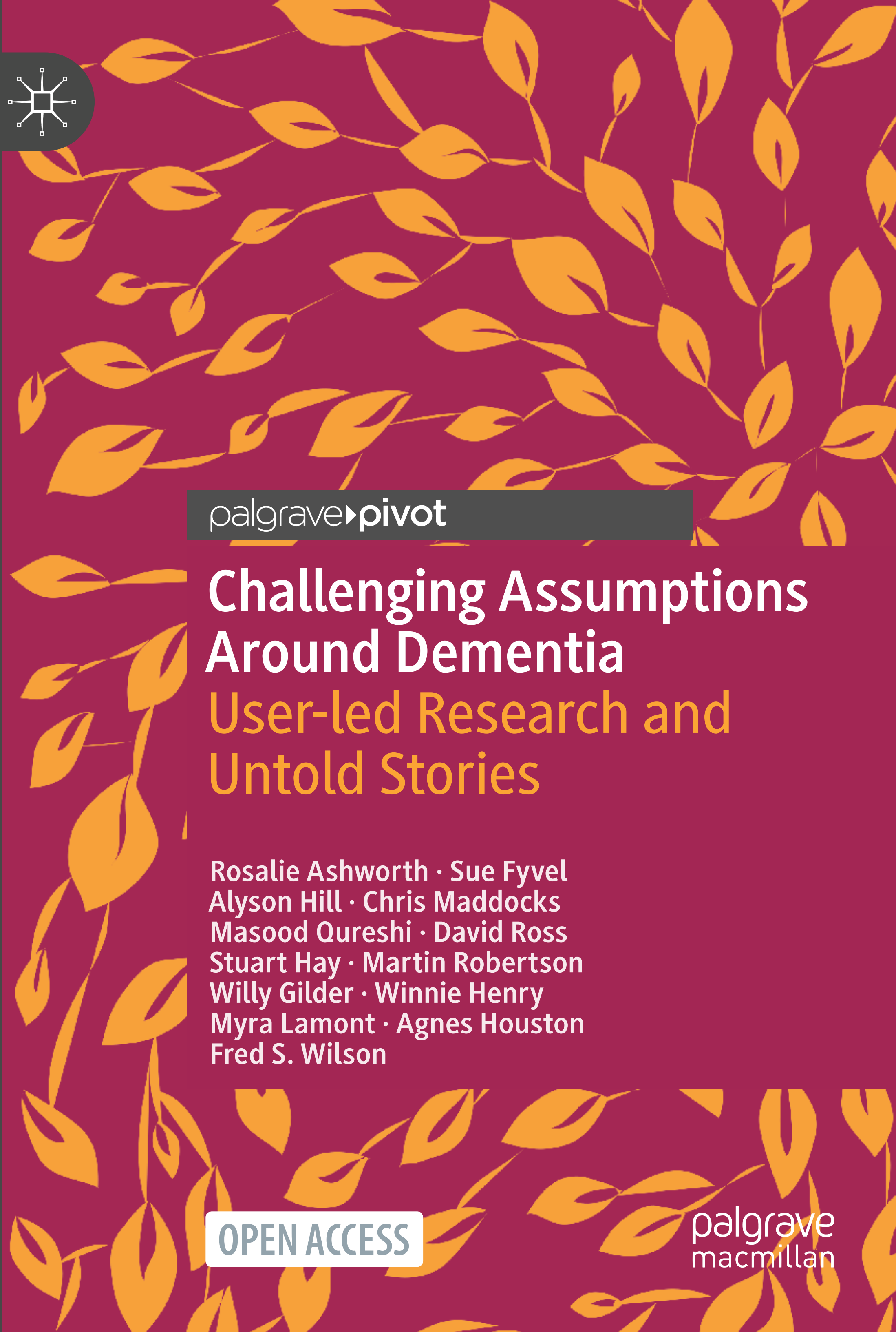


palgrave▸pivot

Challenging Assumptions Around Dementia

User-led Research and Untold Stories

Rosalie Ashworth · Sue Fyvel
Alyson Hill · Chris Maddocks
Masood Qureshi · David Ross
Stuart Hay · Martin Robertson
Willy Gilder · Winnie Henry
Myra Lamont · Agnes Houston
Fred S. Wilson

palgrave
macmillan

Challenging Assumptions Around Dementia

Artwork created by Willy Gilder

Rosalie Ashworth • Sue Fyvel
Alyson Hill • Chris Maddocks
Masood Qureshi • David Ross
Stuart Hay • Martin Robertson
Willy Gilder • Winnie Henry
Myra Lamont • Agnes Houston
Fred S. Wilson

Challenging Assumptions Around Dementia

User-led Research and Untold Stories

palgrave
macmillan

Rosalie Ashworth
Partners in Research, Neuroprogressive
and Dementia Network
NHS Tayside
Dundee, UK

Alyson Hill
Partners in Research, Neuroprogressive
and Dementia Network
NHS Tayside
Dundee, UK

Masood Qureshi
Partners in Research, Neuroprogressive
and Dementia Network
NHS Tayside
Dundee, UK

Stuart Hay
Partners in Research, Neuroprogressive
and Dementia Network
NHS Tayside
Dundee, UK

Willy Gilder
Partners in Research, Neuroprogressive
and Dementia Network
NHS Tayside
Dundee, UK

Myra Lamont
Partners in Research, Neuroprogressive
and Dementia Network
NHS Tayside
Dundee, UK

Fred S. Wilson
Partners in Research, Neuroprogressive
and Dementia Network
NHS Tayside
Dundee, UK

Sue Fyvel
Partners in Research, Neuroprogressive
and Dementia Network
NHS Tayside
Dundee, UK

Chris Maddocks
Partners in Research, Neuroprogressive
and Dementia Network
NHS Tayside
Dundee, UK

David Ross
Partners in Research, Neuroprogressive
and Dementia Network
NHS Tayside
Dundee, UK

Martin Robertson
Partners in Research, Neuroprogressive
and Dementia Network
NHS Tayside
Dundee, UK

Winnie Henry
Partners in Research, Neuroprogressive
and Dementia Network
NHS Tayside
Dundee, UK

Agnes Houston
Partners in Research, Neuroprogressive
and Dementia Network
NHS Tayside
Dundee, UK

ISBN 978-3-031-27222-6 ISBN 978-3-031-27223-3 (eBook)
https://doi.org/10.1007/978-3-031-27223-3

© NHS Tayside 2023. This book is an open access publication.

Open Access This book is licensed under the terms of the Creative Commons Attribution 4.0 International License (http://creativecommons.org/licenses/by/4.0/), which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence and indicate if changes were made.
The images or other third party material in this book are included in the book's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the book's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder.
The use of general descriptive names, registered names, trademarks, service marks, etc. in this publication does not imply, even in the absence of a specific statement, that such names are exempt from the relevant protective laws and regulations and therefore free for general use.
The publisher, the authors, and the editors are safe to assume that the advice and information in this book are believed to be true and accurate at the date of publication. Neither the publisher nor the authors or the editors give a warranty, expressed or implied, with respect to the material contained herein or for any errors or omissions that may have been made. The publisher remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

This Palgrave Macmillan imprint is published by the registered company Springer Nature Switzerland AG.
The registered company address is: Gewerbestrasse 11, 6330 Cham, Switzerland

Paper in this product is recyclable.

ABOUT THE BOOK

Welcome to our book! Over the next six chapters, we will share our experiences of living with and/or supporting someone living with dementia. The chapters share our discussions on topics that we identified as particularly important to us. We also share our individual stories throughout the book.

Below is an outline of what you can expect to find in each chapter. During the process of book writing, we involved other voices where possible to present a wide range of experiences. Those authors have been named in the chapter or within their individual story.

CONTENTS

3 'How Does Your Dementia Affect You?' 45

LIST OF FIGURES

CHAPTER 1

Introduction

Abstract This chapter captures the working process behind creating this book. We look at the writing sessions, the experiences of getting involved, and reflect on the missing voices. An overview of dementia is given to act as a starting point for the rest of the book to build upon. The book is arranged around four core chapters, as well as individual author stories interspersed throughout.

Keywords Collaboration, Untold Stories, Dementia Statistics, Lewy body dementia, Vascular dementia, Lived Experience

Our book reflects a partnership between people with lived experience of dementia sharing their stories with academics, researchers, and clinicians to raise awareness, reflect on positive and negative experiences, and share hopes for future work and research.

The partnership stems from the work of the NRS Neuroprogressive and Dementia Network (NDN) Partners in Research. The group

---

Co-authors: Rosalie Ashworth, Sue Fyvel, Alyson Hill, Chris Maddocks, Masood Qureshi, David Ross, Stuart Hay, Martin Robertson, Willy Gilder, Winnie Henry, Myra Lamont, Agnes Houston, and Fred S. Wilson
Email: tay.ppipartners@nhs.scot
Neuroprogressive and Dementia Network, NHS Tayside, Dundee, UK

R. Ashworth et al., *Challenging Assumptions Around Dementia*,
https://doi.org/10.1007/978-3-031-27223-3_1

developed from the NDN 'Patient and Public Involvement' group, which is made up of people with lived experience of dementia and other neuroprogressive conditions with an interest in research-related activities.

As part of the latest NDN Strategy, people with lived experience have been positioned at the core, with space expanding within the NDN to prioritise working in collaboration with the group, who renamed themselves 'Partners in Research' (https://www.nhsresearchscotland.org.uk/research-areas/dementia-and-neurodegenerative-disease).

We hope our book helps people living with dementia, their family and loved ones, professionals who work with people with dementia in some way, and members of the public. We have taken a wide approach to our target audience because we see the book as a starting point for people to learn more about dementia. We have provided examples of resources that our co-authors have found helpful, as well as academic references to allow you to explore the content in more depth.

Meet the Co-authors

Each author has been involved in every chapter, as well as having their personal stories told between chapters of the book. We hope that you can get to know us better as individuals, as well as take away information that may help you.

Rosie Ashworth shares her experience as academic lead for NRS Neuroprogressive and Dementia Network Partners in Research.

Fred, using a pseudonym, shares his experience of living with Alzheimer's disease.

Sue Fyvel shares her experience as a carer supporting her mum, who had Alzheimer's disease.

Willy Gilder shares his experience of living with 'atypical' Alzheimer's disease.

Stuart Hay shares his experience as a carer supporting his wife Eileen, who has Alzheimer's disease.

Winnie Henry shares her experience as a carer supporting her husband Wullie, who had vascular dementia.

Alyson Hill shares her experience as a carer supporting her mum Sheila and her dad David with vascular dementia.

Agnes Houston shares her experience of living with 'atypical' Alzheimer's disease and supporting her husband with dementia.

Myra Lamont shares her experience as a carer supporting her husband Archie, who had semantic dementia.

Chris Maddocks shares her experience of living with Lewy body dementia.

Masood Qureshi (known throughout as MAQ) shares his experience of living with frontotemporal dementia.

Martin Robertson shares his experience of living with posterior cortical atrophy (PCA).

David Ross shares his experience as a carer supporting his wife Anne, who had frontotemporal dementia (Fig. 1.1).

Fig. 1.1 Co-authors joining together using video conferencing

LET'S WRITE A BOOK

One of the challenges our Partners in Research have faced is feeling that their experiences are being heard but not listened to. There is a sense that working in partnership to share people's experiences could add more credibility in certain contexts and ultimately reach a wider audience. We therefore decided to work together on a book that shares individual experiences as well as links with academic and clinical work in this area.

Partners in Research were invited to develop the book proposal as well as express interest in being co-authors of the book. We have been incredibly fortunate to have people living with different types of dementia, family of people living with dementia (spouse or child), and people who have worked around dementia join the book writing as co-authors.

We have worked together to ensure that the book is accessible in terms of both language and format. For instance, quotes have not been presented in italics to make them easier to read. We have opted for a larger font and greater line spacing than seen in other books. References to support our discussions can be seen as numbers within the text, and the reference list is provided by chapter at the end of the book. We have also worked with the Palgrave Publishers and Chief Scientist Office Scotland to secure open-access funding for the book, which means it will be freely available online.

The inside-cover art was provided by one of our co-authors Willy Gilder. The abstract art piece was created while attending the '100 In 6000 Dundee Dementia Conference'. A conference by people living with dementia, for people living with dementia.

WRITING SESSIONS

The book was written following the COVID-19 pandemic, with all book meetings taking place online. Although this meant that people who were unable to use platforms such as Zoom were less able to take part, it also meant that people from across the UK could contribute more easily.

Over the course of several months, online 'drop-in' sessions took place twice a week with the sessions dedicated to different chapters. Collectively, co-authors contributed over 50 hours of discussion and several hundred thousand words in transcripts. The discussions and transcripts were then used to form the final book.

Throughout the book, the priority has been keeping the wording of the co-authors as much as possible to ensure that their voices are what you hear as you read through. The quotes are grouped to reflect the different subsections of the chapter.

Individual stories were either typed up and sent through for Rosie to include in the full book or people had one-to-one sessions with Rosie. The one-to-one interviews were then transcribed, with as little editing as possible to stay true to the original, before being sent to the individual to review and approve.

The co-authors all had different preferences for the format of the chapters, how much of the drafts they were able to review at different times, and whether this was a physical or an electronic copy. In an ideal world, we would all have been able to edit the same document at the same time. However, due to things such as technology barriers, access to printing, and postal strikes, we had to coordinate comments as we went along with the understanding that this may change depending on when and how feedback was given. Where possible, additional drop-in video sessions were made available for co-authors to share feedback about the drafts and resolve ongoing queries.

Writing a book was a new experience for us all. Several co-authors have reflected on what being involved in book writing has been like for them:

> It's been really interesting, a good learning curve, and really interesting to learn from other authors. It has been a good platform to exchange opinions and lived experiences. I learned a lot of new skills in book writing. Hopefully, users will take on board the recommendation from the book. Co-production is the way forward. (**Fred**)

> When I joined Partners in research, I was not quite sure what I was expecting, but it certainly came as a surprise to me to become a co-author in a book. That was not the only surprise I received. I met a group of strangers online, with the only common thread to tie us together being the diagnosis, either for ourselves or for a loved one, of dementia. As time went on, these strangers became colleagues and then friends. I now look forward to seeing what other surprises Partners in Research can throw up in the future. (**Winnie**)

> I found it helpful to learn of others' experiences, which perhaps prompted thoughts of my own experience. I've learned more about different dementia types and how the book will be the beginning of something to build upon. (**Alyson**)

> One of the biggest challenges for me was accounting for the time it would take to go through transcripts and make sure that the key areas of interest were covered. As a group, we created a broad template of ideas for the book content, but we were fortunate to be able to keep this flexible. As the group got to know each other better, they began to offer each other peer-to-peer support, and areas that we hadn't originally planned started to come through. It is this mix of experiences and unexpected areas of interest that make me so excited for others to share in our work. (**Rosie**)

Missing Voices

Before moving forward, we also feel it is important to acknowledge the voices of people missing from this book. We have been very fortunate to have people from across the UK with experience of living with or supporting someone with dementia. We know that there are also people whose voices have been missed, whether that is due to technology literacy, access to post-diagnostic support, previous experience with or awareness of research opportunities, capacity for dementia activism, etc.

We do not intend for the experiences in this book to be generalised across all people living with dementia. Instead, we hope that it acts as a starting point for some of these conversations and a resource to build upon.

Emotional Content

Early research found that people respond best to a healthcare procedure when the information they were given fit with their preferred coping style, that is, knowledge-focused and information-rich, or emotion-focused with a more stripped-back amount of information.

Similarly, Rosie found that people facing a 'time-limiting' condition such as dementia tend to be driven to maintain their emotional well-being. In practice, this meant preferring to take a 'one day at a time' approach rather than looking too far ahead [1].

We know that learning more about dementia can be emotionally challenging, and it is important to be mindful of this when going through the book, especially for people for whom this is a present concern. The co-authors have shared some of the most difficult parts of their experiences in the hope that others will be able to find some solidarity, comfort, and useful information. You may find you want to read every chapter, or you may wish to use it more as a reference point. There is no 'right' way to use this book, and we encourage you to pick it up and put it down as needed. We sign post to other possible resources at the end of the book that you may find helpful if you would like to know more about specific topics.

Dementia Statistics Overview

Dementia is a neuroprogressive condition, which means it is something that affects the brain (neuro) and worsens over time (progressive). Alzheimer's Research UK [2] reports that just over 500,000 people in the UK have a diagnosis of dementia. However, the estimated number of people living with dementia is much higher at 885,000 [3]. The difference highlights that hundreds of thousands of people still do not seek or receive a diagnosis, potentially due to stigma, fear, not recognising signs and symptoms, and distrust of healthcare [4, 5].

Approximately 7% of people over the age of 65 are estimated to have dementia. Importantly, this also means that over 90% of people over the age of 65 do not have dementia. Approximately 5% of people living with dementia have early onset, meaning they are diagnosed under the age of 65 years old. This equates to approximately 42,000 people living with early-onset dementia in the UK. [6]

Alongside statistics about dementia, it is worth noting that there are also approximately 700,000 informal carers associated with dementia in the UK, that is, family and/or friends who provide unpaid support [7]. Carers supporting people with dementia are also more at risk of psychological and physical health difficulties [8], with lower quality of life than carers of people with other health conditions [9].

Finally, research has shown that the relationship between dementia and quality of life is not a linear correlation, that is, an increase in symptoms does not uniformly show decreased quality of life [10]. Research has highlighted the importance of activities of daily living and independence as contributors to quality of life, as well as the ability to adapt to change [11, 12].

Chris's Story

The first diagnosis was vascular dementia. I felt lonely, hopeless, lost, all those things. It felt like I'd had a death sentence. That was in 2016. But before that, I had three mini strokes between 2013 and 2015, which left me with some cognitive problems. I noticed such a change in things, but they kept saying to me, there’s nothing wrong with you. It is just because you’ve had the strokes.

I thought I was going mad. There was one day where I got up and I could not remember how to get dressed, and I just sat on the bed for ten minutes, and it came back to me. In the mornings, I have three things to do, feed the cats, take my tablets, and make myself a drink. I found myself wandering around the kitchen, and not actually doing any of them. I was struggling to get things done in the correct order. I went to my GP and I told them that something was not right in my head and she told me that she was there for my physical health and not my mental health. I left there in tears. The GP should be your first port of call, but my symptoms were ignored. It was only some months later when they saw I was having another stroke, and I lost some coordination in my hands. I ended up in hospital, and it was a consultant in the hospital who referred me to the ‘Elderly Care Assessment Unit’ even though I was 60. Even the name of that felt wrong. I thought I was just going there for an assessment, so I went on my own, but that’s when I got the diagnosis. I wasn’t expecting to get a diagnosis. It wasn’t good. I was given no information. I wasn’t directed to any services. It is just like, you’ve got dementia, get your affairs in order, type of thing.

I got a leaflet on vascular dementia. When I read it I thought, well, that’s me. That’s me. I ticked all the boxes. I gave a copy to my brother and my sister to read for them to understand it slightly better. I still do not know whether they read it. They never spoke to me about my dementia. It’s difficult, I was the eldest kid. My sister was a single parent, and so I was always back up support. However, when I got my dementia diagnosis, I could no longer do a lot of those things that I had automatically done for her. I had to start saying no. I like to help people and saying no to my sister was particularly hard.

I moved from Wales to England, now I’m living hundreds of miles apart from my siblings. I suppose it’s given me that time to look after me a bit more. However, getting continuity in healthcare support was impossible. The GP said ‘oh you’ve had your diagnosis’, and they didn’t want to know me. I had to keep on at them for three years before I eventually got to see a neurologist. That’s when I got the Lewy body dementia diagnosis. I don’t know whether I was misdiagnosed originally, or whether you can have more than one form of dementia. After that second diagnosis, I had a tremor in my arm, so I went to the Parkinson’s clinic because my dad had Parkinson’s disease. They said it wasn’t Parkinson’s but that I had a vascular Parkinsonism.

So, when I moved from England, I suppose my records were sent through, and the Parkinson’s nurse picked up on this Parkinsonism. She sent me an appointment to see her, and she said, ‘I think you’ve got Parkinson’s disease, and I will start you on the medication’. She said if it doesn’t work, you haven’t got Parkinson’s, and honestly, I was like a new person when I started taking the medications. I was sleeping all the time before, but with the medication I had more energy, I was more with it. So, I was then diagnosed with Parkinson’s disease.

I was so stressed and anxious at the time, which meant the tremor got worse. It was so visible to other people, and you don’t want other people to see that you have a tremor. I could feel that things were changing. For example, I lost my sense of taste and smell (and this is before COVID-19, so before that became a sudden phenomenon that everyone had), and I still get this problem. I have really painful restless legs every evening, to the point where I don’t know what to do with myself because of the pain. So, I pace up and down, and that is one of the symptoms. I get between three and five hours of sleep at night, which then leaves me tired in the daytime. My spatial awareness is being affected; I’m always covered in bruises because I walk through a doorway and bump into the door, or something.

I was not allowed to work. They would not consider reasonable adjustments. When I tried to go back to work, they put me on a disciplinary process and claimed I had already had a meeting about the first stage. The supposed meeting was on a day that I wasn’t even working, it had not happened. I ended up being signed off for work-related stress before they retired me against my wishes. I have always worked. The emotional impact was huge. I just could not stop crying, and I became a prisoner in my home for about three months. I’m not exaggerating when I say it felt like I’ve been given a death sentence. My dad had dementia. I’ve seen him go through his journey, and I saw that that was my future. I was reading a leaflet about vascular dementia, and they said the average lifespan of somebody from the time of their diagnosis is five years, and that was in 2016. That was six years ago, and I’m still, still going. I’m okay.

The only good thing with Lewy body is that after my diagnosis, when I was given nothing, I found the Lewy Body Society in the UK. I rang them and started working with them. An admiral nurse was also working with them, and they’ve just taken on a second one. There has been so much support from the Lewy Body Society. We've had zoom sessions and talks, and one-to-one support as well as a group. One of the things that we did, and I still think is amazing to this day, Heather and I had to put ourselves in each other's shoes. So, Heather had to imagine what I'd be thinking and vice versa. We know each other so well, but we still got it so wrong. I thought Heather would be thinking one thing, and she said, 'oh, Chris would be thinking that', and we were miles off.

Heather and I met in 2010. We are both retired police officers. We met at a police rehabilitation unit. We were both having treatment, but she was from England, and I was from Wales, so we would never have ordinarily met one another. I put off moving in with Heather for quite a while because I didn't want to impose my dementia on her, and I thought it's not fair. I'm not going to get to a place where it's not better. We had our retirement mapped out, we were going to go around Europe, so that has changed very much. Sometimes we make plans but then I've got to say, 'sorry I cannot go. I'm too tired. I'm not having a good day' or something like that. It's hard for Heather, sometimes she says it's like going back to being single, because she cannot count on me to be there to do the things that we were going to do, and I feel guilty about that.

I was unfortunate enough to have a one-week stay in the hospital during the COVID-19 lockdown. I was put in the COVID-19 ward even though I had tested negative, and I knew I didn't have COVID-19, but I had some symptoms. People walked in with full PPE and without a name tag. I didn't know who I was speaking to, and I wasn't getting my Parkinson's medications on time, which caused hallucinations. Nobody said to me, 'How does your dementia affect you?'

The experience was so disempowering. My care plan was pushed to the back of the pile. They hadn't looked at it even though it had everything about me, what I like, and how my dementia affects me. My time in the hospital would have been far better if I had just been asked that question, but nobody asked me. I'm now involved in the training of medical health professionals, and it's now mandatory that they must spend time with people living with dementia and their families. Doctors have realised that you can learn a lot more from people with lived experience than from textbooks. One doctor gave the example of a lady who was getting very agitated and who people were dismissing it as 'oh she's got dementia'. They were not recognising that the lady was trying to communicate something or had a need that was not being met. They were at the stage of calling security to come and deal with her. But thanks to the training, the

doctor felt more confident in supporting the lady. He got down on her level, just spoke to her, and calmed her down. He said he could see that there was something causing her to react in this way. It might be that she was in pain or needed the toilet. He said, had he not done the 'Time for dementia programme', he would not have known this, and the worst thing that could have happened is security being called to this lady who is already distressed. On top of that if you are thinking that dementia is all about memory, you won't understand the other symptoms. The doctor says that they are getting a lot out of this experience, and it will make things better.
Chris

Useful Resources:

Lewy Body Society: Shining a light on Lewy body dementia https://www.lewybody.org/ or 01942 914000

Alzheimer's Society: Time for Dementia programme. https://www.alzheimers.org.uk/get-involved/time-dementia-programme.

LGBTQ+ Community

As part of her story, Chris has shared some of the challenges she has faced as a member of the LGBTQ+ community, as well as challenges she worries about for others, including the pressure to conceal sexuality as an LGBTQIA+ person needing to engage in dementia services [13]; additional challenges trans-people with dementia can face [14]; and the greater need to plan for the future [15] to manage the heteronormative culture in dementia care [16].

There's still that stigma attached to dementia, and I think that if you're LGBTQ+, that's another stigma, so it's like having a double stigma sometimes [17]. I was a police officer, and I did not realise until I was in my 30s that I was gay. I certainly hid my sexuality while I was a police officer because there was discrimination, and they would have made life difficult for me. Approximately three years before I joined the force, two women got kicked out of the Police Force because they were Lesbians. (Although of note, there have since been strong efforts to improve the work environment for LGBTQ+ police officers [18]).

My partner Heather knows me, what I like to eat, the types of clothes I like to wear. My brother and sister were originally going to appeal when I put Heather as my Legal Power of Attorney. If I had died, my house and my savings everything would have gone to my brother and sister because they were my next of kin. My brother does not even know I'm gay. I have always said that if he asked me I would tell him the truth, and I think he probably knows, but he's never asked me, and he's never spoken to me about it. My sister is very different from me, and she does not know what I like. So, Heather is my next of kin, and I want to safeguard her. (Similarly, research has discussed the importance of chosen family and the desire for more open policies for end-of-life care and non-biological family members [19].)

I have worked on something with the Alzheimer's Society called 'Bring Dementia Out', which tried to find LGBTQ+ people living with dementia. But we could hardly find anyone to come forward. Maybe because they're very much in the closet, or they're too scared because they do not think they'd be accepted by society. I'm also in a Dementia Advisory Group for people who identify as LGBTQ+. We have a Peer Support meeting where the group has said it is just so nice to have somewhere they can feel safe, and they can talk about whatever they want to talk about.

It is time to break down those barriers and rules and get the support for marginalised groups of people. It does not matter about my sexuality or the colour of my skin or my religion. What matters to me is that I need to raise awareness about dementia, and I think this is sometimes where the focus is lost.

Chris

Useful Resources:

Alzheimer's Society

How Everyone can help to Bring Dementia Out. https://www.alzheimers.org.uk/get-involved/bring-dementia-out

Source of Strength: A Woman with Dementia who is Fighting Back. https://www.alzheimers.org.uk/dementia-together-magazine/june-july-2018/source-strength-woman-dementia-who-fighting-back

LGBTQ+ Living with Dementia. https://www.alzheimers.org.uk/get-support/daily living/lgbtq-living-with-dementia

LGBT Health and Wellbeing (Scotland)

Proud to Care LGBT Dementia Project (June 2018–July 2020). Impact report. https://www.lgbthealth.org.uk/wp-content/uploads/2021/01/Dementia-Impact-Report.pdf

LGBT Health and Wellbeing. A Guide for Health and Social Care Providers. A Dementia Toolkit. https://scottishcare.org/wp-content/uploads/2021/02/LGBT-Dementia-Toolkit.pdf

Alyson, Sheila, and David's Story

My mum Sheila and my dad David were diagnosed with vascular dementia within six months of each other in 2013. Mum resisted the diagnosis initially and therefore resisted any attempts that we made to try and organise things. She had a series of mini strokes, similar to her mum.

Mum also didn't recognise that dad had dementia. Things came to a head in 2014 when dad was admitted into hospital after a fall. Dad had always been more of a homemaker than mum. He cooked and cleaned—they didn't share the same interest in diet. Dad could cook anything; mum was accused of watery juice and poor tin can opening (Fig. 1.2).

Mum has retained her ability to source food, as she knows when she is hungry. When it would get to a mealtime, mum would ask dad if he was hungry to which he always replied 'no'. So, she would feed herself. Dad always refused on the basis that he did not like what she would prepare. Mum assumed he was just not hungry. Dad was dependent on mum's mobility as he broke his hip in a fall and did not regain much of his own mobility. Walking around the flat to and from the bedroom and toilet was his daily exercise.

At a set part of the day, mum would say to dad 'I'll get your medicine', which meant she would fetch him a glass of whiskey and then continue to fill his glass through the night. As a result, dad fell, put his head through the plasterboard, and lay all night on the floor. Mum couldn't lift him, so pulled the blanket over him, left him there, and went to bed. Mum was clearly unconcerned and considered that his own behaviour had got him there, but it did lead to injury and a hospital admission. At a case conference with the family and nursing staff, it was agreed that they could move to my house. I had the facilities at the time where they could have a

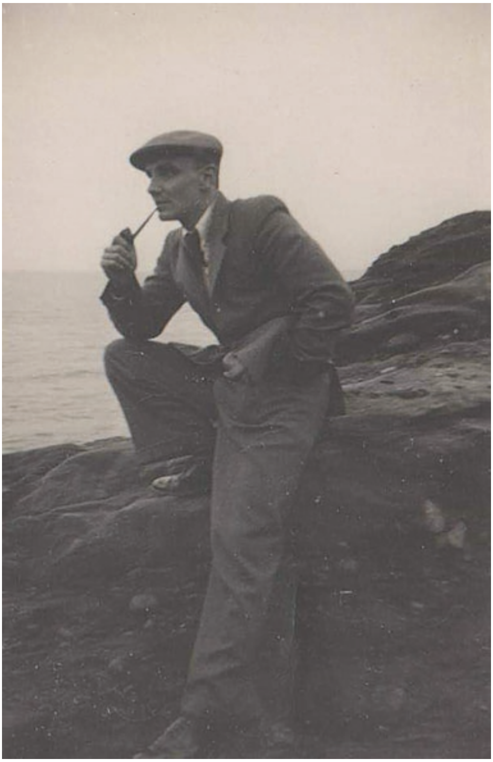


Fig. 1.2 Alyson's dad, David, as he would like others to see him

bedroom, a bathroom, and a living room to themselves at the front to maintain their privacy as a couple.

Two weeks after they moved, I could hear a car engine running, and there was Mum leaving via the back door with a suitcase in hand. She had ordered a taxi for herself and left dad behind. Mum did not care for living so remotely, as she was still physically able and liked going to the shops, so she wanted to be in the town. Dad's circumstances were different: he physically lost strength quite quickly, and he was incontinent and catheterized. With the separation, I had to think of ways to continue their relationship so organised date nights, etc. Mum would come back to mine at the weekend.

They were grateful for the support initially until they received an invoice for meals on wheels and they cancelled quite quickly. So, then I had to limit and supervise their contact as mum would sabotage the care given to dad, saying he didn't need it. This arrangement lasted for about a year, and the month before dad died, we had taken him back to their flat to be with mum. We are thankful for this ending. Mum took some time to adjust. At least 18 months. She couldn't articulate her feelings but was self-soothing with expressions like 'dad had told her he loved her for 60 years'.

