

Practical advice based on evidence, when people most need it: producing a guide on dementia

by June Andrews (FRCN 2014)



June Andrews
OBE, FRCN, LLB, professor
emerita, University of
Stirling, Stirling, Scotland;
adviser, Dementia Services
Development Trust,
Edinburgh, Scotland

Email
profjuneandrews@icloud.
com

After more than three decades as a nurse in hospitals, government, a university and care homes, I was working on improving the public understanding of dementia. People affected by dementia, whether directly, or through a relative or patient, often asked me after we talked, ‘Why did no one ever tell me this before?’ Public information and consultations with professionals did not seem to provide people with what they wanted to know. Profile

Books asked me to write a book with sensible advice for people when they most need it.

I put the commonest answers to the usual questions, describing in plain language what ought to happen, and what in real life does happen, when you have dementia and are in the hands of the health and social care system. The need for this did not abate in the following five years and the book went on to international editions and sold in tens of thousands.

Dementia: the One Stop Guide; Practical Advice for Families, Professionals, and People Living with Dementia and Alzheimer’s Disease

Abstract

Written in response to the prevalence of people living with dementia in 2015 (44.4 million world-wide) and in the absence of hope of a cure, this book fills the gap experienced by people who feel unsupported in their search for practical information and support for living with, or caring for, dementia. With clear and sensible information about recognising symptoms, getting help, managing financially, staying at home, treatment, being a carer and staying positive, it sets out to help those with dementia and their families to stay well and happy as long as possible. Information and options are provided in clear language. It advises on getting financial and legal affairs in order, well in advance, and how to survive the risks associated with an acute hospital admission. Correct information can help people stay better for longer, along with certain lifestyle changes.

Virtually all of the information in the book could be accessed on the internet, but people faced with this problem are tired, troubled, busy and running out of options. They might lack the knowledge and experience to sift through the multitude of open sources of variable quality and reliability, in order to access practical, evidence-based information. They also may have no time. I decided to put in the time to produce the One Stop Guide.

Citation

Andrews J (2015) Dementia the One Stop Guide; Practical Advice for Families, Professionals, and People Living with Dementia and Alzheimer’s Disease. First edition. Profile Books

Link

profilebooks.com/dementia-the-one-stop-guide.html

Introduction and background

Years before writing Dementia: What You Need to Know (Andrews 2016a), I had used the travel time on regular train journeys

between London and Edinburgh for a major dementia writing project. A colleague professor of liaison psychiatry in the medical school at Leeds, Allan House, with his team was

facing the challenge of disseminating findings of research on what matters to people with dementia and their carers (Hulme et al 2009). Memory problems didn't even feature in the top six issues. They needed help with aggression, anxiety, sleeplessness, wandering, repetitive vocalisation ... a wide range of issues which are amenable to non-pharmacological care solutions. I translated the huge volume of their findings into a little yellow covered plain English pamphlet called 10 Helpful Hints for Carers of People with Dementia (Andrews and House 2009).

It had sold over 60,000 copies. Andrew Franklin, director of Profile, an independent publisher in London, approached me and commissioned a larger book, which would be a one-stop guide to the issues. The essential elements were that it would be down to earth, based on what people with dementia or carers say, and evidence-based. It would bring together science and the real experience of people with dementia and those around them.

My clinical experience is as a mental health and general nurse caring mainly for older people. I have worked in the independent sector and charities, helped to shut down a psychiatric hospital as part of the large-scale closures of psychiatric hospitals in the later stages of the deinstitutionalisation of UK mental health services, and been the adviser to the Royal College of Nursing (RCN) on ethics and HIV. I was an NHS director of nursing at hospital and board level and had worked in the senior civil service and, in addition, was working at the Dementia Centre at the University of Stirling.

More recently I'd been advising charities and businesses on care of older people and people with dementia. Through all of this I spent a lot of time with people who were struggling with every aspect of 'acquired cognitive impairment', whether age related or not. At all levels in government, policy settings, acute care, care homes, care at home services, financial support, carer's needs; every part of the system was struggling to find a way forward. At that time, rates of dementia diagnosis were standing at about 20% in many parts of the UK, meaning that eight out of ten people with dementia could die without ever seeing a nurse or doctor who specialised in their condition. From personal experience working on improvement of dementia diagnosis across the UK, some doctors consciously withheld the diagnosis in the misguided belief that there is no benefit

in imparting it. Bradford et al (2009) suggest something similar has happened in the US.

Hospitals in the UK were then unsafe places for patients with dementia (Andrews 2015) and delirium was largely unrecognised and untreated, sometimes because it was mistaken for a sign of dementia itself, and therefore regarded as an inevitable stage of later life, not amenable to any positive intervention. National dementia strategies in each part of the UK existed, but implementation was slow, and the planned future improvements were of little value to those affected. I would regularly hear from people who were told at a clinic that they had dementia and that they should come back in a year's time. There was an emphasis on awareness raising with campaigns such as 'dementia friends', a programme launched by the Alzheimer's Society in the UK in 2014 for people to wear 'Dementia Friend' badges after viewing a short lecture in person or online. The programme was misconstrued as education for health and social care staff in some places though it was at best awareness raising for lay members of the public or service providers who were not directly providing care, such as shop assistants. The practical help and advice for those living with dementia seemed to be in inverse proportion to the publicity effort.

