

Riding the

Lucy Whitman is a writer and editor. Her first anthology, *Telling Tales About Dementia: Experiences of Caring* (JKP 2010) was selected for inclusion in the Reading Well Books on Prescription for Dementia Scheme. Her new book, *People with Dementia Speak Out*, is also published by Jessica Kingsley Publishers. Some of the contributors will join Lucy for a symposium on "What can professionals learn from people with dementia?" at the UK Dementia Congress in Telford (November 3 – 5).

If there is one thing that infuriates people with a diagnosis of dementia, it's when other people refuse to believe them. "It is very difficult when people say I do not look like I have dementia," says Ann Johnson, "and they are very surprised they can communicate with me." Jennifer Bute agrees: "When people say to me that they can't believe I have dementia, I find it very hurtful." Sometimes it is doctors who scornfully doubt what their patients have told them: "You don't have Alzheimer's!" said a doctor to Edward McLaughlin when he arrived in A & E with a suspected stroke, some years after his diagnosis.

Why do people find it hard to believe someone when they say they have dementia? Could it be because the majority of the population, including some members of the medical profession (but probably not most readers of the *Journal of Dementia Care!*), have a stereotyped idea of a person with dementia as someone who is by definition confused and helpless, unable to communicate at all, let alone hold a rational conversation, or contribute their own ideas to a discussion of what care and support they may need?

Sadly, for people with advanced dementia, this image may be close to the truth.

Yet, of course, dementia does not happen overnight; it is a progressive condition, and while some abilities may be lost quite early on in the process, people may be able to communicate with others, retain a good deal of independence and make a meaningful contribution to society for years after the first symptoms of dementia appear.

My new book *People with Dementia Speak Out*, aims to challenge some of the stereotypes of what people with dementia are like, and what they may or may not be able to do. The different accounts reveal the wide variety of symptoms that people with dementia may experience, as well as the wonderful variety of personalities and personal histories to be found among those individuals who are referred to by the collective term 'people with dementia'. "The thing is," says retired psychiatrist Daphne Wallace, who has vascular dementia, "different people experience dementia differently.

rollercoaster of dementia

Lucy Whitman introduces her new book, *People with dementia speak out*, a collection of personal accounts by people with dementia

We are all different, and even if you have the same pathology as the person sitting next to you, it won't manifest itself in exactly the same way."

Contributors to the book come from a wide range of social and cultural backgrounds; some developed dementia in early middle age, others in their seventies or eighties; some had little formal education, others are doctors or professors. Some are dedicated activists, who have made it their mission to educate people about the reality of life with dementia; others are just getting on with their lives, adapting to their new circumstances, and revealing remarkable resilience: "I know that I've got dementia," says Midge Flint, "but I don't let it hold me back. I'm pretty tough like that. To put it crudely – 'Sod it!'"

The book is aimed at anyone with a personal or professional interest in dementia. I hope that people who are living with dementia, and their families, will find the book reassuring and encouraging. I also hope that professionals in any discipline who encounter people with dementia in their working life – whether they are care assistants or consultants, hospital porters or commissioners – will take the opportunity to listen to what people with dementia have to say for themselves.

Key themes

While every individual who has dementia is unique, certain themes recur. Several contributors experienced a long delay in getting a diagnosis. "Doctors don't always recognise dementia," says Clarice Hall. "They wave it off." Lorna Moore performed so well in all the puzzles and mathematical tests she was given that the doctor assessing her concluded she had "nothing to worry about," despite her family's and her own concerns about her failing memory. It was only when a second consultant took the trouble to find out more about her, and discovered she had been a pioneering computer scientist, that a correct diagnosis of Alzheimer's was arrived at. Jennifer Bute, a highly regarded GP, had to see three different consultants, and wait five years after she first reported alarming symptoms before she finally received her diagnosis.

Other contributors to the book report that when they did get their diagnosis, doctors provided no information or explanations, and offered no follow-up appointments. "The only down point," says Graham Browne, "which I have since found out most people come up against, is the fact that although you are told the diagnosis, you are not given any information about it."