During a casual conversation about something else, I mentioned Mum's diagnosis to her. She was furious and denied it before calling the GP practice to demand a retest. She scored better the second time around, which she took as evidence that she was okay. My mother was very headstrong as an individual. Even though you may say at 92 with dementia that she was vulnerable, she could still demonstrate some boundaries, and whilst there may not be a verbal cue when she is unhappy, there will be non-verbal cues. Looking back, we think of mum's determination after her latest fall to seek a doctor's opinion, rather than take the word of a paramedic, as evidence of her condition. That and the view that only a certain cream prescribed by the doctor to treat her bruised back would do.

In June 2020, I had to be assertive with mum to move in with me. There were several reported falls in the flat and we had to respond to each one. Mum only had one hour of private care per day for shopping and socialising. We couldn't risk anyone's safety, so additional care was necessary. Given the bleak news of a high number of older people dying in care homes due to COVID-19, this was not an option. None of my siblings were in a position to offer care. I was working from home and had the space. At the last visit to mum's flat, I told her I was going to come back for her that afternoon as soon as I'd made up a room for her. Once at mine, you could see that she felt it was a relief. We hadn't appreciated how much care and support she actually needed. A masking had been going on to quite a sophisticated level. Within two weeks, she was very, very ill. My brothers' always say, and I agree with them, that had mum not gone into hospital when she did, we would have lost her two years ago. She was so unwell. She was not eating.

Mum has never asked about my dad since the day she's been here. She sometimes does not recognise she's been married and recently gave her maiden name in a memory test. At times, she will take off her engagement and wedding ring asking them to be put in a drawer as they were her mothers. Mum could be quite a difficult person and had a small circle of friends. Everything was invested in her husband and her children, which makes it even more curious that she does not remember that she was married.

My oldest brother, who mum would probably save the greatest welcome for, is not always recognised now, even if mum has a picture with them both together in front of her. She is not able to make that connection. When my brothers talk about things that are going on in their life, it is meaningless to her. If she has been out somewhere I will say ‘mum, tell them about such and such’, for example, you went out for your tea. So, I will feed her information, which keeps her part of the conversation, and there might be something that prompts her memory, ‘Oh. that is right they had that lovely soup!’.

She will eventually connect in some way. An iPad was purchased with the aim of connecting to family a distance away, although this isn’t used as much as it could be. Communication is one of the most important elements in our relationship. Even though there is a high risk of it not being retained, I do give mum updates and news on plans. Mum will look round, and you can see her just trying to work out who you are or say something. Just wanting to communicate. She wants to socialise. I’ll stick my tongue out and she will laugh and she will do it back. I will say something like, ‘You could go to jail for that!’ and laugh, and she’ll say, ‘if I could go to jail for that, you will too!’ So sometimes it is just that cheeky communication that’s her way of saying, ‘I’m still in there’.

There are times when mum is seeking reassurance, and this is usually in relation to an old memory. She will often say, ‘is mum coming for me?’ and I will say, ‘How old are you?’ … ‘I’m 92’ … ‘So how old do you think your mum would be?’ She then logically knows that it cannot be right but doesn’t get upset about it. She asks for her sister, who has been dead for 23 years, or her brother, who has been dead for 50 years. It does not distress her, which is great, and she does think things through. She’s very good at problem solving still in her own way. She’s very, very brave, and she’s got a high pain threshold. She’s been dealing with a hurt wrist, and the gout has been dreadful.

She doesn’t recognise me sometimes, although she can sometimes recognise situations. I had a break away and when I came back, she said ‘are you the one that we were waiting on coming back from America?’ She says ‘well, the man that lives up the stairs is looked after me very well’. (Referring to my son/her grandson who stayed to look after her.) The fact that she could do that is quite remarkable.

She has this thing about the curtains being closed that drives me mad, but I tolerate it for her. She loves the curtains shut, and I hate it. So, every night she'll ask, 'can you draw the curtains?', and I say, 'have you got a pencil!' Mum laughs at this, but still wants the curtains shut. So, shutting the curtains was a job that she had to do. Although she's not always able to do it now and last time I tried that joke with her, it just fell flat. Open curtains are clearly still something that bothers her because I've found that if I leave the room and come back the curtains will have been shut. She's like the 'Kit Kat Panda' that comes out of the cave when the photographers got his back turned. That's what mum's like at times, she has got up and shut them. It shows that there is still some spark there.

My younger brother finds it difficult to see mum in her current situation. If I take her down to his, then there is somebody who can 'speak mum'. Otherwise, I don't think he feels confident that he could help if she needs something, no matter how much reassurance I give. The most strenuous time for me was probably negotiating the incontinence care, and the first time I had to give her personal care. It was not something that I thought I was prepared to do, but it becomes easier because the priority was preserving mum's dignity. We have the community alarm, you could call and get them to come out, but you have got to balance that against a weight of them having more urgent appointments and potentially waiting three hours before mum could be clean and return to bed/chair.

Our relationship has gone through a number of changes and has been strained at times through frustrations and difficulty communicating. We didn't think that she would accept care from me and for as long as she has. But, I have had 56 years of mum, I can speak Sheila. The fact I understood mum so well, this caused conflict in younger years. We got better over time; we have a routine and we have learned how to work together. Mum is very easy to care for. She will happily accept most care. There was only one real flashpoint when that was not the case. It was 3:00 AM, and I needed to get her in the shower, shampoo the carpets, and change the beds. Mum was refusing, so I said 'if you cannot let me help you, then I cannot look after you, and if you don't want me to look after you, then I will have to look at other arrangements. I do not want to have to do that.' It was a negotiation; she understood the logic and cooperated with what I was trying to do.

She was still in there, and still is my mum. We accept her in a different guise now, her personality has changed, and she would sometimes say things that might hurt if we didn't understand. We haven't been 100%

Fig. 1.3 Evidence that there is life with wine after diagnosis

with it, you know, just limped along as best we could. Incidents that happen are quite funny to me now unless they're at 3 o'clock in the morning and I'm needing sleep!

I want people to know that dementia is not all bad, you know? Just because that diagnosis is given, it is not the end of the world but the beginning of a new one. Mum is a resilient woman who has a desire to live and is ageing with a real cheekiness to her. She makes me laugh so much (Fig. 1.3).

David and Sheila helped shape who I am and give me the motivation and capacity to care. I am still learning from their examples.

Alyson

Useful Resource:

Angus Carers Centre. https://www.anguscarers.org.uk/

References

1. Ashworth, R. (2019). Looking ahead to a future with Alzheimer's disease: coping with the unknown. *Ageing and Society, 40*(8), 1–22.
2. Alzheimer's Research UK. (2022). *Diagnoses in the UK*. Retrieved October 2022, from https://www.dementiastatistics.org/statistics/diagnoses-in-the-uk/
3. Wittenberg, R., Hu, B., Barraza-Araiza, L., & Rehill, A. (2019). *Projects of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040*. LSE Care Policy and Evaluation Centre.
4. Hill, N. L., Bratlee-Whitaker, E., Sillner, A., Brautigam, L., & Mogle, J. (2021). Help-seeking for cognitive problems in older adults without dementia: A systematic review. *International Journal of Nursing Studies Advances, 3*, 100050.
5. Werner, P., Goldstein, D., Karpas, D., Chan, L., & Lai, C. (2014). Help-seeking for dementia: A systematic review of the literature. *Alzheimer's Disease & Associated Disorders, 28*(4), 299–310.
6. Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, M., Wittenberg, A., Adelaja, R., et al. (2014). *Dementia UK: Update*. Alzheimer's Society. Retrieved October 2022, from http://www.alzheimers.org.uk/dementiauk
7. Lakey, L., Chandaria, K., Quince, C., Kane, M., & Saunders, T. (2012). *Dementia 2012: A National Challenge*. Alzheimer's Society. Retrieved October 2022, from https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/alzheimers_society_dementia_2012-_full_report.pdf
8. ARUK. (2019). *Dementia in the family: The impact on carers*. Alzheimer's Research UK. Retrieved October 2022, from https://www.alzheimersresearchuk.org/wp-content/uploads/2019/09/Dementia-in-the-Family-The-impact-on-carers1.pdf
9. Karg, N., Graessel, E., Randzio, O., & Pendergrass, A. (2018). Dementia as a predictor of care-related quality of life in informal caregivers: A cross-sectional study to investigate differences in health-related outcomes between dementia and non-dementia caregivers. *BMC Geriatrics, 18*, 189.
10. Missotten, P., Tlieff, M., Di Notte, D., Paquay, L., De Lepeleire, J., Buntinx, F., & Fontaine, Q. (2007). Quality of life in dementia: A 2-year follow-up study. *International Journal of Geriatric Psychiatry, 22*(12), 1201–1207.
11. Giebel, C. M., Sutcliffe, C., & Challis, D. (2014). Activities of daily living and quality of life across different stages of dementia: A UK study. *Aging & Mental Health, 19*(1), 63–71.
12. Ettema, T. P., Droes, R.-M., de Lange, J., Ooms, M. E., Mellenbergh, G. J., & Ribbe, M. W. (2005). The concept of quality of life in dementia in the different stages of the disease. *International Psychogeriatrics, 17*(3), 353–370.

13. Moreno, A., Laoch, A., & Zasler, N. D. (2017). Changing the culture of neurodisability through language and sensitivity of providers: Creating a safe place for LGBTQIA+ people. *Neuro Rehabilitation, 41*(2), 375–393.
14. Baril, A., Silverman, M., Gauthier, M.-C., & Levesque, M. (2020). Forgotten wishes: End-of-life documents for trans people with dementia at the margins of legal change. *Canadian Journal of Law & Society, 35*(2), 367–390.
15. Adelman, M. (2016). Overcoming barriers to care for LGBT elders with Alzheimer's. *Generations: Journal of the American Society of. Aging, 40*(2), 38–40.
16. Roe, L., & Galvin, M. (2020). Providing inclusive, person-centred care for LGBT+ older adults: A discussion on health and social care design and delivery. *Journal of Nursing Management, 29*(1), 104–108.
17. McParland, J., & Camic, P. M. (2018). How do lesbian and gay people experience dementia? *Dementia, 17*(4), 452–477.
18. Jones, M., & Williams, M. L. (2015). Twenty years on: Lesbian, gay and bisexual police officers' experiences of workplace discrimination in England and Wales. *Policing and Society, 25*(2), 188–211.
19. Wilson, K., Kortes-Miller, K., & Stinchcombe, A. (2018). Staying out of the closet: LGBT older adults' hopes and fears in considering end-of-life. *Canadian Journal on Aging, 37*(1), 22–31.

CHAPTER 2

'You Don't Look Like You Have Dementia'

Abstract This chapter explores different people's perceptions of dementia. We look at the visibility of dementia and the consequences of being told 'you don't look like you have dementia'. The group debates whether it would be best for people to recognise dementia and the ways in which we can raise awareness and educate people. We ultimately wish to reduce the stigma (negative perceptions and being treated poorly) surrounding dementia and those with lived experience.

Keywords Stigma, Stereotypes, Awareness, Education, Frontotemporal dementia, Vascular dementia, Atypical Alzheimer's

The question of what dementia looks like cannot be answered in a single sentence. The word itself is an umbrella term for several different 'neuroprogressive conditions' with more details on the different types of dementia in Chap. 3.

Co-authors: Rosalie Ashworth, Sue Fyvel, Alyson Hill, Chris Maddocks, Masood Qureshi, David Ross, Stuart Hay, Martin Robertson, Willy Gilder, Winnie Henry, Myra Lamont, Agnes Houston, and Fred S. Wilson
Email: tay.ppipartners@nhs.scot
Neuroprogressive and Dementia Network, NHS Tayside, Dundee, UK

R. Ashworth et al., *Challenging Assumptions Around Dementia*,
https://doi.org/10.1007/978-3-031-27223-3_2

> People always say, 'Well, you don't look like you've got dementia', or 'You function really well, we wouldn't know'. I then have to say, 'you don't spend a long time with me for one, and you don't know how much effort goes into me going to a meeting or being on a zoom call'. I think that's where lived experience comes in, in the way you explain things. Somebody once said to me, 'it's like you have a glitch on your computer, and it's not running smoothly, at full speed'. That's a bit like the brain of a person living with dementia. I think we get tired because it takes so much more effort for us to do things than people who don't have dementia. I think once you start explaining these things to people, It's like a light bulb moment. People say, 'Oh, that makes sense now'. (**Chris**)

> I was doubting myself at the beginning. I had the diagnosis, but I was doubting it myself. I don't look like I have dementia. Do I really have it? Will doctors really think so? People in society don't think that I have it. My wife thought I had it, even before I was diagnosed, but other family members didn't believe I had it. (**Martin**)

> It's a bit like if you think you have cancer and you're going along to see somebody and they say, 'well what are you doing here?' There's this tinge of, 'you're not being quite honest, maybe you're faking'. I suppose it is also partly that my symptoms are atypical, I don't have the memory problems that everyone focuses on. I went to the extent of getting copies of my MRI scan on disc so that if the worst comes to worst, I can show people and they can see for themselves. (**Willy**)

When people are told that they 'don't look like they have dementia', it undermines their experiences and can lead to symptoms being trivialised as 'normal silly things' impacting the person and their wellbeing.

> I felt so let down by my family when they kept saying that 'you don't look like you have dementia'. I would say some of the things that I was finding difficult, and they would reply with examples such as 'Well I go upstairs and forget what I'm going up for!' I felt like I was going mad, and in some ways the diagnosis or explanation of symptoms was a relief. I still had to fight constantly to show I had dementia. I've said, well what does somebody with dementia look like?! I've had to fight, but how long do I have to keep on fighting for? (**Chris**)

> I was attending a dementia café a couple of weeks ago, and suddenly one of the carers of somebody I know says to me, 'Why are you here Fred? Do you live with dementia?' I said, 'Yeah, I do. I was diagnosed with Alzheimer's disease three years ago.' They said, 'Well you look as if you are actually one

> of the organisers'. If somebody just met me then they might say well actually you don't look like somebody with dementia, but they need to spend time talking to me. (**Fred**)

> It isn't just that you don't look like you've got dementia. I've had comments like, you don't dress like you've got dementia. So, I don't know what we are supposed to look like or supposed to dress like. (**MAQ**)

We have found that people hold a very narrow view of what dementia looks like, and because of this, people who do not align with this view are challenged and undermined.

> My son-in-law who lives ~200 yards away took a good couple of years after my diagnosis to accept I had dementia. He goes offshore three weeks at a time, so he didn't see me all the time, and when people come around you put a face on. My wife said, 'stop doing that, be yourself. If you're tired, go and lay down.' I think after that, once they realised how much I was having to leave them to lie down or leave the conversation, they had to realise it was real. However, when most people meet me, their first impression is that they don't think I have it to be honest. (**Martin**)

It can also mean that people who may fit more with the stereotypical image, such as being withdrawn or less able to communicate, may be further excluded if the assumption is that there's 'no point'. The experiences that people have had exemplify just how damaging being challenged or questioned about a diagnosis can be. Particularly, as it is very normal for people living with dementia [1] and carers [2] to be in denial about such a diagnosis or not trust the results of the test.

> My dad was slightly more compliant with the diagnosis of dementia, but it truly bothered my mum, and she insisted on being retested. She scored better the second time, which led to a real distrust of the system. It also does not help that when she shows certain symptoms, such as struggling to find the bathroom, carers will ask why she is behaving that way. Therefore, we are constantly having to validate her experiences because they do not know what to expect. (**Alyson**)

> There is a psychiatrist on social media who has challenged a few individuals living with dementia for being able to present and speak well. In some cases, it has led to them thinking, 'Well maybe I don't have dementia, after all this person is a trained medical professional who works in this field'. As a result, they sought out a second diagnosis, only to receive the diagnosis again. (**Chris**)

> I disputed my diagnosis at first, knowing only one thing about dementia, memory loss. I didn't have memory problems so it's not dementia, you know? Prior to the diagnosis, I was treated for anxiety and depression. I was afraid they had misdiagnosed me. So, all these factors were taken into consideration. I just didn't know what to do. After a couple of years, I asked for a second opinion. It took approximately four years for them to actually do the scan again. It is also not just the public that holds an incorrect image of dementia. It can also be professionals. I feel that they don't truly talk to you, they hear you, but they don't listen to you, and I think that's a big problem. Memory can be an issue, but it is not the only issue. There's a perception that people living with dementia cannot truly communicate and don't express their feelings. They forget that yes, there are times where it is harder to express them, but we do experience them. Everyone only knows the worst-case scenario. (**MAQ**)

> I think looking for a second diagnosis is not purely a dementia problem. It is human nature to look for a 'problem fixer'. Any serious health problem has most people looking for a cure, a way out of this mess they are in, dementia is no different. The 'perhaps?' questions creep in before final acceptance. For example, perhaps 'they' (meaning the professionals) got it wrong. 'Let's consult someone else' applies just as much to any life-changing diagnosis as it does to dementia. I know that when one of my daughters was diagnosed with a terminal brain tumour, I spent hours researching all the latest research about her condition. If someone had said there was a cure, I would have given everything I had to get it. The point I am trying to make is looking for a second diagnosis is no different for people diagnosed with dementia, as it is for other life-changing illnesses. In that respect, 'we are awe Jock Tamson's bairns' as the saying goes. (**Winnie**)

Diagnosing dementia is not perfect, and there will be times where people are diagnosed with dementia and that diagnosis is overturned (known as false-positive) or are told they do not have dementia when in fact they do (known as false-negative). Such circumstances are very difficult for the person who received the diagnosis as well as the clinician [3]. Therefore, such a scenario should not be trivialised or assumed to be a common occurrence. There is also an increased range in diagnostic measures, including testing for biomarkers, brain imaging, and neuropsychological assessments. Misdiagnosis is rare [4]. Therefore, it is more important to recognise that if someone does 'not look like they have dementia' is more likely to be due to an incorrect image of what dementia looks like than due to misdiagnosis.

What Does Dementia at the Different Stages Look Like?

As a group, we reflected on what we thought people expected to see when they met someone living with dementia. In doing so, we consider stigma about dementia from the perspective of those with lived experience [5].

Stigma can be thought of in terms of public- and self-stigma and forms the umbrella for stereotypes, prejudice, and discrimination [6]. Social psychology suggests that stereotypes are a way for the brain to process information [7]. However, this results in oversimplification and overgeneralisation. For example, assume that all footballers are male. Prejudice is a result of treating these stereotypes as fact, for example, believing that females cannot be footballers. Discrimination is where you act on this prejudice, for example, not allowing females to play football. Research has identified that stigma can have damaging effects on people affected by dementia, including making it harder to seek help [8], lowering self-esteem, and increasing social isolation [9]. Our co-authors share some of the stereotypes people have about the stages of dementia.

> My wife and I both thought dementia was all end-stage until my diagnosis to be honest. I had worked with middle- to end-stages previously. I think seeing that has made it easier. For two reasons: I can relate to the staff, and I know you have both good and bad stuff; and I know that in the latter stages my body will be there, but I always say I'm not gonna suffer. It's tougher for the carer because they would see their loved one's declining and not being themselves. (**Martin**)

> There is so much ignorance and lack of understanding around dementia and that's why it's good that we're doing things like this to raise awareness. I think people automatically go to the 'end stage', and they don't think that there's a beginning and middle. It wasn't long ago that people would be put into mental asylums. People thought they were 'crazy'. I can remember how my grandmother used to say, 'Mrs So & So up the road, she's gone doolalley'. But clearly now when you think about it, it was dementia. We are where we were with cancer many years ago; it's all about raising awareness and explaining to people. (**Chris**)

> Even the word itself matters, as people expect someone to act 'demented*' (*Cambridge Dictionary: *unable* to *think* or *act clearly* because you are *extremely worried*, *angry*, or *excited* by something). You expect to see

> someone acting aggressively. I think people are frightened that this 'aggressive part' will come out. People also expect to see someone sat in a corner, not communicating and dribbling. (**Chris and Winnie**)

> I think people expect to see a person who is very forgetful, confused, and doesn't know who they are or what situation they are in. It's a very stereotypical picture. When I was first told I have Alzheimer's disease, I think I found it very hard to believe because it did not fit with my own stereotype of the illness. Nobody actually took the time to explain to me that it might not be as you expected. (**Willy**)

If someone does not fit that image, they are assumed to not have dementia.

> Wullie would tell people he had dementia; he wasn't ashamed of it and did not think it should be hidden away. But people would still say to me 'he doesn't look like he has dementia'. Our neighbour whispered to me 'well I don't think so, I was talking to him over the wall there and he's as sharp as a tack'. (**Winnie**)

We know that dementia does not look like one thing, and everyone living with dementia may present differently. There is also a question about the visibility of the symptoms and how people manage them.

> I lived with my wife for many, many years, she had dementia, and I didn't know. So how would I know what you are supposed to look like if you have dementia? There's just no way. There are so many different types of dementia and so many different symptoms that it's impossible to ask that sort of question. I don't think there are any signs apart from the ones that eventually come out after many years. (**David**)

> I would say that people diagnosed in the later stages present with more complex issues and changes in appearance due to dementia. The people who come forward for research involvement are likely to be more able-bodied and more able to raise awareness of dementia. We often do not say enough about the trajectory of the condition and what people face as the condition progresses. When people say 'you don't look like you have dementia' they really seem to be saying 'you don't look like you have advanced dementia' as that's the only image people picture. (**Myra**)

As a group, we have spoken about how knowledge of dementia (or lack of knowledge) is not just about public understanding but also what people close to you and what medical professionals know about the different types and presentation. Additionally, having lived experience of dementia does not take away from the fact that you are still a member of the public and you will be shaped by what information is out there.

> Eileen's got Alzheimer's disease and it's been gradual over ten years. I've been with her the whole time. Most people don't know what's wrong with her at any stage. But I'm the public as well, I'd be the same, I wouldn't know what to look for. We've been to coffee mornings and things, but Eileen's in a wheelchair now, she can't speak, and there's nobody like Eileen or people like me who are in the same boat. (**Stuart**)

It is important that as we write this and share our experiences, we stay mindful of the fact that there will be people living with dementia who are unable to participate in some activities, whether it be book writing, coffee mornings, etc. We wish to raise awareness of the different signs and symptoms of dementia, while advocating for more work on ways to engage others meaningfully.

> My experience with my wife was that she so quickly succumbed to this horrible illness, where she now sits in the chair, can't walk, talk, do anything. So, if you walk into the care home, you can see that she has dementia. But there are other people around who have had dementia for 10 years, and they look okay. We did not recognise the early signs, and within two years, she had succumbed to this terrible situation. My wife never admitted she had dementia, she denied it, and to her it did not exist. So how do you describe that when it's so varied? (**David**)

Fighting for Financial Aid

One of the challenges our co-authors have faced due to others not recognising dementia or believing diagnoses is that it can interfere with the types of support people have access to. Lack of access to financial services can particularly impact people with young-onset dementia who've had to end work because of their dementia diagnosis [10, 11]. At a time of distress, adjusting to a very loaded diagnosis, Chris, MAQ, and Martin (among others) have had to deal with the added stress of fighting for their condition to be recognised as life limiting and progressive.

When I lost my job and tried claiming benefits, I was refused. Employment Support Allowance (ESA) said you must score fifteen points on the interview to be eligible, and even with the dementia diagnosis I scored zero points. This was very upsetting, and I had to go to a tribunal before a judge and a doctor. I went from scoring zero points to scoring thirty points, which meant I was entitled to the benefits. But how many people living with dementia can go through that process? I feel strongly that when you get a dementia diagnosis you should automatically get the benefits you are entitled to. I know of people who do not get any benefits and cannot even live. Sadly, there are a number of people not getting any benefits following diagnosis who have then committed suicide. Those things are not mentioned. They're not spoken about. You are meant to carry on as normal, but if you lose your job as well, you feel you have lost everything. We do not talk about it enough. It also doesn't help that dementia is an invisible disability a lot of the time, whereas if you broke a leg, for example, people know you have got an injury. (**Chris**)

I wasn't fully diagnosed until 2019. Due to my previous history of being a fraud officer, I was really quite paranoid at times, and it was difficult not having the label for my type of dementia. I knew what they were capable of if you like. My assessment for benefits was terrible. Within five minutes, I was out of it, and my wife was answering the questions. I do not blame the woman doing the assessment because the rules state that you must ask all the questions. But it was obvious within five minutes that I was going to get the full ranking. I was literally on the sofa for two weeks afterwards and not able to do much. I am now in framing the Scottish Adult Disability Payment. (**Martin**)

They took my driving licence away after my diagnosis and that sort of brought it home to me that I must have a problem, otherwise they would not have done that, although I challenged it and they gave me the licence back. The Department for Work and Pensions (DWP) then came into the equation. I fought and fought and fought, and I still think they owe me. I'm still not on the right benefit and I was diagnosed in 2010. I went on Employment Support Allowance, and they wanted me to do this training somewhere, and of course, being a worker, I wanted a job. So, I did this course and on the second day, the lecturer says 'you know more about this than I do, you do not need this'. So, they then said, 'Okay we will pay you this benefit', but it was peanuts. Two years later, I was contacted by DEEP and their local advocates for people with dementia. I went to see them and found out about the Disability Living Allowance (now Personal Independence Payment). I applied and I was refused, but I appealed and

> went to the tribunal and won. So, I got the full rate for a few years, but then my father-in-law passed away. I told DWP that I would be going abroad to be with my wife and they said I needed to return within eight weeks to continue my benefits. So, I planned to stay for eight weeks to support my wife and balance the cost of going, but while there my wife needed surgery. It had a three-month recovery time. She then needed another surgery. I couldn't leave. When I came back, the DWP said that I had been out of the UK too long, and now had to stay for 104 consecutive weeks before I could reapply for benefits. I couldn't go and see my wife for two years, and she couldn't visit me because of the income threshold for a visa. After 104 weeks, I reapplied, and I got refused again. The appeal was due when COVID-19 hit, and everything came to a halt with courts and tribunals. I waited for two years without any income. I was up to my eyeballs in debt. They finally phoned me up almost a year after reapplying and said they were prepared to pay the basic but not advanced rate, with no mobility payment. I felt like I had to accept this, even though things were much harder now than when I first qualified for the advanced rates for both daily living and mobility. I just reached a point where I couldn't take the stress of fighting it. If I didn't have dementia, I don't think I could have lasted with all that stress. (**MAQ**)

If you would like to know more about your financial rights as someone living with or support someone with dementia, Dementia UK [12] and the Alzheimer's Society [13] host a range of information.

Raising Awareness Through a 'dementia card'

We are unable to simply look at someone and know whether they are living with dementia. It can be both a visible and invisible disability, depending on anything from time of day to individual capacity to compensate. Although of note, dementia has not always been viewed as a disability. It is only in more recent years that researchers have looked at how dementia and disability align [14], which further adds to the struggle people have had in accessing financial aid for disability support.

People living with dementia may find themselves in situations where symptoms of the condition make it harder to carry out an activity and additional patience and understanding are needed. In an ideal world, we hope that individual support needs will be considered as needed. However, we know that this is not always the case, and as a result, there are different ways people have tried to communicate that they have dementia.

> I have often thought it would be nice to have an Alzheimer's badge to show people there are some things wrong with Eileen. When you speak to people, they're always quite glad to know what it is. It would also increase the visibility of dementia within the community, as people often assume she would be in a care home. (**Stuart**)

> I also thought a badge would be a good idea, although I did not want to label my husband. I would say he has a condition called dementia, he needs slightly more time and patience. For example, at airport security, he was asked to remove his belt and shoes, he wasn't understanding the instruction or able to understand why he had to remove items of clothing at an airport. Alzheimer Scotland developed a little card [available here], and it was discreet. I kept in my wallet after that airport incident. Everywhere we went and before any words were spoken, I put the card in front of the person we were communicating with. It was quite incredible how much I used that card. I didn't want my husband to constantly hear me state, 'He has dementia'. What I liked about the card was no one knew which of us had dementia as I was the person using it. It was so helpful for everyone concerned. (**Myra**)

> I've used the card when I was in the bank and there was a big, long queue of people behind me and I did not want to say out loud, 'I've got dementia', you know? So, I just showed the card and straight away they took me off to a separate office which was beneficial because you don't want to have to keep saying, 'Excuse me, I've got dementia'. I've also used the 'hidden disabilities' sunflower lanyard which I use when I am travelling. (**Chris**)

> I have a colleague who has found that the card is very supportive. He would show it to people, and he found it very helpful. Of course, it is not always helpful, in the same way that having a pull alarm in a sheltered accommodation setting is only useful if you know to pull it when you are in need. (**Sue**)

The ability to disclose a diagnosis discreetly in different contexts can be beneficial. It does not mean that people want to use the card all the time, or even that they particularly like the card, but that it provides the option for disclosure and potentially access to support.

> I will only use the sunflower lanyard [available here] when I am travelling on a bus or a train, specifically so that staff know to help a bit. Then, it comes straight off as it marks you out as different. I can see how the card could be useful, but I'm loud and proud about my dementia. Using the term dementia, cards, lanyards, etc., are a gateway for doors to be opened. (**Martin**)

> I think some of these cards and lanyards have lost their potency as there as so many different signs and symbols being used, whether it's a wristband for cancer, a sunflower lanyard, a butterfly sticker, etc. It is important that we have choice and that there are options, but it can be very difficult for a card or a lanyard to help people recognise your needs. It is helpful if people are keeping an eye out for reasons someone may need additional support, whatever the cause may be. (**Agnes**)

Does It Help if People Know?

The 'dementia card' and the 'sunflower lanyard' work on the principle that by disclosing a dementia diagnosis, people may be better equipped to offer support. However, we also know that this relies on people having accurate knowledge about dementia. It is perhaps unsurprising to know that this is not always the case, despite various efforts to raise awareness of dementia (including Share the Orange campaign [15], Prime Ministers Challenge [16], and Understand Together [17]).

> The public fears dementia. Some people have been very surprised when they find out my diagnosis and say they didn't expect 'somebody like me' to have dementia. I think there's a worry that if you get too close to someone with dementia you might catch it. I feel like I have to get my 'script' ready—'you know I've got this, but it isn't quite what you think it might be'. (**Willy**)

> A lot of people think that when they see me at my worst, I'm drunk. I've lost a whole load of friends. Although the positive side is that I have also made a lot of new friends. (**Martin**)

> My brother and sister know my diagnosis, but they refused to talk about it and were not willing to change their behaviour to support me, even with things such as talking slower on the telephone. They suggested I move away to where my partner was living. I felt very shocked and let down. I've lost friends too, but I'm still me. Sometimes I want to stand up on the rooftops and say, 'I'm still me, I'm the same person today as I was the day before my diagnosis'. (**Chris**)

A shift in how people treat you can also happen in contexts such as doctors' visits, where you would hope people would be the most informed and therefore least stigmatising.

> I find that if I go to a hospital appointment or something and I'm with my partner or somebody else, they automatically talk to them and don't talk to me. I have to say to them, 'Excuse me, you're talking about me, so please talk to me'. See the person and not the dementia. (**Chris**)

Our co-authors regularly shared how much they value peer support and how writing this book has created its own form of peer-to-peer support. It is worth remembering that when friends living with dementia are treated badly in appointments, visits, etc., their experience will be shared and may prevent others from seeking help or sharing their diagnosis in the same context.

