant, general human contact is a key factor in our daily interactions, whether it is hugging your partner, children, or pets (unless you have goldfish, that is). In many situations, actions can speak louder than words. I recall talking to the head nurse on duty one day about life, the universe and everything and stating that I felt pretty rough. Spontaneously, she came over to me and hugged me. That gesture was so reassuring and positive, but it painfully reminded me just how much I was now on my own.

You may well feel that you are now, like me, in life's waiting room, so to speak. And it's pretty excoriating. In the clever and poignant words of that song, with music composed by Jerome Kern in the 1930s, 'when a lovely flame dies, smoke gets in your eyes'. My advice in regard to just about every part of the situation where your loved one is in a care home is: do not rush into any decisions, let the feelings and emotions which can cloud your judgment dispel over time. Be patient. Accept that there will be a longish period of grieving of various kinds, and if fate decrees (sorry, that sounds a bit pompous), things may change for the better at some future time.

Lack of 'closure'

The later stages of dementia can come in as many shapes and forms as there are people, but with a loved one who has followed that path, when they may not recognise you or be able to speak at all, it is a particularly challenging situation. In the closing stages of a long, loving relationship it would be a comfort to be able to talk through the experiences of the past and express once again your love for and gratitude to the person in the end stages of life, but all that is wrenched away from you when that person cannot interact with you in any meaningful way.

Being unable to say a proper goodbye is one of the cruellest aspects of later stage dementia, and it adds yet another burden to an already challenging and distressing experience.

Chapter Seven — Trauma, PTSD and survivor's guilt

I am now going to explore feelings and emotions — again very personally, and based on my own experiences — drawing on the concept of trauma which triggers PTSD (Post-Traumatic Stress Disorder) and survivor's guilt and generally threaten to challenge your attempts to come to terms with your current plight and to establish some kind of future for yourself. If you baulk at the terms trauma, PTSD and survivor's guilt, claiming that these are conditions that only happens to ex-military men (and women), bear with me, read on and I hope to persuade you that it is far from irrelevant to your present circumstances. But first, let me consider a question which burns at the back of the carer's mind and in many cases constantly comes forward to haunt them.

Why me?

Why have you drawn this particular short straw of a loved one with dementia? The unkind answer to that, but probably the most truthful is: Why not? Why should the shocks and horrors of that four-letter word — L - I - F - E — bypass you and inflict its hurt on others? There are times when most of us are dealt a pretty dire hand of cards, and it is up to us to cope with it or not, as the case may be. In this chapter, I am going to explore how the feelings of anticipatory grief and the burden of those years spent caring can be considered as similar to the trio of concepts most often applied to military men and women, namely: trauma, PTSD, and survivor's guilt.

PTSD and triggering a flashback

The very first and possibly the most important point to make is this: do not let others (or yourself) respond that seeing a mate's head blown off during a military operation is, of course, a lot worse than what you have been through and still are experiencing. That is simply not the standard by which PTSD should be measured. The trigger for trauma does not have to be either a single earth-shattering event nor an extended period of suffering, what is significant is the existence of that trigger and the enduring impact it has on you.

Your trigger situation must be judged not on how it rates on a scale of one to ten of awfulness of the actual cause in the past, but on how deeply it has affected you and continues to intrude into your thoughts and actions. Whether brief or long lasting, it is still a trauma. In your case, the burden of caring together with certain key moments and events will threaten to haunt you for the rest of your days with no less force and destructive power than a life-threatening moment in battle or continuing violent physical assaults from another person.

Let me get very personal here, as I am writing for the most part on the basis of my own experiences. During my time as an informal carer, I was traumatised by a series of situations which completely shattered me, but which I had to ruthlessly suppress at the time for a variety of reasons. Here is just a selection of those situations, and do note just how varied they are:

- standing within a couple of feet of my wife who was in the midst of a severe psychotic episode, as she screamed into the telephone to the police emergency call operator that I was physically attacking her.
- a quieter moment when she was still quite rational and came up to me, saying: ‘Are you going to put me in a home?’ And I replied, ‘No, this is your home where you are now.’
- visiting my wife in a locked mental health ward to which she had been sectioned, and receiving a torrent of abuse from her, being accused of fornicating with other women and sundry other misdemeanours.
- the whole set of events surrounding the time of her placement in a care home, and her tearful requests to be allowed back to ‘her’ home. At the time, she did still recognise what was happening, and that awareness was like a knife in my chest.

- coming back one dreich November afternoon from visiting her, entering what was our bedroom and seeing her stuff still set out as if she had just gone out visiting but would come back soon.

I could go on, but I now want to draw your attention to a couple of aspects of that list which are common among folk who have suffered this kind of trauma. The first, as I have stressed already, is that the actual cause could be a highly charged crisis or an apparently innocuous situation or interchange. The second is that each of them and others continue to haunt me as flashbacks, completely unbidden, and sometimes at an awkward moment in the company of others. Even more damaging, you can find the past almost literally transported into the present by the intensity of the emotions involved, and that is (dare I say it?) the classic manifestation of PTSD.

Let me take a parallel from literature, from the sequel to the most famous of all anti-war books ever written, which accurately highlights the nature and causes of these effects.

Triggers and flashbacks explored

Everyone has heard of *All Quiet on the Western Front*, whether it be Remarque's original novel or one of the film versions, but not so many people realise that he wrote a sequel, *The Way Back*, a title loaded with bitter irony which charts the faltering attempts of a group of battle-hardened young men in their struggles to come to terms with the ordinariness of civilian life. As one of them complains:

> In the field our nerves were always stretched to the limit because it was a question of life and death. Now they flutter about like sails in a dead calm.

They cannot stop themselves reacting as if they were still in the trenches, and they respond to the sound of the screeching wheels of a passing tram as if it were incoming artillery and dive into a ditch for protection and self preservation. In the turmoil of military conflict, they lost their youth but gained a bond of loyalty and friendship with their fellow soldiers which instilled in them a meaningful sense of a structured community that came to replace the former role of their families. On returning home in fact, their actual families appear to them to have lost all relevance, and their childhood lives before have become mere shadows in the face of their more recent experiences on the battlefield.

Note their reactions to events when they are back home. First, triggers drag the past into the present. The screech of the tram wheels literally becomes the howl of incoming shellfire. Secondly, there is no way of turning the clock back to their pre-war lives. What's done is done and they are forced to attempt, with varying success, to cope with life as it actually is. Dull, everyday routine seems impossible to embrace again. It's an awful paradox: the absence of a life and death struggle leaves a huge gaping hole in their lives, rather than a sense of relief that those ghastly days are over. Thirdly, the comradeship which was so key to their survival and formed a central point of their lives in the trenches no longer has any worth. One of the enduring themes of Remarque's work is his injunction never to look back. Keep going forward, however hard the journey, despite the many obstacles along the way. There is no choice, even when there appears to be little future in the bland routine of civvy street and no longer any relevance in what you have experienced in the past.

Now I am sure you can see many parallels between the lives of these young boys become old men and your experiences as a carer. Do not be lured away by the siren voices telling you that it cannot be the same for you as it was for them, as war was far more horrendous than having to care for someone with a terminal illness. As I have stressed, that would be to miss the point entirely. The issue here again is quite simply that it is not the 'severity' of the trauma itself which you can measure your reactions against, it's how much that trauma impacts on you.

Triggers are not easy to deal with. They can be very powerful and cause past trauma to overwhelm the present moment. Take my example of the psychotic episode which my wife suffered, when she called 999 claiming I was attacking her. Sometimes I can still find myself reliving that moment in horrendous and vivid detail, watching the police car race up the driveway, blue lights flashing, the two young officers on the doorstep nervous and icily polite. And so it goes on. In its most intense form, the flashback does not simply open an unwanted window on the past, it overwhelms you to the point at which you are actually reliving a past experience, a kind of reverse time-travelling if you like in which the past comes to you. The real mystery about triggers is their complete unpredictability. Some events or circumstances that you think might cause an enduring and recurrent trigger obstinately refuse to do so, whilst seemingly innocuous episodes from your past can haunt you with horrifying persistence.

Before moving on from this topic, there is another aspect of triggers which I really must draw your attention to, and which you might well find as challenging as I have done. Let me begin by telling you what happened to me many years ago near the peak of an Austrian mountain a few days after England won the World Cup (at football, in case you didn't know, and in 1966 if you didn't know that, and the score was 4-2). It was on a bright summer's day that my aunt, uncle and myself were clambering up a steep pathway leading towards the summit. As we finally came within sight of the Gipfelkreuz, the cross which marked the highest point, we realised that the sky had suddenly darkened.

In seconds, a ferocious hailstorm burst on us without warning, and we were pinned against the rock face as stones, not quite the size of footballs, but pretty impressive nonetheless, pounded down on to us. My uncle told me to see if I could make my way back to the hut (the term is used for a simple bed and breakfast establishment in the mountains) where we had spent the night before, as he had to try and cope with my aunt, who was pretty shattered by the experience and finding it challenging to move. As the hail continued, I staggered my way back along the marked pathway, realising in shock that we had come pretty close to death in those moments. It was the worst summer storm which Austria had experienced in many years.