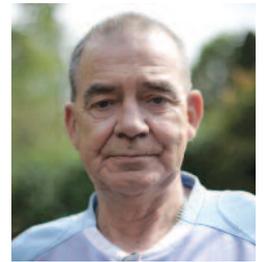
Those who required treatment for other conditions often encountered a lack of dementia awareness among professionals in other

specialisms, and a reluctance to adapt established practice to take account of the patient's dementia. The medication prescribed for Brian Hennell's cancer exacerbated his dementia symptoms to such a degree that he decided to stop the treatment, against the advice of the oncologist, so that he would not be plagued with extreme confusion and unbearable hallucinations for the remaining months of his life. When Alex Burton went into hospital for heart treatment, no one took any notice when he told them he had dementia. "I was moved about twenty or thirty times during the day – it was a busy ward, different beds, different bays, and I thought, oh my word, what's going on here." Eventually he was discharged abruptly, without any escort or discussion of whether he might need additional care at home.

Many of the contributors express gratitude for the loving support of their wives and husbands, daughters and sons. Relationships with affectionate grandchildren are especially treasured. But not everyone has a family to support them: more than one contributor lost their marriage and their home when dementia struck; some are divorced or widowed, some never married, some have no children. Yet, as Alex Burton points out, the whole social care system is predicated on the expectation that for every person with a long-term condition, there is a relative, able and willing to look after them.

For those who have previously cared for parents or other relatives who had dementia, there are no illusions as to what the future may hold. They are honest about the despair they felt when they first suspected or realised they had dementia, and about their fears for the future. Carol Cronk says: "My internal trauma at my diagnosis was highlighted in such fear and dread because of the experience I had lived through with my father during his battles and struggles with Alzheimer's and vascular dementia. My immediate devastating feelings were not of dying but having to live in one of those 'dementia homes.'" Several disclose that they contemplated or even attempted suicide. "The deep blue water seemed to beckon me as it was a swift and merciful escape from a living hell," says Alex Lindsay. "I was dragged out of the River Clyde twice and Loch Lomond once."

Nevertheless, one of the most striking features of the book is the number of people who describe going through a traumatic time initially, but who now feel very positive about their situation. "Since I had dementia, I've had some wonderful experiences, I really have," says Ross Campbell, who has travelled to Istanbul and Singapore to give talks about dementia on behalf of the Scottish Dementia Working Group. "Before that, I used to ➤



Ross Campbell: "Since I had dementia, I've had some wonderful experiences, I really have."



Jennifer Bute: "I went to see the consultant and he said, 'Hullo Jennifer, lovely to see you! There's nothing the matter with you!' Before I'd even sat down! He didn't do any investigations at all."



Pearl Hylton: "Anybody been very kind to me, it stays with me."



Graham Browne: "Dementia has given me something to fight for, for other people."



Rukiya Mukadam:
“I hope something can be done to help raise awareness in the Asian community about dementia, to break down the taboo and get rid of the stigma. I’ll be very happy if that happens.”



Alex Burton: **“There was no follow up, no ‘We’ll see you in six months’ time’. It was just, ‘Here’s a prescription.’ I just stared at it. I didn’t know anything about dementia or Alzheimer’s at that stage. Not a thing.”**

References

Moriarty J, Sharif S and Robinson J (2011) *Research briefing 35, Black and minority ethnic people with dementia and their access to support and services*. Social Care Institute for Excellence (SCIE), London.
 Ward R (2012) *Making Space for LGBT Lives in Health and Social Care*. In Ward R, Rivers I and Sutherland M (Eds) *Lesbian, Gay, Bisexual and Transgender Ageing: Biographical Approaches for Inclusive Care and Support*. Jessica Kingsley Publishers, London.

➤ just eat, sleep, work; eat, sleep, work. Now I have time to myself. It’s maybe not the most charming life, but I thoroughly enjoy it.” Edward McLaughlin is similarly upbeat: “I’m full of optimism – the optimism in the full glass.”

Jennifer Bute comments that as dementia progresses, “Feelings remain, even if facts are forgotten.” This is echoed by Pearl Hylton, who says, “It’s funny, I can remember things from a way back, from I was little. And things that happen to me like yesterday, I can’t remember. But I can remember things from I was little. And if people do me very bad thing, it stays with me. And if they do good thing, it stays with me too. Anybody been very kind to me, it stays with me.”