> My friend who is living with dementia needed surgery on her arm, and the surgeon initially said that they wouldn't do the surgery because she had dementia and did not need the use of her arm. She did eventually have the surgery, but that is how even professionals see us. It's frightening. As dementia develops, it can increase the risk of falls and injuries. But some of my friends with dementia won't go to A&E for fear they will suddenly be made an inpatient. (**Chris**)

It is worth reiterating that this is not to say that people only have negative experiences with healthcare professionals. There are excellent examples of people being treated with compassion, dignity, and respect. In sharing the experiences where this has not been the case, we hope that we can see more positive experiences in the future.

> When I went back to the GP and told them I had posterior cortical atrophy (PCA) she said 'Oh, I have never heard of it'. I thought it was brave of her to say that. The next time I went back, she said, 'Oh I have looked it up!' and they had a staff meeting to discuss PCA and what I need to make my visits easier, for example, I don't like bright lights, so they make sure the lights are dimmer when I go in. It's good and I'm quite surprised. (**Martin**)

Educating People About Dementia

The previous section questions how helpful it is to know a person has dementia. We note that this is often dependent on the accuracy of their dementia knowledge. Dementia strategies regularly refer to the need to raise awareness about the condition on the premise that awareness will lead to understanding, which in turn will reduce stigma.

The co-authors of this book are passionate about improving people's understanding of the condition, with a lot of dementia activism on their part stemming from a desire to change people's understandings of dementia.

> There is fear about dementia through a lack of understanding and stigma associated with the illness, possibly due to how people were treated in the past and so often the stigma is associated with mental health services, where dementia predominantly sits. (**Myra**)

> My favourite TV detective is Colombo. He always says, 'All I do is look and listen, listen and look'. I think that if this was practiced by the professionals, they would see the uniqueness of people living with dementia. As we are all unique, we need to be treated differently, not the same test for everybody. (**MAQ**)

The uniqueness of experiences is linked to the distinction between equity and equality. The approach aims for overall equality between people with different types of dementia, but to achieve this, different resources and support may be needed.

> It is all a matter of how you educate people. We always think about memory, but how do we get people to see it is so much more than memory? (**Winnie**)

> It is important to observe people and notice. If you don't know what you're looking for then you're going to miss a lot of signs and symptoms. I see dementia as a cocktail shaker of factors that build up into more complex or mixed dementia. (**David**)

As a group, we have also reflected on how education and support for people living with dementia can be different from other disease areas.

> As a nurse, it didn't matter what department you'd be in, you know that everybody has different challenges. Everybody can have the same problem on paper, but it's challenging them in different ways because of comorbidities. As a nurse, you see the whole person and how they are being affected. Why is it so different for dementia? When a nurse looks at cancer and all its variants and challenges, they can deal with it. Why is dementia so unusual or so spectacular? I've stopped expecting a good experience. I just go with the flow now. (**Agnes**)

> When you walk into a GP surgery, a hospital, or a library, there is nothing about dementia. There are 101 things about lung cancer, heart and lung diseases, sex education, and so on. There should be space for people to learn about dementia. You know? Even just a poster, like an umbrella with the major types underneath it. Dementia can happen to anyone, and the public needs to be made aware of how it is something that they should know and learn about. (**Fred**)

> There is some recognition and education regarding dementia care and support through the work of dementia-friendly communities and other voluntary sector organisations. In addition, dementia care has been a priority for the Scottish government since the first dementia strategy of 2010 until 2020, and continues to be included as part of the 2021/2022. Moving on to a dementia COVID-19 recovery plan. There are education programmes through the NES and SSC Dementia Champions programme and university dementia courses that involve people with dementia participating in courses, but is it enough? Is it far reaching? Is it the right content? The more people with dementia and unpaid carers become involved in education, the better the programmes will be and the better the experience will be for students. Instead of programmes talking about behaviour, the focus should be on communication, health and well-being, diet, exercise and observations. (**Myra**)

We recognise that dementia awareness is very important, and, ideally, integrating things such as dementia into school's curriculum would hopefully result in reduced stigma and fear surrounding the condition. As a former teacher, Fred is passionate about integrating dementia awareness in schools:

> Young people will encounter someone with dementia, either through family, friends, neighbours, people in their community, or through the media. Teaching young people about dementia will hopefully remove any fear of the illness or stigma in relation to a person who has dementia. Learning about dementia provides an opportunity to explore intergenerational relationships, build respect and equality for older adults, and help children explore their capacity for compassion and resilience. (**Mike**)

Research has highlighted the need to provide credible and relatable images of dementia to the public [18], which would hopefully reduce the number of times people experience being told that they 'don't look like they have dementia'. Recent research supports the discussion of our co-authors, drawing attention to the issue of stigma [19] and demonstrating that improving education, as well as contact with people living with dementia, could have a positive effect on stigma reduction [20, 21].

MAQ's Story

I have got three children who live with me. My daughter lives with me and my two other boys, and the other two are married and have a place of their own. When I had my heart surgery, my mum was alive as well, and she also lived with us. She was very active. She looked after me more than I looked after her. It is the motherly thing and that is what they do. What really hammered me was the fact that I was recovering from the surgery I had in 2009, and in 2010, I was diagnosed with frontotemporal dementia based on a post-surgical brain scan. It took me over 12 months to tell the family about the second diagnosis, simply because they were already looking after me. I was recovering from my heart condition, and I did not want to put this on them as well because they have got their own lives, they've got work, etc.

So, sharing the diagnosis took quite some time, and it was stressful. I did not tell anybody. I stayed away from my friends, and they automatically assumed that it was because of my surgery. I do not drive, and I do not go anywhere, but I used to talk to people on the phone. There were some people who visited me. I did not stop that, but I did not go out. The thing is that when I was told that I had a heart condition and they were going to operate, I was not scared. You can see people who have had similar surgery and they're living a good life; you know that there is something that they can do about it.

When I was told about dementia. I had limited knowledge. I did know that is it not curable and that there is only one end. I was petrified. That was one of the reasons why I did not tell my family. I thought that if they knew as much as I did, it would hit hard. They only had me, they had already lost their mother, so there was only me looking after them.

I speak and write in 14 different languages and dialects, but there is not always a word for dementia. It's confused with mental health, and in some cultures, even associated with possession by an evil spirit or punishment for bad deeds. So that is one reason some people may not be able to relate to this illness. You've got culture, customs, faith, all these things that make it difficult. I'm struggling trying to get that across to my community. There is also not enough training on the emotional side of dementia and how to express everything you are trying to hold in to stop others from suffering. I cannot stress the details of dementia too much because I do not want to say that it is an incurable condition. We do not want anyone to suffer.

I truly suffered from dementia. I suffered squared because I thought I could not tell anybody about it because it was embarrassing to talk about it. From the experiences that I have had talking to people about dementia, I think there is also a family stigma. The children and their families and their sisters, etc., they are all around and they keep saying ‘do not forget us in your will’ and ‘do this’ and ‘leave this and that to me’ etc., and then I do not see them for months and months. That is another added stress.

By the time I told my family about my dementia, I knew quite a bit about it. Therefore, when I did tell them, I ‘cushioned the blow’ as it were. I did it in a manner that they could understand, and I also told them not to think it means that there is no life. I said that I’m not going to be a burden on you, and I do not expect you to be around me all the time. That time might come, but it is going to be a long, long time. Deep down inside of me, I was thinking I hope I do not see that.

DEEP were the backbone to my recovery. I was deeply down, and DEEP pulled me up with such a high level of support from people also living with the condition. I often think that the first person you are referred to should be a psychologist. I know psychiatrists are also medically trained, but we need verbal support; a safe space to share. When you hear psychiatrist, you automatically think you’re seen as ‘loopy’,

Family look after you, they will feed you, they will wash and iron your clothes, they will do loads of things for you, but that is very different to doing activities with you. The DEEP community enabled me to travel. I went to different universities and made speeches here, there, and everywhere. It got me out because there was somebody holding my hand. I had any physical support that I needed, and there were people around me who were living with the condition, so we could connect better. I have always said that people with dementia connect better with people with dementia, more so than even the professionals because there is a trust factor. We do not trust a lot of professionals because they have let us down.

I think if I had not been diagnosed when I was, through the routine scan as opposed to from having symptoms, I do not think I would have asked for help. Knowing what I know about dementia and knowing how I behaved for the last 10 years, I don’t think it would ever come to a point where I would have recognised a problem. The biggest damage that’s happened to me is the thought of having this condition, not the condition itself. It is the psychological and emotional side that's been tarnished, things like my concentration and confidence. My senses have magnified. I listen more, I hear more, I see more. I try harder to concentrate because I know the condition is making that harder.

I have got this thing in my mind that is a progressive condition. It can only get worse. It doesn't get better, and I don't know when it's going to get worse. I don't know how much time I have to be able to do what I'm doing now. Therefore, I want to do things yesterday.

I think it is a journey that, in my case, I think is unique. Obviously, we're all individuals, but I have got sort of added struggle coming from my ethnic background as well. I was not able to speak the language when I came to this country, and when I came here, racism was at its peak. I went through all that. I think things will get keep getting better, school kids now don't see colour, whereas when I was at school they did. I educated myself here and ended up a professional in the community, in good standing, both in the Asian community and wider community. It has been difficult, but fruitful, and enjoyable.

I would like to be the change I want to see in the world.

MAQ

Useful Resources:

DEEP—The UK Network of Dementia Voices. Available at: https://www.dementiavoices.org.uk/

Social Care Institute for Excellence—Black and Minority Ethnic (BME) Communities and Dementia. Available at: https://www.scie.org.uk/dementia/living-with-dementia/bme/

Alzheimer's Society—Black, Asian and Minority Ethnic Communities and Dementia Research. Available at: https://www.alzheimers.org.uk/for-researchers/black-asian-and-minority-ethnic-communities-and-dementia-research

Race Equality Foundation—Dementia and BAME Communities. Available at: https://raceequalityfoundation.org.uk/projects/dementia-and-bame-communities/

WINNIE AND WULLIE'S STORY

My name is Winnie. I have a BA in Psychology and Philosophy. I had many roles throughout my working life, but perhaps my most satisfying one was working in the field of addiction. My career was cut short in my early 50s by a life-changing Illness, and although I did some part-time voluntary counselling for various organisations, I still managed to fit in a great deal of travel with my husband Wullie, who, by this time, had retired from the Fire Service. We had a marvellous life and enjoyed each other's company, as well as the company of our family (Fig. 2.1).

The story of Wullie's dementia journey starts here.

Fig. 2.1 Winnie and Wullie

On 10th September 2012, when Wullie was 72 years old, we flew to the beautiful island of Malta. On that day, a thief robbed us both, robbed us of the future we had planned for ourselves. That thief's name was Dementia.

What happened was as follows: my husband suddenly lost his memory. The next 24 hours were a complete nightmare. I suddenly was faced with this man child, who looked like Wullie, responded to questions asked of him just as Wullie would, but as I later put it, the lights were on but nobody was in. His actions were bizarre. For instance, he went for a shower and could not remember how to turn it off, so it flooded the whole room. We were in a hotel we had stayed in several times, and the staff had even allocated us our favourite room, so he was not unfamiliar with the working of said shower. He looked and acted strange, and although his memory returned 24 hours later, he was still quite confused. This was diagnosed as 'transient global amnesia'. A rare form of memory loss. Further investigation found seven dead spots on his brain. From then on, Wullie would tell you that he felt as though he had a fog in his brain. But he was still very savvy and would explain, in detail, what dementia was to anyone who asked about it. His words were, 'This condition should not be hidden. If I had a broken leg, people would see and sympathise. In my case, I have a broken brain. Let's do as much as we can to make people understand that I, and others like me, are not stupid.'

On thinking back, I now realise that some of the signs of his illness were present at least 10 years before he was actually diagnosed. One of those signs was as follows: Wullie was always a great raconteur. He kept our family, as well as all the nephews and nieces, enraptured for hours with his stories, and like all great storytellers, truth and fiction were sometimes interchangeable. Now, approximately 10 years before he was officially diagnosed with mild vascular dementia, I started to notice a subtle change in the content of his stories. He became the hero. He twisted the stories slightly, so he was almost like 'the caped crusader'. By the time he was diagnosed, this phenomenon had a name. This is called confabulation. Honest lying, it is sometimes called. He truly could not tell truth from fiction and whatever story; even from a daily newspaper he was recounting, he was part of the story, at least in his mind. On reflection, there were other signs, but I put them down to advancing age. One of these signs was that he incessantly watched the same TV programmes but did not remember that he had watched the same content very recently.

All that changed in November 2019, when Wullie took a stem cell stroke. This is a type of stroke involving the stem cell area of the brain. Overnight, his cognitive ability was halved. Even then, he still knew and spoke to all his visitors, but physically he needed 24-hour nursing, so, very reluctantly, it was decided that a nursing home was where he could be best looked after once the rehabilitation from his stroke was complete.

He still retained the larger-than-life character he always had. The strength of his character was such that in the rehabilitation unit of our local hospital, not only did he get back on his feet and walk but he made what the nursing staff later named 'The Great Escape'. He was in a locked ward and had poor balance, but twice he managed to get out. The first time he only went a few yards then fell over. However, Wullie had tasted freedom and that only made him more determined. He secreted away a dinner knife and used it to remove the screws from his window. Luckily, the staff spotted the damaged window before he could make his escape. Another time, I came into his room to find a pillow laid across the windowsill and the bold boy trying to slide out of the space between the open window and the sill. The worst time and a great source of worry to us all saw him walk out of an emergency exit from the ward and into adjacent woods. As you can imagine, there was a great hue and cry. The police, local people, family, and even off-duty staff joined in the search. He was eventually found after he tripped and fell into a small gully. Luckily, he suffered no real damage from his escapade.

Wullie suffered badly from 'Sundowning Syndrome', and this worsened to the extent that he had to be confined in a locked ward for his own safety. 'Sundowning Syndrome' causes the person with it to become agitated and disoriented as the day progresses. By this time, the world was in lockdown because of COVID-19. Wullie could not understand why he had no visitors and could not even get out into the garden of the nursing home. I tried facetiming [video calling] him, but he could not understand the technology. I phoned the nursing home every day and spoke to him. He would ask me to come and see him and tell me it was like being in prison. I would have a wry smile at that, 'some prison at nearly one thousand pounds a week', I would think to myself. He was safe and looked after, and that was the most important thing to me, although I missed him terribly.

Wullie suffered another cerebral incident in December 2020 and passed away with the family at his side. He knew all his family until his death, and he never lost his cheeky chappie attitude to life. The staff in his nursing home adored him and said they would never forget him.

Winnie

Useful Resources:

Alzheimer's Society—Sundowning and dementia. https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/symptoms/sundowning
Ciprani, G., Lucetti, C., Carlesi, C., Danti, S. & Nuti, A. (2015). Sundown syndrome and dementia. *European Geriatric Medicine, 6*(4), 375–380.
Stroke Association. https://www.stroke.org.uk/ Helpline: 0303 3033 100

Willy's Story

I was admitted to a psychiatric hospital in England with depression following an incident in my personal life that had left me profoundly low and suicidal. The consultant psychiatrist decided, for reasons that still baffle me, that I had a personality disorder.

I went through every known anti-depressant, but even when I knew the depression itself had lifted, I was switched off and apathetic—and one day realised that my empathy towards family members seemed to have left me. I began to be convinced that something else was going on—that some kind of organic change was happening. I put this to the psychiatrists, who commissioned psychological tests: I scored 97 out of 100. The consultant told me that this ruled out any possible dementia. I was unconvinced.

After discharge I moved to Scotland, but with no explanation for my apathy that made sense to me—but when I came to the attention of a new old-age psychiatrist his reaction was 'Your symptoms are interesting, we could at least run some tests'. Therefore, a series of brain scans began.

A CT scan showed a degree of atrophy (cell loss). This was followed by a SPECT scan that showed blue blobs where there should have been yellow, suggesting that there were issues with imperfect blood flow within my brain. Finally, an MRI scan pinpointed damage to my parietal lobes, and a lumbar puncture confirmed this as being caused by Alzheimer's disease.

However, my form of the disease is atypical in that my hippocampus remains intact: I don't have issues with my episodic memory, that is, memory that focuses on events and experiences. Tests show that my verbal working memory is slightly compromised (I struggle with strings of letters or numbers), but my visual memory is flourishing.

The major issues I face are to do with my eyesight, in that I see things that aren't truly there—specifically a 'blob' in my left field of vision, and reflective surfaces covered in hair. I also have strange issues perceiving black: such that I have struggled to use the black zip on a suitcase as it somehow vanished. Everything now has orange tags!

I note too that my once faultless navigation has gone wonky: orientating myself on a map is hard, as I don't have a good sense of direction. The other area of difficulty is balance, which means I find riding a bicycle much harder work than it once was.

My passion in life has always been painting and drawing, but my interest in this seemed to disappear with the advent of my brain disease. It seems that the right parietal lobe plays a vital role in controlling drawing. I was aware of the therapeutic power of music, so I devised my own therapy programme: a couple of weeks of listening to The Beatles and The Stones turned up loud. Happily, this 'rewired' my brain enough for my drawing to return.

The other major hurdle I have faced is over driving. The DVLA took my licence away when I was diagnosed, and I appealed against this, as it seemed unfair to me that they could do this without evidence. After a legal battle lasting more than a year, I win the right to have my driving ability assessed, and I am now back on the road.

Willy

Useful Resources:

Alzheimer's Society—Sight and Hearing Loss with Dementia. https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/sight-hearing-loss

Alzheimer's Society—Driving and Dementia. https://www.alzheimers.org.uk/get-support/staying-independent/driving-dementia

Video summary: 2-Minute Neuroscience, Neuroimaging. https://youtu.be/N2apCx1rlIQ

References

1. Grunberg, V. A., Bannon, S. M., Popok, P., Reichman, M., Dickerson, B. C., & Vranceanu, A.-M. (2022). A race against time: Couples' lived diagnostic journeys to young-onset dementia. *Aging & Mental Health, 26*(11), 2223–2232.
2. Parker, M., Barlow, S., Hoe, J., & Aitken, L. (2020). Persistent barriers and facilitators to seeking help for a dementia diagnosis: A systematic review of 30 years of the perspectives of carers and people with dementia. *International Psychogeriatrics, 32*(5), 611–634.
3. Howard, R., & Schott, J. M. (2021). When dementia is misdiagnosed. *International Journal of Geriatric Psychiatry, 36*, 799–801.
4. Larner, A. J. (2004). Getting it wrong: The clinical misdiagnosis of Alzheimer's disease. *International Journal of Clinical Practice, 58*(11), 1092–1094.
5. Van Wijngaarden, E., Alma, M., & The, A.-E. (2019). 'The eyes of others' are what really matters: The experience of living with dementia from an insider perspective. *PLoS ONE, 14*(4), e0214724.
6. Rusch, N., Angermeyer, M. C., & Corrigan, P. W. (2005). Mental illness stigma: Concepts, consequences, and initiatives to reduce stigma. *European Psychiatry, 20*(8), 529–539.
7. Quadflieg, S., & Macrae, C. N. (2011). Stereotypes and stereotyping: What's the brain got to do with it? *European Review of Social Psychology., 22*(1), 215–273.
8. Benbow, S. M., & Jolley, D. (2012). Dementia: Stigma and its effects. *Neurodegenerative Disease Management, 2*(2), 265–172.
9. Mukadam, N., & Livingston, G. (2012). Reducing the stigma associated with dementia: Approaches and goals. *Future Medicine, 8*(4), 377–386.
10. Bayer, A. (2020). Next steps after diagnosing dementia: Interventions to help patients and families. *Practical Neurology, 20*, 296–305.
11. Mayrhofer, A. M., Greenwood, N., Smeeton, N., Almack, K., Buckingham, L., Shore, S., & Goodman, C. (2021). Understanding the financial impact of a diagnosis of young onset dementia on individuals and families in the United Kingdom: Results of an online survey. *Health & Social Care in the Community, 29*(3), 664–671.
12. Dementia UK. (2022). *Financial and legal sources of support and advice*. Retrieved October 2022, from https://www.dementiauk.org/get-support/legal-and-financial-information/sources-of-support-and-advice/
13. Alzheimer's Society. (2017, April/May 17). Assessment for PIP. *Dementia Together Magazine*. Alzheimer's Society. Retrieved October 2022, from https://www.alzheimers.org.uk/dementia-together-magazine/april-may-2017/assessment-pip#:~:text=Getting%20PIP,%2C%20planning%20and%20following%20journeys

14. Shakespeare, T., Zeilig, H., & Mittler, P. (2019). Rights in mind: Thinking differently about dementia and disability. *Dementia, 18*(3), 1075–1088.
15. ARUK. (2015). *#ShareTheOrange: Help change the conversation around dementia and support research*. Retrieved October 2022, from https://www.alzheimersresearchuk.org/orange/
16. Department of Health. (2012). *Dementia campaign launches*. Retrieved October 2022, from https://www.gov.uk/government/news/dementia-campaign-launches
17. Health Service Executive. (2022). *Dementia: Understand together*. Retrieved October 2022, from https://www.understandtogether.ie/
18. Devlin, E., MacAskill, S., & Stead, M. (2006). 'We're still the same people': Developing a mass media campaign to raise awareness and challenge the stigma of dementia. *International Journal of Non-profit and Voluntary Sector Marketing, 12*(1), 47–28.
19. Harper, L., Dobbs, B. M., Stites, S. D., Sajatovic, M., Buckwalter, K. C., & Burgener, S. C. (2019). Stigma in dementia: It's time to talk about it. *Current Psychiatry, 18*(7), 865.
20. Bacsu, J., Johnson, S., O'Connell, M., Viger, M., Muhajarine, N., Hackett, P., Jeffery, B., Novik, N., & McIntosh, T. (2022). Stigma reduction interventions of dementia: A scoping review. *Canadian Journal on Aging, 41*(2), 203–213.
21. Kim, S., Richardson, A., Werner, P., & Anstey, K. J. (2021). Dementia stigma reduction (DESeRvE) through education and virtual contact in the general public: A multi-arm factorial randomised controlled trial. *Dementia, 20*(6), 2152–2169.

CHAPTER 3

‘How Does Your Dementia Affect You?’

Abstract This chapter is designed to draw attention to the types of dementia and how the different diagnoses can influence the brain and the body. The chapter offers some background information about the brain and myths surrounding dementia before taking the different types in turn. We have included some common features of the conditions alongside lived experience. Finally, the chapter explores experiences of diagnosis and questions how we might improve this process.

Keywords Brain myths, Dementia myths, Types of dementia, Diagnosis, Alzheimer’s disease, Vascular dementia, Posterior Cortical Atrophy, Frontotemporal dementia, Semantic dementia, Lewy body dementia

---

Co-authors: Rosalie Ashworth, Sue Fyvel, Alyson Hill, Chris Maddocks, Masood Qureshi, David Ross, Stuart Hay, Martin Robertson, Willy Gilder, Winnie Henry, Myra Lamont, Agnes Houston, and Fred S. Wilson
Email: tay.ppipartners@nhs.scot
Neuroprogressive and Dementia Network, NHS Tayside, Dundee, UK

Emma Law
Email: tay.ndntayside@nhs.scot
Neuroprogressive and Dementia Network, NHS Tayside, Dundee, UK

R. Ashworth et al., *Challenging Assumptions Around Dementia*,
https://doi.org/10.1007/978-3-031-27223-3_3

Understanding the Brain

Our book aims to draw attention to the lived experience of people with dementia and part of that involves learning more about the brain and how the brain interacts with the rest of the body.

The brain is arguably the most important organ in the body; however, it is also one of the hardest organs to learn about. Much of our earliest understandings about how the brain works come from seeing how brain damage impacts a person. A well-known example of this is that of Phineas Gage, who survived an accident where a metal pole went through his frontal lobe. The changes to Phineas' personality helped us learn what the frontal lobe is responsible for [1].

The brain is made up of two hemispheres that control opposite sides of the body, that is, the right side of the brain controls the left side of the body. The two sides of the brain communicate through a structure called the corpus callosum, a large bundle of nerve fibres that connect both sides of the brain. As with the Phineas Gage example, we have learned a lot about the corpus callosum from people who have had their corpus callosum severed, so that the two sides no longer communicate.

Myths About the Brain

There are many myths about the brain that are part of popular culture, including 'the left side of the brain is logical' and 'the right side is creative', and 'we only use 10% of our brain'. These myths can make it harder for people to trust the accuracy of more up-to-date information about the brain.

It is a popular belief that the two sides of the brain are responsible for different tasks, for example, the left side of the brain is responsible for logical thinking, and the right side of the brain is responsible for creativity. However, we know that the brain is complex, and few tasks are localised to just one area of the brain. Neuroimaging has added to the scientific evidence to show global rather than one-sided properties of the brain network [2].

The myth that we only use a small proportion of a brain has been used in films and advertising, spurred by the idea that we have space in our brain to 'activate' [3]. However, we can see from brain imaging that activity spans across the brain, with billions of neurons (nerve cells) working together. It is important to challenge such myths; examples such as 'we only use 10% of our brains' could impede better scientific literacy [4].

Areas of the Brain

The brain is made up of approximately 100 billion nerve cells that work together to send information [5]. The surface of the brain is covered in bumps and grooves (as seen in Fig. 3.1), which increase the surface area of the cerebral cortex, the largest part of the brain or the top layer. Greater surface area results in an increase in cognitive function.

The cerebral cortex is separated into several areas that are responsible for different functions. Understanding how these areas of the brain work can help with understanding why damage to these areas can result in changes in both the mind and body.

- The frontal lobe is involved in our personality, decision-making, and problem-solving.
- The temporal lobe helps us understand speech and language.
- The hippocampus is a brain structure that sits deeply within the temporal lobe and plays a major role in memory, including the movement of memory from short-term to long-term storage.
- The parietal lobe processes sensory information.
- The occipital lobe focuses more on visual information.

The wide range of functions that are performed by the brain shows just how complex it is as an organ, as well as how much it impacts the rest of

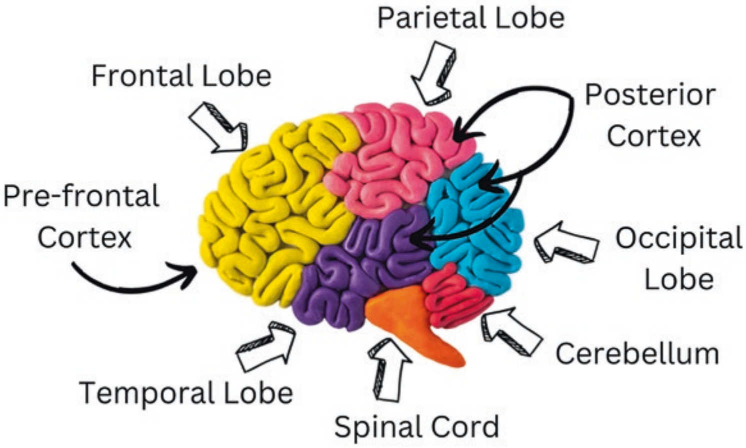


Fig. 3.1 Anatomy of the brain

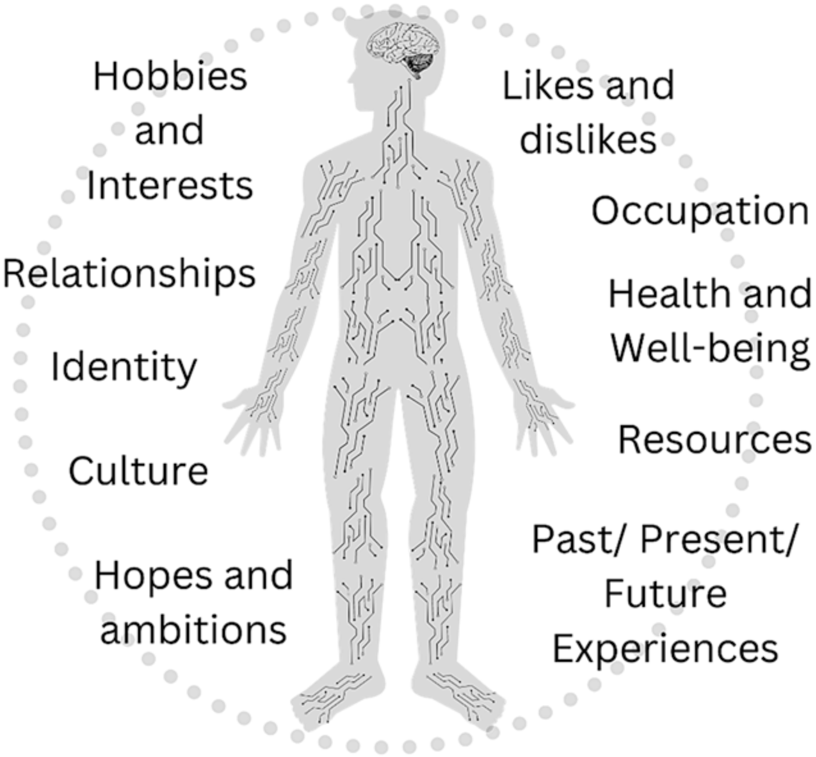


Fig. 3.2 Holistic view of the person

the body (as we have illustrated in Fig. 3.2). It is vital that when we think about people living with dementia, we consider the whole person and how the brain and body are at the centre of a huge number of facets.

Myths About Dementia

Research has shown that public knowledge of dementia is generally low [6, 7], which, as with brain myths, can result in people believing false information. Falsehoods such as 'dementia only affects older adults', 'there is nothing you can do to change your risk of dementia', and 'Alzheimer's disease and dementia are the same thing'.

Myth 1: 'Dementia Only Affects Older Adults'

As we age, our memory can worsen, which is a normal age-related decline caused in part by changes in hormones and a reduction in cells that protect and repair. Approximately 40% of people aged 65 years and over are likely to experience age-related memory loss. However, of these, only 1% are likely to go on to get dementia each year.

> Are you at a higher risk of getting dementia as you age?
>
> Yes. It is the largest risk factor.

This means that people aged 65 years old and above are more likely to develop dementia than people aged under 65 years old. Approximately 2 in every 100 people aged between 65 and 69 years old will develop dementia. This risk roughly doubles every five years. Therefore, by 90 years old, approximately 33 people in every 100 may develop dementia [8].

Although age is the largest risk factor for dementia, it is still worth remembering that if approximately 2 in every 100 people over 65 years old get dementia, it also means 98 people out of the 100 do not.

Despite the risk associated with age, we also know that younger adults can also develop dementia. Approximately 1 in every 20 people who are given a diagnosis of dementia will be diagnosed with young-onset dementia (under 65 years old).

There are several age-related challenges people can face. People under the age of 65 can take longer to get a diagnosis due to misattributing symptoms to a different condition, such as depression, or assuming symptoms cannot be dementia for this age group [9, 10]. We can see this in Willy and MAQ's stories. Research has shown that it can take an average of a year longer to get a diagnosis of young-onset dementia [11, 12].

As dementia is assumed to be an older adult condition, younger adults can have to fight to be recognised as having dementia, which can impact job status, access to benefits, family dynamics, and responsibilities [13]. Equally, older adults can face a double stigma as an older adult in an ageist society and having a stigmatised condition such as dementia [14].