Now to the point of my narrative. That escapade was a potentially seriously traumatic event for me, and one which has occasionally intruded into my thoughts over the years since that time, but not in any particularly powerful way. However, since my wife went into a care home, that situation and others like it had impacted on me with more frequency and vividness than ever before. It appears to be the case that not only will we be reliving the traumas caused during caring, but also suffering from an intensified reenactment of other challenging events in our other past which had previously lain dormant and had lost their impact. And I'm still pretty annoyed that I didn't get to sign my name in the visitor's book on the summit to prove I had been there.

There is no intrinsic harm in thinking back to the past, it is damaging only when it becomes uncontrollable and excessive in its impact. If you pause to consider flashbacks for a moment, you will soon recognise that our experience of the past is constantly impinging on our present. A letter (remember them?) arrives from an old friend and your mind flashes back to the time you last saw them waving goodbye on the platform as you left university to enter the big wide world of work. A sad moment visiting a colleague in hospital shortly before he died rubs shoulders with delight at the wedding of our eldest son in a village in the south of France. We are all made up of memories, good and bad.

Why do sudden recollections of past unhappiness not have the bruising, debilitating effect of a PTSD-generated flashback? I'd contend that there are two kinds of flashback. We mainly experience a benign one when, instead of our minds forcing us to relive past traumas, the flashback comes and informs and even enhances our present. The question which obviously arises is: What, if anything, can we do to mitigate or even eliminate the impact of these debilitating flashbacks? PTSD is a memory breakdown when something occurs which makes the mind believe that the past trauma is happening now, in the present. And that makes it a real challenge. If you experience PTSD to any degree, the advice can only be to seek medical support.

Survivor's guilt

Coupled with PTSD is survivor's guilt which again tends to be associated with the military. Why did I not die? Why was it my best pal whose body was blown in half by an anti-personnel device, and not mine? Why did that bullet not have my name on it instead of theirs? Why did my wife get dementia and not me? Similar questionings can and will affect you as you try to struggle and come to terms with your feelings and emotions.

So, before moving on to seeking to find a way through this crisis situation, let me summarise. The first and most important point to remember, and one which I make no apology for stressing once again, is that it is not the severity of the cause of your trauma which is significant. The key element is the effect which it has on you as a person. In dealing with this, you should be wary of the blandishments of many who will say: ‘Get over it.’ I’m tempted to quote Shakespeare here, so here I go:

> He jests at scars that never felt a wound.

That’s Romeo accusing Mercutio of not empathising with his emotional state. You, Mercutio, have never suffered from the anguish of lost love and you cannot hope to get inside my head and begin to cope with my own tortured feelings.

What you do need to hear instead is someone you respect telling you these two simple facts:

> I believe you.
> It’s not your fault.

The first indicates that the speaker comprehends and recognises that what you are saying is genuine. The second statement affirms that it is not a matter of personal culpability when you do experience such feelings, it is just a fact of life that we are all individuals and we react differently to stimuli of whatever kind. So, if you can express yourself to a trusted friend, colleague or relative, do so. Otherwise you can try and internalise that debate and seek to persuade yourself that those two statements are true. Suffering is such a personal experience that it may well be too challenging for you to speak to others. Avoid like the plague those who are minded to say: ’Pull yourself together. Get over it.’ They do not realise or recognise that your position has become so bad that you are genuinely seeking help or support for dealing with it.

The person you have confided in — or your inner self — recognises that your seriously unpleasant reactions are genuine.

They believe that you are actually suffering in the way you describe, and secondly, it’s nobody’s fault, it’s just what happens when the mental challenges you face become overwhelming. Such folk recognise too that it is not self-inflicted, a seriously unjust and unpleasant assertion which is often held by others in their ignorance. At its least vindictive, that kind of argument follows a pattern. You voluntarily took on caring. You knew it would be a tough gig. Accept the consequences and bite the bullet. Grow a pair, as our American cousins might say. Stop whingeing.

That fatuous argument fails to take account of a couple of simple facts: if you love your partner or whoever falls victim to dementia, you feel both duty bound by the ‘in sickness and in health’ of the marriage vows or a similar strong commitment to them to accept the challenge. The second fact is that you did not at the time have the faintest idea of the increasing severity and long-term impacts which that challenge might throw at you. There is a world of difference between ‘knowing as a fact’ that caring is going to be difficult and the actual experience of that role being played over an extended period of time. The soldier going into battle ‘knows’ it is going to be very challenging and life-threatening, but it is only when the worst happens that the true awfulness of the experience can be felt.

Another blunder made by well-meaning family and friends arises when they try and tell you what your needs are, or rather, what they think or believe your needs to be. They should refrain from such a simplistic approach and try to find out what *you* perceive your needs are, not to impose alien non-solutions on you. It also contains a strong element of ‘things aren’t that bad, you’ll soon get over it.’ They are cordially invited to step into your shoes and give it a whirl themselves.

Now that I am edging towards considering what kind of steps you could consider taking in order to come to terms with the challenge of PTSD and the rest, let me turn directly to two basic points which you should bear in mind. I quote from the excellent advice of April Goff:

> The only right way is what is right for you… Healing from trauma isn’t pretty.

In other words, each person reacts to trauma in a different way, just as they respond in a wide variety of bereavement patterns to the death of a loved one. Secondly, the healing process itself is unique to you. There is no way that an outside observer, however noble their intentions or however close their relationship with you may be, can possibly second guess what that pathway might look like for you. Only you can do that. Now for the most challenging prospect: healing. April Goff describes it as 'not pretty'. In fact, it is very messy indeed. And it's hard. Worst of all, it isn't a neat linear process you usually follow if, for example, you broke an arm or a leg, and on top of that, there is no guarantee that the process will ever be over.

In some ways, that is not a problem, because you should not deny that a painful and unpleasant part of your life ever existed. Remember that we are who we are now as the culmination of all our past, good, bad and indifferent, and the best we can hope for is to come to some compromise, if you like, with the trauma of caring and loss, and make it part of yourself. I'm still pondering this one myself, but I offer to you a wise Buddhist saying which I came across online:

> Pain is inevitable. Suffering is optional.

Having an excess of time to ponder can itself be damaging, and many carers are now retired and may find themselves at a loose end with hours to brood on the past and what it did to you. The challenge is well expressed by a counselling psychologist writing online, Dr Elaine Ryan:

> The more you think about it, the more intense the feelings become. You may feel extremely angry or upset each time you think about it. You re-live it. I might as well be by your side every day, kicking your shin. When this happens, it is no longer me that is causing your pain. *You* suffer because you do not let it go.

Self pity is no way to seek to go forward. Let me not mince my words: this is going to be one hell of a challenge, but if you had the strength of personality and depth of love to undertake the caring of your loved one in the first place, surely there lies within you the potential to face up to the supreme demands of facing the future now and accepting it. Let me put a couple of quotes from the German philosopher Friedrich Nietzsche together:

> To live is to suffer, to survive is to find some meaning in the suffering…
> He who has a ‘why’ to live can bear almost any ‘how’.

He is putting into words a paradoxical basic truth of the human experience, namely, that if it wasn’t difficult, it would not be so worthwhile making the attempt to stitch your life back together again.

Chapter Eight — Finding a way forward

I turn now specifically to explore what I hope is the more positive stuff. We have spent quite a lot of time mulling over the multiple crippling problems of being an informal carer of a loved one with dementia. So now let's tackle some of these issues and see if there is a way of dealing with them and managing them. First of all, a word of warning. I am going to try and avoid throwing huge piles of useful advice and encouragement at you, otherwise you will simply suffer from information overload and none of it will sink in. What I intend to do instead is to consider the key issues in broader terms and then point you in the direction of useful resources where you can explore things in more detail at your leisure. By the way, when looking online for information, ensure that you check that the website you are scanning is appropriate to your needs. If you are in the UK, don't get too caught up in American websites, not least because not a few of them would like to part you from your hard-earned dollars. Legal and financial considerations apply differently from one country to another. And there's a resources section at the end of this book to guide you in the right direction towards more help.

The focal point in your steps away from despair and directionless wanderings is that you have to recognise that there is no silver bullet, no Harry Potter magic wand invoking dog Latin spells to whisk the problems away and send you soaring into the sunny uplands of a bright new future. Life isn't like that, and your present circumstances are a particularly unpleasant example of just how bad things can become. You really are at 'Stunde Null', hour zero, the phrase employed in Germany at the end of the Second World War to describe the almost complete obliteration of civil society and its physical infrastructure. You have to face the ruins and lost lives, rebuild from scratch, as it were, as the whole fabric of your life has been torn apart.