Influence and impact

The publisher printed 7,000 copies of the Guide in advance, but then had to reprint before publication day because of significant advance orders. For the first two weeks after publication it was in the top ten Amazon overall best sellers' list. I was interviewed on BBC radio and television and on daytime TV on commercial channels. As of now, over 40,000 copies of the UK edition have sold. It has been translated into Polish (Andrews and Kotowska 2017) at the request of a Polish publisher and further editions have been produced for the North American market (Andrews 2016b) and other international markets in English speaking countries, such as Australia, New Zealand, Hong Kong and Singapore. I have been teaching and lecturing in each of these settings, giving opinion based on the fundamental ideas in the book.

Not everyone was happy, however. Chapter 12 was about the dangers of a hospital admission for someone with dementia, showing how hospitals were, and may still be, places where older people with cognitive impairment as part of their diagnoses may soon become systematically deconditioned,

Open access

This is an open access article distributed under the terms of the Creative Commons Attribution-Non Commercial 4.0 International (CC BY-NC 4.0) licence (see <https://creativecommons.org/licenses/by-nc/4.0/>), which permits others to copy and redistribute in any medium or format, remix, transform and build on this work non-commercially, provided appropriate credit is given and any changes made indicated

whereby they lose fitness or muscle tone, especially through lack of exercise. Decline is accelerated by: disturbed sleep and poor diet; minimal exercise; overuse of anti-psychotics (Simmons et al 2018); and failure to prevent, diagnose, treat, record and follow up delirium, all of which can be compounded if the people concerned are kept in long after the clinical need has ended. Indeed, delayed discharge is often due to administrative processes and budget constraints.

I took a detailed and forensic view about what you need to do as an individual to keep someone you care about safe when they are in the hospital system. This would often be based on three levels of evidence: published research on what makes a practical difference in dementia, which at the time was rare; extrapolation from research on the needs of any person with sensory and physical impairment, because a person with dementia is less able to compensate for their own needs and usually has multiple problems; and extensive personal experience, including gathering international examples of best practice and consensus about what works.

Falls and infection risks were not the only hospital-acquired problems. This caught the imagination of the press (Puttock 2015), which has the privilege of exaggeration and I suffered criticism at many hands, including the chief executive of the NHS at the time who telephoned me to say that I was undermining public confidence in the NHS, and asking me to retract. I offered to withdraw any part of the book that he could tell me was not based on evidence and consequently heard no more. Some nurses and other clinical staff working in the dementia field ('dementia champions') also felt insulted, as if the book implied that they were not doing their job. I only had to point them back to the 80% of patients who never saw or heard of a 'dementia nurse consultant' or other clinician with 'dementia' in their job description. The book was intended for those patients and their families who were on their own with this devastating diagnosis. The main audience, however, the people who needed this book, described it as easy to read, useful and 'cutting through the current narrative'.

It was put to me by a nurse teacher that the absence of references and footnotes made it unsuitable for nursing students, but I did not agree. Student nurses need plain language as much as anyone if we are to encourage them to make change happen. They also need evidence-

based advice couched in plain language to show them examples of how to help patients and families in language that everyone understands. I was, and still am, happy to respond personally to anyone who doubts the evidence base of the book's messages. For example, one family court judge thought that the section on legal issues was superficial, so I asked him to rewrite it and that section is now available, open access, on my website under his name (Ashton 2020). I was and remain happy to support anyone who wants to improve one of the chapters.

Current and future relevance

Five years after publication, an updated second UK edition is due for publication in January 2021 by Souvenir Press. Very little content needed to be changed. Some things have certainly improved, but people are still very much on their own with dementia to a larger extent than they would be with other life-limiting conditions. Improvements include better access to diagnostic and post diagnostic support.

Awareness of the risk of delirium for people with dementia and its prodromal role in dementia appears to be increasing in hospitals. Nursing staff in acute hospitals have a much better understanding of the needs of agitated people with cognitive impairment. I saw this with my own eyes when volunteering in an acute ward during the COVID-19 pandemic in early 2020. The public attitude to dementia may have improved in that it is now an open topic of conversation more than it was before. Another improvement is (in the absence of any prospect of a cure) a real slowing of the incidence of dementia, as public health measures, management of metabolic conditions and lifestyle changes are delaying acquired cognitive impairment in increasing numbers of the population (Alzheimer's Research UK 2019).