> I don't think my parents would have accepted my diagnosis. They're dead now, but I don't think they would have accepted it. My dad was very intelligent right up to the very end. He started learning how to use the PC in his 70s and he was well into spreadsheets and databases until his late 80s. He

> was highly intelligent, and my mum was too. So, I don't know whether they would accept that someone could have dementia at an earlier stage. I think that they were old fashioned is what I'm trying to say. (**Martin**)

Despite differences between people with early- and late-onset dementia, research has also shown that there are shared experiences in terms of preferred coping strategies and how they look to the future [15].

Myth 2: 'There Is Nothing You Can Do to Change Your Risk of Dementia'

Everyone has a chance of developing dementia. However, some people are at higher risk than others. Some risk factors are unavoidable, for example, ageing is the biggest risk factor, and genetics can play a greater role in some rarer dementias [16]. Other risk factors are called modifiable, for example, stopping smoking, reducing alcohol intake, and increasing physical activity.

In general, factors that support a healthy heart and body will support a healthy brain. For example, managing blood pressure and cholesterol, exercising regularly, drinking responsibly, and staying engaged socially. Research suggests that we need to improve public education about brain-health behaviour changes that can be made to lower the risk of dementia, with current efforts less effective for people with low education [17]. In addition to being more receptive to brain health campaigns, people with higher education are thought to have an element of cognitive protection known as 'cognitive reserve' [18, 19]. The theory suggests that if a person has multiple routes to access a piece of information within their brain, it results in more pathways to cope with change or damage. This is not to say that people with high education will not develop dementia but that they may be able to compensate for changes for longer.

Recent debates have suggested that up to 35% of cases of dementia could be prevented or delayed based on the modifiable risk factors described above, among others [20]. However, it is important to note that evidence remains limited. It can be incredibly difficult to single out particular risk factors in a more definitive way because of the complexity of individual, social, and environmental factors [21]. We also need to be mindful of the fact that most dementia is sporadic (no family history or obvious risk factors), and when we look to raise awareness of the different types of dementia and the modifiable risks, individuals do not feel responsible or to blame for developing dementia [22].

The Alzheimer's Society [23] has produced a resource to help people understand their risk of dementia. Available here: https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_reducing_your_risk.pdf

Myth 3: 'Alzheimer's Disease and Dementia Are the Same Thing'

Dementia is an 'umbrella term' that covers over 200 different types, including Alzheimer's disease [24]. A survey of public knowledge of dementia found 58% of people believing that Alzheimer's disease and dementia were synonymous terms [25]. It is perhaps unsurprising given that the most recognised UK charities for dementia—Alzheimer's Research UK and Alzheimer's Society—refer only to Alzheimer's disease in their name despite aiming to represent all types [26]. The same can be seen in USA [27].

> Alzheimer's disease is the most prominent form of dementia, so everybody recognises, and to an extent understands, the word or knows that it can be something about memory. What people don't know, and I did not know, are all the other types of dementia. I've heard of related illness like Motor Neurone Disease, Parkinson's and Huntington's, but I think we need to be more aware of the many other forms of dementia. There is a large educational need for the public to be aware. (**David**)

> I have real problems describing my illness. It MIGHT be PCA, but that hasn't been formally diagnosed. I tend to say 'atypical Alzheimer's' but am aware that Alzheimer's disease has all kinds of assumptions that don't apply to me. Sometimes I just say 'I have a brain disease'. (**Willy**)

> I can speak well, and my memory is not so much of an issue, but I find things like sensory issues and balance difficult. I struggle now using the phone, especially when people talk too quickly. Robin Williams also had Lewy body dementia, and he thought he was going mad. I keep thinking, if only he had a diagnosis he may still be here today. (**Chris**)

> For me, dementia is a neuroprogressive condition that affects different parts of the brain and I relate it to a cancer type thing that is either a slow growing tumour that affects one particular part of your brain, or it can be tangled throughout your brain. If you know what part of the brain is affected, you can then deal with the condition because you know what kind of thing you need to focus on. (**Myra**)

Our book aimed to represent people with different types of dementia. Within the group of co-authors for this book, we have experience with Alzheimer's disease, vascular dementia, posterior cortical atrophy (PCA), frontotemporal dementia (FTD), semantic dementia, and Lewy body dementia. The following sections will take each in turn, with further information within people's individual stories.

Alzheimer's Disease

Alzheimer's disease is the most common type of dementia for early- and late-onset, accounting for approximately 70% of dementia. Alzheimer's disease is characterised by a build-up of proteins known as beta-amyloid, which form 'plaques', and tau-protein, which cause 'tangles'. These proteins stop messages going between cells, which causes the cell to die. Neuroimaging looks for things like brain shrinkage from this cell death [28]. There is no specific gene that directly causes Alzheimer's disease; however, there are variations in a gene called apolipoprotein E (APOE) that can increase or potentially decrease the risk of late-onset Alzheimer's disease. Similarly, there are three gene mutations associated with early-onset Alzheimer's disease. Despite these genetic markers, we still have a lot to learn about the genetics of Alzheimer's disease [29].

Key clinical features of Alzheimer's disease:

- Tends to begin in the hippocampus, which makes it harder to learn or retain new information. Emotional content is more likely to be preserved by the amygdala.
- Gradual, slow decline in cognition across months to years.
- Changes in language skills, including word finding, reading, and writing.
- Complex tasks can become more difficult, particularly problem-solving skills.
- Changes in spatial awareness and orientation to time and space.

Lived Experience

Fred shares some of his lived experience of Alzheimer's disease below. More information can also be found in the stories of Willy, Agnes, and Stuart.

I was properly diagnosed with Alzheimer's disease about three years ago. Prior to that, it was the family that noticed there was a massive change in my short-term memory. I was forgetting short-term things like what day it was, or if my wife told me something, like what would be happening during the day, I needed her to repeat it a couple of times. I think that was the first symptom. Then, the spatial awareness thing, I keep sort of missing things, nothing dangerous but just wee things like knocking over a glass of water. I never used to do that because my profession was scientific experiments, and I'm usually very careful. So that was the first thing. It was my wife who first noticed it, and of course my children as well.

So, I was referred to my own doctor and they just dismissed it as just one of these things that happens as you get older. They weren't very interested, you know? My wife then pushed to see a different doctor and he did the usual diagnostic test and all that, we talked about it, and he thought, yes there is something there. He referred me on to the clinic at the neurology department and I was given the proper diagnosis with the MRI scan, blood tests, genetic tests, and a whole lot of lumbar punctures. They came back saying right, this is early onset of dementia, under the Alzheimer's banner. That was the first time I knew that dementia is not just one thing.(**Fred**)

VASCULAR DEMENTIA

Vascular dementia is the second most common type of dementia. For every 100 people who have dementia, 20 will have vascular dementia. Essentially, vascular dementia occurs when there is a lack of blood and nutrients to the brain, which can cause cells to die. This can be caused by a stroke or a series of small strokes or small vessel disease usually caused by high blood pressure. There are many individual differences in the presentation of vascular dementia because of the varying distribution of 'vascular involvement' or 'scattered impairment' [30, 31]. We also know that there can be overlapping symptoms with Alzheimer's disease, which can lead to a diagnosis of 'mixed dementia' [32].

Key clinical features of vascular dementia:

- Significant decline in cognition that interferes with independence in everyday activities.
- Evidence that the change is associated a cerebrovascular event, that is, a stroke
- Can have speech and language difficulties such as aphasia.

Lived Experience

Emma shares some of her care experience with vascular dementia.

'If you've met one person with dementia, then you've met one person with dementia.' As I heard one of the Partners in Research, Agnes Houston, talk about dementia, her quote felt particularly true of vascular dementia. The symptoms can be very different depending on which part of the brain is affected.

Most commonly, memory is affected by other symptoms, such as slower thinking, confusion, changes in speech, and communication difficulties. Slowed thinking can show itself with difficulties in organising thoughts and planning, sometimes resulting in the person having problems with everyday tasks such as making a meal, choosing what to dress in, or doing the usual household chores.

Sometimes the personality can change, which can be very upsetting for loved ones. There may be changes in mood, and someone may experience depression for the first time in their life or become emotional at events they would not normally have been affected by. Any of the senses, such as sight, hearing, smell, or taste, may change depending on the brain area affected. Carers and friends have noted a person's aversion to certain smells or experiencing 'phantom smells' or developing a sweet tooth. Sometimes people experience difficulties in walking and lose spatial awareness—seemingly becoming unbalanced and more prone to falling.

There's a great publication on the Alzheimer's Research UK website which is an easy to read guide on vascular dementia (available here)

I have nursed people with vascular dementia and have seen all of the possible symptoms in some form or other. I can also share my personal experiences with my stepfather, who had a diagnosis of vascular dementia when he was in his 80s. We first noticed that his memory was beginning to fail, and my mother noted that sometimes he would be very disorientated and confused. Following these spells, he would have a day or so of being extremely sleepy. Often his memory would deteriorate further following these spells. He lost interest in reading books and would look at the newspapers but was not aware of what was happening in the world.

He loved to watch opera and continued to get great pleasure from watching and listening to opera and classical music. His tastes changed, and he later preferred sweet foods. He remained essentially the gentlemen he had always been and fortunately did not undergo some of the personality changes that I used to hear about from relatives of people in the ward where I was a nurse. There were stories of the husband who never spoke in anger until the disease took hold or the wife who swore using words that their family didn't even know they knew. Very troubling for everyone involved. My stepfather remained a gentle and kind person to the day he died despite his advanced vascular dementia.

Emma

Posterior Cortical Atrophy

There are many inconsistencies in the terminology and diagnosis of posterior cortical atrophy (PCA). Many of the changes seen could also be attributed to Alzheimer's disease, which has led to difficulty in isolating PCA-specific features [33]. The age of onset tends to be younger in people with PCA than in those with typical Alzheimer's disease. There remains a lack of consistent cognitive and neuroimaging evidence to help distinguish subtypes of PCA [34].

Key clinical features:

- Progressive decline in visual processing and posterior cognitive functions.
- Visuospatial impairments—find it difficult to interpret what you see due to brain struggling to make sense of things, not eyesight errors.
- Difficulties with working memory, which is used to hold information in mind as part of carrying out cognitive tasks.
- The ability to form new memories tends to be relatively preserved compared to that in Alzheimer's disease.

Lived Experience

Martin shares some of his experiences of living with posterior cortical atrophy.

My dementia is sensory based, and I can get sensory overload. I cannot see the captions on a TV, and in the autumn with the low light filtering through the hedges (we live rurally), it blows my mind as I can't watch TV more than approximately 30 minutes as I am using my eyes and ears. My brain could not cope with the sudden change from daylight to darkness; however, we have put in daylight lights and put them on early so I can adjust, hopefully that will help. I would love to go to the cinema to watch the new Bond film, but I would be catatonic within minutes. I have gone catatonic several times, I say catatonic, I mean my brain just shuts down and the only voice I hear is my wife's. All I need to do is get to a quiet dark room for an hour to let my brain reset. Luckily, I have had my wife Ethel with me each time.

One time I visited Peterhead prison for an audio-visual experience. They give you headphones to have on and you go around the cells. I never even thought about it, but it was too much for me and by the end I was staggering like a drunk. Someone actually said, 'he should not be here, he's drunk!', so Ethel stormed over like she does and said, 'He's not drunk. He's got dementia!' and the poor woman felt very sorry for me. She got a wheelchair and pushed me to the car, which I thought was quite nice. However, the problem is when I'm not with Ethel.

I carry a card that says what to do if I go catatonic. It says please try and take me to a quiet room, but I know that might not happen and I might end up in A&E (Accident and Emergency Department). If I did, I'd get worse because it's noisy and bright. … So that's what I'm terrified of, because I'd end up in a dementia ward and it would be noisy and bright. There is a flag on my electronic notes at the GP telling them that I have got PCA. I really don't know if it's linked up to the hospital though.

I have lost my hearing; it goes somehow when I'm reading something. When I'm looking at something it's like my like ears automatically shut down. The brain is highly intelligent in that sense, it's trying to narrow the focus. I close my eyes now, but I didn't realise I wasn't hearing until I was reading something. As well as the sensory changes, my emotions have got a lot more intense and sometimes hard to control. It wasn't a problem before dementia, but I have learned what my trigger points are, and I try to avoid them. It has a big impact on Ethel, but not really on the rest of the family.

My cognitive functions are fine, as is my memory. I truly believe that posterior cortical atrophy is the usual 'later stages'—I also get very easily tired and could sleep the day away. I want to let professionals know what it is really like in the later stages, for example, bright colours and lights are terrible and noise is confusing.

(Martin)

FRONTOTEMPORAL DEMENTIA

Frontotemporal dementia (FTD) is the second most likely cause of young-onset dementia, with most cases (60–80%) believed to be sporadic, that is, not linked to a genetic cause [35]. There are three main subtypes of FTD: behavioural variant (bv-FTD), semantic dementia, and progressive non-fluent aphasia. Semantic dementia is explained in more detail in the next section. The remainder of this section will look at behavioural and language types. Unlike Alzheimer's disease, there are no clinical biomarkers for FTD, which means diagnosis relies on clinical assessment [36]. It is made harder by the overlap between FTD and other neurodegenerative diseases, such as motor neurone disease, [37] and is often mistaken as a primary psychiatric disorder [35].

Key clinical features of the behavioural variant:

- Gradual and progressive changes in behaviour.
- Difficulty understanding the social demands of a situation.
- Lack of inhibition, for example, impulsive or inappropriate behaviour.
- Can be repetitive or compulsive behaviour.
- Lack of insight (awareness) of changes.
- Significant impairment to activities of daily living.

Key clinical features of the language variant:

- Gradual and progressive changes in language.
- Relatively preserved memory.
- Difficulty expressing language can lead to less language use and mutism.
- Significant impairment to activities of daily living.

Lived Experience

David shares his experience of supporting his wife, Anne. Experiences of FTD can also be seen in MAQ's story.

Like most people I had never heard of FTD, which exists in approximately 5% of dementia cases. Most people know of Alzheimer's disease, but not what the many other forms of these neurological conditions truly mean or how they affect us. Loss of memory usually springs to mind! However, this is a fallacy, although a part of the condition, it is neither the only symptom nor the first sign of these degenerative conditions. Eventually Anne and I were having arguments where memory became a factor, then speech was affected, and only after diagnosis did eating problems arise and violent behaviour sometime known as ‘sundowning’ occur, again another term I was unaware of (more information on sundowning available here).

Sadly, all my findings are retrospective in their discovery. I am not an academic or a clinician, but I am sure that Anne’s dementia was incubating for many years. The signs were there, and we didn’t understand or know why her behaviour was gradually changing. The very first sign that we missed was apathy, followed by hoarding over a long period of time.

The toiletries in Fig. 3.3 are the tip of the iceberg of Anne’s hoarding. Discovering these toiletries really affected me, I felt so guilty that I didn’t know about them or the reasons for all this hoarding. I know that hoarding is an early sign of FTD, but the extent of it overwhelmed me. In addition to many toiletries, shoes, trousers, coats, etc., we now must have close

Fig. 3.3 Example of hoarding activities

to 500 tops, shirts, and woollens. No one could possibly wear all these things, yet Anne, for the most part, kept them hidden from me.

Following Anne's death, my sons and I went through the range of hoarding. We did a tally of the volume of clothes collected, totalling over 1000 items, including 757 tops/jumpers, 70 pairs of trousers, and 84 pairs of shoes. Importantly, many of these items had never been worn, but the collection continued to grow.

David

Semantic Dementia

Semantic dementia is classified within a group of frontal- and temporal-lobe syndromes that presents with deterioration of the temporal lobe. Semantic dementia can be the cause of early-onset dementia. There are overlaps between semantic dementia and other neuroprogressive conditions [38, 39]. Semantic dementia causes a breakdown of conceptual knowledge, which means that people are more likely to have effortless fluent speech that appears vague or empty in meaning [40].

Key clinical features of semantic dementia:

- Loss of the semantic component of language, for example, general knowledge and features of concepts.
- Reduced ability to generate exemplars from semantic categories, for example, animals or transport.
- Likely to struggle in memory test tasks that look at things like how many different animals can you name?

Lived Experience

Myra shares her experiences with her husband Archie's symptoms of semantic dementia.

Semantic dementia is very rare, and life expectancy is 7–10 years. In our experience, it was seven years, three years following the second diagnosis, which was worse than the initial diagnosis of Alzheimer's disease. We had no idea of the syndrome, nor had the professionals we were in contact with, other than the neurologist who gave us the diagnosis. Once a professional meets someone with semantic dementia, they would very quickly diagnose another, as it is a very defined syndrome.

The most recognisable feature of this syndrome is aphasia: progressive word-finding difficulty that affects the understanding of words and their meaning. There is an initial loss of words with a rapid decline in forming sentences and deficits in visual and auditory non-verbal tasks.

Recognition and comprehension aphasia causes difficulty in the expression of thoughts, the ability to recognise faces, difficulties in object naming, and subsequent conversations. Often errors in speech, substituting words to describe an item, for example, 'item–paper', 'animal–creature', 'object–thing'.

Eventually losing language skills. Family and carers get to understand key words in a limited vocabulary.

From personal experience, numeracy was preserved, evident with number games such as sudoku, solitaire card games, and dominoes.

A person living with semantic dementia needs one-to-one support as they lose the meaning of everything and life around them. Orientation and short-term memory are preserved, and individuals can live a fairly normal life, particularly if they have routines in place. However, they are living with continuous risk, as there is no comprehension and understanding of the world around them, and they struggle to express feelings.

People living with semantic dementia can be unable to tolerate noise or new experiences. They are unable to understand road signs or any written instruction. They take people at face value and have difficulty recognising faces, leading to vulnerability. They can also find crowds threatening. Despite all these difficulties, a person can live well with good care in familiar surroundings and with encouragement to continue with low-risk activities.

There is preservation of social conduct and activities of daily living. Behaviour issues can arise as the disease progresses depending on the environmental situation. Loss of inhibition, not recognising faces, images, and places, again due to lack of comprehension, and loss of conceptual knowledge.

Capacity is difficult to establish due to a lack of comprehension. Early in the syndrome, reading and writing is difficult, spelling words phonetically. As the disease progresses, the level of risk is much greater. The home environment must be assessed, especially in the kitchen, where a bar of soap could be confused with food due to recognition and loss of conceptual knowledge. Risk of being home alone, includes not recognising door callers for example.

Diet can change with a preference for sweet foods, and choices cannot be made because the person cannot read menus or understand what food is being eaten. It is important for the carer to prepare a plate of well-balanced food and manage the diet and serving of food.

On a positive note, disorientation and sleep disturbance in our case were preserved; however, they can change as the disease progresses, sleeping more and physical weakness developing.

Myra

Lewy Body Dementia

Lewy body dementia encompasses 'dementia with Lewy bodies and Parkinson's disease dementia'. Medication can be a challenge. You may find that the medication that addresses one symptom can worsen a different symptom [41]. More research is needed that looks at the views of people affected by Lewy body dementia as well as pharmacological treatments. There is much variation between people with Lewy body dementia, and it is often misdiagnosed as a result [42, 43, 44].

Key clinical features of Lewy body dementia include:

- Fluctuating attention and alertness.
- Repeated visual hallucinations.
- Sleep disturbances.
- Possible biomarkers in relation to dopamine (a chemical messenger between nerve cells).
- Interference with things such as activities of daily living.

Lived Experience

Chris describes her experiences living with Lewy body dementia and Parkinson's disease.

Everyone thinks that dementia is all about memory, but they forget about all the sensory issues. I'm having more difficulty walking now, and balance issues. My mobility scooter gives me my independence. Today, I had a long walk in the hospital to get to where I needed to go, and I felt like I was walking through sludge, every step was a real effort. I never used to be like that before, but now must take it into account. How far can I walk? or if I walk somewhere, will I be able to walk back again?

I was never an anxious person, but anxiety and depression became a big issue, and I was never like that. It goes with Lewy body dementia. There were times when I used to feel really scared, but I couldn't think of what

I was scared of. There was just this, I'm scared and anxious feeling, but I don't know why.

The one symptom that I don't really get that's typical with Lewy body dementia is hallucinations. I do not get hallucinations, but sometimes I might think there is somebody next to me, and I'll talk to them, and then I realise that there is nobody there. It's quite fleeting. So, it comes and goes quite quickly. Or, if I'm tired, I will talk to someone, and there is no one there, but some people get really bad hallucinations. I sometimes get a smell-based hallucination where I can smell wood burning. I always check with somebody and say can you smell wood burning? If they can, then there is actually burning, and if they can't I know it's not. I did not realise that it was linked to my dementia. Luckily, I love the smell of burning wood, but some people get smells of things like sewers. I also cannot multitask anymore, and I used to be good at multitasking.

It is interesting that Parkinson's disease comes into physical health, whereas dementia comes under social care. It is so wrong, because at the end of the day dementia is a disease in the brain, and it should come into health care, not social care. It's little things like, I see my Parkinson's nurse every three months or every six months, and if I get any sort of symptoms, I can ring them up and talk about things. I also got referred to an exercise class in the hospital for Parkinson's and a hydrotherapy class because exercise helps. These are all things that I have because I have Parkinson's disease. You don't have this for dementia.

I think back to Robin Williams, he had Lewy body dementia; it was not diagnosed until after he had killed himself. I sometimes think, if only he had his diagnosis, he may have still been alive today. The Lewy Body Society are clear that it is so important to get the correct diagnosis, especially as there are certain medications that you should not be given if you have Lewy body dementia.

Noise levels are also a big thing with me; I struggle with things like public transport, the underground, and things like that. It's just a lot of noise. People don't realise that a noise in the background on a zoom call can be very distracting; for example, if people are not muted my attention is drawn straight to the noises and not to what's being said. I can no longer read a book because by the time I get to the second chapter I forget what's in the first chapter. I'm watching films and things like that, and Heather goes mad because I'll stop and ask questions. Therefore, I do not even ask the question now because she says I'm watching the film. If it's an easy feel-good film, I can watch it and go along with it, but anything that has got a plot, forget it.

I also think my emotions are more heightened. They are more on the edge of where they were. I also notice if somebody talks too quickly. For example, my sister and I are so different, and my sister talks a hundred miles an hour. I was with her one day, and she was talking about this that and the other, and when I asked a question, she said, 'Chris, that was two conversations ago!'. I had to say, 'Well my mind is still concentrating on the first thing that you were talking about, so I have not even heard items two and three'. People do not think like that. I also always say, don't ask multiple questions in in one sentence, for example, Do you want to drink? Tea or Coffee? How do you take your coffee? Do you take milk and sugar? If it is all in one, I probably wouldn't be able to answer.

One of my coping mechanisms is I play games on my phone, because when I'm looking down and playing the game, I'm not aware of all these people stood around me. I used to love playing a farm game on Facebook, but they stopped doing that game. I've got a couple I do now, a drawing game and some puzzles. I quite like things where you do things like sow seeds in a virtual farm and plough it. I also try to do ones that are mind stimulating.

People do not realise dementia totally changes your way of life. I loved cooking, but sometimes the process of cooking throws me a little bit. I can only cook from an actual recipe book now. It affects your whole life, and when you're not sleeping well, you do not function well in the daytime. So, I'm having lots of naps in the day now, especially early evening. Most evenings Heather's gone to bed by the time I wake up. Sometimes I'll wake up at three o'clock in the morning on the sofa and then go up to bed. I know that is not good for me but it's how I get by.

Chris

Diagnosis Experience

We know from the difference between the number of people with suspected dementia and the number of people with a diagnosis of dementia that there are several barriers to diagnosis. Some of which are noted in Chaps. 1 and 2. In the following section, we reflect on different diagnostic experiences of our co-authors.

In my experience, it is difficult to determine a diagnosis in the early stages of dementia because you will look for other reasons for someone's situation. Infection or whatever could be going on, which makes it very hard to diagnose. This may be more the case for people who are under 65 years old, as doctors are less likely to think of dementia. My mum never accepted that she had dementia. She would acknowledge that her memory is not so good anymore, but in hindsight, there was a lot of behavioural stuff that we did not attribute to her dementia at the time. We just thought there was an exaggeration of her usual behaviours, and everything was fine. (**Alyson**)

It took me two years to convince the GP that something was wrong with my wife. I lived with her, so I saw it every day. I saw it every minute of the day. I was not aware of dementia, or all the various forms of dementia. When Anne was diagnosed, I was handed an information pack that made for terrible, frightening reading. It's ironic that you devote your working life to improving your situation and planning for this thing called retirement, only for something unexpected to come along and slap you down. It happened to me, my brother, my sister, as if we are cursed as a family, life's a lottery truly. (**David**)

One of the things to think about is whether you are diagnosed with dementia because you had symptoms or for other reasons. I didn't have any symptoms; it was a real shock when I was diagnosed after a post-heart surgery MRI. I had to research everything myself. There was nothing out there to help me, to guide me. I was diagnosed and sent home to wait for death. That's it. I feel like I'm now trying to do everything yesterday. I do not want to lose my identity. I do not want to lose the stance that I have in the community, the position that I hold, and the respect that I have. By sharing my experiences, I hope to make sure other people do not experience the same. (**MAQ**)

Everyone you speak to has a very different experience of diagnosis. Professionals do not give you the information you need to live with the diagnosis of a terminal condition requiring palliative care and therapeutic interventions to live well with your diagnosis. Our experience was no different; we were left with no hope, not knowing what was ahead. Despite my own past professional career as a nurse, I had little knowledge of dementia. I had no idea of the prognosis until I shared my fears with the mental health nurse who assured us that we would get a few good years of normal life. She was right; we did have many good years living with the diagnosis. However, if that had been explained at our diagnostic visit, I believe I would have coped better with the diagnosis. The benefits of having a diagnosis are

> many, including self-directed support, reduction in council tax, blue badge scheme, attendance allowance, and carer support plans. In addition, and importantly, anticipatory care planning involving the person diagnosed with dementia at a stage when important decisions can be made. Our experiences show that this only happens when the caregiver reaches a crisis point. (**Myra**)

> I have had some mostly negative experiences with medical health professionals. Sometimes, once they know that you have dementia, they talk to your partner and do not talk to you. They make assumptions about you rather than ask you, and I have been in situations where I'm having a consultation and the doctor is talking to my partner and not talking to me. I now say, excuse me, but you're talking about me, and I can understand everything you're saying so please talk to me. Heather will say the same thing too now. (**Chris**)

Research suggests a split preference for how much information people would like to receive at diagnosis [45] and supports the tailoring of information to an individual's coping style [46]. Recent research at the University of Edinburgh explored the experience of diagnosis during the COVID-19 pandemic. They found that it was important to allocate sufficient time to people when giving a diagnosis, giving space to tailor information needs. Further, healthcare professionals should show patience and compassion and prioritise helping people focus on doing the things that they love for as long as the can [47]. Post-diagnostic support that includes social participation, physical and mental health support, and opportunities to have a voice are all positive ways to support people with a diagnosis [48]. Partners in Research is one way we hope people living with dementia have opportunities to be heard. Co-authors have described writing this book and other Partners in Research opportunities as a social prescription to cope with dementia.

Martin's Story

My first job was to polish smarties, we used to put Vaseline on them to make the polish. When I shared this with one of the co-production projects that I am a member of, we decided to make 'The Smarties' our group name. After the Smarties factory and a few other jobs, I became a benefits fraud officer.

When I was in my late 20s/early 30s, after my marriage broke down, I became an environmental activist. Somewhere there are photos of me chained to a bulldozer. But that was at the weekends, and in the week, I was the fraud officer, so I don't think nowadays you'd get away with it. Both sides knew about the other, but the activists didn't talk about benefits in front of me. The other benefits people got a great laugh about it, 'what did you do last weekend Martin?!'

I don't know if it's because I went to a posh school or just my opinion, but I was always told to look at both sides of an argument. I had a breakdown over my role as a benefits officer, it was just not me. So, from there I went into the shop floor in care on minimum wage. My first job was an independent-living key worker with a young person. It was one of the best times of my life because I took him to the Canary Islands, Euro Disney, we went to see Robbie Williams, Meatloaf, etc. He was non-verbal, and nobody had really bothered to think about what he wanted, but it just came naturally to me. The first time we went to a concert, and he saw the marquee, he was not sure what it was. But the next time we went, he kind of danced with joy because he knew what was coming. There was a problem in that often I was not back by the end of my shift, but I just acknowledged that I did quite a lot of unpaid hours because it was worth it for his smiles to be honest and knowing that he was enjoying himself.

I then went to work in a council day centre, which was a day centre for learning disabilities and older adults. Before I started, I had a quick look at a few of the gent's case histories, and all I did was sit around and chat with them and laugh. I remember the manager came in and said Martin, you're supposed to be doing art. I said, OK, then and we just carried on laughing. After a while I got moved over on rotation back into a different service. That was on the Monday, but by the Thursday the gentlemen were in the office saying 'if Martin isn't back with us by Monday, we're not coming in'. So, I was put back to the day centre. I was basically doing 'life stories' without realising it to be honest. For instance, I took them in a minibus to farms because they used to be farmers, so we went to where they worked or whatever to take photos. I realised from you guys [researchers] that I was essentially doing life stories.

I don't think my daughter Fiona realises just how much of a rock she has been to me throughout the years. For 10 years I used to drive between York and Glenrothes to see her each month. She's now got two lovely kids, who are 17 and 12 years old. We talk about once a week on Messenger. She is a carer who goes around people's houses, so she deals with supporting people daily and has seen that end stage.

I knew my driving was usually very good, but I started to become very cautious, and I started to forget a few things at work. I was approximately 55 when this started. For some reason I was getting one-sided headaches or cluster headaches, and I was getting treated for that. One evening in 2016, I went back for an appointment, and they did the Montreal Test (MOCA). I still scored well (26 out of 30) which would be considered normal, but the infinity symbols were on either side of the page, instead of linked. So, the guy turned around and said 'you have got dementia and you cannot drive anymore' basically. I asked if that meant I couldn't work anymore, and he said, you've got to see your GP. Luckily my wife was with me, we walked out to the waiting room but there was no one there to talk to, no leaflets to hand, we basically got sent home and that was it. However, by the time I got back to the car, I was jumping up and down in the seat because I saw it as, I could do what I wanted, when I wanted, if I wanted, rather than clock watch. I was telling Ethel, 'Oh I'm happy'. At the time I was told it was frontotemporal. It was an older doctor who I doubt had heard of PCA to be honest, but it is pretty rare to be fair.

So, we got our affairs in order and moved back to Scotland because that is where we're from. However, we did not realise what a steep change moving would be. We went and registered with a GP who said, 'I'll send you over to the consultant'. I was then sent a letter where the letterhead said 'old age psychiatry'. When we saw that title on his letterhead, we had to laugh, as even now, I am of working age. I thought, 'that's not me at all', but I went along, and the guy did a few tests. He said, 'Well, you haven't got frontotemporal dementia, so I'll send you to the neurologist', and I was given a Community Psychiatric Nurse (CPN). When the CPN first visited, she said that she was probably going to learn more from me than me from her. In this sense, I felt lucky, as she wanted to continue her visits six-weekly throughout my dementia journey, not stop after a year. She was a very nice person, so we benefited from her visits. The visits stopped once I had a neurologist, but I still receive excellent service.