I'm reminded of a newspaper cutting reporting a serious crime in South Africa. It states that almost 20,000 fake Harry Potter wands were seized by police in a toy shop. Not exactly the crime of the century, but you can second guess my question: How could they tell? My point is this, that even the genuine ones can't be genuine, and it takes a similar leap of faith for you to believe that you really can pick yourself up and start all over again. I've said elsewhere that there are times when, believe or not, you have to act 'as if' everything were fine, and that very act of faith will help to drag you out of the seriously bad place in which you find yourself. There's a phrase in computing which points in the same direction. Loading a computer system from scratch is called 'bootstrapping', where a program, usually the operating system, almost literally lifts itself up by its own bootstraps, something of a scientific impossibility, and starts to function. And that is what you have to do with your own life.

But be patient, though. I used to encourage students to come to me with any problems they needed resolving, and I would always tell them that if it is a half decent crisis they are facing, it can't be resolved in an instant, it will take quite a while to go through all the necessary stages to bring about a satisfactory resolution, if at all. There won't be a simple pathway to slay their particular dragon, but it will be well worth the effort trying. In the field of caring, it's pretty clear that each individual is just that: an individual, who will react differently and at different points to the severe challenges which they face now and the ones which are lurking round the next corner.

Love yourself

When I first encountered this little gem of advice, I was hardly overwhelmed with enthusiasm. In fact, I was pretty cynical. Surely someone must be pulling my leg, because the last person I wanted to be in that moment was — me. Why on earth should anyone who had spent years up to their necks in everything from house cleaning to cookery, preparing and helping with showering your loved one, and clothes washing or repairing that leak in the bathroom, even want to consider themselves and their lovability?

And it makes them even less loveable now that they are on their own busily feeling sorry for themselves. Perhaps I was muddling it up with the demand in Luke's gospel, 'Medice, cure te ipsum' in Latin, 'Physician, cure thyself', which has an entirely different connotation. That phrase means: Don't go around pointing out the faults and blemishes in others, sort your own out first. It's similar to that other Biblical quote, from Matthew this time, about the mote and beam. Don't take the mote (tiny speck) out of someone else's eye until you have moved the beam (whopping great plank) from your own.

This irritating injunction to love yourself keeps popping up, however, and I have found the following rather odd comparison helpful. In fact, it made me change my mind. It concerns the words of advice from the aircraft flight attendant before take-off that if the cabin pressure is suddenly lost and those strange little bits of headgear with masks in them come tumbling down, you must put your own mask on first before caring for anyone else. It's not a matter of selfishly betraying the concept of women and children first, but of ensuring that you personally are not going hypoxic. You can't help anyone else if you are — to put it bluntly — incapacitated or dead.

Then I began to grasp the concept of loving yourself and the need to do so. It's strange how the stresses of caring can cause the mind to function at way below par, and now the injunction makes perfectly good sense to me. I thought at first blush it was just too selfish for words, but on mature consideration it does make perfect sense. There is no point in attempting to look after someone as challenging as a loved one with dementia unless and until you are in tolerably good shape yourself.

There's another aspect to the advice, too, and that is that you should not only be in reasonable physical shape, you should also be as mentally sound as possible. Your self-esteem levels should be moderately good, and your general life attitude within normal tolerances, as it were. It makes good sense to have a regular check with yourself that you are, for example, not just avoiding setting up a doctor's appointment on the alleged grounds that you have more than enough to cope with already, or that you are really feeling desperately miserable about your role but simply have neither the time nor inclination to do something about it.

Coping with negative feelings — guilt

I promised earlier to examine guilt more closely, and after a deal of head scratching, note scribbling and reading of pamphlets, I think I have arrived at a systematic way of looking at guilt and managing it. Let's start with the obvious question: What is guilt?

Guilt is usually a complex tangle of feelings and emotions which derive from a sense, justified or not, of having done something which is plain wrong. That kind of guilt gets processed one way or another in everyday existence and you live and learn — and move on. The guilt you feel when you are struggling to cope as a carer seems to me to be quite different from the reaction you experience after forgetting someone's birthday card, or pinching a bar of chocolate from your brother's stash, or exceeding the speed limit and nearly, but not quite, getting caught.

Somehow life allows you to process guilt in a number of ways, including confessing to the crime, exhorting yourself to keep your foot less firmly on the accelerator when passing a speed camera, and so on. But dealing with a loved one with dementia is a different kettle of fish.

First, where does the guilt come from? What kinds of guilt are out there waiting to entrap you? And most importantly, what can you do about it? Guilt in a relationship with a loved one, I would argue, is not so much about having done something 'wrong', but more about measuring yourself up to some standard or other and believing that you are falling short. Quite often, that standard you set is impossibly high. And, if we are honest with ourselves, we may well have deliberately set the bar too high. We almost need to fail. I'll divide guilt into three categories:

(1) about yourself;
(2) you and your loved one; and
(3) you and the wider world.

Guilt and yourself

By that I mean an overwhelming sense of inadequacy about your coping skills. I am not doing well enough in this role as carer, you may feel. Worse perhaps, you may suspect that you are not doing as well as other folk, because they appear to be managing far better than yourself. Of course, the others may just be a little better at pretending all is well than you are.

You and your loved one

In this element of guilt, you are finding that your relationship with your loved one is shifting, and it may not be as positive as it once was. My feelings towards the loved one are no longer as committed and powerful as once they were and should still be, that little voice in your head insists. Also, you recognise that you must not criticise them because it's the disease, not them, which is to blame. This kind of guilt is all too understandable, as it is founded in the inescapable fact that the loved one does change, does become more inward-looking and detached from the world and people about them, including you.

You and the wider world

You ask yourself whatever happened to the person you were before you somehow found yourself in this role as carer. You had a career, which you may have had to step back from altogether; you had friends and relationships, for which you no longer have the time or energy and, in any event, the attitudes of others towards you may well have undergone a not so subtle sea change. It is as if you have become tainted by being so closely associated with a person suffering from an unpleasant, incurable, terminal illness which will afflict a significant portion of the population as they age, maybe even including your (ex-)friends and acquaintances.

Now you also feel trapped in an impossible situation which can only get worse, and which is damaging to your emotional and mental health, because we are not static as people, we evolve, and that constant shift and maturation process is put on hold by having to deal 24/7 with someone who is slipping cruelly away from you. As in anticipatory grief, the same questions arise with guilt, the most challenging one being: When will this all come to an end? When will the burden be lifted from me? Now, before we all give up and burst into tears, let's look at a couple of ways in which, using your own inner resources, you can challenge this enemy guilt head on and make some headway in keeping it under control. The first and most important consideration is that feeling guilty is not abnormal, but there are two particular aspects of the kind of guilt you experience in your informal carer role. First, as I indicated earlier, it's a different kind of guilt from that experienced in 'normal life', as it relates more to a sense of falling short in our challenge rather than after committing an offence, doing something which is plain wrong.

More than one observer of the guilt scene proposes a sensible way forward in these terms. Give yourself permission to forgive yourself for feeling guilty. You are measuring yourself against impossibly high standards, and you should accept the fact that you will inevitably fall short in what is a supremely challenging and complex role for which you have had no training or skills assessment whatsoever. That's one of the paradoxes of being a carer, and the way I put it goes something like this: the better you are the worse you will feel. What I mean by that is that there is a conflict going on between the high standards you are working by and the impossibility of achieving them. And the higher you set those standards, the better carer you have become, the more guilt you will feel at falling short of that unattainable goal.

Without getting too technical, it's rather like Sigmund Freud's model of human psychology and his division of the mind into ego, superego and id. I'm referring mainly to the first two here. The ego (in Latin, myself or I) is who you are, the superego is what you are measured against, your ideal self, if you like. And the id (= 'it') is the wild base animal self which the superego holds in control. If the gap between who you are and your idea of what you would like to be is huge, then you are heading for trouble. There has to be a reasonable balance or distance between the two for a satisfactory state of mind to be achieved. You will always fall short of a high ideal, but you must be able to keep that ideal firmly in your sights.

There's another point, too, which I'm doing my best to put into words. Let me try and express it like this: in the case of guilt and all the other elements of the gamut of emotions we experience in the everyday, two things happen. First, the feeling is put into context because so much else is going on all the time, and secondly, it gets processed and dealt with in a positive way which allows you to move onwards and upwards in the world. That does not happen with carer guilt, not least because there isn't a ready mechanism in your life as a carer for contextualising and absorbing that guilt. It tends instead to grow out of all proportion and make you feel far worse about yourself than you ever should. Or, to put it positively (and ironically), if you don't feel a modicum of guilt about your caring abilities, you aren't doing much of a job as a carer.

You can make a deal of progress in managing your guilt if you recognise the nature and intensity of 'carer guilt' and help to keep yourself on an even keel, despite the fact that you sadly recognise that the loved one is deteriorating and changing for the worse gradually, day by day, and that you are going to have more and more difficulty in meeting that challenge, not least because, as I've noted before, things tend not just to get a little bit worse, but to become very much more severe and accelerate in their downward spiral. It doesn't matter if that guilt is largely or wholly imaginary, the important recognition to grasp on to is that it is an intense feeling which needs to be recognised, accepted for what it is, and managed.

Coping with negative feelings — anger

Another common response to the situation of the carer, especially when matters appear to be running out of your control, is anger. You may well find that you become very angry, perhaps irrationally so, when you consider what has happened to you and how your relationship with your loved one has been shattered, together with any plans you had made for future time together.