Being on your own with dementia is still largely about the funding of home care and residential or nursing care when needed. Successive governments have failed to propose a fiscal solution to this looming problem. Up to 90% of people in care homes and a significant number of those in delayed discharge hospital beds have dementia as part of their diagnosis. The second edition of the guide was timed to come out along with a new book, *Care Homes: The One Stop Guide* (Andrews In press).

At the time of writing, while the world is rocking from the COVID-19 pandemic,

the care homes book is a source of sorrow, because I was not prescient enough to include a chapter on how to manage a pandemic in a care home. Every day in the media, we heard of the mounting toll of tens of thousands of people in care homes, many of whom have dementia, who are dying from this virus or related issues. With hindsight, one can see that it was the wrong decision to move old people with dementia out of hospitals into care homes over a matter of weeks. It may have helped to save the NHS, but at a terrible cost. It did not require hindsight to know that keeping those older people with dementia in hospital was building up trouble, a situation that should have been addressed well before this point, so we could have prevented the circumstances that gave rise to this tragic error of judgement. It is the very thing that I was criticised for talking about five years earlier.

In a Cassandra-like stroke at the start of the pandemic, I asked politicians at the Scottish Government public audit committee hearing if they were waiting for a pandemic to clear away their delayed discharge problem. In mythology, Cassandra was given the power to see the future, but also the curse of never being believed. I was not believed

when I suggested that the health service and social care service in the UK has not been designed to include the needs of the ageing population, especially those who are frail and cognitively impaired (Andrews 2018, Scottish Parliament TV 2020).

The official response was silence, while on the ground thousands of older people across the UK were suddenly forced out of hospital and into care homes. Deaths of older care home residents from dementia are now well above normal rates, as a direct result of the loneliness, isolation and disruption created by the management of this flow during the pandemic. Even if they have avoided death or if the immediate impact of COVID-19 has passed, the rushed policies that did not take dementia into account caused excess suffering for people with dementia (and their families).

My guide book on dementia, with its emphasis on avoiding hospital where humanly possible, and staying by the side of the person living with dementia when possible, is as relevant now as it was when it was first written. It will continue to be relevant until someone finds a cure, fixes the health and social care system, or writes a better book.

References

Alzheimer's Research UK (2019) International Research Shows Dementia Rates Falling by 15% Per Decade Over Last 30 Years. www.alzheimersresearchuk.org/international-research-shows-dementia-rates-falling-by-15-per-decade-over-last-30-years (Last accessed: 21 September 2020.)

Andrews J (2015) Why hospitals are dangerous for people with dementia – and why it's up to families to help. *The Conversation*. theconversation.com/why-hospitals-are-dangerous-for-people-with-dementia-and-why-its-up-to-families-to-help-38738 (Last accessed: 21 September 2020.)

Andrews J (2016a) *Dementia: What You Need to Know*. Profile Books, London.

Andrews J (2016b) *When Someone You Know Has Dementia; Practical Advice for Families And Caregivers*. First edition. Greystone Books, Montreal.

Andrews J (2018) Workforce issues in Health and Social Care— Dated 18.4.2018. juneandrews.net/blog/6/3/2020/

workforce-issues-in-health-and-social-care-dated-1842018 (Last accessed: 21 September 2020.)

Andrews J (In press) *Care Homes: The One-Stop Guide: When, Why and How to Choose a Care Home*. First edition. Souvenir Press, London.

Andrews J, House A (2009) *10 Helpful Hints For Carers*. Dementia Services Development Centre, Stirling.

Andrews J, Kotowska A (2017) *Demencja*. First edition. Grupa Wydawnicza Harmonia Universalis, Gdańsk.

Ashton G (2020) Some Important Legal Issues. juneandrews.net/chapter-13-some-important-legal-issues/ (Last accessed: 4 September 2020.)

Bradford A, Kunik ME, Schulz P et al (2009) Missed and delayed diagnosis of dementia in primary care: prevalence and contributing factors. *Alzheimer Dis Assoc Disord*. 23, 4, 306-314. doi:10.1097/WAD.0b013e3181a6bebc

Hulme C, Wright J, Crocker T et al (2009). Non-pharmacological approaches for dementia that informal carers might try or access: a systematic review. *International Journal of Geriatric Psychiatry*, 25, 756-763. doi: 10.1002/gps.2429

Puttock H (2015) Expert: Hospitals Are Meat Grinders that Chew Up Dementia Sufferers. www.heraldscotland.com/news/13199802.expert-hospitals-are-meat-grinders-that-chew-up-dementia-sufferers (Last accessed: 18 September 2020.)

Simmons SF, Bonnett KR, Hollingsworth E et al (2018) Reducing antipsychotic medication use in nursing homes: a qualitative study of nursing staff perceptions. *The Gerontologist*. 58, 4, e239–e250. doi: org/10.1093/geront/gnx083

Scottish Parliament TV (2020) Public Audit and Post-Legislative Scrutiny Committee. www.scottishparliament.tv/meeting/public-audit-and-post-legislative-scrutiny-committee-march-5-2020 (Last accessed: 18 September 2020.)