The neurologist performed all the tests, and I was obviously fed up by this time. He said he wanted to do a lumbar puncture and I initially 'stomped my feet' because in England I was given six lumbar punctures in half an hour because I have scoliosis. Luckily, once I let them do the lumbar puncture, I didn't feel a thing. We were given a form that said if we heard back within three days, then I have Creutzfeldt–Jakob disease (CJD). I didn't, so that was okay, but what I did have was raised Tau levels. All my MRI scans were clear at the time, so although my symptoms were obvious, they were not shown on the scans. But the raised Tau confirmed it for the neurologist. He diagnosed PCA (posterior cortical atrophy) at that point, and he wanted to keep a hold of me because it's very rare, and he wanted to see how I progressed. Pre-COVID-19, we went to the local NHS conference. He gave a speech with a lot of medical language. I then talked a bit about how dementia affects me, and then my wife Ethel talked about being a carer. She received a standing ovation. I did not. I still do not let her off with it!

I'm now on SIGN, which delivers the national treatment guidelines.

I'm gonna stop taking on work because I'm also on a working group that meets every fortnight looking at excellence in nursing care. The first meeting was all slightly too bureaucratic, so I told them that dignity or human rights are not an optional extra. I got worried because I was then asked to join a call about the meeting. It turned out that they were giving me a mentor and she's going to speak to me after each meeting to see how I feel, and I check if I have got anything else to say. After the meeting, there was a huge e-mail conversation about 'that public-facing representative who dared to speak up and was very good about the human rights, and they all admired him for it'.

I'm not a member of any national organisation because I don't really want to be stuck in a silo. I want to talk to other people. I'm not that academic, or I wasn't, but I get on well with all of you researchers. Then, COVID-19 happened, and I was sent for an MRI scan in the hospital car park. I went for more neuropsychological testing, which took three hours, and it turned out that I still had an IQ of 120. The woman was saying, 'what's going on here cause your physical symptoms are obviously all further down the line than your brain?' We never really discussed it, but I went back to the neurologist, and he told me all this. It turns out that all the research and work I do is keeping the brain active. In that sense, research has been very good for me. He said he cannot ask why other people with my physical symptoms do something or how they feel. But he knows he can ask me. So basically, he is gonna see me every six months. I think for the duration.

My brother is an Oxbridge (Oxford and Cambridge University) Don and I get away with the fact I told him he was not human. Until he retired, I could not hold a conversation with him. I'm trying to teach him the benefits of co-research, but his subject does not lend itself well to co-production. However, he can see what it is doing for me, so he likes it for that reason if nothing else.

When I first started doing research, my wife Ethel would tell me I was doing too much, and I was getting tired. Then, I learned the signs of overdoing it, and she can see the benefit it has had. The Alzheimer's Society had an IT session in the area, so we went along. It was a 'foggy' day for me, and there was a VR headset there. I was offered it and the whole room just stood back in amazement because the minute I put it on my body straightened and it was obvious that the fog had lifted. It really had lifted. When it came off, I was not quite buzzing, but I was certainly 'with it' rather than foggy, and that lasted a good few days.

I decided if it helps me, it should help others, so I did a sponsored simulated bike ride to London and back on an exercise bike to buy the local group a virtual reality (VR) headset. Nobody seems to understand why it is so effective, not even the neurologist understands it. But it works. I was given a VR headset that I could use on foggier days. To start with, I got hooked on it. Now I'm not so bad. From what I know, a lot of people with dementia who use headsets do things such as 3D paintings in the air. But that's just nonsense to me. I use it to do things like visit where I went on holiday and things like that. So, no one truly understands how it is working, but it is. Apparently, they have tried it with other types of dementia, but it doesn't seem to have the same impact. I think it is to do with PCA.

It sounds terrible, but I think COVID-19 was a lifesaver to me. Everyone suddenly realised MS Teams and Zoom existed. It was Agnes who told me that if I got registered visually impaired, then I could get a free rail pass. We received an appointment at the hospital with the consultant. It only took a few seconds to do it. I was then sent down the corridor to the Sensory Services. The consultant said, 'Oh, I've got a strange one here, I've got a Terry Pratchett for you!' Terry Pratchett had PCA too and called it an 'embuggerance', which is a great description. I sometimes wear a fedora (as can be seen in Fig. 3.4). The Sensory Service was a great example of the gold standard because I went into the room with this volunteer, and we had two hours discussing things like bins and all the other obstacles you might have when you're blind. It would be ideal if this service was available for other people who are diagnosed.

We love dogs and I have a wee Dandy Dinmont called Judy. She is kind and lovely, and she knows when to come and be with me. We looked at having a dementia dog, but I didn't like that it was the carer who is responsible for the dog. I thought I would think outside the box and see about a guide dog. I went through all the tests, and it was very strange because

Fig. 3.4 Martin wearing his ‘Terry Pratchett’ fedora

a woman had a guide dog harness on her arm, and I had to lead her around the streets. They agreed I was capable of it, and I was passed. Earlier this year I went down for a fortnight of training. I was teamed up with Dollar the guide dog, and we worked very well together. The staff themselves were very—and I don’t like the term but—dementia friendly. They made sure there was always a nice quiet, dark room for me to use. They made changes, so I got two half hours instead of one hour, etc. Adjusting the training came naturally to them, which I thought was good. They filmed Dollar and I working together so that they could show how people living with dementia could work with guide dogs.

After the two weeks, Dollar came home with me but within a couple of days Ethel’s lungs were blocked up. Dollar was a golden retriever, and they shed like nobody’s business. Therefore, unfortunately, Dollar had to go back. I'm now waiting for, ideally, a Labradoodle or maybe a Labrador. I would still have to go back and have two weeks training as that's kind of the bonding part. It's truly amazing how intelligent they are (Fig. 3.4).

Getting the diagnosis allowed me to just do what I truly wanted to do, which is obviously research, and some work with the government, which goes back to my activism days, I think. I feel confident and able to fight against researchers who are being tokenistic. If that happens, I will send them an e-mail, but I will also send them a copy of The Smarties guidebook as a way of saying this is how it should be done. If it stays tokenistic, I will say to them, I'm sorry, I do not want to take part anymore. The diagnosis has also built my confidence in speaking to academics, I think. The diagnosis told me in no uncertain terms that time is limited. I think that is why I have dived so deep and hard into research to get as much done as I can. I'd like to think I have done something good.

Martin

Myra and Archie's Story

We were looking forward to a long busy retirement, travelling, spending time with family. We wanted to spend more time in our island homes, which we had both left at an early age for the mainland, for further education and careers. It's also where we met and married. Archie was an academic in physics and maths with a successful career in research and teaching. I had a long and varied career in nursing.

We were both proud parents and grandparents.

The day we received a diagnosis of Alzheimer's disease will live with me forever. In that moment, our lives changed, and time stood still as I gazed at the amount of literature presented to me, stating 'you will get a lot of information in these booklets'. All I could see were pictures of grey-haired old people holding hands. I thought, 'is this what we have become?' It was traumatising, worse than the diagnosis I knew was coming. These images stayed with me for such a long time, as a young person I could not relate to them, and I could not see Archie in that way either. I aged 10 years, just staring at these images.

My first campaign was to get changes to information leaflets and make them more appropriate, diverse, and inclusive. I tried very hard to get that message across by joining online groups and organisations who published dementia patient information. I was listened to, and it made a little bit of difference, but not enough, there is more work to be done.

We need to have information that is relevant to the type of dementia you are diagnosed with, and the contact details of professionals who can help. No one needs a handful of literature straight after receiving a life-changing diagnosis. Your emotions are all over the place. You need simple, accurate, relevant information that is disease-specific and gives you information on treatments, clinical or palliative, and ways to cope with a long-term condition.

Archie retired early, I could never understand why, but he knew something was wrong and he kept stating he had 'something wrong with his head'. I saw changes, but thought he was becoming depressed at the thought of retiring. He made frequent visits to his GP, who always reassured him following memory testing that his memory was ok. For the duration of the illness, short-term memory was preserved, but long-term memory was declining.

I retired to be with him, thinking he was depressed, but I soon began to recognise difficulties that could be due to an underlying medical cause. I was not sure what. It was when he had a memory test in my presence, I realised he could not answer any of the questions, as he could not understand what was being asked. He felt extremely inadequate with very low self-esteem following memory testing. I felt it served no purpose in identifying Archies' condition and with no treatment, why subject him to memory testing? So, we agreed that it would stop.

I wasn't convinced it was Alzheimer's disease I thought he had a brain tumour. As his carer, I felt clinicians never took heed of me or my observations. Archie was later diagnosed with semantic dementia after four years of my research and search for answers. The second diagnosis of semantic dementia was so much worse than the first diagnosis of Alzheimer's. We were living with a much more progressive dementia. Archie accepted it, but I soon realised that he was not fully comprehending what it meant.

We made the best of our lives, but we had to make big adjustments. We planned for our future together while we could and travelled as much as possible. There was always a story, but we managed with support from family. I did feel the stigma. We lost good friends, who found it too hard not being able to communicate with Archie as they had in the past. But we made new friends who gave us such support. Archie struggled so much to communicate and understand the world around him. He couldn't have lived his life so well without me or our family.

We were offered help by Alzheimer Scotland, but Archie could not participate in group activity or socialising with peers. He was so much better in a one-to-one situation, and I can understand why. Communication was an ongoing struggle. The support helped me as I got actively involved during my time while caring, researching, and joining peer groups. I eventually joined the National Dementia Carers Action Network, which opened many doors for me to get my voice heard. I was passionate about getting change and raising awareness of early-onset rare dementia. I do believe my voice was heard, it was certainly loud enough, and we got some change. Other factors helped, especially as dementia became a priority for the Scottish government, leading to dementia strategies. I had an active role as a carer in many of the strategy groups.

It was my greatest desire that I would stay healthy and able to care for Archie at home, as going into care was not an option. I put structures in place in case anything happened to me. I did all I could, but when it came to negotiating anticipatory care plans and the benefits we were entitled to with health and social care, it was a different matter. I reached a crisis point due to overwhelming tiredness and the need for more clinical interventions towards the end of Archie's illness. We received a reactive response from health and social care; it was like a tsunami of professionals and equipment coming through the door. It was fraught with difficulty for me, I was finally being listened to, but it all added to my stress. It could have been avoided if the right community structures were in place in a more planned way, rather than a reactive crisis response.

Again, the carer's voice was not heard, I was never a partner in care! Yet, I cared for Archie throughout his illness of seven years with very little health and social care input or support. I also recognise I could only have done this because of my professional nursing knowledge, community experience, good health, and family support. In addition, Archie had no other medical conditions other than semantic dementia, which we managed together as we understood his illness through our own research.

Having lived with dementia as well as being an unpaid carer has given me insights into an illness that is manageable with the right support, targeted therapeutic interventions, and good holistic care, but the interventions must come early in the disease.

A timely accurate diagnosis is so important to achieve good outcomes. I am now using my experiences, knowledge, and passion for change to help others.

Myra

AGNES' STORY

Agnes is a bit of a celebrity in dementia activism and was awarded an MBE in 2015 for her services to dementia. Agnes was diagnosed with Alzheimer's disease at 57 years old. She has worked tirelessly for many years to help others learn more about the lived experience of dementia.

> I went for a second diagnosis because people don't think I look like I have dementia, and if you're told that enough you doubt it.

She has since done a lot of work focused on sensory issues that people living with dementia can face and the importance of seeing more than just memory.

Over the past year, Agnes has faced a series of difficult circumstances within her personal life. Her son-in-law passed away due to motor neurone disease. This was sadly followed by the passing of her husband. Agnes had been caring for her husband who had dementia, while coping with her own diagnosis. Shortly before his passing, he was moved to hospice care due to the progression of cancer.

To reduce the amount of work Agnes was being asked to do, I [Rosie] offered to write some of Agnes' story for the book to go alongside the various extracts Agnes has provided within the other chapters. I hope that in doing so, I can do justice to some of the many reasons people love working with Agnes.

Agnes has always been very generous with her time and sharing her story of living with dementia, as well as noting the additional challenges faced by being a carer. She shared how the different visibility of her husband's dementia resulted in him being at more risk.

> My husband is totally vulnerable but doesn't look like he's got anything wrong with him, which makes him at high risk. Things like losing his way, he would be lost for hours because he wouldn't think to ask someone for help.

I have worked with Agnes on several projects, including Dementia Enquirers, Ecredibles, and Partners in Research, which are discussed in more detail in Chap. 5. Agnes became Chair of the Scottish Dementia Working Group (SDWG) in 2010, a group of people with lived experience looking to draw attention to the lived experience of people with dementia and challenge assumptions that people have about the condition. As part of their research agenda, the SDWG asked researchers who wished to work with them to provide accessible summaries about their work. Researchers also needed to clearly show how they would adhere to the group's core principles and what the benefits of involvement would be for people with lived experience.

As part of self-directed support, Agnes is aided by a personal assistant who makes it possible for Agnes to attend a variety of meetings and events internationally. Her personal assistant takes responsibility for a range of organisational tasks, which leaves Agnes with more capacity to be involved. Importantly, it shows that people's ability to get involved is not black and white but often dependent on what other conflicting demands they have going on at the same time.

One of the many reasons Agnes is so vital to Partners in Research is due to her background in nursing, as well her experience over the last 15 years of the dementia landscape. Agnes is always keen to know how researchers and organisations will move forward, instead of 'reinventing the wheel'. Her background also means that Agnes can reflect on why things may be the way they are,

> I don't think professionals are deliberately trying to make things difficult. I think it is maybe a learned response. A nurse on the ward trying to take that extra time with a person living with dementia may also have superiors telling them off for wasting time. When I worked on the wards, I used to get sent on a task but then stop to help someone. When I got to my destination, I would be told off. I had one job and one job only; it wasn't a reflection on the patient, but I was being told it wasn't my responsibility. I disagree, I think everybody in the hospital is my responsibility as a human being, but you have that knocked out of you. It becomes a learned response that you should only focus on the task you've been given. There is also not enough support to staff taking on that additional emotional load.

One of Agnes' frustrations to share with those in a position to change practice is that unlike many other conditions, dementia is not given the multidisciplinary approach that other disease areas are. Most of the time, it is focused only on older adult psychiatry. However, over the course of her dementia, Agnes would have benefitted from a more connected approach to the care that she needed.

> Why in the dementia world do you not have a team of doctors? It would mean you see different specialties as and when you need them.

Agnes' experiences of 'brain blindness' and 'brain deafness' are important lessons in the atypical aspects of Alzheimer's disease. They refer to vision and hearing changes that cannot be fixed by hearing aids or glasses, as it is to do with how the brain interprets sound and images, as opposed to issues with the eyes or ears.

Among the co-authors there has been a lot of discussion about which professionals should be involved in the care of people living with dementia. There is a consensus that neurology would be helpful; however, Agnes adds that this may not be the fix people expect,

> I've heard a lot of people who've been referred to neurologists and they've had a very negative experience, so I think it less about their role and more about who the person is and how they treat you.

Agnes reminds us that people with dementia are just 'ordinary people living ordinary lives', and as such, their experiences with dementia need to be considered in the context of other comorbidities, family circumstances, financial support, etc.

Below are links to some of the resources that Agnes has created for people with lived experience.

Finally, thank you to Agnes for trusting me to share her story.

Useful Resources:

Houston, A. (2015). Dementia & sensory challenges: Dementia can be more than memory. Life changes trust. https://www.lifechangestrust.org.uk/sites/default/files/Leaflet.pdf

Houston, A. (n.d.). Sensory changes and dementia- sense of taste and smell. Life changes trust. https://www.lifechangestrust.org.uk/sites/default/files/publication/files/Sensory-Changes-and-Dementia-Booklet-Final.pdf

Houston, A. (2016). Think dementia, think sensory. Winston Churchill Memorial Trust. https://www.ed.ac.uk/sites/default/files/atoms/files/houston_a_report_2016_final.pdf

References

1. Macmillan, M., & Lena, M. L. (2010). Rehabilitating Phineas Gage. *Neuropsychological Rehabilitation, 20*(5), 641–658.
2. Nielsen, J. A., Zielinski, B. A., Ferguson, M. A., Lainhart, J. E., & Anderson, J. S. (2013). An evaluation of the left-brain vs right-brain hypothesis with resting state functional connectivity magnetic resonance imaging. *PLOS ONE, 8*(8), e71275.
3. Jarrett, C. (2015). *Great myths of the brain.* John Wiley & Sons Ltd.
4. Swami, V., Stieger, S., Pietschnig, J., Nader, I. W., & Voracek, M. (2012). Using more than 10% of our brains: Examining belief in science-related myths from an individual differences perspective. *Learning and Individual Differences, 22*(3), 404–408.
5. Herculano-Houzel, S. (2009). The human brain in numbers: A linearly scaled-up primate brain. *Frontiers in Human Neuroscience, 3*(31), 1–11.
6. Ashworth, R., Bassett, Z., Savage, S., & Webb, J. (2022). Risk, worry and motivation: How is public knowledge of dementia shaped? *Dementia, 21*(3), 851–861.
7. Cahill, S., Pierce, M., Werner, P., Darley, A., & Bobersky, A. (2015). A systematic review of the public's knowledge and understanding of Alzheimer's disease and dementia. *Alzheimer Disease and Associated Disorders, 29*(3), 255–275.
8. Small, G. (2002). What we need to know about age related memory loss. *BMJ, 324*, 1052–1055.
9. Rohra, H. (2016). *Dementia activist: Fighting for our rights.* Jessica Kingsley Publishers.
10. Roach, P., Drummond, N., & Keady, J. (2016). `Nobody would say that it is Alzheimer's or dementia at this age': Family adjustment following a diagnosis of early-onset dementia. *Journal of Aging Studies, 36*, 26–32.
11. Chiari, A., Tondelli, M., Galli, C., Carbone, C., Fiondella, L., Salemme, S., Vinceti, G., Bedin, R., et al. (2022). How long does It take to diagnose young-onset dementia? A comparison with late-onset dementia. *Neurological Sciences, 43*, 4729–4734.
12. Van Vliet, D., de Vugt, M. E., Bakker, C., Pijnenburg, Y. A. L., Vernooij-Dassen, M., Koopmans, R. T. C. M., & Verhey, F. R. J. (2013). Time to diagnosis in young-onset dementia as compared with late-onset dementia. *Psychological Medicine, 13*, 423–432.
13. Millenaar, J. K., Bakker, C., Koopmans, R. T. C. M., Verhey, F. R. J., Kurz, A., & de Vugt, M. E. (2016). The care needs and experiences with the use of services of people with young-onset dementia and their caregivers: A systematic review. *International Journal of Geriatric Psychiatry, 31*(12), 1261–1276.

14. Milne, A. (2010). The ‘D’ word: Reflections on the relationship between stigma, discrimination and dementia. *Journal of Mental Health, 19*(3), 227–233.
15. Ashworth, R. (2020). Looking ahead to a future with Alzheimer’s disease: Coping with the unknown. *Ageing and Society, 40*(8), 1–22.
16. Alzheimer’s Society. (2021). *Risk factors for dementia factsheet*. Alzheimer’s Society. Retrieved October 2022, from https://www.alzheimers.org.uk/sites/default/files/pdf/factsheet_risk_factors_for_dementia.pdf
17. Van Asbroeck, S., van Boxtel, M. P. J., Steyaert, J., Kohler, S., Heger, I., de Vugt, M., Verhey, F., & Deckers, K. (2021). Increasing knowledge on dementia risk reduction in the general population: Results of a public awareness campaign. *Preventive Medicine, 147*, 106522.
18. Meng, X., & D’Arcy, C. (2012). Education and dementia in the context of the cognitive reserve hypothesis: A systematic review with meta-analyses and qualitative analyses. *PLoS ONE, 7*(6), e38268.
19. Stern, Y. (2012). Cognitive reserve in ageing and Alzheimer’s disease. *Lancet Neurology, 11*(11), 1006–1012.
20. Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., et al. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet commission. *The Lancet Commissions, 396*(10248), 413–446.
21. Montero-Odasso, M., Ismail, Z., & Livingston, G. (2020). One third of dementia cases can be prevented within the 25 years by tackling risk factors. The case “for” and “against”. *Alzheimer’s Research & Therapy, 12*(1), 1–5.
22. Lawless, M., & Augoustinos, M. (2017). Brain health advice in the news: Managing notions of individual responsibility in media discourse on cognitive decline and dementia. *Qualitative Research in Psychology, 14*(1), 62–80.
23. Alzheimer’s Society. (2021). *Dementia: Reducing your risk*. Alzheimer’s Society. Retrieved October 2022, from https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_reducing_your_risk.pdf
24. Dementia UK. (2021). *What is dementia?* Retrieved October 2022, from https://www.dementiauk.org/about-dementia/dementia-information/what-is-dementia/#support
25. McManus, M., & Devine, P. (2011). Dementia: Public knowledge and attitudes. *Research Update, 77*, 1–4.
26. YouGov. (2022). *The most popular charities & organisations in the UK*. Retrieved October 2022, from https://yougov.co.uk/ratings/politics/popularity/charities-organisations/all
27. Heerema, E. (2020). *12 Leading Alzheimer’s and dementia charities and organisations*. Retrieved October 2022, from https://www.verywellhealth.com/leading-alzheimers-and-dementia-charities-and-organizations-4145316

28. National Institute of Aging. (2022). Retrieved October 2022, from https://www.nia.nih.gov/health/how-biomarkers-help-diagnose-dementia#:~:text=Magnetic%20resonance%20imaging%20(MRI)&text=Repeat%20scans%20can%20show%20how,picture%20of%20brain%20blood%20vessels
29. Ridge, P. G., Ebbert, M. T. W., & Kauwe, J. S. K. (2013). Genetics of Alzheimer's disease. *BioMed Research International, 2013*, 1–13.
30. Bir, S. C., Khan, M. W., Javalkar, V., Gonzalez Toledo, E., & Kelley, R. E. (2021). Emerging concepts in vascular dementia: A review. *Journal of Stroke and Cerebrovascular Diseases, 30*(8), 105864.
31. Engelhardt, E., Tocquer, C., Andre, C., Moreira, D. M., Okamoto, I. H., de Sa Cavalcanti, J., & Working Group on Alzheimer's disease and Vascular dementia of the Brazilian Academy of Neurology. (2011). Vascular dementia: Diagnostic Criteria and supplementary exams. Recommendations of the scientific department of cognitive neurology and aging of the Brazilian academy of neurology. Part I. *Dementia & Neuropsychologia, 5*(4), 251–263.
32. Deardorff, W. J., & Grossberg, G. T. (2019). Chapter 2- Behavioral and psychological symptoms in Alzheimer's dementia and vascular dementia. *Handbook of Clinical Neurology, 165*, 5–32.
33. Crutch, S. J., Lehmann, M., Schott, J. M., Rabinovici, G. D., Rossor, M. N., & Fox, N. C. (2012). Posterior cortical atrophy. *The Lancet Neurology, 11*(2), 170–178.
34. Crutch, S. J., Schott, J. M., Rabinovici, G. D., Murray, M., Snowden, J. S., van der Flier, W. M., Dickerson, B. C., Vandenberghe, R., et al. (2017). Consensus classification of posterior cortical atrophy. *Alzheimer's & Dementia, 13*(8), 870–884.
35. McKhann, G. M., Albert, M. S., Grossman, M., Miller, B., Dickson, D., & Trojanowski, J. Q. (2001). Clinical and pathological diagnosis of frontotemporal dementia: Report of the work group on frontotemporal dementia and pick's disease. *Archives of Neurology, 58*, 1803–1809.
36. Ducharme, S., Dols, A., LaForce, R., Devenney, E., Kumfor, F., van de Stock, J., Dallaire-Theroux, C., Seelaaar, H., et al. (2020). Recommendations to distinguish behavioural variant frontotemporal dementia from psychiatric disorders. *BRAIN, 143*, 1632–1650.
37. Leyton, C. E., & Hodges, J. R. (2010). Frontotemporal dementias: Recent advances and current controversies. *Annals of Indian Academy of Neurology, 13*(2), s74–s80.
38. Kertesz, A., Jesso, S., Harciarek, M., Blair, M., & McMonagle, P. (2010). What is semantic dementia? A cohort study of diagnostic features and clinical boundaries. *Archives of Neurology, 67*(4), 1–7.

39. Hodges, J. R., Patterson, K., Oxbury, S., & Funnell, E. (1992). Semantic dementia. Progressive fluent aphasia with temporal lobe atrophy. *Brain, 115*(6), 1783–1806.
40. Goral, M., Clark-Cotton, M. R., & Albert, M. L. (2006). Language disorders: General. In *Encyclopaedia of gerontology*. Elsevier.
41. Taylor, J. P., McKeith, I. G., Burn, D. J., Boeve, B. F., Weintraub, D., Bamford, C., Allan, L. M., Thomas, A. J., & O'Brien, J. T. (2020). New evidence on the management of Lewy body dementia. *Lancet Neurology, 19*(2), 157–169.
42. McKeith, I. G., Boeve, B. F., Dickson, D. W., Halliday, G., Taylor, J. P., Weintraub, D., Aarsland, D., Galvin, J., et al. (2017). Diagnosis and management of dementia with Lewy bodies: Fourth consensus report of the DLB consortium. *Neurology, 89*(1), 88–100.
43. Stinton, C., McKeith, I., Taylor, J. P., Lafortune, L., Mioshi, E., Mak, E., Cambridge, V., Mason, J., Thomas, A., & O'Brien, J. T. (2015). Pharmacological management of Lewy body dementia: A systematic review and meta-analysis. *American Journal of Psychiatry, 172*(8), 731–742.
44. Walker, Z., Possin, K. L., Boeve, B. F., & Aarsland, D. (2015). Lewy body dementias. *The Lancet, 386*(10004), 1683–1697.
45. Mastwyk, M., Ames, D., Ellis, K. A., Chiu, E., & Dow, B. (2014). Disclosing a dementia diagnosis: What do patients and family consider important. *International Psychogeriatrics, 26*(8), 1263–1272.
46. Proctor, R., Martin, C., & Hewison, J. (2002). When a little knowledge is a dangerous thing…a study of carers' knowledge about dementia, preferred coping style and psychological distress. *International Journal of Geriatric Psychiatry, 17*(12), 1133–1139.
47. Alzheimer's Scotland Dementia Research Centre. (2022). *Understanding dementia diagnosis during the COVID-19 pandemic: Project report*. Retrieved October 2022, from https://www.alzscotdrc.ed.ac.uk/sites/default/files/Full%20project%20report%20%281%29.pdf
48. Stamou, V., La Fountaine, J., O'Malley, M., Jones, B., Gage, H., Parkes, J., Carter, J., & Oyebode, J. (2021). The nature of positive post-diagnostic support as experienced by people with young onset dementia. *Aging & Mental Health, 25*(6), 1125–1133.

CHAPTER 4

'I Didn't Know I Was a Carer'

Abstract This chapter reflects on how many of the carers in this book prefer not to identify with this label but have had to use it to access appropriate support. The chapter looks at how people have had to adjust to working with paid carers and sharing home space. Co-authors share examples of having to fight to be recognised for their expertise and how this can shape current care and future needs.

Keywords Carer, Informal care, Paid carers, Formal care, Advance Care Planning, Caring responsibilities

People living with dementia do not experience their diagnosis in isolation, and there is a ripple effect on family and friends. This chapter reflects on some of the challenges that people who take on a carer role can face.

Co-authors: Rosalie Ashworth, Sue Fyvel, Alyson Hill, Chris Maddocks, Masood Qureshi, David Ross, Stuart Hay, Martin Robertson, Willy Gilder, Winnie Henry, Myra Lamont, Agnes Houston, and Fred S. Wilson
Email: tay.ppipartners@nhs.scot
Neuroprogressive and Dementia Network, NHS Tayside, Dundee, UK

Jennifer England
Email: 15001845@uhi.ac.uk
University of Highlands and Islands, Inverness, UK

R. Ashworth et al., *Challenging Assumptions Around Dementia*,
https://doi.org/10.1007/978-3-031-27223-3_4

> People say we suffer from dementia. I don't think that we suffer from dementia, but I do think carers may suffer. In the latter stages, I won't be aware of my suffering, whereas my wife will suffer in worrying about what will happen. (**Martin**)

> When we think about care, it is not just personal care. It is vital for people to understand our psychological needs, our financial needs, our culture, and faith, and how these different aspects influence each other. (**MAQ**)

Collectively, the co-authors have shared their experiences of both receiving support and providing support. We want to acknowledge that the term 'carer' is contentious [1]. Much of the time, it is used as a door opener, similar to how dementia cards and sunflower lanyards are used when needed (as seen in Chap. 2).

> The term carer is a term that some people use, but I don't like it. You are looking after someone you love and that's not care, that's love. It's a different thing. (**David**)

> The term carer fits better with paid professionals. They are needed when someone either does not have other help or their loved ones are not trained or supported enough to meet the care needs. I see our loved ones as helpers. We work together as partners. That's unconditional because there are other reasons for a partner to support you, not just because of the condition but because of the bond and the relationship. (**MAQ**)

> I am resentful of the term carer because it means nothing to me. I am not a paid carer. I have a full-time job, which is more than 40 hours, sometimes 60 hours, as well as having mum and my kids. I don't get any benefits. The term does not consider the obligation to a loved one to make sure they are okay. I know that I am a good advocate on my mum's behalf, and when I took her in, I knew what to expect. I was most surprised by other people's attitudes to what they think I should and shouldn't do. I did not anticipate that my mum would be staying with us so long. COVID-19 made a huge difference. When she moved in, we didn't know how long the lockdown would extend to. We hadn't anticipated how difficult things were, but so much was hidden from us when my mum and dad were living in their flat. (**Alyson**)

> I think the turning point is when you acknowledge that you are a carer. It's very difficult to do. There are so many people who do not recognise or know when they become a carer. It is such an important realisation and allows you to open up to support options. It was important to acknowledge when we hit the crisis point. (**Myra**)

It's so hard for carers to fully realise that their loved one is dying of this awful disease. It is a terminal illness and that is not acknowledged enough. It is a terrible thing to acknowledge, but it is also so important that we do. You try to go on as normal, whatever normal might be for them at that time. You are also trying to do all the jobs that would usually take multiple people to do, but you just have to get on with it. (**Winnie**)

Working with Paid Carers

I don't have any experience with paid carers. There's a massive difference for me between paid and unpaid carers. Paid care depends on who they are, what they understand about the person, and where you are based. For some, it is just a job, the caring part is very different. Unpaid carers offer unconditional support. My family, my children are all very involved with me, although I am fortunate at this time to not need much support. (**Fred**)

There is infighting between whose responsibility it is to provide certain types of care. Everybody in the middle is trying to say that they need help or support, but they are lost between all the political infighting. (**Alyson**)

In my wife's case, she had no idea that she was ill. It was really strange, especially when we got to the stage of carers coming in to help her. Even with the best intentions, the care they could offer fell short of the mark. You could not guarantee when they would arrive or who they would be. There was so much inconsistency, and people often did not turn up. She never complained, but she got upset with strangers coming in. I think the people who try to provide the care are trying to do the best they can but are hindered by lack of resources and time. I was trying to do everything. I had to because I couldn't keep up with the stress of coordinating outside carers. I never thought of myself as a carer; I was just looking after my wife. I continued to do it until it was absolutely impossible to do so, and then I had to put it into the hands of so-called professionals. Some are good. Some are bad. You need to get to know the individual. You cannot possibly care for a person if you don't understand their needs. (**David**)

In a typical week, we were very lucky to have regular carers coming in. The teams have more or less been the same. We have managed to have good experiences with council and private care. (**Stuart**)

We have carers who come in four times a day, but they keep looking for validation that my mum remembers them. She doesn't remember them; it could be four different carers in one day. They need to understand more about dementia so that they are not looking for validation. I don't know if they

> have very firm beliefs about dementia. I don't know how to change people's perspectives. Hopefully, our shared experiences will help with this. (**Alyson**)

It is very clear that there are major inconsistencies in paid care. In some ways, the increased hybrid approach (in person and via online video conferencing) has highlighted the postcode lottery more than ever [2]. Instead of having solely local support, we are learning more about the different scenarios people face.