Quite often that anger is driven by a feeling I have certainly experienced, namely, of a situation which is spiralling out of control. We want to be in command of our lives, our situation, our emotions and so forth, and when that feeling is threatened, anger is an understandable reaction. We are all emotional as well as rational, so anger is not necessarily a bad thing. In the literature on the subject, it is often described as a defence mechanism against feelings you want to keep buried. It is also a safety valve:

> We went from being a couple with our best years ahead to one where I have to salvage moments of pleasure from the exhausting and upsetting process of care and deterioration…. The experience of watching my husband disappear before my eyes was one of endless repeated grief, and I was angry about the turn of fate, about his friends and family's behaviour and about the assumptions society and makes about caring and carers. (Bates, p145)

Grief and anger are near neighbours in the context of caring, and if you can accept their presence, you are well on the way to controlling them. It is hardly possible to wipe them out altogether, given the fact that you are in a situation which is slowly, but inevitably, heading downwards, but it is possible to stay on top of them. Note a recurrent theme which lurks beneath what I have been maintaining throughout this book, namely, that society, friends and family tend not to form the positive circle of support you believe they should provide. I guess much of that attitude derives from a fear of the illness and the possibility that it may strike them because of genetic family links, and another key element is a guilt on their part for not getting involved as much as they should in the care and management of the loved one with dementia. Do remember, though, that they are very much on the outside looking in.

Coping with negative feelings — denial

Here's an example of a common intractable problem which I have been fortunate in not having to face with my wife, but which was a serious bone of contention in the case of our close relative with schizophrenia. Your loved one refuses to let the doctor discuss their condition with anyone, you as carer included. It may be that they are in denial, or too proud or embarrassed to talk about their cognitive deterioration. We have discussed this to some extent earlier in relation to the carer's role. This is a situation in which there is a clear conflict between the need for doctor-patient confidentiality and the ability of the loved one's carer and others to ensure that the appropriate medication is taken at the right times, for example. It's an issue which over time may well resolve itself, but it is very frustrating not to be able to offer the level and appropriateness of care because the legal eagles drawing up the notion of the contract between doctor and patient hadn't thought through the problem in the first place. A gentle nod in the direction of 'exceptional circumstances' might do the trick. Just a thought.

Denial is one of those unpleasant features of dealing with dementia. The loved one themselves can be in a state of denial, and relatives can and do deny that there is actually something wrong with their mother, grandfather, or whoever. What I have learned is the rather dull notion of moderation in all things. In other words, grieve, but not to excess. If you feel isolated, don't fight shy of indulging in a touch of self pity. Then try picking yourself up and doing something about it. Also, do remember that everything is not about dementia. Give a chance for other things to have their moment in the spotlight: read a book, watch a film, go for a walk, because, the old cliché has it, a change is as good as a rest. Time-outs are not just essential in some sports, but also in life itself. Every moment spent focusing on something other than dementia is a healing moment, and should be embraced and cherished. But please don't start feeling guilty about that, too.

In addition, don't expect the sun to shine every day, if at all. What I mean by that is that you should not deny your feelings, however negative they may be. If you are grieving, grieve, just not to excess. If you feel guilty about your caring skills, it doesn't hurt to do so, as a preliminary stage to talking yourself out of it. Henry Wadsworth Longfellow wrote a sad little poem, called 'The rainy Day', which ends with this couplet:

Into each life some rain must fall,
Some days must be dark and dreary.

And a propos of nothing, he was also the poet on the receiving end of the worst literary joke ever: ‘His head was in the gallery, his feet were in the stalls’ — Longfellow.

Coping with negative feelings — depression

There are, as I understand it, two variations on this particular state of mind: (a) depression and (b) Depression. What I mean by that is there is the kind which most of us suffer from time to time, and which can easily bubble up to the surface in bad situations, like when your loved one enters a care home, and there is Clinical Depression, which is a serious mental illness which requires proper treatment. If you are suffering from that, go see a doctor. Let me tell you about a situation I found myself in many years ago, when I was having symptoms which I knew were badly impeding my ability to function properly. I thought I should visit the doctor, and when I sat down in front of him, he asked me what the problem was. To my eternal embarrassment, I burst into tears and blubbed that I was a mess. That’s Depression. Again on a very personal level, it seemed completely bizarre that I should be suffering from the big D. I was an aspiring successful young academic with an international reputation as one of the pioneers of a whole new area of research in language and literature on the computer, and here I was howling like an infant torn from the maternal breast. There seemed to be no logical reason for being even mildly discontent.

I am no particular fan of the Chinese philosophical notions of yin and yang, which relate to opposite forces balancing one another in the life experience, but it does seem that there is a sense that, somehow, that there actually is validity in the notion of ‘too much of a good thing’, that when you are riding high, even in a situation like long-term caring, something tugs on the reins and reminds you to keep a balance in your life. Not the most lucid of explanations, I’m afraid, but it does seem that we need both the light and the shade in life. I’m reminded of a brilliant turn of phrase from that great Irish writer George Bernard Shaw, best known for his play *Pygmalion*, adapted into the musical *My Fair Lady*. His notion of yin and yang goes like this:

> Both optimists and pessimists contribute to society. The optimist invents the aeroplane, the pessimist the parachute.

First, though, if you do want to check yourself out, there is a multiple choice test called Beck's Depression Inventory. Go online and search for it. Answer the questions as honestly as you can, and it should provide you with a good indication of your state of mind.

As for the common or garden version of depression, I take the view that nature abhors a vacuum. What I mean by that enigmatic statement is this: if you are in an emotional void, so to speak, something will come along and fill it, usually something unpleasant. If you are in a state of anticipatory grief, you will easily fall victim to depression with a lower case 'd', and I suspect, although I am no expert in this field, that it can almost as easily degrade itself into Depression which will need medical attention. In other words, if you are indulging in self-pity or just feeling numb, try hard to extricate yourself, distract yourself, anything to avoid being dragged down into dark and negative feelings. I never said this was going to be easy, and it will definitely get harder as time passes.

Coping with negative feelings — insomnia

One of the side-effects of being left on your own after long years of caring is a sleep problem. This is an issue which affects large swathes of the population for a range of different reasons and can be very challenging to overturn.

In my own situation, I asked my GP what I should do about it, and his first response was: Do not reach for the pill bottle (let alone the gin bottle), especially as you are on a whole load of medication for a range of medical issues. He recommended a cognitive therapy approach, a website called Sleepio, which I tried but not with any great success. That is probably down to me rather than their line of attack. You may well find it useful. The reasons behind poor sleep hygiene are so diverse that it is unwise to offer a one size fits all approach, and I recommend that you contact your medical practitioner.

Referring to my own situation, I am also one of countless ageing gentlemen with bladder issues, requiring not infrequent nocturnal trips to the toilet in the wee (pun intended) small hours of the night, an additional complicating factor in sleep deprivation. Another mouthful of a medical term coming up: bladder issues are caused in my case by benign prostatic hyperplasia, or BPH for short. All I will say about that is if this is the benign version, you should avoid the non-benign variety like the plague.

Problem-solving

When a problem relating to your caring arises in your mind and you get yourself in a muddle, try sorting it out yourself with a series of steps. This is my attempt at a general problem-solving approach, which may help in one or more of the issues I have been referring to in this chapter.

(1) What/who is the cause?

First, who or what is the cause of the problem? Is it an individual, for example, a relative, your loved one, your GP, and so on? Or is it you that's the cause of the problem? Having identified the cause(s), here comes the next step.

(2) What problem is facing you?

Try and be precise, and name the problem. For example, if your loved one keeps on waking up at three in the morning demanding the toilet, or if a relative keeps banging on about your loved one getting — allegedly — the wrong medication, or if you just feel so distraught about a particular aspect of the caring role, write all those causes down on a sheet of paper or into your phone. Don't just assume it's one thing or person at the root of the problem, more often than not it will be a whole raft of different issues. I believe that actually physically scribbling something down or keying it into your smart phone somehow objectivises it, makes it less of a threat, more of a logical problem which can be resolved. Try and break your problem down into categories: caring, financial, mental health, and so on.

(3) What solutions do you have?

Can you think of a way of either solving or mitigating the problem yourself? Don't expect to be able to resolve a complex problem or range of problems to vanish with a wave of your magic wand, especially a counterfeit Harry Potter one, but you may at least be able to get them down to a dull roar, so to speak.

(4) If none, what do you do now?

Say that you cannot think of a way out of the particular can of worms you find yourself in. What do you do next? The one thing you should not do is: nothing. Don't try and brush it under the carpet, not least because that location will already be filled to bursting with a hundred other matters you have tried to avoid dealing with in the past. There are a number of pretty obvious ports of call, depending on the nature of the problem(s).

If it is health related, either for your loved one or yourself, get on the phone at once and call for an appointment with your doctor, or if it is urgent, dial 111 in the UK for advice, support and, if needed, action. If it's legal, try your solicitor or Citizen's Advice. One important suggestion: if you are about to contact any of these agencies or individuals, make a written note (or electronic memo to self in your phone) of all the issues you want to discuss or ask about. Otherwise, given that you might well be in a stressed state, you will surely forget to include something important.