Contributors express warm appreciation for good local support services such as the Joint Dementia Initiative in Falkirk, Singing for the Brain sessions provided by Alzheimer’s Society branches, or independent organisations with a creative approach to dementia support, such as the Healthy Living Club in Stockwell, south London.

Crucially, it appears that setting up or joining a peer support group, such as the Scottish Dementia Working Group or the Brighton Hope Group, or becoming an ambassador for Alzheimer’s Society – focusing on raising awareness about dementia, supporting others in the same boat, and campaigning for improved services – has given people a whole new lease of life. “In a strange sort of way I have a new life with my Alzheimer’s,” says Ann Johnson. “Doing my talks about living with Alzheimer’s and associated subjects throughout the country gives me a purpose for living.”

The importance of listening

Listening to people with dementia telling us their stories in their own words is not just important for the public, to raise awareness and encourage empathy. It is also a vital part of good practice, for those of us who believe in person-centred dementia care.

It can help us in so many ways, not only to find out what types of support are most valued by people with dementia and what ideas they have for how services can be improved, but also to illuminate aspects of people’s personal experience which we may not have been aware of before, or may not have given due attention to.

This book is not primarily a collection of reminiscences, but everyone was invited to say something about their life before they had dementia. Some describe what it was like to live through the Second World War as children or teenagers. Others, who came to Britain from another country as migrants or refugees, mention the racism they encountered, or relate how they were separated from their children for years before they were able to make a home for them here. Abdul Haque, Romanina Contucci and Halide Eames all had to leave their children behind, while Peter Mittler, aged eight, had to leave his parents behind when he came to England, escaping the Holocaust on the ‘Kindertransport’.

Those who are now elderly may have experienced great hardship, danger or trauma

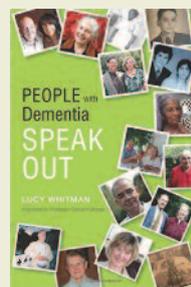
which may affect their current emotional state, as vivid memories from decades ago rise to the surface. Additionally, people with dementia from minority communities may be reluctant to access services for a variety of reasons, including possible past experience of prejudice and discrimination within the health service (for example, lesbians and gay men regarded as mentally ill, and subjected to brutal aversion therapy). Within some black, Asian and minority ethnic (BAME) communities, there is low awareness and understanding of dementia, leading to additional stigma, so that in some cases families may try to hide the situation and cope in isolation, rather than asking for help.

“In Asian families, if someone gets Alzheimer’s, they want to cover it up. They don’t want the person to come out. It’s a taboo,” says Rukiya Mukadam, a former GP who grew up in Kashmir. With a recent diagnosis of dementia, she is keen to tackle this taboo head on.

The ‘narrative’ or ‘biographical’ approach to care and support, familiar to most of us in the dementia world as the ‘life-story’ approach, is based on seeing each person as a unique individual with their own personality and personal history. This approach, coupled with an appreciation of the collective experience of particular communities, and how this may affect the way people interact with health and care services, is regarded as particularly helpful when supporting people with dementia from minority communities (Moriarty et al 2011 and Ward et al 2012).

Sharing these experiences helps to validate them for people with a similar background, as well as to enlighten those who come from different backgrounds. Listening to each other’s experiences can help us to deliver inclusive and culturally sensitive services which meet the needs of people with dementia from all sections of the community. I hope that the varied stories in this book will help us all to see both the things that make us different from each other, and the things we have in common. ■

WIN a free copy of *People with Dementia Speak Out*



We’re giving readers the chance to win one of five copies of Lucy Whitman’s book, in which 23 people from diverse backgrounds share their experiences of living with dementia. Just apply in one of the following ways saying you would like a free copy and five entries

will be randomly selected to get the book free. Send your entry with your postal address to hello@jpkp.com with subject line “People with Dementia Speak Out – competition”. Or you can enter by post to Jessica Kingsley Publishers, 73 Collier Street, London N1 9BE.