> I was thinking about my mum's experience. She had regular people come in to support her, they were very busy but there was consistency in who she saw time and time again. In my job as a social worker, there were always the pressures of who you were seeing and the many time constraints you were under. There's nothing ideal about the situation. We need to think of ways to help people learn about each other while juggling time constraints. Sometimes the little things can make all the difference. (**Sue**)

There is also a challenge around how to help people learn more about dementia and the needs someone might have [3].

> The carers come to the door, and they do not always have knowledge of dementia. They have to find their feet. In between seeing my wife, they are seeing half a dozen other people, all with different things wrong. It can be very hard for them; they are not paid well and they do not have consistency. (**Stuart**)

> When a unpaid carer comes to see you, you may be the fourth or fifth person who they have seen. That person is trying to get to know people, but they may not be able to give 100% each time. We can't get away from that. Travelling from one place to another puts strain on a person. All these things add up, and we may not know what makes a bad day for a carer coming in. (**MAQ**)

> Our experience showed me that traditional therapeutic interventions to support living well with dementia do not work well for a person with semantic dementia. You need to do a continuous risk assessment to ensure a safe environment in the home and outside if necessary. As the disease progresses, the level of understanding diminishes, and the level of risk is much greater. The home environment must be assessed for situations such as the risks of being home alone, the risks from not recognising door callers, and especially risks in the kitchen where a bar of soap could be confused with food due to recognition and loss of conceptual knowledge. (**Myra**)

When people have had difficult experiences, this can put others off facing a similar situation, whether that is attending hospitals or accepting care.

> It's so important that we know who our carers are, as well as them knowing us and our needs. I spoke to a woman recently who had a replacement carer sent to her home. The organisation ignored her care package, where it was agreed that only female carers would come to offer support. When a male carer was sent, she was told after that you either see him or nobody. She would have preferred not to have a visit at all. He came in and made her a cup of tea with no milk or anything. Her difficult experience could have been avoided if they had checked her care plan or checked with her first. (**Fred**)

> If there is a real desire for people to remain at home, then the people who facilitate that need to do better and need to actually provide support at home. There needs to be a will to make sure it works. I have struggled at times, and I know the system. I never anticipated how difficult it would be. I said to my son and daughter, 'it was never this hard to support your Granddad. What's the difference? Is it because I'm older? Maybe my work's slightly more intense or Grannie's living slightly longer? What is it that is so different about this time?' And I suppose it is a combination of all those things. (**Alyson**)

> Care workers also need support to take on other people's needs. In other care professions such as social work, supervision and self-care are an important part of working in the field. If people working in care do not get the help to support themselves, they will burn out. Even if they are fantastic and love their care role. (**Sue**)

Being Recognised as Experts by Experience

Our co-authors have a clear desire to work well with others to facilitate the care of people living with dementia. However, to do so, it is important that carers feel that their expertise is being recognised and valued. Unfortunately, this is not always the case.

> Living with any degenerative, long-term illness makes you an expert in the management of symptoms and recognising signs of deterioration and decline. However, you need professional input for that additional knowledge and support, therefore making you 'partners in care'. Professionals need to understand that your support and knowledge of the person you care for is equally important for a good outcome. I took my husband for a routine dental appointment requiring root extraction. The usual department was closed, and we had to attend day theatre. I explained why I needed to

> be present at the procedure, which was carried out in a place he was not familiar with. I was denied based on infection control procedures, but I know about infection control, and I was just going to stand at his head and not touch anything. They tried to get me to leave, but I had to say no, I'm not leaving. They did not recognise that allowing me to stay would have helped. The experience for all concerned was traumatic, especially for my husband, who was denied his right to an interpreter. He could not follow instructions because of semantic dementia. I was not recognised as a 'partner in his care', which also traumatised me; on reflection, I should have stopped the intervention and procedure, knowing the risk. It impacted me greatly, knowing I had let Archie down. It never happened again as I used my rights as his carer to get the right care and interventions for him. (**Myra**)

> When mum came here, the idea was just to get over that initial period of the COVID-19 lockdown and get her back home. However, she had things like fluid on her lungs, and there was one night I lay beside her bed, thinking that it was going to be her last night. I could not get the doctor's surgery to take any interest in coming to do the assessment. I could not get anybody to respond to the situation. She was struggling to breathe. I phoned NHS 24, and it was just sheer luck that the doctor who came out had been to see my dad at my old house, and she remembered him and the dog. She said your mum needs to go into hospital today. It was just such a relief that someone was listening. Somebody is responding to what I have told them. If she hadn't gone to the hospital that night, she would not have lasted. (**Alyson**)

Sharing Home Space

When considering the involvement of paid carers, it is important to remember that they are going into peoples' homes, a deeply personal space that may be shared with others. It has been difficult to find research that explores this change in privacy for all household members, although there is research that considers paid carers as 'guests' in the homes of people with care needs [4].

> An issue for us has been that carers do not always announce themselves when they come in. My mum lives with me and my family. They forget that. It changes our privacy, the privacy of my children, my nieces, and nephews. I could be having friends around. Even just a 'hello, there is somebody here' would be an improvement, rather than finding them in the bedroom and my mum gone. When the carers first started coming to support my mum a

> couple of years ago, they were excellent, absolutely brilliant, but the way they were treated by management made them leave. We were left with carers who weren't worried about bad practice, but who could put up with the behaviour of bad managers. I know that most people try their best, but without the right training they cut corners. My mum is lucky, she's got me, but there are a lot of people who won't have someone looking out for them or able to chase up inconsistent carers. In some ways, it has strengthened the relationship with my mum. When she moved in, I made the decision to wipe the slate clean of any past recriminations and avoid situations that cause conflicts. We haven't done too badly over the last two years. There have been a couple of flashpoints, but we managed to get over them. (**Alyson**)

> I ended up employing my own support. I had gone through an agency, but it was so inconsistent, and they kept sending the wrong people. I also determined that carers were getting less money than the administration costs. I got self-directed support, and I went with the option of employing some mature ladies who were just brilliant. They helped keep the home feeling like a home, whereas having strangers in and out truly changes that feeling. It is very important to build positive relationships with doctors, consultants, and support organisations. It becomes key to how you work together. (**Myra**)

Examples of Best Practice in Care

It is only natural that our co-authors have formed a bond over sharing their difficult experiences [5]. We also felt that it was important to share the positive experiences people have had in regard to care.

> I have done activities that involve providing personal information, but it's a piece of paper, a tick box exercise. However, there was one lady who supported my wife who was absolutely wonderful and got to know her so well. It was fantastic help because she truly cared. She truly took the time to get to know her. It wasn't just 14 minutes at a time. (**David**)

> If you meet one person with dementia, you meet one person with dementia. If you treat everybody the same, you're not going to get anywhere. I believe that knowing the person and building rapport is vital. We need care to be compassionate and empathetic. (**MAQ**)

> At first all my thoughts were occupied by the instances of bad practice we had experienced. I had to work very hard to separate the wood from the trees, so to speak. However, on reflection, there was good professional prac-

> tice at times, also. One person who truly stands out in this respect was the nurse who had Wullie as one of her charges in the care home. She recognised that although he had health and memory problems, he still had a wealth of lived experience to offer, and she told us how she would ask, and take, his very sound advice on family matters. Another outstanding professional was the maxillofacial surgeon who looked after him when his skin cancer needed to be operated on. By this time, Wullie's dementia was becoming more advanced, and the surgeon gave him a depth of respect and a feeling of dignity that was missing in so many other parts of his life as his dementia worsened. (**Winnie**)

> I was giving a talk with this chap one day, and he was telling me a story about how he had given a talk at a care home and sat to have tea and biscuits with the residents. He noticed this one man would not have a drink or have a biscuit. So, he just sat and chatted to him and said, 'would you like a drink of tea or a biscuit?' The resident said, 'no'. So, he asked him, 'whys that?' The resident replied, 'because I have not got any money to pay for it!' So, they gave him a wallet with some coins in it, and he started eating again. It makes perfect sense when you think about it, all through your life, you have a purse or a wallet with you, and then you just suddenly have those things taken from you. (**Chris**)

> I'm part of a carer support group. We are all just trying to support each other. We have good facilitators who let us get on with it. We all have our experiences to share. We know what it is like, and we have people who have experienced different 'stages' of dementia. We have a good laugh, it's not all doom and gloom. It is truly quite funny some of the things that have happened and some of the things we share. (**Winnie**)

Planning Ahead

Early diagnosis of dementia is often encouraged to allow people to plan for their future. However, we know that people hold different coping styles and that it is often difficult for people to look to the future, instead preferring a day-at-a-time approach [6]. Unfortunately, this can mean that people can hit a crisis point in support needs before putting plans in place [7].

> As a family, we had to decide how best to manage. My mum and dad were both diagnosed with dementia within six months of each other, which arose

out of crisis. We were oblivious to what was going on in their house until that crisis point. We had some future proofing by getting powers of attorney in place, and we spoke with their GPs and made sure everything was sorted. I'm so glad that we did. When my dad passed away, I did not feel comfortable leaving my mum on her own. She lived in a complex of flats for people who could do with certain support in place. That was no longer going to be enough to sustain her, and I managed to get her to agree to come and stay with me and my family, as I was the only family member who had room. There was a tangible relief for her that things were easier. (**Alyson**)

I got to thinking, 'if anything happens to me, what's going to happen to Archie?' My husband's semantic dementia had progressed to the point that he couldn't be on his own or do anything for himself. I was living his life for him, in many ways, making decisions and thinking about everything. It was a real reality check. I was sitting having a coffee and I just looked at him and thought, 'if anything happens to me, what will happen to him?' Semantic dementia was so badly understood. It was such a turning point when I realised that I was living with a very sick person. I hadn't realised he was sick. Maybe I was in a bit of a crisis, but until that morning when it suddenly hit me, I hadn't really recognised what was happening. I went straight to the phone to arrange a social work assessment. I needed to make our circumstances more future proof. I also needed to recognise the impact it was all having on me and that the trauma of the situation was not getting better. (**Myra**)

If anyone says I will suffer, I say no, my wife Ethel will. She's very pragmatic, she's an accountant. The first thing we did after I got my diagnosis was get the power of attorney signed. They're not in place, but they're signed waiting to go when needed. It is very important to do because most people leave it too late. Being very practical, I also went to the doctor and said I want to discuss 'end of life'. He dedicated half an hour to discuss it with me, I could not believe it. We were able to discuss 'end of life'. So, if I'm in the latter stages, there is a DNR (Do Not Resuscitate). There is also information available that draws attention to how any unmet needs I might face could be mislabelled as challenging behaviours. They must not use chemical restraint as I would be trying to tell them something. Ethel would be right to sue them. I have learned that from my work obviously. (**Martin**)

Jenny and Her Mum's Story

Jenny is involved with Partners in Research as part of her doctoral research. Jenny's mum recently passed away, and we felt we could support her by providing space to share her mum's story within our book. Jenny deliberately chose not to explicitly name her mum to respect her mum's feelings around disclosing her diagnosis.

My mum had two big fears: cancer (her own mum died of cancer when she was 16) and dementia. She always said if she got dementia, she would rather die. I want to share some snapshots of the ups and downs of our dementia journey over the last five years.

Like many my mum had signs of dementia many years before a diagnosis. The early signs were growing anxiety and a refusal or rejection of support, which is often called 'oppositional behaviour'. It has made me realise how challenging these early years can be when there is no understanding that your loved one is going through changes in the brain that make navigating small and big realities of life desperately confusing. I imagine that's how mum often felt. She refused to go to bed, began to repeatedly go to the toilet, and ate extra portions of ice cream, insisting she had not had any. She received responses like, 'You've just been to the toilet' or 'you've had two portions of ice cream'. Imagine how confused she must have felt, having no recollection of this and of course would say 'no, I haven't'. She sometimes got angry as she tried to defend her version of reality and tried to maintain a sense of self and dignity. We learned this as time went on, but it took blunders on our part and research, with no help from health professionals.

The 2022 World Alzheimer Report (available here) revealed that 37% of people in high-income countries receive no post-diagnostic support. Our family fell into that percentage. About a year after my mum's diagnosis, I actively searched for some support for my dad and I got sent a booklet in the post. That was it. We had to become dementia experts ourselves. I already had a background in an empathic communication process that focuses on the needs behind actions and how this can help us step into another's shoes, which helped me greatly. If I could not understand one of my mum's behaviours, I would know that she was doing her best to express herself and meet her needs. If she was going to the toilet repeatedly, which at times became exhausting (for both of us), I would remind myself that perhaps this was her way to feel safe. Going out created anxiety, or perhaps she simply had a urinary infection! If I managed not to object, and instead remain calm and loving, eventually, we would find a way to continue with our day.

The worst times we had were extended hospital stays; this is where my mum's anxiety and paranoia reached all-time highs—understandably. For a person with dementia, like my mum, it is terrifying to be left in a hospital room by yourself. Imagine if you don't know how or why you came to be there. You are bed-bound and want to go to the toilet, but you don't know how to use a buzzer. Eventually, someone comes by and puts you on a bedpan, leaving the room saying briskly 'buzz me when you're finished'. You don't know how to use a buzzer. Someone comes back half an hour later, you are in pain from the position you have been in, they say 'why didn't you buzz?'. You couldn't go to the toilet—you were too anxious; you still need the toilet. They come to give you a pill and by now you think they are trying to poison you and you say 'no', slamming your mouth shut, they say, 'don't be silly you have to take your medicine' and try to roughly coax it into your mouth. You choke. For these and many other reasons we did our best to not leave mum in the hospital alone. My sister and I took it in turns, giving up work for months at a time, filling slots in the day when we couldn't be there with a paid carer. There was the odd nurse that had dementia awareness, but overall, this was shockingly absent. We taped 'press for help' to the red buzzer. We put pictures up in her room, a whiteboard in front of her that said where she was, why she was there, and when we would be there next and that we loved her. She nearly died twice. I feel she may have if we hadn't been there beside her coaxing her on, offering her miniature sips of water and protein drinks we bought ourselves. Fortunately, she did survive and went on to have another three full years of life. However, she was now wheelchair-bound, and along with her other needs, it was no longer feasible for her to remain at home.

Our first care home experience was a disaster with very poor care. I couldn't bear seeing her being treated in such a way. She needed a hoist at that time, two carers would hoist her into the air talking over her in their native language—not hers—and place her on a commode in the middle of the room, continue talking over her while she is expected to go to the toilet. They told me I could leave the room, but I could see mum was terrified. We had been through the intimacies of toilet cleaning together before, so I said I'd prefer to stay. I did what I could to reduce her anxiety level: hold her hand, explain slowly why she was there, tell her I love her. There are many similar stories. It was not my mum who was at fault; it was the environment and systems she was in that were not able to support her; to the contrary, they increased her anxiety.

We found a better home; she had a lovely bedroom with double doors onto a patio. The sun streamed in from a long view towards Arthur's seat. She loved the view. My sister created an amazing array of colourful potted flowers on her patio that she maintained even throughout the pandemic. By then I would say my sister and I were becoming 'dementia experts' at least where my mum was concerned. We were strong advocates for her. The first day in her new home she relapsed, spinning into paranoia and confusion. The new surroundings created extreme anxiety. The carer that day had dementia awareness and I was so grateful for her response to this exchange:

Mum (in extreme agitation):	'I have to get ready to get the plane otherwise I'll be late to give the talk to teachers.'
Carer:	'Okay, so you want to get ready, let's see what we can do.'

Mum immediately relaxed, as here was someone not denying her version of events. Gently we were able to help orientate her to the new surroundings.

Mum settled in and recovered some mobility, and we began to have a wealth of enjoyable times together. Dementia was opening a door to other ways of being and relating together. She became more expressively loving, and it was a joy to exchange affection and reciprocal words of 'I love you' at any moment. In this period, and until she died, she became my 'singing buddy'. To be clear, we are not great singers and had never sung together as a family. Dementia can lessen some inhibitions, and mum became game for singing and dancing with me in a way she would not have previously.

We created a song file, with her memorable music, that became our music. She loved the picture of a howling cartoon dog I put on the front, and we joked about our world tour. Favourites were 'Cockles and Mussels' and 'A Long Way to Tipperary'. We sang together every day even during the pandemic by phone or video. My sister, a genius at practical solutions, arranged the installation of a wall-mounted 'my home helper' tablet in her room that allowed us to video directly into her room without the need for button pressing on her end. This was a godsend, as although sometimes she could answer the phone, she could not always find it, or it would be out of charge. We were one of the lucky ones during the pandemic, as we didn't have to rely on a couple of Skype sessions a week to speak to our loved ones. In the mornings my sister would video in on her morning dog walk, and in the evening, I would sing with her. We could spend hours a day on screen with mum if we wanted. It wasn't all easy though, there were many tough evenings of us having to phone the care home to get her help with one thing or another.

My mum didn't want to acknowledge she had dementia, but although it remained unnamed, she had moments of clarity. I remember one when she was striving to explain her experience and said, 'I feel I'm speaking about somebody outwith me'. My heart ached as I could tell she felt that loss of sense of self. We did whatever we could to connect her with that self, through reminiscing, singing, talking about her career and early life, reflecting back her words and giving her time, and telling her how she had contributed to our lives.

There were many silver linings in our 'dementia journey'—and while I appreciate this is not the case for lots of people—I'm sharing ours in case it gives hope. We were lucky I know. If the right care/communication was there, mum had a reasonable quality of life in those last few years. Her appreciation of nature—flowers, birds, trees, animals—deepened. We would sit by the nearby canal with picnic lunches, loving the peacefulness of the water and petting every dog that passed. She gifted me the present moment, the pleasure of marvelling at the beauty of a flower, and then we could marvel at it again a few minutes later. It was a joy to enter that aspect of her world. Another delight was her poetic use of words; she often found more alive ways to describe the world around her. Clouds were 'skiffing across the blue' or 'bottle black and white things were out again' (the magpies in the garden) or perhaps it was a 'smug of a day'. I would join in, and we would come up with more made-up words, not caring if we were right or wrong, celebrating our inventions. I enjoyed this creativity in relating, thinking on my feet, asking myself 'what will I say next to create connection and help her feel safe and loved?' I'm not saying I always managed, but I kept that intention there. Of course, there were tired days where it was hard to maintain, and she always knew if I was tired or upset; she had a heightened sense of feeling. There was no hiding, and at times, it took effort to be present and authentic. As much as it was challenging, I appreciated that quality. I also didn't mind on those days when she wasn't sure who I was. I would lightly drop into the conversation 'I'm Jenny, your youngest' repeating it a short time later if appropriate. I knew she loved me. If I was loving, she was loving back, it was often as simple as that.

Reflecting on this experience, it strikes me that when my mum felt safe, acknowledged, and loved, she was mostly content. The question I ask is how can we create this for everyone living with dementia? Education and knowledge seem fundamental to support understanding and empathy. This seems the obvious place to begin.

Jenny

Useful Resources:

Bielak-Smith, P. (2020). *Dementia together: How to communicate to connect.* Puddle Dancer Press.
Feil, N. (1992). Validation therapy with late-onset dementia populations. In G. M. M. Jones. & B. M. L. Miesen. (2014). *Care-giving in dementia: Research and applications.* Routledge.
Rosenberg, M. B. (2015). *Nonviolent communication: A language of life.* Puddle Dancer Press.

FRED'S STORY

I was properly diagnosed with Alzheimer's disease about three years ago. Prior to that, it was the family that noticed there was a massive change in my short-term memory and in my spatial awareness. I was just really forgetting short-term things like remembering appointments, etc. Family and friends will tell me something like what's happening during the day, and I sometimes need them to repeat things a couple of times. Then, the spatial awareness thing, I keep sort of missing things, nothing dangerous yet, but just wee things like knocking over a glass of water.

When I was referred to a doctor, he just dismissed things. So, we then saw a different doctor and he did the usual diagnostic test and all that. We talked about it, and he thought, yes there is something there. He referred me to the neurology department, and they gave me the proper diagnosis with the MRI scan, blood tests, genetic tests, and a whole lot of lumbar punctures. They came in and said, 'right, this is early onset dementia, under the Alzheimer's banner'. That was the first time I knew that dementia isn't just one thing.

I started going to different lectures at a local University. I went with my friend, who's not got dementia, but he's interested in research. We went to quite a few of these talks and learned a lot about dementia, which coincided with me finishing reading the book, 'My name is Doddie'. It's the autobiography of Doddie Weir, who had motor neurone disease. His philosophy was 'if you can't beat them, you join them'. I thought that's very good advice. I started looking into different areas that do a lot of research. I went straight to my old University and discovered that it has a fantastic dementia centre. The researchers there said that they had a few things I could get involved in, and that's really how I first joined co-production or co-research. The rest is history. I met so many people and that lasted the best part of two years. I got involved in Partners in Research and writing this book.

I've been doing all sorts of bits and pieces including literature reviews, co-produced research, and applying for some funding for a new project. I'm backing out quite a bit now because it is just too much, but hopefully if the funding comes through, I will be doing less of the other activities. I was also invited to the Deepness Board, and I continued to do some work with them to do with dementia. Recently, we wrote and launched a course about money management, 'You are not alone: Living well with your money'.

I am a part of About Dementia. I first join their subgroups about two years ago. I was invited to join the groups on human rights, technology, and befriending and peer support. There's been all sorts of involvement with About Dementia. A year ago, I was asked to join their grant assessment panels as a person with lived experience. When one retires, people say you are not to do anything; but that is the worst thing to do. You want to be keeping fit, healthy, and work your brain, meet friends, meet people socially, not just sit in front of the TV or read books. So, the idea of my involvement really is just to keep the brain working. The physical thing is not great, I had this big operation [knee replacement]. It has taken a long time to get there.

I retired from full-time teaching about 12 years ago. But after that I did a bit of part-time teaching for about five years because I'm not in charge of the department, so I'm only there to teach my subject and I really enjoyed that. I was contacted by a university to write an online higher biology course for SQA. The course is still live on their website.

I just feel that all my life I've liked to find answers, whether it's biology, dementia, or football, I like answers. I love my research, and when I was asked if I would like to join Partners in Research, I thought yes, that's right up my street. A lot of people say, 'Well you've not got a PhD or anything like that. Why do you want to do all that research?', and I say that research is not so that I could get more qualifications, I couldn't care less, I've got first degree and I'm happy with that. My research is for my own experience. That's why people look to me and other dementia activists. They look to life experience. You know, we don't need qualifications. We don't need a whole load of degrees to say that. In a way, it's quite nice because it means that I'm sort of independent in what I'm doing. I've got the autonomy of doing what I'm doing, which is good. It's not that they don't care, but they just want to let me get on with it. The people I've been able to work with are like my research octopus legs.

I wish that some of the professionals, like the doctors, were willing to talk about research more. I wish there were more doctors who have the same attitudes as Partners in Research and About Dementia and would talk more about it. But I think it's the lack of funding and a doctor is not just dealing with dementia. They could also be dealing with heart diseases, common cold, and all sorts of things. So, I don't think we've got the resources and we are underfunded in terms of mental health and cognitive impairment in Britain. So, the short-term solution is not going to be a quick fix, and I think it's going to get worse before it gets better. It's not going to get better immediately. I mean, we're blaming the aftermath of COVID-19, but it is everything, isn't it? It is just everything.

There is a kind of naivety with my younger family members, where they don't see something wrong with my dementia, it's lovely. I wish the rest of the world was like that. I wish the rest of the world dealing with diseases like dementia would see it that way. A person living with dementia is still the same person. It's like how just because somebody's got cancer, or some people have got a lung disease, just because he's got dementia, he is still the same person. I wish a lot of people would remove the stigma of different diseases.

The bottom line is that I'm going to get worse. It's a case of the time scale. Everything's all done. But with all the involvement in the world, I just don't think about it too much. If you've got something that worries you and you start doing something different, then it takes your mind off it. Everyone has the same attitude. Take your mind off what's in front of you, do something different, and you can always go back to it. That would be my case anyway, so I don't think about it all the time. I go to things like football. I do all the research work. I meet up with families and friends and all that and that takes your mind off things. I'm hoping that it will help but I wouldn't say it definitely is an improvement or slowing things down. It's a case of when it happens, it happens.

Fred

Useful Resources:

About Dementia. (2021). *Our Sub-groups*. Retrived November 2022, from https://www.ageuk.org.uk/scotland/what-we-do/dementia/about-dementia/our-groups/

Deepness Dementia Media—Online Course: *You Are Not Alone: Living Well with Your Money*. Retrieved November 2022, from https://www.deepnessdementiamedia.com/updates/you-are-not-alone-living-well-with-your-money

David and Anne's Story

When we embark on life's journey, everything seems to be positive and exciting; thankfully, no one mentions the pitfalls that we may encounter or the dangers, such as dementia, that could set upon us in later life. This is probably a good thing; we have to make the best of our life and not spend it worrying or fretting about what might happen. In saying that, should we be ignorant or unaware of the early signs or symptoms of dementia or neurological condition? Could it be treated, or even in the future eradicated if we are more aware of these early signs or possible genetic connections? It's ironic that you devote your working life to improving your situation and planning for this thing called retirement! Only for something unexpected to come along and slap you down. It happened to me, my brother, my sister. It's as if we are cursed as a family, life's a lottery really.

Anne was finally diagnosed with frontotemporal dementia (FTD) in August 2018. This was almost two years after our GP said there was nothing wrong, despite my observations and fears. When Anne was diagnosed, we were handed an information pack and told a health visitor would see Anne each month to monitor her and advise us on how to locate various council and government assistance, which as it turned out is very scarce or in some areas not available. In March 2020, Anne was admitted to full-time care, the very day of the COVID-19 lockdown. I was unable to see her for three months. Video calls did not work, and she deteriorated rapidly due to social isolation (See Fig. 4.1). Within just a couple of weeks, she could no longer walk, talk, or feed herself and had developed amyotrophic lateral sclerosis (ALS), the most common form of motor neurone disease (MND). After more than six months, restrictions were eased, and

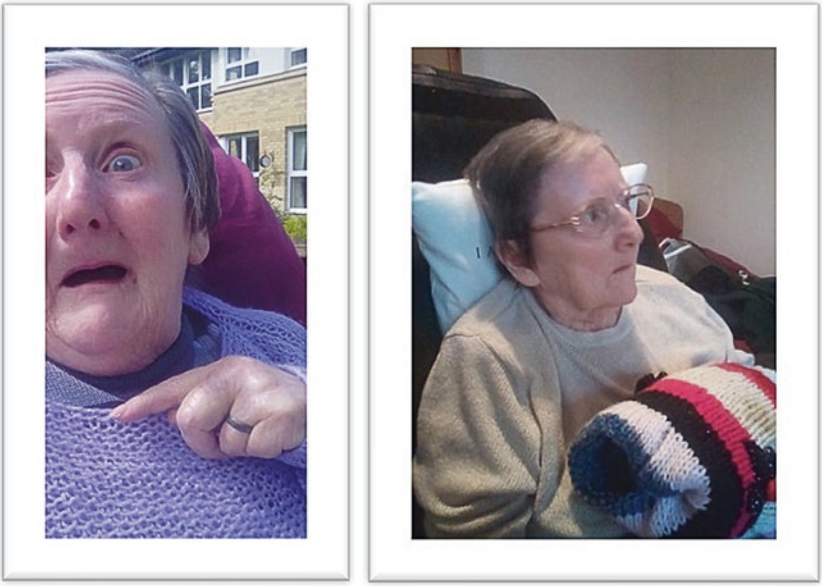


Fig. 4.1 Photos of Anne shared by David. The photo on the left was during the latter stages of lockdown. The one of the right was 6 months later when Anne's demeanour had improved, showing social isolation caused great distress

her general demeanour improved, but the progression of FTD and ALS was irreversible. I cannot speak for Anne, but I know she suffered greatly during this time, as did I, going through every stage of grief imaginable, even having suicidal thoughts.

No one could answer my question, 'why did this happen?' Coupled with my lack of knowledge and understanding of the illness, I embarked upon 15 months of research into the potential causes of her illness. I discovered a multitude of possible causes. A great deal more than clinicians had made me aware of when asked. My research started with Anne and all the incidents, whether medical or social, that she experienced; this included a great deal of stress with the tragic loss of close family members, constant high blood pressure, genealogical and gynaecological conditions, and lifestyle and environmental issues. I also looked into my brother and sister, both of whom succumbed to dementia. My brother died from vascular dementia, and my sister, coincidentally, followed the same pattern of incident in her life as Anne, also has FTD. Anne's immediate family was also scrutinised, and her maternal grandfather had Parkinson's disease (which can have clinical overlaps with FTD). Her father had issues with delusions, and her mother had behavioural problems, similar to Anne, but both died from cancer before any other diagnosis was available.

My own father was showing very clear signs of Alzheimer's disease, although again his death certificate registered cancer. In the past, many cases of dementia were never actually diagnosed, probably for a variety of reasons, such as misattributing 'old age' as the probable cause. Hindsight is a wonderful thing, but we have narrowed Anne's dementia down to what I believe was a combination of many factors. I likened it to a cocktail of ingredients, and the more that were added, the worse her condition eventually became. We, as a family, are now convinced we can see the signposts that were placed in front of us. We consider the start of this terrible journey as far back as 1981 when a great deal of stress entered Anne's life, not helped by the fact that I was working overseas in what was then Burma, a place where she couldn't be with me. There were various other stress-related family issues, medical conditions, lifestyle factors, and the tragic death of her younger sister to undiagnosed pancreatic cancer in Australia in 2006, just 40 days after Anne had visited. The build-up of stress over many years, culminating in this loss, was the trigger or the cocktail strength now exceeding what was safe.

One morning in 2010, Anne suffered great pain and had to be rushed to A&E. She had a contorted ovary and a non-malignant tumour, which resulted in a full hysterectomy eight years before her FTD diagnosis. Another addition to the cocktail of events. As I write this Anne is now receiving palliative care and is unable to swallow any food or liquid, and her prognosis is not good. We are nearing the end of a journey, we were completely unaware of that we believe started when the seeds were sown more than 30 years ago and only officially diagnosed four years ago!