Dear journal

One way of seeking to come to terms with the declining state of your loved one which gets an occasional mention in books on the subject, and which I have found very valuable in trying to hold myself together during that period, is to put your thoughts down on paper, particularly when you are especially distressed, and then revisit them in a quieter moment. You can read through them more objectively, and this can assist you to see them with a more detached frame of mind. I know, I am repeating myself here, but as I used to say to my students, I never let repetition or incoherence get in the way of my lecturing. Seriously, though, it is a notion which I hope you feel is worth having a go at.

The idea came to me some years ago when my wife asked me to buy her a couple of blank notebooks in which she had two main objectives: first, to note down the growing challenges and confusions of her advancing illness in an attempt to make some sense of them and to record her daily experiences; and secondly, to step back from day to day concerns and put into words the more general nature of her experience and how it was casting a growing shadow across her abilities to cope with life and comprehend what was happening to her.

Her accounts spoke of the daily struggle to achieve ordinary things. This is a representative example of what she would write, taken from one of her journals:

> I fell in the second bedroom … I'm bored but I also like the quiet time. Rex has his plans for the day and gets going with it. He makes breakfast, reads the newspaper and is determined to complete the daily crossword, having had his Alpen. … I get anxious and stutter/stammer… My conversation just goes round and round about medication… I must have spent years trying to perfect the schedule for the day's medicine charts… My letter writing is so erratic, as is everything around me…My tremors — I have become more openly aware of them, and my wobbly leg.

This poignant (not to say heart-rending) account is typical of what she wrote in down in an increasingly illegible hand and it brings more than a tear to my eye just to read it. Experiencing those feelings and emotions is bad enough; it's almost worse to revisit the insights of someone who is aware of what is happening to them but is powerless to challenge the inevitable onward march of the illness.

My wife had long since given up her writings, at first partly because of attention span issues, but because her state of inner confusion increased way beyond the point at which she could stand aside and evaluate her condition with any degree of objectivity. I suppose it was observing her scribbling away that partly prompted me as a writer to express my own experience of caring for someone with Parkinson's and its shift towards dementia. You may derive some comfort from reading your loved one's writings and your own, if you are a closet diarist.

Talking to someone

Let me turn now to another aspect of external help. I have stressed in an earlier chapter how much you are on your own in your situation, but that does not mean that you should avoid seeking specific support from others. There are a number of considerations to bear in mind here, setting aside the likelihood that there will be a waiting list and you may have to be patient for a time before someone is available to talk to you. In that respect, I was extremely fortunate, particularly with the local GP service, when I had an appointment booked within a few days.

The first consideration is who you should talk to, and in my own view, it should not be anyone who knows you personally, but rather an individual who has some training and expertise in this area. You might well find that a good friend will be reluctant to stray into difficult questions which might cause challenges to your friendship itself. In other words, they may pull their punches and not be inclined to call the proverbial spade a spade. So given my own experience, I recommend an outsider. Now there are two more questions to resolve. The first is: should it be a one-to-one personal meeting on a regular basis, or something more detached, like phone line consultations? The second question is: would you rather talk to a man or a woman about your problems?

Then there is one more issue. Where do you go in order to find help? One good starting point in the UK is the NHS website. Go there and search for 'talking therapies'. You will see that you can either refer yourself or opt to go via your local GP or Health Centre. Such arrangements are both confidential and should be free of charge. The Alzheimer’s Society has very good information on the subject, and I recommend going to their UK website and typing ‘talking therapies’ into the search bar. I am not qualified to explore in detail the various kinds of therapy from CBT (cognitive behavioural therapy) to a friendly chat, and that is in any event a matter for discussion between you and the organisation or individual potentially offering support.

Having experienced various forms of therapy in the past, though, my personal view, for what it’s worth, is that an unstructured conversation is far more beneficial than an interaction based on some outwardly imposed orthodoxy. An intensified version of a private chat is far more effective than working though a predetermined series of steps in the hope of bringing you some unspecified benefit.

You may be wondering what kind of help I sought and the value I placed on it. It began with a lady from social work, then a local charitable umbrella organisation offering telephone counselling, and thirdly a scheme running in Scotland by the Alzheimer’s Society, again by phone. Those past consultations ran intermittently over a period of years. Finally, I somewhat hesitantly agreed to a face-to-face talking therapy consultation with a volunteer in our local Health Centre. All these sessions were weekly and lasted over a period of five weeks or more. That appears to be the normal lifespan, as it were, of the number of sessions which produce the most benefit without becoming too repetitive or running out of steam generally. Each session would last around an hour. In each case, I found the outcomes extremely valuable and the people concerned delightful and professional. There was just one separate situation where I parted company with a counsellor at the end of the first hour, as we both knew that the discussion was going to get nowhere, as she was bringing too many of her own opinions to the party. Do not be afraid to cut short any arrangement which isn’t working for you.

Why women? I just felt more comfortable talking about certain difficult matters with them than I guess I would with a male counsellor, but that is just my personal view and experience. OK, I was a war baby, my father spent six long years in Ceylon (as it was before being rebadged) and during the aftermath he was in Berlin, and it was a bit of a bumpy ride for us both when he reappeared on the domestic scene.

In each case, of course, what was said was entirely confidential and the greatest value I drew from those sessions was that I was able to explore in a more positive way some of the problems which were, to put it mildly, bugging me, without finding myself going round in an unproductive circle. The counsellor was able to encourage me to develop a position on a subject and move forward, maybe not in huge amounts, but gradually over time. My own experience of each of these ladies, who shall remain anonymous but they know who they are, was entirely positive, and I have nothing but praise for them. Two issues which I thought might cause problems were first, meeting someone face to face, when most of the previous sets of consultations were by phone, but the counsellor put me at my ease almost immediately. The second issue comes after four or five weeks when you might feel that the consultation process with that counsellor has run its course, and it can be tricky to articulate that without wanting to sound in any way as if you were tiring of that particular individual or that their input has not been of much value. Don't worry; they are prepared for a series of sessions to come to their natural close without in any way reflecting negatively on themselves.

Going online for help

Many people who should know better turn their pretty noses up at recommendations to go online for information and support. Wikipedia comes in for a lot of criticism, and Google's search results are not always welcomed with open arms. Why is this the case? The fact that Wikipedia is created and maintained by volunteers seems to bring academics in particular out in a rash. And if you Google 'medication' you will find that just about everything except plain water can kill you if you happen to be susceptible to some obscure side effects. And water, too — you can drown in that.

I am not defending misinformation or badly written or presented material, although I might delicately point out that such stuff is not the exclusive property of the internet. There has been plenty of dubious material in the old-fashioned print world going way back over the centuries. All I would recommend is that you use the common sense you were born with to check facts, take second and third opinions and ensure that you are reading material from a reputable source. Just because some of the people are scammed some of the time does not logically mean that the whole enterprise should be condemned out of hand. Hard cases make bad law. Anyway, enough polemics.

The internet is an incredible resource and, used wisely, makes life immeasurably easier for all of us. There are enough reputable sites out there in the sphere of public information — government and local authority information — and from the charitable sector — Mind, Alzheimers Society, and so forth — for you to draw on their expertise to help you confront the challenges of caring for a loved one with dementia. So, be wary, but do not be deterred. Remember the well-known computer saying: Garbage in, garbage out.

Maintaining a routine

The one aspect of daily life with a loved one with dementia which dominates all else is the routine, from getting up first thing in the morning, then 'gardy loo' from the commode chair, followed by washing, teeth cleaning, dressing and so it goes on—and on—until the lights are turned off at some late hour of the evening. Then, suddenly, one day, there is no one to care for, and the lack of a pattern for the day imposed from outside can be pretty devastating. At this point, you should sit down with pencil and paper and sketch out a daily routine for yourself. It will be wildly different from one person to the next. If you are a keen gardener with a reasonable amount of outside space to indulge your passion, the problem solves itself. If, like me, you are a writer working on this book and a fifth novel at the same time, the day can fly past in the blink of an eye. At the other extreme, you may have no particular dominant activity, and you may occupy yourself with daytime

TV, the cryptic crossword in the newspaper, a walk with the dog and a chat with a neighbour over a fence.

All those situations have their dangers: I buried myself excessively in my work, and it became an obsessive cloak covering my distress at the painful situation I found myself in. So, to be rather dull and boring again, do acquire a sense of moderation in all things. If you have a keen interest, ration it to a reasonable extent; if you have little outside to attract your attention, go out in search of some activity which can fill part of your day or week. In addition, it is vital that you continue to run the house and ensure your own well-being. Have regular mealtimes and do have at least one hot meal per day. Make sure the bedding and other washing is properly managed and the house or flat cleaned regularly. Impose a pattern on your day, if you have to, but sitting staring at the living room wallpaper and that wretched flight of ceramic ducks for hours on end is a self-destructive activity which will not end well.

Exercise

Being a long since retired academic, I tend to follow the observation of some wise person or other, namely, that the only exercise professors take in their retirement is jogging their memory and jumping to conclusions. My kind of exercise is based on a quotation from an unknown source which went something like this: ‘Exercise is playing chess with the window open.’ However, I must confess that I am an outlier on this subject.

Here comes one final point which I hope you have absorbed by implication, but for the medics who might read this, it is vital to recognise that my intention is not to promote the cause of the carer to the exclusion of all else. Quite the contrary. Improving the lot of the carer has a direct positive impact on the condition of the loved one. The more informed the carer is, the higher the quality of interaction with the loved one, and that implies a direct measurable benefit to the loved one. For more detailed information, read Kitwood (p119ff. See Bibliography), especially with reference to attachment theory.

Chapter Nine —Home alone

At age eighteen, our daughter entered education college just a few miles down the road from here. What surprised both my wife and myself was my wife's strongly negative reaction to this event. To her astonishment, she found herself almost grieving for the loss of her child from the nest. At that time, no one had come up with the phrase 'empty nest syndrome', or if they had we had not heard of it, but the impact was nonetheless pretty powerful, and it took her some while to recover. Now it is a well-recognised part of a rite of passage which somehow goes awry, and a while back the former poet laureate Carol Ann Duffy edited a collection of poems entitled *The empty Nest. Poems for Families.* Her own understated contribution tells of how 'the house pines when you leave' and contains the beautifully crafted line:

> Our house hides its face in hands of silence.

Only it's not the house which is grieving, it's her. And this kind of reaction to loss is not the exclusive province of parents with fledgling children straining to fly away on their own. It can also happen with carers who now suddenly find themselves on their own. When you return from taking your loved one to the care home, ensuring that the settling in process is as painless as possible, you open the door and enter a building from which one long-term occupant is now permanently absent. If it can be that painful when you are sending a child away to college or university, from which they will return at intervals, their luggage bulging with unwashed laundry, possibly trailing a new boyfriend or girlfriend in their wake, how much worse it must be when you send your loved one away to a care home where they will fade away over a lengthy period of time and never return.

In Duffy's collection, there is a poem by C Day Lewis which summarises the departure of the grown-up child in these poignant words:

> How selfhood begins with a walking away,
> And love is proved in the letting go.

But in the case of the loved one with dementia, selfhood is no longer evolving, it is beginning to wane, and the letting go is not a sudden rupture of the apron strings, as it were, but a drawn-out painful and increasing sense of loss. That pain may well be acute, the sense of abandonment raw, not infrequently mingled with an intensity of guilt at somehow not having done enough to spare yourself and your loved one the chasm that has now opened between you, but please do remember one key factor in all this. Do not be tempted to jump to hasty conclusions. Do not even consider moving house, for example, unless circumstances compel it, because of the siren allure of the ‘fresh start’ in a shiny new sheltered apartment. You are part of the home which remains, and the wrench of being displaced from it and deposited in an alien environment with no sense of the past in it could well be far worse. If you are tempted to move, can I suggest you take a peek at my book *Parkinsons — the slippery slope to dementia* (pp79ff; check the Bibliography under Bill King for details), and read my in-depth section on the pros and cons of contemplating a house move after the loved one has moved. Apart from all the many practical and financial issues involved, you should be aware of the potential problems in relation to your overall mental health that it might cause.

Finally, by way of a footnote: no, I am not trying to medicalise (to use the awful term) yet another aspect of the carer’s sufferings, I am simply pointing out that the time of transition from home to care home potentially constitutes yet one more serious challenge to you in your journey as a carer. Some people may overcome that experience quite swiftly, with others the sense of distress can endure for a very long time.

Rewards

One of the most difficult aspects of being a carer in this new situation is that there appear to be precious few rewards for an exhausting job well done, and even less for those looking back on past daily caring. Rewards are important in life generally, and in a positive relationship, we are always offering one another rewards, often in simple, verbal form: ‘Thank you, that dinner was great’, to ‘I like the dress/suit/jacket/shoes, etc.’

When the dementia reaches a certain stage, that level of interaction disappears and you have to endeavour to seek an alternative approach to rewards. Do not take an absence of reaction by a loved one to be a negative response, as they are simply lacking the ability to do so any more. It is also frequently the case that the loved one shows a lack of any reactive response in their facial features, and that is also an aspect of the disease as it progresses. With dementia, you have to prepare yourself for the fact that on many levels the kind of interaction you have grown accustomed to over the years disappears, and it can be incredibly isolating to recognise and understand this. I recall a little while ago receiving a very positive response to a book manuscript of mine from a publisher, which I printed out and showed to my wife on my next visit to the care home. The response was zero. It went down like a lousy comedian on a Friday night at the Glasgow Empire. It was all part of a world long lost to her.

So I showed it to a couple of close friends, but it wasn’t the same. I needed her to react and share my pleasure, but that ship had long since sailed. Human beings thrive on interaction and responsiveness at all levels, and to find myself, as it were, talking to a brick wall was pretty hard to face. If you are not familiar with the wall reference, I was beginning to empathise with the eponymous Shirley Valentine and her one-sided conversations with the kitchen wall at home and a rock by the sea on a Greek island (a play by Willy Russell which became a successful film).

But how do you cope with this kind of situation? Sounds a bit daft, but what you could try is to find some means of rewarding yourself. You may react to such advice by saying that it is a very artificial and unreal thing to do, but believe me, it can work, even in the face of the evidence. It brings to mind a research project (there may have been many more) in which patients were given genuine medication or a placebo. It reached the point at which even when they knew it was a placebo being administered, it still worked for them and improved their symptoms. And that, I believe, is how you can make self-rewarding work. So, how do you go about this?

A demonstration of this placebo effect, I believe, can be found in the behaviour of young children. When they perform a task well, like cleaning their teeth or helping to walk the dog, you can reward them with a sticker which can say something uplifting like ‘Well done!’ These modest merit badges seem to be very much treasured by the children and the adult version could be a list of rewards from which you could select one. Smokers could award themselves a cigar, drinkers a single malt instead of a blend, chocaholics one of those seriously expensive bars of 80 per cent chocolate, and I am sure that human ingenuity can come up with very many more such delights specially tailored for your pleasure. Reading about this concept of self-rewarding, I actually came across a suggestion for one reward somewhere online, and that was to spend an hour or so painting your bedroom. I can think of kinder forms of torture than that, but, in the powerful words of the Yorkshire dialect, ‘There’s nowt so queer as folk’.

Chapter Ten — Answering the question

At the beginning of this book, I set out to answer questions. The first was why am I writing it, which I hope I have answered, and the second was who am I writing for. I began by writing for carers of dementia patients. That grew into an awareness of a need for broadening my theme, bewailing the lot of the carer from the rooftops, and finally into a recognition that this was not just a disaster happening to our current generation of carers, but one which is growing exponentially as the years go by.

So, in summarising the answer to my second question, I am going to ask you to imagine two patients turning up at the doctor's surgery and come to a conclusion about each of them. First, let me set the scene. We are a fly on the wall in a doctor's consulting room and there are just two patients left sitting in the waiting area at the end of a long day's series of appointments.

The first patient is called, enters the doctor's consulting room and sits down. 'I hurt — here,' says the patient, pointing to a spot on his anatomy. The doctor examines the location, explains what the problem is, and reaches for the computer keyboard to print out a prescription form.

'Take two of these tablets per day for a week and you should be fine. Otherwise, come and see me again.'

The patient exits, satisfied by the interview and heads for the pharmacy.

The remaining patient in the waiting room is summoned and sits down in the doctor's consulting room. 'Where do you hurt?' asks the doctor. 'Nowhere,' comes the rather puzzling reply.

'Then why are you here?'

'I'm told that my circumstances mean that I will be suffering from all these symptoms in five or ten years time.' The patient hands a sheet of paper to the doctor.

‘In that case,’ says the doctor. ‘Come back in five or ten years time.’

How do you react to those scenarios? I pause the story at this point. There is more to come in a moment.

Let me try and disentangle what is going on here so far, and what is signifies. In the first case, the typical pattern of patient-doctor interaction is described: the patient indicates there is a problem, the doctor investigates, uses their knowledge of medicine and of the individual before them, prescribes a treatment pattern, and gives a prognosis. Problem solved. But what about the patient with no symptoms? Please believe that I am being deadly serious here, it’s not one of my obscure attempts at humour. I am using one individual patient to represent the countless thousands who will develop debilitating symptoms in the future but for whom there is currently no pre-emptive treatment pattern. Let me just add a finishing touch to the account of the two patients in the doctor’s consulting room.

As he leaves the surgery, the second patient turns back to the doctor and says: ‘You are right. I have no symptoms, but I represent all the countless thousands like myself who will darken your doors in the future. If you do not now give us the tools to mitigate the mental burden of caring and loss which will be our fate, you will be overrun and overwhelmed by a tsunami of suffering carers yet to come.’