Following the loss of Anne, my younger son came to look through her things to see what he wanted to keep, both of us ending up in tears. I had already made two trips to the charity shop, with a third one planned. He said, 'have you looked in the two drawers in my old room?' I hadn't and lo and behold at least 100 tops of various kinds were discovered! Not being a medical professional, I cannot even guess why she took to buying so much, even things that didn't fit her. I must assume it was partly her illness and partly depression, which I worry I hold some responsibility for, with all my work travel.

My reason for co-producing this book and joining Partners in Research is that I don't want anyone to go through the agonies and grief that we have experienced. We should be more aware of the warning signs and reasons for debilitating, neurological conditions. We must not believe that the only symptom is a memory problem. Academics and scientists are doing their bit, but there is more to be done by all of us to raise awareness of research and dementia, and the importance of lifestyle, genetics, and other medical conditions. Hopefully, together we can understand the reason for dementia and find a treatment and cure for all.

Over a hundred years ago, Alzheimer's was discovered, and we still have no cure; COVID-19 had vaccines available within months. There is a message here and a need to prioritise how we research and find a cure for what could be the world's worst epidemic since the Black Death! (Fig. 4.1)

Anne 30/08/1948–20/08/2022 a lovely individual, not a bad bone in her body, which has finally given up the battle, after 55 wonderful years together and with lots to ponder; thanks for the memory kid!

David

REFERENCES

1. Molyneaux, V., Butchard, S., Simpson, J., & Murray, C. (2010). Reconsidering the term 'carer': A critique of the universal adoption of the term 'carer'. *Ageing & Society, 31*(3), 422–437.
2. Giebel, C., Hanna, K., Tetlow, H., Ward, K., Shenton, J., Cannon, J., Butchard, S., Komuravelli, A., et al. (2021). A piece of paper is not the same as having someone to talk to: Accessing post-diagnostic dementia care before and since COVID-19 and associated inequalities. *International Journal for Equity in Health, 20*(76), 1–11.
3. Polacsek, M., Goh, S., Hallam, B., Gahan, L., Cooper, C., Low, L-F., Livingston, G., Panayiotou, A., et al. (2019). I know they are not trained in dementia: Addressing the need for specialist dementia training for home care workers. *Health & Social Care in the Community, 28*(2), 475–484.
4. Oresland, S., Maatta, S., Norberh, A., Jorgensen, W., & Lutzen, K. (2008). Nurses as guests or professionals in home health care. *Nursing Ethics, 15*(3), 371–383.
5. Jong, J., Whitehouse, H., Kavanagh, C., & Lane, J. (2015). Shared negative experiences lead to identity fusion via personal reflection. *PLoS ONE, 10*(12), 1–12.
6. Ashworth, R. (2020). Looking ahead to a future with Alzheimer's disease: Coping with the unknown. *Ageing and Society, 40*(8), 1–22.

7. Sinclair, J. B., Oyebode, J. R., & Owens, R. G. (2015). Consensus views on advance care planning for dementia: A Delphi study. *Health & Social Care in the Community, 24*(2), 165–174.

CHAPTER 5

What Research Means to Us: NRS Neuroprogressive and Dementia Network

Abstract This chapter is a collaboration with several additional authors, reflecting on their time working in the field of dementia research, taking on co-produced projects, and exploring dementia activism. We look at the

---

Co-authors: Rosalie Ashworth, Sue Fyvel, Alyson Hill, Chris Maddocks, Masood Qureshi, David Ross, Stuart Hay, Martin Robertson, Willy Gilder, Winnie Henry, Myra Lamont, Agnes Houston, and Fred S. Wilson
Email: tay.ppipartners@nhs.scot
Neuroprogressive and Dementia Network, NHS Tayside, Dundee, UK

Tom Russ, Emma Law, Jacqui Kerr, Tiffany Stewart, Bernie McInally, Julie Scott, Neil Wright, and Alison McBain
Email: tay.ndntayside@nhs.scot
Neuroprogressive and Dementia Network, Dundee, UK

Lesley Cousland
Email: tay.enrichscotland@nhs.scot
ENRICH Scotland, NHS Tayside, Dundee, UK

Charlie Binnie
Email: tay.ppipartners@nhs.scot
Neuroprogressive and Dementia Network, NHS Tayside, Dundee, UK

Keith Oliver
Email: tay.ppipartners@nhs.scot
University of Edinburgh, Edinburgh, UK

R. Ashworth et al., *Challenging Assumptions Around Dementia*,
https://doi.org/10.1007/978-3-031-27223-3_5

different types of research and what participating might look like, as well as consider what we want to see in the future.

Keywords Clinical trials, Research participation, Types of research, User-led research, Co-research, Patient and public involvement, Future research

The final part of our book brings us back to how the book proposal started as a collaboration between Partners in Research within the Neuroprogressive and Dementia Network. The chapter aims to inform people living with dementia and their loved ones about what research is and the different opportunities that may be available. We also hope that in covering a range of research, and research engagement, those working with people affected by dementia will feel more confident in having discussions about research.

The Neuroprogressive and Dementia Network (NDN), previously known as the Scottish Dementia Clinical Research Network (SDCRN), is funded by the Chief Scientist Office and aims to improve research recruitment into high-quality studies. The NDN matches people to studies that they can take part in. In doing so, it reduces the burden on prospective participants so that they are only approached for opportunities that might be relevant and of interest to them.

GETTING TO KNOW THE NEUROPROGRESSIVE AND DEMENTIA NETWORK

Partners in Research have continually shown the importance of getting to know the person behind the 'dementia label'. We hope that by getting to know the person behind the 'researcher label', we can make the world of research less daunting to potential participants. NDN staff were asked,

1. What got you into researching dementia and neuroprogressive disease?
2. Could you share your experiences of dementia research over the past 10–15 years?
3. Why is research important?
4. What do you wish people knew about research?

What Got You into Researching Dementia and Neuroprogressive Conditions?

My venture into health research wasn't planned, but as a clinician with a special interest in the field of dementia, my involvement improved my practice considerably. It encouraged me to not just accept common practice, to question every clinical decision, and seek out the supporting evidence, which resulted in me being able to justify my own practice at every turn. It also encouraged me to complete a Masters in Health Research. My ownership of this gave further weight to my clinical decision making, particularly if slightly outwith the accepted norm. (**Bernie McInall**, *Clinical Studies Officer NDN/ENRICH Scotland*)

My high school report once said, 'Tiffany asks too many questions', something which makes perfect sense to me now! I have always been inquisitive, particularly regarding human behaviour and the inner workings of the mind. I enjoyed studying psychology and imagined myself in a role where I could be helping people and making a difference to their lives. You could say that I fell into my first research post. I saw an advert in the local paper (back when that was the done thing!) for a research assistant post with Dundee University, this was my foot in the door! I thoroughly enjoyed the world of clinical research, but I quickly learned that I was more interested in diseases affecting the brain. This led me to pursue a further post at Edinburgh University, where I completed my first MSc and gained the valuable skills and expertise to lead me to apply for a post within NHS Tayside in the NDN. (**Tiffany**, *Clinical Studies Officer*)

I have been a nurse for many years and supported people living with dementia in a range of settings. Nursing practice is underpinned by research, and I value how research can influence positive change and well-being in people's lives, offering hope to those with life-limiting conditions. Since retiring from my NHS post, I am now privileged to work with ENRICH (Enabling Research in Care Homes) Scotland. We support and develop research in care homes, an environment that is often excluded from research. I believe that people living/working/supporting people in care homes should be able to get involved in research. That could be taking part in a research study and/or getting involved at the outset of designing a research project (co-production). Getting people involved from the outset I believe can ensure research is focussed on what is important and valuable to people for now and for the future. (**Lesley Cousland**, *ENRICH Scotland Clinical Studies Officer*)

I have been in this field for just over a year but got interested in neuroprogressive disease and research much earlier than that when—like most of us—someone I cared for fell ill with a neuroprogressive disease. (**Neil Wright**, *Past Employee of NDN*)

I started my professional life as a nurse more than 35 years ago and worked in many areas of psychiatry until I became the senior charge nurse in an acute admissions ward for people with dementia; from then, I knew my path was set. I established a unique day hospital called the Fast Track Day Hospital for people with dementia, and for my efforts, I was awarded the Nursing Standard Nursing Older People Nurse of the year. From there, I did some clinical research with the two consultant psychiatrists that I worked with, and we established a dementia research group for NHS Tayside. I was the study coordinator on an early treatment for dementia (the study did not show any positive results), but this gave me a taste of clinical research. I went on to do my Master's in Public Health and chose to study what difference would be made to people with dementia in introducing a specialist dementia nurse into the acute hospital setting (the local Royal Infirmary). I'm pleased to say it did make a huge difference and this service is now a mainstream service. Following this, I spent six years doing a doctorate in applied social research, studying whether research in care homes fostered a sense of inclusion, citizenship, and involvement for residents, including those with dementia. I completed my doctorate while working full time as the NDN network manager. I'm very pleased that I passed! My research interest remains focussed on dementia as this is the area I know best and have a clinical and managerial background in this field. (**Emma**, *NDN Manager*)

Could You Share Your Experiences of Dementia Research Over the Past 10–15 Years?

Before my work with the NDN, I did not have a lot of experience with dementia research outside of some awareness of national campaigns by big charities like Alzheimer's Scotland. I have come to appreciate the incredible amount of hard work and dedication that goes into dementia research all over the country. (**Neil,** *National Administrator*)

Over the past 10–15 years, the field of dementia research has experienced peaks and troughs in potential treatments that ease the burden of dementia for the person experiencing the disease and their loved ones. Since I started working in dementia research 16 years ago, I have seen hope and excitement when new studies for dementia are beginning their journey. Unfortunately, on too many occasions I have seen the disappointment when the research analysis does not indicate a positive outcome. This disappointment not only impacts the researchers but also impacts the participants and their families.

How do we keep the dementia research momentum going … by continuing to be the NDN and share our passion for dementia research for the benefit of all. (**Jacqui Kerr**, *NDN*)

My experience with dementia research over the last four years is sporadic due to COVID-19. I have worked on several trials, including EPAD [1] where I was a 'rater'. I worked on all aspects of the trial, booking appointments, organising room availability, MRI scans, and lumbar punctures. I obtained and processed specimens in the labs. Like most dementia studies, the trial visits are lengthy, and as part of the team, we would try to make the visit run as smoothly as possible. We would build up a rapport with the participant. Getting to know what the best time of day was for them, what their day-to-day life was like so that we could work around their valuable time also. We also set up a local participant panel for EPAD that ran across the network. From this, participants would organise meetings, attend conferences, etc. (**Julie Scott**, *NDN*)

When I first started nursing in dementia, the only available treatments were just finishing clinical trials and were the now well-known cholinesterase inhibitors of donepezil (Aricept), rivastigmine (Exelon), and galantamine (Reminyl). Then there were trials for Memantine (Ebixa), and this has since been licenced too. Since these drugs were licenced, there has been very slow progress in drug treatment breakthroughs, although initial studies involving aducanumab and, more recently, lecanemab have shown some promising results. Dementia research is not all about drug treatments, and there are many research opportunities around social care, health, and well-being. The best way to keep up to date with what is going on is to sign up to the neuroprogressive and dementia networks 'Permission to contact'. See our strategy for more information about how to sign up (available here). We continue our efforts to ensure that Scotland is involved in all kinds of studies involving people with dementia. (**Emma**, *NDN Manager*).

I started my first research project almost 15 years ago, and I think one of the main things that has changed—for the better—is a recognition of what people with dementia can contribute to research. Many years ago, people in a study were called 'subjects', which later changed to 'participants'. However, many people are now contributing to research as co-researchers which is very exciting. Of course, there are important issues about how to support people to do this, but the fact that it is becoming accepted and more mainstream is very exciting. **(Tom Russ**, *NDN Network Champion*)

Why Is Research Important?

I think that all medical research is important—it is how we make healthcare better for everyone—but since I started finding out more about the neuroprogressive research field, I have been truly impressed at the number of people who are looking into improving quality of life as well as diagnostic and symptom-based research. We all know the cure for dementia and other neurological conditions is not going to be coming soon, but if we can make people more comfortable and able to engage with the life still around them, I think we will have done well. (**Neil**, *National Administrator*)

There are many reasons why research is important. Research is how we will develop new treatments or approaches to care, understand more about the experience of having dementia, or understand more about the illnesses that result in dementia. Taking part in research can be interesting and rewarding—as a 'professional' researcher or as a person living with dementia. It can bring hope that one day we may have an effective treatment. (**Tom**, *Network Champion*)

Without research, much of the population worldwide would not be receiving the level of care and treatment needed for their health and well-being. Each form of care we receive began somewhere, from the simplest to the more invasive of treatments, they all began with research and asking the questions—'How does it work?', 'Why does it work?', and 'Will it provide the best outcome?' Research in any form provides us with the knowledge that evidenced-based practice has been used to ensure that we are receiving the best care and treatment available. (**Jacqui**, *Clinical Studies Officer*)

Research is essential for the prevention and management of disease. Enhancing people's lives through the disease process and hopefully eliminating or reducing the impact of dementia. It also gives hope to the individual, their families, and for the future. (**Julie**, *Clinical Studies Officer*)

What Do You Wish People Knew about Research?

I wish people would not be afraid of saying 'Yes'. There are different levels of inclusion in research. If you are a participant in a drug trial you do have to give some chunks of your time, but the return for that is that you become part of something exciting, you are never out of pocket, and you are a part of the research team building relationships with the staff over time. You truly matter to the staff, and they will bend over backwards to accommodate your requests and ensure your comfort and safety while you are in the trial. You can also choose to be less involved but still contribute your valuable

> time to completing questionnaires, being part of one-off focus groups, or even becoming a 'partner in research'. You may choose to not participate in any studies that you are offered, but if you do not say yes to hearing the opportunities, you will never know what is available to you. There are many options with differing levels of involvement. Say 'Yes! (**Emma**, *Network Manager*)

> As a researcher, I wish that more people understood what research is and how everyone should have access to it, and if not then question why not I also wish that people understood the great importance of research, without research we would not have many of the things we take for granted in life, such as medications/vaccines, healthcare services, or any of the various routine tests and investigations that we as members of the public have throughout our lives. Researchers are also patients and relatives too, and we want to find the best possible practices because it affects all of us in some way or another! (**Tiffany**, *Clinical Studies Officer*)

Approaches to Clinical Trials in Dementia

There are thousands of different proteins in the human body that have different functions. Medical researchers exploring Alzheimer's disease tend to focus on two proteins: beta-amyloid and tau. Research suggests that these two proteins are fundamental in the brain changes you see for people living with Alzheimer's disease. Beta-amyloid essentially clumps together to form plaques, which damage cells. Abnormal tau protein prevents messages from being sent as they become entangled. The damage caused by these two proteins in stopping information from getting through or preventing new connections being formed can lead to symptoms such as memory loss, difficulty planning, and change in language.

Although a very simplified example, one of the suggested reasons for the lack of success in Alzheimer's disease clinical trials is that the medication is introduced too late in the disease process, that is, tangles and plaques have already formed. As a result, research is moving towards involving people earlier and earlier to try and prevent changes taking place, whether that is recruiting people with mild cognitive impairment or identifying people with biomarkers [2] (e.g., blood work that flags up the potential risk of developing a condition).

> There is no cure. We know that. The most important thing we can do is prevention efforts. If we can find what is causing it and stop it, then we don't need the cure we just need the prevention. (**David**)

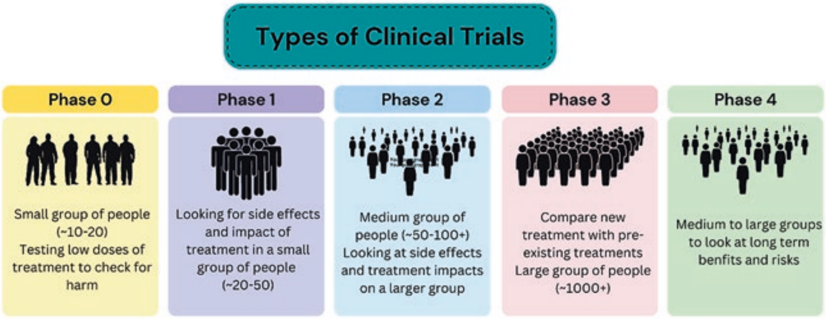
Another approach being taken is to look at repurposing existing medications. A repurposed medication is one that has been approved for use in a different context and testing for its use in dementia. Taking this approach can be quicker than completely new medicines because the safety of the drug has already been established. For example, looking at whether a drug licenced to treat blood pressure could also reduce cognitive decline or dementia symptoms.

Lessons from COVID-19 Clinical Trials

In December 2020, the UK government reported that over 600,000 people have taken part in public health research into the effects of and treatment for COVID-19.[2] The COVID-19 pandemic has had an overwhelming impact across the world. Participation in clinical trials resulted in over 50 million people across the UK receiving at least one dose of a COVID-19 vaccine.

> Research is all splintered instead of coming together as we had an example of with the COVID-19 research being done—suddenly everyone was reading from the same page and things got done very quickly, we need more of that. (**Winnie**)

The spotlight on clinical research and its potential to develop cures and treatments for health conditions could have important benefits to dementia research. Although the speed of vaccine development in COVID-19 is unique, a typical clinical trial can take 12–15 years from study design to the availability of a new licenced medication. The timely process is explained through trial 'phases' as shown in Fig. 5.1.



Types of Clinical Trials

Phase 0	Phase 1	Phase 2	Phase 3	Phase 4
Small group of people (~10-20) Testing low doses of treatment to check for harm	Looking for side effects and impact of treatment in a small group of people (~20-50)	Medium group of people (~50-100+) Looking at side effects and treatment impacts on a larger group	Compare new treatment with pre-existing treatments Large group of people (~1000+)	Medium to large groups to look at long term benfits and risks

Fig. 5.1 Types of clinical trials

Within the clinical research sphere, trials are often referred to by 'Phase' from 0 to 4. The phases essentially represent increasing sample size, with tailoring of study medication based on feedback from the early trial phases. A successful clinical trial for new medication will involve completing phases 1–3. When it finishes phase 3, it is recognised as a working treatment, with phase 4 studies looking at the longer-term effectiveness.

Hear from Research Participants from the Neuroprogressive and Dementia Network

Many of our Partners in Research have been involved in research in a co-researcher capacity as opposed to research participants. However, this should not take away from the importance of research participation, as research participants are fundamental to advancing knowledge. As shown in the COVID-19 pandemic, willing participants led to a vaccine. The nature of randomised control trials means that individuals with lived experience are not identifiable but considered part of an experimental group. This can mean we do not get the chance to capture their experiences of being involved in the same way we can with co-production.

To capture some of these missing voices, NDN staff asked research participants with whom they worked closely if they wanted to share some of their experiences.

> We joined the trial to help research into this cruel disease. The drug might help to slow down Alzheimer's, but we are aware he could be on a placebo. The trial environment is very welcoming with very friendly smiley staff. They are happy to explain any concerns we have and will listen to the carer as well as the person living with dementia. It's very comforting we have this support, and they check the person with dementia's health every visit, which is very reassuring. I would recommend anybody thinking about going on a trial not to hesitate. I hope this is helpful to know. The team has all been fantastic. (**Research Participant A**)

> The motivation was that it was such a shock to my wife and I to get the diagnosis, and my local health centre offered no support. They had referred me to the hospital where the staff were extremely kind and helpful and gave me the assurance that I was not alone in coping with the diagnosis. Joining the research study has been trying and exhausting, so many questions, and for me it was a shock to realise just how much my brain had deteriorated, in what appears to have been a short time since retiring from work. I had worked for 30 plus years in Oil & Gas Sector as a Senior Consultant Engineer

> in an extremely demanding and responsible position. It has been reassuring to get checked every month for weight gain/loss, blood pressure, blood, which again have not been reviewed by my health centre. I would recommend that to be given the opportunity to participate in anything that extends an inevitable outcome of Alzheimer's is worth taking?! Thank you to the research project team for the opportunity. (**Research Participant B**)

> I thought at first it is too early for us to make any meaningful comment about research involvement. But we are thankful to be on the trial which gives support, information, and a purpose, with everyone involved being very attentive, professional, and caring. It is difficult to be hopeful and make the most of now when you know what's ahead. It is very important to [person with dementia] that he is doing his bit. We are also hopeful that medication for depression will help him accept what he can do now. (**Research Participant C**)

> I got involved in the research as a patient because I thought there was something wrong with my memory, and the tests they did confirmed this. It made a lot of sense and has motivated some minor life changes that have helped me adapt. (**Research Participant D**)

Charlie Binnie has been involved in several research studies and has chosen to share his experiences of being a participant.

What got me involved in research first was that I had got diagnosed very early. I was at the doctor three times, with a year in between, and each time they said that there was nothing wrong with me. However, I still thought I was losing my memory. Each time it had been a different doctor. On the third time, it was the ‘head doctor’, and when I went into him, he said, ‘Yes, I've seen in your notes you've been here twice before and that you're okay’, but I said, ‘well yes, but I honestly think there's something wrong with my memory’. He said, ‘Well you've come to the right chap because it's in my field, I'll get you an extra-long exam to go through’. So, he did that and that's when he came back and said that ‘yes, you've got a very early stage’. A couple of years prior to me going, my wife and I went forward for experimental MRIs at the hospital, not that I thought I had the disease at the time. It meant they could go back into my records, and they found a scan of my head from that time, and there was nothing there. However, this time, there was a slight shadow on it. That's why they were saying I have it at the very early stage. They had scans to compare it to. Therefore, I said, well I've caught it at an early stage, do you think I could be a guinea pig? My cousin, who had a different disease, he was a guinea pig and he was doing that for a long time, whether it was because of that he lived longer, I've no idea. But it made me think maybe I would try it.

There were many people who came out to see me in the first couple of months. I thought I must be bad because I could remember their names but not their faces. It wasn't the case; it was just the number of different people coming out at different dates and trying to get it all in my diary that made it harder. In the very early stages, I used a whiteboard. I still have that, and I put down names that I'm likely to forget. It has come in handy one way or the other. I also use the diary a lot more than I ever did. My wife does more to help now too, she has a diary and keeps notes of where we are meant to be at certain times. All the things we do are important and must fit in. It gets overpowering and gets to you a wee bit when things start to clash. I know it is important to keep the cogs going as it were, so I've been to things like the Alzheimer's World Conference in London. I've taken up sudoku, and I play a lot of sports, including curling, golf, and hill walking.

So, I got through all of that, and I've been under their wing ever since. Except for lockdown and things like that where we couldn't get in. I was on a different drug at one time, but the last one I've been on longer. They had stopped it because they thought it wasn't doing any good in Britain, but then they discovered that the experiment worldwide showed there was a difference; I was put back on the drug again, and I've got another year on that. It's an infusion in the blood into the vein. I go in every month. Plus, the fact they do other tests, like take away 7's from 100, drawing and things like that. My wife comes in sometimes because she gets asked questions too. We are also asked some of the same questions to see what I've forgotten or haven't forgotten.

It's a big commitment to take on this type of research but I think being a guinea pig is the right thing to do. I didn't realise how much of a commitment it was going to be. In fact, the first month or two I thought, 'well wait a minute, what have I taken on here?' Trying to get my COVID-19 injection made life slightly more hectic, as we had to find a window between the infusion and injection so that it didn't upset the drug I was getting. This 'covid thing' has added more work for us. Sometimes you think it's too much work. It's a lot more unpredictable. Plus, the fact that you cannot get hold of doctors when you want them, trying to wait on them picking up the phone. You're pushed to somebody else, then somebody else. Chasing people down impacts a lot of your lifestyle because you've got other things to do.

There is not really anything that would put me off clinical trials. The physical thing of going in and getting infusions and meeting people there, nurses, doctors, and such like, it's a complete break. You are in there for a couple of hours, or whatever it is, and you're handing over all the responsibility. It's a sense of relaxation and distraction. Yes, you come back to the problems that were there when you left, but research brings hope as far as Alzheimer's is concerned. Of course, you're always hoping it will get better anyway. Up to now, some people say I don't have dementia, because it looks like I haven't got anything wrong with me. I must say I'm quite chuffed about that, not fitting the stereotype. Some of them have been quite serious that my dementia is false. But those people, the people they are referring to 'looking like they have dementia' by that time it's too late. There's nothing you can really do for them, it's the ones that catch it early that you need. I consider my situation; I've had it for eight years. Others have told us that the longest living person at that time was 14 years since diagnosis. Now I've heard of a person in Dundee who lived for 21 years. There are people even older than that. There must be different strains of this Alzheimer's for these people, whether I'm one of them or not I have no idea.

We try and find out a bit more about it too. We were down in the borders, for the Jackie Stewart Iinitiative, and I fell in with this lady who was focused on the scientific side. It turned out she had never spoken to someone with Alzheimer's before and she was more an experimental scientist. We had a long chat about it; I was interested in what she was saying, and she was interested in what I was saying. We have been doing other things to try and find out about things. I find it difficult through emails. I can't take that in, it's a waste of time. I'm far better speaking to people; I'm enjoying chatting with Rosie.

We can't do research without participants. The person I spoke to in the Borders said that there should be a big difference within 5 and 10 years. They're trying to see people and diagnose earlier. They were talking about injecting something that would help you tell if someone was going to go on to get symptoms in the next few years. If they had that kind of test, I think you'd be stupid not to have it. Sorry to be so blunt. I know of people who have lost loved ones to cancer, but they still avoid screening for early stages of cancer. I don't know if its fear, but I can't understand it. You've got to think of your family, things like that. If you might have a disease, you've got to think of others and try and do something. You've got to be bold and fight it.

Charlie

Spectrum of Research

The 'gold standard' for clinical trials is to compare whether a group of people trying a new medication experience differences to people who are taking a placebo, which looks the same as the new medication but does not contain the 'active' ingredient. In an ideal world, the research needs the two groups to be as similar as possible so that any changes the groups show can be linked to the medication. We know from clinical research in other disease areas that this approach can be incredibly effective in finding cures and treatments, such as cancer, heart disease, diabetes, etc. However, there are also many people living with different types of dementia who are either not able to take part in this type of research or do not have options for this research.

We need to both increase the amount of clinical research around other types of dementia and look at alternative approaches to research that allow others to become involved if they would like. We need to recognise the value of learning about dementia through the eyes of people with lived experience [3].

> My first impression of research is white coat scientists; there is an assumption that research involves microscopes and is essentially biochemical/medical. I have been thinking a lot about this, and we need more research into what people with dementia want. Millions of pounds are pumped into finding a magical pill, but there is a desire among the dementia community to find other things that impact quality of life. Yes, it's a terminal illness, but it doesn't mean that nothing can be done to make things better. Nobody has any guesses about the speed of progression, whether I have five years, eight years, I might have twenty years. I just have no idea. My interest is in how research can enable people living with dementia and carers, and how I can make the best out of the good years. (**Willy**)

Partners in Research aim to celebrate the clinical trial work taking place alongside recognising the importance of social science research.

> I increasingly want to bang the drum and make sure people consider how social interventions could slow down progression and ultimately save a lot of money in terms of health and social care. (**Willy**)

The number of people who choose to be involved will depend on several factors, including time, type of research, and feeling able to contribute to the topic area.

> I do not wish for anyone to suffer through ignorance as we have and for the public to be more aware of the risk factors, signs, and symptoms of dementia and neurological conditions. I want the scientific community to engage with us as people with lived experience of the condition. (**David**)

Understandings of Research

People have different preferences for how much information they would like about dementia, which could also shape their research involvement.

> I haven't done a lot of research. I kind of just go with the flow. It can depend on the doctor and how much awareness they have of research. I feel like I've kind of drifted along with it. I don't know how to make a difference. I've never been offered peer-to-peer support or a lot of information. I just want to know how to look after Eileen. I want to know the minimal amount of information to make a difference. (**Stuart**)

> I think of research as reflecting on my experience and the experience of others to see if there are similar trends. I often find that if something comes up, I will then try and find more information on that subject. I want to educate myself and try and understand the system, but it is messy and tricky, and the rules are complex and bureaucratic. Even if we are aware of evidence-based practice, it doesn't always get through to what's happening on the ground. (**Alyson**)

> The reason I started researching was simply because no one could answer any of my questions. Why did it happen? Why did my wife get frontotemporal dementia? There is so much we don't know because we don't have the knowledge. We need to have the knowledge, but we also need to spread and share that knowledge. (**David**)

> I just accepted my parents' diagnosis of dementia because it was something that I've worked with before. I had a two-pronged approach to research, in that it was important for me to know how to support both parents, as well as learn more about prevention or a cure at some point, whether that be now or in the future. In the meantime, we've got the here and now and how to support my loved ones needs. I kind of look with envy to other European countries who seem far more advanced in terms of how they support people living with dementia. The ethos needs to be about making people feel loved, wanted, and supported. (**Alyson**)

We know that research is fundamental to the progression of knowledge. Historically, this has been within research laboratories at universities or within hospitals. The process of information flowing between research institutions and the 'real world' is often slow and full of hurdles, and as a result, there is an ever-present feeling of 'us' and 'them' between researchers and people with lived experience. The 'ivory tower' of scientific knowledge excludes people from opportunities and makes it harder for people to access sources of knowledge. Involving people with lived experience in the development of research or research-related activities aims to build bridges between researchers and the community.

> I have a complete bugbear about academic language, I mean I went to a presentation the other day and looked at posters on various research projects and I have no clue what they were about. I'm prepared to bet that nobody else did either, but most people are too polite to say. The language used was so dense and impenetrable. It should not be that only specialists in that area could understand, it's like a game people play to exclude you from what is happening. Academics need to learn how to communicate in everyday language. (**Willy**)

Building a Partnership

In recent years, there has been increasing focus on the involvement of people with lived experience in the research process. There has been a shift in focus from participation to a more collaborative way of working with people to ensure that the research being done is relevant and meaningful to those with lived experience.

> Research is important to people living with dementia, and I'm glad that researchers are seeing that carers and people living with dementia can contribute on an equal footing and should be treated with respect and acknowledged for what we are contributing. We are human beings who bring different things to our dementia experience. Come into our world and see us as human beings, not just a label. (**Agnes**)

It has been recognised that there is a limit to how much can be learned without including people with lived experience, as well as a need to rebuild people's trust following negative experiences of participation or tokenism [4, 5].

> My very first research project was a one-to-one at the house, it was a PhD student, and I never had anything back. I was trying several different dementia drugs, and it made me think, 'I don't want to be a guinea pig anymore, I want to get involved'. When lockdown came, I needed something to do, it was a catalyst to research involvement. That's when I went to a meeting about the Life Changes Trust, and I got involved in decisions about funds. I soon realised that I'm too independent to be a member of anything. I thought well I like reading and researching so I started that, and it seems to be working well. (**Martin**)

> There is a gap between what researchers see as important and what people with lived experience of dementia see as important. We need to bridge the gap between academia and the nitty gritty lives we live. When I talk with other people with dementia, we see that we have things in common that we don't read about in textbooks. We would like a voice—it's only fair, and only right. I hope a shared sense of purpose comes from collaboration. There are things we all want that I think are givens in terms of cures and medicine, but there's much less on how to live well with dementia and cope with those little things that are truly confounding. (**Willy**)

> There is not much research involving people living with dementia as contributors. Partners in Research offer an equal partnership to bounce ideas off of each other. It's not about us versus them it's about sharing our experience. We have got to learn from each other, work together as a team. The legacy of Partners in Research will open doors into things like heart diseases and cancer as the blueprint for future research. (**Fred**)

> We want to be in the driving seat of research, but we still need a sat nav. We need a platform where we can put our point across and have a voice. At the end of the day, there's a common goal in doing something about this horrible condition so there is a need to talk to people with it. (**MAQ**)

> Researchers are human beings too; they need to give some of themselves as well, so that we are researching together. It is also important that research makes a difference to the person. The process needs to be simpler to ensure that people can get on with the work. We will all be learning from each other. Our experiences and academic expertise make for a more powerful collaboration. (**Agnes**)

Examples of Best Practice in Co-produced Research

Over the course of writing this book together, many of the co-authors have been involved in co-produced research including, an Evaluation of The Life Changes Trust [6], The Smarties [7], The Ecredibles [8], and BUDDs [9]. We share some of our research experience here and the impact it had on us.

Meet The Smarties

The Smarties are a co-produced research group made up of people with young-onset dementia. The group collaborated on Rose Vincent's PhD research, exploring volunteering and dementia through the co-analysis of

Dementia Diaries [10]. As part of their work together, The Smarties [7] produced a guide to support other researchers looking to do co-production.

Co-author Chris shares her experience of being involved.

I've done quite a lot of research groups and things. The Smarties is just absolutely, simply the best, and I think that was down to the facilitators of our group. Rose had really taken the time to speak to us individually before we even started in the group to find out things like how our dementia affect us and ask what she could do to make it easier for us to join. We had, not rules, but a code of conduct that we would stick to. I think it is so important to have things like that and everybody is different. So that respect was gained before we even started coming together. I think it also worked because the group was chosen well, and we gelled.

It was also the little things like getting the little goody bags from Rose, and just the excitement of having a little sash of coffee, and a little chocolate bar, it just made you feel appreciated. Not that I expected anything, but it was a 'Oh, that's really nice!'. The vouchers were also lovely, and again I didn't expect to get anything for it, but it enabled me. I was able to buy things that I could use, mostly crafty stuff. That gave me more of a sense of purpose as well. So it was going the extra mile, and making us feel that we were appreciated, and we were valued. I think even the fact that you got a file and a notebook that would have been enough, because very often we have got to go out and buy them ourselves. It's about not assuming that people just have all those materials to hand. Generally, people living with dementia are on benefits and perhaps do not have the money to go out and buy these.

It was brilliant, everybody was listened to, everybody was included, and it was a safe place. It's hard to get that. Feed into the safe place. Even though there can be topics that are awkward, it's okay to talk about anything. If you've got the right facilitators, you can gain the trust of the people within the group. Rose and Rosie both did that, and it is rare. It is rare to actually see that. (**Chris**)

Another Smarties' member, Keith Oliver, also shared his experience of taking part in research.

Since being diagnosed with Alzheimer's disease at age 55 in 2010, I have tried to deal with the frustration and challenges it presents by engaging in a range of worthwhile dementia projects, some of which have been linked to my three driving passions. First, there is a thirst for knowledge and to share this knowledge. Second, there is a desire to teach and work with supportive undergraduates and postgraduates. Third, there is a need to connect to others. Research ticks all these boxes for me. I am a long-term member of the Alzheimer's Society Research Network and have sat on one of their GAP (Grant Advisory Panel), usually as the only person with a diagnosis.

I have read and advised from the side-lines on many dementia-related research projects. The best projects are those that genuinely seek to involve me and others with lived experience in the direction the research is taking. The Smarties project supporting Rose Vincent's PhD was an excellent example of this. Co-production does create better research—it is authentic, impactful, meaningful. (**Keith**)

Dementia Alumni

The Dementia Alumni includes two of our co-authors, Agnes and Martin. They worked with DEEP to start ECREDibles. Martin shares some of his time with the Dementia Alumni.

Somehow, I don't know how, I got involved in looking at toilets and dementia. We literally went around photographing toilets, and you had to answer if they're dementia friendly or not. The worst example was a local Tesco because in the disabled toilet there was a mirror on the door opposite the loo. We have published a report called 'A Public Inconvenience'. We presented it in Edinburgh to civil servants. I met Agnes through that. She said, 'Do you want to join the "Dementia Alumni" because someone had gone into care so is unable to participate anymore?'.

The alumni created a multiple-choice game for 10-year-olds. We ask questions and children run to either answer A, B, C, or D.

We did a trial run down in Edinburgh. It was obvious that they could not care less about the first couple of questions, but after that they did, they would stop and think about the questions and answers. With one question, one person got it right and she stood there on her own and you could see she was thinking, 'should I move?' but she was adamant she was right, and she was. Afterwards they felt comfortable enough to ask questions, such as 'Does dementia hurt?', 'What does it feel like?', things like that. Agnes and I felt that they were really quite hard questions to answer. The feedback we got was that most of them went back and told their parents about it and discussed it with them. Most of them knew a grandparent with dementia, but obviously the last stages. So, they were quite surprised that there was an earlier stage. It was James or Agnes who decided we had to do something multigenerational. That was why the Dementia Enquirers funded it. We are ready for further funding to carry on with a group called Science Ceilidh. (**Martin**)

Dementia Enquirers

We have covered examples across the spectrum of research, from clinical trials with very strict criteria for who can take part to research that has been designed and developed in collaboration with researchers. The other end of the spectrum is research that is based in the community and led by people with lived experience, with advisors available to support research development.

The Dementia Enquirers are a group of people living with dementia who have been funded to support several grassroots projects designed and carried out by people living with dementia. The core team of Dementia Enquirers known as 'The Pioneers' work with Innovations in Dementia to review research plans, consider ethics, and help these projects. The Pioneers and the projects they have funded provide an example of user-led research, or 'putting people with lived experience in the driving seat of research'. The Pioneers are supported by several Advisors who have expertise in the areas of dementia, disability, and mental health. The role of the Advisors is to help make research more accessible, provide useful resources, and troubleshoot research queries. The group shared some of their experiences in academic journals [11, 12], as well as research guidebooks [13, 14], films, webinars, and podcasts [15].

What We Would Like to See from Research Going Forward

Our final section explores what research our co-authors, research participants, and NDN would like to see from research in the future.

> When people have given up their loved one to care outwith the home, have they been satisfied with that? Was that their decision process? Were other factors involved, you know? Also, learn of other people's experiences of care and whether episodes of care have been missing for them. Have they just gone ahead and covered for it because they have maybe been retired and they do not have the pressures of work or whatever, you know? Has it not been as big an issue for them because they have not had the pleasure of

> going out to work or anything else? I'd really be interested to find out how many people have missed out on episodes of care. (**Alyson**)
>
> It is great to see how much the study portfolio within the NDN has expanded over the years to include a spread of neuroprogressive conditions and the ability to offer a variety of different types of interventions (both medical and psychological/behavioural). Moving forward, I would like to see more health and social care research to ensure that we bridge the gap in health inequality and look at the best ways to ensure healthcare access and equal treatment for all. I would also like to see more studies looking at prevention of disease and interventions to support this. (**Tiffany**)
>
> Obviously, I'd like to see a cure for dementia, and you might be the person in a trial which finds positive outcomes. We're getting closer! I also value research that looks at issues chosen by people with lived experience. We continue our efforts to ensure that Scotland is involved in all kinds of studies involving people with dementia. My lived experience is of a nurse, a manager, and a researcher, as well as a granddaughter to my beloved grandma who had dementia and my mother, who had Parkinson's. We all have something to contribute, and I would like to see more research from the perspective of people with lived experience—'What is important to you?' and 'How can we answer these questions?' (**Emma**)
>
> I want to see future research focus on speeding up the transition process into care homes. One person can only look after a person with dementia for so long until it gets to them. I asked about this within the first few years since my diagnosis. I was given a phone number and told you just call that. However, I've discovered from a few people that it just doesn't happen like that. The people at the front, who are organising these homes, they're making money, which I think maybe is the problem. We need to tackle this and do better. It is so important for a person living with dementia and their loved ones to have a timely, supported transition into care homes if that is what is best for them. (**Charlie**)

Stuart & Eileen's Story

For 35 years, I taught in an Angus secondary school before I was fortunate enough to get early retirement in 2006, when I felt I had done my stint. Eileen had started off working in two well-known Dundee factories (Carhartt's jeans and Timex watches) but spent most of our married life helping to bring up 4 children, 9 grandchildren, and 25 foster children.

Fig. 5.2 Stuart and Eileen in 2015

We were lucky enough to have about eight years of retirement together before the first signs of forgetfulness began to be noticeable (see Fig. 5.2). I made an appointment for Eileen at the GP, who gave her the usual memory test. When she suggested to Eileen that there was a problem and that she wanted to refer her to the hospital, all hell broke loose. Eileen refused to take any part in tests for the next two years, and the matter was not discussed (I knew my place). Slowly things deteriorated. She would get disorientated, repeat herself, and then began to have bladder control problems. When we next returned to the GP, Eileen did not appear to be aware that there was a problem, and she quietly went through the tests that led to a diagnosis of Alzheimer's disease in 2016. She was 69 years old at this time.

Soon, Angus Council appointed a Care Manager who was then responsible for Eileen's care plan and effectively coordinated carers and specialised equipment as the need arose. After that first alarming visit, Eileen never showed any distress about her condition. Not to say there were no problems (Fig. 5.2).

Our last holiday to our eldest son in the USA was in 2015—she was just too erratic for air travel after that. We managed a week's holiday in London in 2016 (bladder control was becoming a major issue and I had not yet found out about Tena Lady Pants or disabled toilets) then cottage holidays in the North of England with our daughter's family. We had to keep an eye on Eileen all the time in case she wandered off. Indeed, this was also a major problem at home. She could no longer walk the dog on her own, and on one occasion, three police cars were searching for her before she walked back around the corner completely unaware of my distress (we never did find out where she had been). Eileen got a tracker to go around her neck and still managed to 'escape' the house and walk a mile crossing a busy road before I tracked her down on my phone.

An even more difficult time started in late 2017 when she would become really argumentative, especially when I tried to get her changed for bedtime. On two nights over Christmas of that year, she talked continuously for hours until I had to find another bed. Then, after a few distressing months, this too passed (Fig. 5.3).

By now, she was finding it harder to walk. I acquired an old wheelchair for the summer of 2018, and we had a lovely time visiting local towns, enjoying the weather, and having picnics. However, she appeared increasingly sleepy (it turned out her tablets for reducing agitation were becoming too strong for her); until October of that year she could not get out of her bed for a few days. The GP reduced her tablets, and she wakened up, but never walked on her own again. The bathroom was converted into a wet room in early 2019. I was now completely responsible for her care—washing, cooking, cleaning, showering, toileting—although she still chatted and recognised visitors.

The care manager was actively searching for a suitable care company, and after two false starts, we engaged our present firm in July 2019—four visits a day! This has been a tremendous benefit and has allowed me to keep Eileen at home even through COVID-19. Gradually, all speech and recognition has gone. Eileen is completely dependent on me and her carers. After her shower and breakfast in the morning, she is returned to bed for a nap, and this is when I get the chores done, a badminton session on Tuesday or a coffee with a friend. I have been

Fig. 5.3 Eileen in 2017

offered longer breaks but personally have not felt the need to be away from Eileen for any longer. She has only one tablet a day as thankfully she has been healthy otherwise in life. She has a good hospital bed, a recliner chair, a modern wheelchair, and a ramp at the front door—all provided and serviced by NHS or Social Work. We go for short walks or enjoy sitting in the back garden. Our nearby family visits regularly, and those farther away keep in touch by phone and video. The few times we have needed medical help, the GP has attended promptly. Speech therapists (for swallowing), physiotherapists, a hairdresser, and a chiropodist attend periodically as needed. She now dozes a lot but sleeps all night.

Fig. 5.4 Eileen in 2021

Her argumentative period is long behind us, and I pray she is at least content (Fig. 5.4).

Stuart (husband of 51 years and carer)

Sue's Story

My lived experience of dementia was through my experience of my mother's Alzheimer's with which she lived for 15 years until she died in 2005. So, it was a long time ago and quite a lot has changed since then. A change for the better is that living with the disease is far more openly discussed now than it was then. I often, particularly as my mother's only surviving child, felt very alone in struggling to get the best care for her, and like to think that nowadays it might have been a little easier. I remember how important it was for me when my employer arranged for me to talk to a carers' support person, which made all the difference to how I felt about blaming myself for the inadequacies of my own support for my mum. Just a couple of meetings made so much difference.

However, listening to the many stories of people in the Partners in Research co-author group, where I often felt very humbled, I learned how much further still there is to go. I think a lot more is known about ‘best practice’ in professional help and care, but the resources to provide it are just not remotely or evenly available. Within our co-author group, there was so much wisdom about what that should look like, which boiled down so much to a combination of enough time and emotional sensitivity, continuity of relationships, as well as knowledge and experience.

I came to the group via a doctor member of our family who knew about Rosie’s work and suggested I might volunteer to be part of it. I think she thought that because of my experience with my mother and because, for many years I was a social worker, I might be able to contribute something. I was constantly amazed at the input of the others in the groups with their current lived experience. So, I think I learnt far more than I contributed, in particular the importance of distinguishing different types of dementia and the differing patterns of symptoms, and the courage and resourcefulness of those with dementia and their carers. When I read the others’ stories in the draft of this book, I was further humbled to think that those who talked so positively and constructively during our sessions had been through and were going through so much. It has been a long time since I was a social worker, and when I think back, I am appalled at our lack of awareness of dementia, and the suffering that those with it, and their carers, must have experienced. It was a long way from the experience of co-creating this book, not that there isn’t still a long way to go. It would be great if that way included new medical treatments, but even without these, a lot more can be done with resources and guidance from projects such as this. This was also my first experience of research and user partnership, and I have become a big fan.

Sue

Rosie’s Story

Over the course of writing this book, I have gone back and forth about whether I should include my story. It felt strange to put my story alongside the co-authors and their experiences. The group has been so incredibly generous with their time and expertise, and it is very much their voices that I would like to spotlight. They have also taught me that for collaboration to work, there needs to be recognition of the expertise on all sides. Therefore, I include some of my story to help emphasise the need for researchers to give some of themselves to gain trust and understanding.

I chose to study psychology at Cardiff University, as it included the opportunity to work for a year within a psychology placement. I knew very little about older adult psychology or dementia before starting my placement at St John's Hospital in Livingston. However, this placement taught me so much about dementia and the challenges faced by older adults. It also taught me that there were so many unknowns in the field and evidenced-based practice was limited by the lack of research in the area. In some ways, this was the real turning point for me. The rest, as they say, is history. I went onto earn my PhD, exploring perceptions of stigma and future outlook for people with early- and late-onset Alzheimer's disease; I was awarded Fellow status for teaching with AdvanceHE; and I became a Chartered Psychologist with the British Psychological Society.

I have been so fortunate that the NRS Neuroprogressive and Dementia Network has been a huge part of helping me achieve my goals. They part-funded my PhD with the University of Stirling and have worked with me on and off for the last 10 years. They have always provided me with a home. I am so grateful to all the team members who took me in when I was new to the world of dementia research and gave me the confidence and support that I needed to become a dementia researcher in my own right. I am so incredibly proud of what we have been able to achieve together and the trust they have placed in me to cultivate a community of people with lived experience.

In the last five years, I have been particularly interested in co-production and the power of research that is designed and developed by people with lived experience. Co-produced research allows me to apply my interest in teaching and developing accessible research activities while working closely with people with lived experience. One of the biggest challenges of co-production is that it takes longer than many other approaches, and there needs to be flexibility for different peoples' needs and preferred direction. Funders need to provide space for this; otherwise, researchers are restricted in what they can do collaboratively.

Of course, it has not always been an easy experience. Loving your job and the people you work with doesn't take away from the fact that dementia is a progressive condition that can have huge physical and psychological impacts on the person diagnosed, as well as their network of family and friends. It is hard knowing that while we have been able to put a spotlight on a range of experiences, there are still many missing voices of people living with dementia and their loved ones. It can also be difficult to balance different voices, particularly as some people may need more support than others.

It is so important to surround yourself with a support network and to establish a good work/life balance—I can't say I've achieved this, but I am very aware that it's something that should be prioritised. Thank you to my amazing friends and colleagues (past and present) who helped me work on this.

Over the course of my time with Partners in Research, I have faced many personal changes. Chronic pain from fibromyalgia and arthritis has resulted in very limited mobility. I have learned a lot of transferable knowledge since I have experienced a lot of these changes. Some days my disabilities are very visible, for example, using a wheelchair; and on other days, not using a chair, it is more of an invisible disability, and I have faced some of the doubt and challenge from others assuming I have no reason to use a disabled space. In some ways, COVID-19 benefitted me in that it made remote working the norm, and so I was able to continue working much more than had I been hospital-based. However, the changes have still had significant impacts on my personal and professional life. Partners in Research have helped me to adjust to disability, understand more about applying to things such as Personal Independence Payments (PIP), and the value of having access to a Blue Badge. Adjusting to disability is not a linear process but a fluctuating mess of acceptance, grieving past abilities, and frustration about new limitations. The group has shown me the value in taking ownership of diagnostic labels, challenging stigma, and sharing your story to help others.

Fig. 5.5 Rory 'helping' with the transcript edits

To the Partners in Research and the various co-production groups I have been part of, including The Smarties, BUDDs, and the Dementia Enquirers, thank you all. I have learned so much from you. I am so lucky to be witness to so many of your stories and expertise, and I am proud that you have felt able to share your stories with the world. I am confident that there will be others who feel seen in your experiences, and hopefully that will be a source of help and comfort.

Finally, I could not tell my story without including our honorary co-author, Rory the cat! It's safe to say that pets have stolen the show in regard to online meetings. Rory has been a constant presence in the group drop-ins and in book writing (Fig. 5.5).

She brought a lot of joy to the group as well as some welcomed support when tougher topics were being reflected upon. Thank you for embracing Rory as our team mascot. She loves showing off to you all.

Rosie

References

1. Ritchie, C. W., Molinuevo, J. L., Truyen, L., Satlin, A., Van der Geyten, S., Lovestone, S., & European Prevention of Alzheimer's Dementia (EPAD) Consortium. (2016). Development of interventions for the secondary prevention of Alzheimer's dementia: The European prevention of Alzheimer's dementia (EPAD) project. *Lancet Psychiatry, 3*(2), 179–186.
2. Ahmed, R. M., Paterson, R. W., Warren, J. D., Zetterberg, H., O'Brien, J. T., Fox, N. C., Halliday, G. M., & Schott, J. M. (2014). Biomarkers in dementia: Clinical utility and new directions. *Cognitive Neurology, 86*, 1426–1434.
3. Beard, R. L., Knauss, J., & Moyer, D. (2009). Managing disability and enjoying life: How we reframe dementia through personal narratives. *Journal of Aging Studies, 23*, 227–235.
4. Bolger, L., Skewes McFerran, K., & Stige, B. (2018). Hanging out and buying in: Rethinking relationship building to avoid tokenism when striving for collaboration in music therapy. *Music Therapy Perspectives, 36*(2), 257–266.
5. Waite, J., Poland, F., & Charlesworth, G. (2019). Facilitators and barriers to co-research by people with dementia and academic researchers: Findings from a qualitative study. *Health Expectations, 22*, 761–771.
6. McCabe, L., Ashworth, R., Bellussi, L., Blair, N., Brown, T., Callaghan, J., Cheung, M., Emond, R., et al. (2022). *An independent evaluation of the life changes trust.* The Life Changes Trust. Retrieved October 2022, from https://www.lifechangestrust.org.uk/sites/default/files/publication/files/LCT%20Final%20Report%20FOR%20PUBLICATION.pdf

7. The Smarties. (2022). *The smarties guide to co-production*. University of Edinburgh. Retrieved October 2022, from https://www.ed.ac.uk/sites/default/files/atoms/files/the_smarties_guide_to_co-production_-_online.pdf
8. The ECREDibles. (2022). *Dementia Enquirers Report: Research Peer Support Group*. Innovations in Dementia. Retrieved October 2022, from https://dementiaenquirers.org.uk/wp-content/uploads/2022/09/ecredibles-september-2022.pdf
9. ASDRC. (2022). *Understanding dementia diagnosis during the COVID-19 pandemic: Project report*. ASDRC. Retrieved October 2022, from https://www.alzscotdrc.ed.ac.uk/sites/default/files/Full%20project%20report%20%281%29.pdf
10. Dementia Diaries. (2022). *Latest diary entries*. Retrieved October 2022, from https://dementiadiaries.org/diary-entries/latest-entries/
11. Davies, T., Houston, A., Gordon, H., McLintock, M., Mitchell, W., Rook, G., & Shakespeare, T. (2022). Dementia enquirers: Pioneering approaches to dementia research in UK. *Disability & Society, 37*(1), 129–147.
12. Berry, P., Davies, T., Fordyce, C., Gordon, H., Hare, P., Houston, A., Litherland, R., McLintock, M., Mitchell, W., & Shorthouse, T. (2020). Dementia Enquirers—People with dementia in the driving seat of research. *Dementia, 19*(1), 68–73.
13. Innovations in Dementia. (2019). *The DEEP-ethics gold standards for dementia research*. Innovations in Dementia. Retrieved October 2022, from https://dementiaenquirers.org.uk/wp-content/uploads/2020/12/9737a_deep-ethics-gold-standards-for-dr-booklet_v4.pdf
14. Innovations in Dementia. (2020). *Dementia enquirers research pack*. Innovations in Dementia. Retrieved October 2022, from https://dementiaenquirers.org.uk/wp-content/uploads/2020/12/9480a_dementia-enquirers-research-pack_a4-wirobound_aw.1.pdf
15. Dementia Enquirers. (2022). *Dementia enquirers*. Retrieved October 2022, from https://dementiaenquirers.org.uk/
16. NIHR. (2020). *Over six hundred thousand participants take part in NIHR-supported COVID-19 research*. Retrieved November 2022, from https://www.nihr.ac.uk/news/over-six-hundred-thousand-participants-take-part-in-nihr-supported-COVID-19-research/26336

CHAPTER 6

Final Thoughts

Abstract This chapter brings together key messages from the book, hopes for the future, and final reflections from the group. We provide information about how to become a Partner in Research or learn more about the Neuroprogressive and Dementia Network.

Keywords Lived experience • User-led recommendations • Patient and public involvement • Researcher reflections and co-research

> Our experiences show that we are so often not listened to, and assumptions are made about levels of understanding and capacity related to dementia. The person living with dementia and the carer can recognise signs some time before a diagnosis is given, whether it is cognitive decline, memory problems, sensory problems, or aphasia, which do not necessarily present themselves at initial assessments and memory testing. Once a person makes that initial contact for help, they should be listened to. We are the experts of our own experience. (**Myra**)

Co-authors: Rosalie Ashworth, Sue Fyvel, Alyson Hill, Chris Maddocks, Masood Qureshi, David Ross, Stuart Hay, Martin Robertson, Willy Gilder, Winnie Henry, Myra Lamont, Agnes Houston, and Fred S. Wilson
Email: tay.ppipartners@nhs.scot
Neuroprogressive and Dementia Network, NHS Tayside, Dundee, UK

R. Ashworth et al., *Challenging Assumptions Around Dementia*,
https://doi.org/10.1007/978-3-031-27223-3_6

As our work together ended, co-authors considered three questions to summarise the key messages we wanted the reader to hold on to.

Question 1

If you met someone who had just been diagnosed with dementia, what would you most want them (or the person they are supported by) to know?

> They are not on their own (we found that the Council Care Manager was our best support initially but was not sure if this is universal even in Scotland). (**Stuart**)
>
> You have met one person with dementia; we are all different. (**Martin**)
>
> I would reassure them and tell them to take it a day at a time, look after yourself, and look forwards to a long life. It might involve adjustments and there is support available in many forms to help you, take all the help you are offered. (**Myra**)
>
> I would want to know what services are out there, including support groups and where family could also be welcomed. Professionals need to know that users and carers do not want professionals' opinions to be forced upon them. We want a range of options. This can happen to any of us. More so for dementias with a genetic link. (**Alyson**)
>
> This is difficult simply because there are so many different types and stages that people have gone through. I think everyone who is involved at the diagnostic stage should not simply be told, 'you have X type dementia' and handed a few leaflets. Depending on the severity and stage of the illness, the affected individual may or may not be capable of understanding any explanation or advice. It's better that the carer is made more aware of the actual illness, what to expect, and what support is available. This should be a one-to-one session and take as long as it takes to ensure they are fully made aware of what to expect and how to prepare. The person with dementia, depending on their cognition, must also be made aware and not frightened by it. (**David**)
>
> If I met someone who had just been diagnosed with dementia, I would most want them, or the person supporting them, to know just how much help is out there and give them information on how to access it. (**Winnie**)
>
> Everybody's journey is different, and what someone struggles with practically might be very different from what causes them distress, and that is ok. (**Neil**)

Question 2

What are some of the things that you have found most helpful in adjusting to living with or supporting someone with dementia?

> There are many forms of support to help you live with dementia and care for someone with dementia. Initially, after diagnosis, you may just want time to adjust to a life-changing diagnosis and come to terms with a new way of living. Take every bit of help you are offered; it may seem overwhelming, and you just want to get on without any support, but the sooner you accept help, the better you will cope. (**Myra**)

> Access to the internet, as living in a rural area, there is no peer-to-peer locally. (**Martin**)

> We never used either of these examples, but in hindsight, Tena Lady pants and using disabled toilets when Eileen became incontinent would have saved us lots of stress if I had made use of them earlier (why I did not use them … mostly ignorance). (**Stuart**)

> Some of the things I found most helpful in adjusting to living with dementia were first, a GPS tracker. There are various ones, but I used one by my service providers. Second, a walk-in shower made life much easier. The third thing I would mention was the service that changed my life as a carer. I would urge everyone to take advantage of any day care support that is on offer. (**Winnie**)

> Learning what is important and what is not. Validation from others you are doing a good job. It is not always important for someone to recall details. It has taken 2 years due to COVID-19 but the wet room is invaluable. Especially if you have someone with incontinence. Appropriate resources are important. Consistent care, that is, a core group of carers providing care at the same time. (**Alyson**)

> This depends on the condition and progression of the illness. I don't think that anything worked to the extent that was noticeable; things like music and artificial aide all played a part. Because most of my experiences were through the pandemic/lockdown, the most important aspect was social interaction. The fact that people were isolated caused all sorts of problems, I suppose it highlights just how important social interaction is. (**David**)

> We found that accessible versions of everyday things—larger clocks, specialised cutlery, that sort of thing—helped with the day to day, while support from social care professionals helped a lot with creating helpful routines. (**Neil**)

QUESTION 3

If the readers of our book went away with one key message, what would you want them to remember most?

I. People living with dementia
II. Family members
III. Professionals
IV. Members of the public

> Take us seriously, dementia is experienced differently by all who live with it. Listen to what we have to say and treat us as individuals, we are experts by our experience. (**Myra**)

> We are all different, with differing abilities. (**David**)

> Seeing a loved one through this stage can be rewarding if the circumstances are right for you to be a provider. It would be upsetting to me that I was unable to care for mum due to a lack of support or resources, rather than my threshold to care. (**Alyson**)

For People Living with Dementia

> They should be loved and supported for who they are not what they have become. (**David**)

> Change is inevitable but can be prepared for. (**Neil**)

> For people who have just been diagnosed with dementia, although it is a massive diagnosis to get your head round, it is not necessarily the end of life as you know it. There are loads of positive stories out there and that is where your focus should lie. (**Winnie**)

Family Members

They should be made more aware of what dementia is and what it does to people and should be given much more support and advice. (**David**)

Treat your loved one with dementia as normally as possible. Try to keep their lives as stress free as possible. They can feel, lost, alone or a burden, so they need a lot of reassurance. (**Winnie**)

Being present is better than being educated, but both would be best. (**Neil**)

Professionals

They must understand that textbooks and medical experiments that have been going on for decades are not the only solutions to dealing with/curing dementia. They have to listen to people outside their own circles who have real-life lived experience and are able to observe what is going on 24 hr/day. (**David**)

It is more complicated than professionals often made out. Patients need time to ask questions and if the doctors, etc., don't have the time, refer them to charities, etc., who do. (**Stuart**)

Listen to the people with dementia and their carers. They are the experts here because they are living with it 24/7. (**Winnie**)

The most specialised education in the world will not tell you about how an individual is coping, or what they are subjectively experiencing. That requires listening to the person, engaging with them and personalised care plans cannot happen without personal interaction. (**Neil**)

Members of the Public

Read the book then read it again, you might miss or misunderstand the first-time round. (**David**)

It is often a hidden complicated illness, especially in the early stages. Be patient. (**Stuart**)

People you know or meet with dementia are still the same people. If you met them limping along on crutches you would be likely to feel sympathetic

> towards them. You cannot see what is going on for a person with dementia, but they are wounded just as much. Their brain is not working the way it should. They are not stupid or crazy. They need your compassion and sometimes your help. (**Winnie**)

> Dementia is a scary topic for everyone, and it is ok to be uncomfortable. It is scary for people with the diagnosis too, and it would be great if you could sit with your discomfort enough to walk with them, or at least engage with improving their care. (**Neil**)

The book has provided a platform for the voices of our Partners in Research. We hope that in sharing these experiences, people reading this book can feel represented and find information that can help them, whether personally or professionally. We hope that by sharing the spectrum of dementia research, people feel encouraged to get involved as participants and/or as co-researchers. Finally, we want to say thank you for reading and for taking the time to understand our experiences.

Get in Touch

Thank you for taking the time to read through our book. We hope that it has been helpful, and that you have enjoyed getting to know us.

If you are interested in hearing more about Partners in Research and the different work we do, please get in touch on TAY.ppipartners@nhs.scot. To hear more about clinical research in your area, please contact the NRS Neuroprogressive and Dementia Network on TAY.ndntayside@nhs.scot

Website: www.nhsresearchscotland.org.uk/research-areas/dementia and neurodegenerative disease

Telephone: 01382 423 086

Facebook: NRS Neuroprogressive and Dementia Network

Twitter: @NRS_NDN

Embedded Links

1. Alzheimer’s Disease International. (2022). *World Alzheimer’s Report 2022*. Available at: https://www.alzint.org/resource/world-alzheimer-report-2022/ [Accessed December 2022].
2. Alzheimer’s Scotland. (2022). *Helpcard*. Available at: https://www.alzscot.org/our-work/dementia-support/information-sheets/helpcard#:~:text=Our%20Helpcard%20aims%20to%20make,help%20or%20support%20if%20required. [Accessed December 2022].
3. Hidden Disabilities Sunflower Scheme. (2022). Available at: https://hiddendisabilitiesstore.com/ [Accessed December 2022].
4. Neuroprogressive and Dementia Network. (2022). *NRS Neuroprogressive and Dementia Network Strategy 2022-2027*. Available at: https://www.nhsresearchscotland.org.uk/research-areas/dementia-and-neurodegenerative-disease [Accessed December 2022].

R. Ashworth et al., *Challenging Assumptions Around Dementia*,
https://doi.org/10.1007/978-3-031-27223-3

INDEX

R. Ashworth et al., *Challenging Assumptions Around Dementia*,
https://doi.org/10.1007/978-3-031-27223-3