When I pointed this fact out to a healthcare professional, the response I got is along these lines: there are many different very deserving good causes out there all jostling together and holding out a begging bowl for resources. This is just one more good cause. Join the queue. The trouble is that if a hundred or more priorities are all jostling for attention at a time of financial pressure and the need for a total rebuild of the NHS, the temptation is to do nothing, because singling one out would be too challenging and too unfair towards the other urgent issues demanding resources. I’m not just making that up, I was a lay member of the local Health Board for long enough to witness more than enough of what I called emulations of the Grand Old Duke of York. A Powerpoint presentation would flash up on the screen and everyone applauded the initiative. Then the financial implications of the proposed innovation were examined and everyone would shake their heads sagely, and no further action would be taken.

My argument would simply be that the crisis of caring is such an overwhelmingly clear and present danger, one which dominates all others, that it would be utterly disastrous to ignore it and fail to take urgent steps to confront the increasing challenges now and in the future. We will live longer, we will probably enjoy much healthier lives, we will cost the nation in pensions and medical bills quite a small fortune, and hardly anyone is taking the issues seriously. One striking exception is the scholar Andrew Steele who tackles the subject of old age and its implications in a society in which we are all going to live — or exist — for many more years. (See Bibliography for details of his book.)

His is a fascinating and persuasive account of a hugely significant subject, one which has been preoccupying me throughout my experiences as a carer and a writer and YouTuber on caring. In it, Steele confronts the massive elephant in the room, namely, the fact that medical science is very good at postponing our deaths but pretty hopeless at ensuring that the extra years you are given on this earth are as disease and disability free as possible. His remarkable wake-up call to the medical and scientific establishment explores in sometimes overwhelming detail the issues facing people living, like me, long past their sell-by date, hoping for a life full of positive health and relatively pain and illness free years, rather than withering away in a care home on a heartbreaking one-way journey to the crematorium.

The message is clear: the opportunities for the biogerontologist like Steele to explore and conquer areas like gene therapy and cell senescence are just crying out for the scientific community to turn their attention to. That is not least because they will all themselves otherwise end up on the receiving end of a painful old age with diminishing powers and awareness, a time of losing and decrepitude, rather than a rich and rewarding culmination of a life well lived. Here Steele distinguishes sharply between ‘lifespan’ and ‘healthspan’. It sounds at times like science fiction, this business of stemming the tide of old age or even to some degree reversing the ageing process, but it is an achievable goal rather than a vague and unattainable aspiration.

The other huge question which remains to be resolved is that of either holding back the progress of mental degenerative diseases, or of preventing or curing them altogether. It brings to mind an acronym popular amongst software developers anxiously being asked when that new program suite will finally be ready. Reply: RSN. Real Soon Now. It's all rather like the politicians who have been seeing green shoots for a decade and more, but they do tend to be elusive, shrivel and fade away.

I have been keeping a tally of articles in my daily copy of *The Times* which hold out what appear to be visions of The Cure for Alzheimer's and other forms of dementia. Hardly a week goes by without one or more such promises of a new dawn, initially praised, then usually qualified in terms that indicate that progress is actually limited and partial, and it only works on white mice anyway. In fact, as I'm checking through the more or less final version of this book, yet another magic bullet is trumpeted on today's front page, but if you turn to the continuation on page two, you read that, unfortunately, all is not entirely sweetness and light:

> There were side effects. A third of patients experienced brain swelling, and in two cases it was severe enough that it was believed to have caused their deaths.

By the end, in a typical back-pedalling from the enthusiasm of the headline and opening paragraphs, the report is now somewhat deflated by an admission from an expert that these new wonder drugs only slow the progression of the disease in some patients, but they do not stop it in its tracks or wipe it out. And, in a follow-up article the next day, the paper's science editor pours further cold water on the breakthrough by underlining the fact that the medication has to be prescribed as soon as possible after symptoms develop. Unfortunately, the typical delay in the UK before a diagnosis is somewhere around three years.

So for now, there remains, of course, the rather vexed question of how to stretch your pension pot over decades of post-work years, but human ingenuity has resolved worse problems in the past. At the end of his book, Steele enumerates ways in which the good life can even now be further extended, including moderate drinking, no smoking, diet, and so forth. His final recommendation is perhaps tongue in cheek, given that the ladies tend to live longer than the gentlemen, and it is: ‘Become a woman’. Now there’s a thought, a real can of worms in our politically correct times.

Before signing off, I have gathered together some of my words of wisdom in the following not too serious list, which you might care to attach to the fridge door to read through on a really bad day.

Caring for dementia — the rules

1. There is no rule.
2. Don’t take it personally.
3. No good deed goes unpunished.
4. Find another cheek and turn it.
5. Do not confront your loved one.
6. Roll with the punches.
7. Why me? Why not?
8. Deflect — don’t react to aggressiveness.
9. The better you are, the worse you will feel.
10. If all else fails, see Rule one.

In conclusion

Let me end by returning to you, the individual carer, and what I hope this book has achieved, in some measure at least. By arming you with the information to confront the demands of caring for your loved one and the even greater challenge of coping with a life on your own with an uncertain future, I do hope that you have gained greater confidence to confront the challenges you face.

I cannot resist a final anecdote, this time once more with the smart young man in the natty sports car, British racing green again, motoring along a country lane when he comes across another old countryman smoking a pipe and sitting on a milestone by the kerbside. In a moment of curiosity at the life of someone so different from himself and his own brash, hectic city ways, he screeches to a halt and leans across to the man.

‘I say, old man, you look happy sitting on that stone.’

‘Indeed, I am, zur.’

‘Tell me, good fellow, have you lived hereabouts all your life?’

The old man puffs at the pipe and smiles at the obvious question. He pretends to ponder long and hard, then speaks.

‘No zur, not yet.’

Uttered without a trace of irony, those words encapsulate the old man’s acceptance of his lot so far in life, the contentment that every day holds for him, and a hint of optimism about the future.

I hope that from reading my book you have gained a measure of that old fellow’s acceptance and contentment, too. Optimism may take a little longer.

Bibliography and other resources

Books

There are almost too many books on the market on dementia and related mental illnesses. I offer a list of those I consulted in most detail during the preparation of this book and found valuable.

Simon Atkins, *Dementia for Dummies*, John Wiley, 2015. One of the huge ‘dummies’ series, with the garish yellow cover, offering advice on a subject aimed at the general public. Almost overwhelmingly comprehensive, and useful as a resource on just about every aspect of dementia.

Richard Bates (ed.) *Who cares? Joys and Challenges of unpaid Carers,* Discript, 2021. A fascinating collection of essays by various hands on a variety of different caring situations..

K H Denning (ed), *Evidence-based Practice in Dementia for Nurses and Nursing Students*, JKP, 2019. Does what it says on the tin. It is a pretty readable and well-organised study course on dementia.

Annie Dransfield, *Releasing the Compassion,* Amazon, 2021, is a blistering account by a carer who, like me, has been driven into print by the way the system treats (or doesn’t) carers and their loved ones. Well worth reading.

Frederick Earlstein, *Dementia. Facts and Information*, Amazon, 2016. A quick read though some of the headline topics surrounding dementia.

Lisa Genova, *Still Alice*, Simon and Shuster, 2007. This debut novel by a neuroscientist became hugely popular as an account of Alzheimer’s and the way in which it impacted on a leading academic. Worth a read, although I found it a bit stodgy in places. Kleenex required.

April Goff, *A Survivor’s Guilt*, Amazon, 2021. Although this personal account is targeted at survivors of sexual abuse, there is more than enough generally useful and valid material for it to be worth a read. Well written, sympathetic and insightful, it covers

many aspects of the process of recovering from traumatic experiences generally.

Jan Hall, *Dementia Essentials,* Vermilion, 2020. This is a pretty uninviting title for possibly the best — and best written — exposition of the issues facing people with Alzheimer's or dementia and those caring for them. It manages to be lucid without shying away from the complexities of the subject matter, and I can do no better than steal part of the contents of the back cover blurb:

‘Among these pages you will find:

- ➢ Latest advice on medication and getting support from local healthcare professionals.
- ➢ Ideas for encouraging independence, while reducing anxiety and confusion.
- ➢ Guidance on preparing for the future, including legal and financial advice, and choosing a care home.
- ➢ Strategies for coping as a carer, understanding your emotions and feeling more empowered.’

Highly recommended. Note that all proceeds from the book go to charity.

Mary Jordan, *The essential Carer's Guide to Dementia*, Hammersmith Health, 2014. Well researched and written guide to aspects of dementia.

Emily Kenway, *Who Cares. The hidden crisis of caregiving and how we solve it*, Wildfire/Headline, 2023. Just out, so I have not been able read this in full. The extract I have seen is a powerful, personal and very angry account of a carer in a different field, cancer, but with many of the same problems and issues. Strong stuff, and positively reviewed.

Bill King, *Parkinsons — The slippery Slope to Dementia*, Amazon, 2021; and *Dementia. what every Carer needs to know*, Amazon, 2022. I can hardly recommend my own efforts. Bill King does not exist, it's a pseudonym I adopted for various reasons, since at the time it was necessary to keep our family identities very private. The two books, copies of which I gave away freely to local organisations, are highly recommended amongst others by Murdo Fraser, MSP, Dennis Melloy, former Provost, Perth and Kinross, and Raymond Jamieson, PKAVS

(Perth and Kinross Association of Voluntary Service). All proceeds to charity.

Tom Kitwood, *Dementia Reconsidered, Revisited. The Person still comes first,* Open University, 2019. This is the second edition, in which Kitwood's text is set against more recent views. Make sure you get this later edition. A fascinating read, if you want to take up the challenge. There is some technical stuff, but the human and humane qualities of Kitwood and the editor of the new edition, Dawn Brooker, shine through. I had to stop reading the book several times, so painfully and poignantly accurate are his observations about patient care.

Wendy Mitchell *Someone I used to know*, Bloomsbury, 2019. A prominent NHS manager works on despite the challenges of dementia. A heart-rending account of one woman's attempts to live on despite her diagnosis. Pass the Kleenex.

Wendy Mitchell, *What I wish people knew about Dementia*, Bloomsbury, 2022, is the follow-up to the previous book. More paper handkerchieves to the ready.

(As I was at the second proof stage of this book, a further 'final' book by Wendy Mitchell has been published. Entitled *One last Thing*, it has been well received.)

Jane M. Mullins, *Finding the Light in Dementia,* DUETcare, 2017. Easy to read information and support for the carer. Filled with practical advice.

David Pulsford and Rachel Thompson, *Dementia. Support from Family and Friends*, Jessica Kingsley. 2013. Offers a detailed guide to dementia and how to care for a person with the illness.

Shibley Rhaman and Professor Rob Howard, *Essentials of Dementia*, JKP, 2018. This is a textbook for students, but is nonetheless well worth reading as it is a model of clarity and comprehensiveness.

Andrew Scull, *Desperate Remedies. Psychiatry and the Mysteries of Mental Illness*, Allen Lane, 2022. A challenging read if you are fascinated by the story of mental illness and its treatment. It's depressing reading, too, as it claims that mental illness treatment underperforms today as it did a century ago.

Andrew Steele, *Ageless. The new Science of getting older without getting old*, Bloomsbury, 2020. This is a fascinating and persuasive account of a hugely significant subject, one which has been preoccupying me throughout my experiences as a carer and a writer and YouTuber on caring. In it, Steele explores the possibilities of extending the healthspan of mankind while at the same time extending the lifespan. You can grow old without passing your final years borne down with disabilities and illnesses dominating your waking hours, but the scientific community has yet to wake up and smell the coffee.

Films

There are a handful of worthwhile films around on the subject of degenerative mental health issues, especially dementia. I have not seen Julianne Moore in *Still Alice* (2014), the film of the novel referred to just now, but I guess it will be worth it just to watch a star actress at work. Alec Baldwin also features.

There are two British films which my wife watched with me way back in the days when dementia was something which happened to other people, not us. The first is *Iris* (2001), another production with two fine actors, Judi Dench and Jim Broadbent. This will just about tug the heartstrings out of you. It's an account of the novelist Iris Murdoch, her younger days and her descent into Alzheimer's. If you see a CD of the musical score in a charity shop, grab it and weep.

Next up is *The Iron Lady* (2011), with Meryl Streep brilliant in the title role, and Jim Broadbent equally compelling as Dennis Thatcher. It explores the contrasts between Lady Thatcher's past glories and the challenges of dementia. Some reviews were unkind, but Streep as Thatcher steals the show.

Can I also mention *Awakenings* (1990), with Robert de Niro in the lead as a doctor who promotes L-Dopa for the treatment of Parkinsons in catatonic patients who are temporarily revived by the experiment. Sounds dry and technical but it is an extremely sensitive and moving account of mental illness.

And finally, for more films on dementia there is a website about them, too:

www.verywellhealth.com/movies-about-dementia-and-alzheimers-disease-97664

This site lists movies on the theme of dementia, but they do come with a gentle reminder that these are above all intended to entertain an audience, so they may not be entirely in line with the facts of dementia, and also they may well sideslip the more uncomfortable issues involved.

Websites

How long have you got? The internet is crawling with sites about dementia in all its manifestations, and many of them duplicate information and advice.

A lot of them are from profit-making organisations but that doesn't mean they are not to be valued. I was very much impressed by www.completecare.ca. This is a company specialising in dementia care. They do have pages of excellent advice, and I acknowledge that I have exploited some of it in this book.

In the UK, the www.carersuk.org website focuses on the needs of carers and is very well worth a visit. There's a well-designed site from www.ageuk.org.uk, but for me top of the list is the Alzheimer's Society website, which has an almost overwhelming amount of quality information on hand. Reach them at www.alzheimers.org.uk. Other websites well worth a look:

www.dementia.org.uk
www.cruse.org.uk (bereavement advice)
alzheimers.org.uk

The Alzheimer's Society has an excellent webpage on the feelings of loss and grief as dementia advances. To access the rich variety of offerings from this excellent site, enter a word or phrase into the search box on their home page.

I end with an annotated list of some of the individual pages I have found valuable in my trawl of the internet for information and enlightenment. For the most part I suggest you just google for the keywords, rather than trying to type in long website names:

Alzheimer's Society pamphlet Caring for a Person with Dementia (in PDF format).

Alzheimer’s Society page on How can dementia change a person’s perception?
Search for Feelings of guilt in Dementia.org.
Cruse bereavement Wales. Search for Bereavement, Loss and Dementia.
dementiaUK has a useful leaflet on Grief, Bereavement and Loss.
Family Caregiver Alliance. Search for The Emotional Side of Caregiving.
Taking Care of YOU: Self-care for Family Caregivers. Also from Family Caregiver Alliance.
On the Cruse website, search for Anticipatory Grief.
The International Longevity Centre (ilk.org.uk) has articles on older age intimacy.

With reference to the last item above, this is a key worldwide organisation which concentrates on all aspects of ageing. The articles on intimacy in old age can be found by clicking on the search icon (the magnifying glass) and typing ‘sexuality’ to see their information on this subject.

One topic which nearly passed me by, but one you can easily look up on, is dementia-friendly baby dolls, animals and pets. These lifelike toy creatures are invaluable in giving emotional support to loved ones with dementia. Search for ‘dementia-friendly dogs’ on the Alzheimer’s Society website, too.

YouTube

You may be surprised to see YouTube gaining special attention and a subsection all to itself, but it is one of the most wide-ranging and widely used resources online. There is hardly a subject on the planet which is not extensively covered by some video or other, from entertainment to self help, and information on anything you can name.

The mental health world is fully covered, and I could not begin to scratch the surface of the wide range of every aspect of dementia which is on offer. All I suggest is that you use the search box at the top of the Youtube home page and type in your request. You will be swamped with results, and you will soon begin to select the approaches that suit you and your needs. I am going to be very arbitrary and draw your attention to two channels (to use the YouTube jargon), which can act as starting points for you to explore further.

The first is Dementia Careblazers where Dr Natali Edmonds dispenses all kind of dementia advice. I find her approach straightforward and persuasive.

Or, if you are really desperate, go to my website at www.locheesoft.com, where you will see a link to my books in the field of Parkinsons/dementia for carers and links to my YouTube presentations in that field, including a couple on making your home more user-friendly, which relate to Chapter Four of this book.

Closing quotes

The difference between an optimist and a pessimist? An optimist laughs to forget, but a pessimist forgets to laugh.
(Tom Bodett)

If you have nothing to say, say it.
(Me — advice to our teenage children)

No good deed goes unpunished.
(Oscar Wilde, but it was first recorded way back in the 12th century)

If you think this Universe is bad, you should see some of the others.
(Philip K. Dick)

At the core of dementia is a gradual retreat from the reality of now.
(Jan Hall)

For after all, the best thing one can do when it is raining is let it rain.
(Henry Wadsworth Longfellow)

Happiness is not a goal...it's a by-product of a life well lived.
(Eleanor Roosevelt)

Fortify yourself with contentment for this is an impregnable fortress.
(Epictetus)

Happiness is wanting what you have.
(Phyllis Reynolds Naylor)

True contentment is not having everything, but in being satisfied with everything you have.
(Oscar Wilde)

At some point, you gotta let go, and sit still, and allow contentment to come to you.
(Elizabeth Gilbert)

Do everything as if your life depended on it — because it does.
(Anon.)

Now and then it’s good to pause in our pursuit of happiness and just be happy.
(Henry Fielding)

Time heals all wounds. But not this one. Not yet.
(Marie Lu)

Some people see scars, and it is wounding they remember. To me they are proof of the fact that there is healing.
(Linda Hogan)

Don’t base your decisions on the advice of those who won’t have to deal with the results.
(Anon.)

Happiness is a butterfly, which when pursued, is always just beyond your grasp, but which, if you will sit down quietly, may alight upon you.
(Nathaniel Hawthorne)

It’s not the years of your life that count. It’s the life in your years.
(Abraham Lincoln)

Love yourself first and everything else falls into line. You really have to love yourself to get anything done in this world.
(Lucille Ball)