

Foreword by Professor John R Hodges

It was a great honour to be asked by Shibley to write a foreword to his amazing book. I have known Shibley for over a decade, since he undertook his PhD in Cambridge in conjunction with his medical studies, and we have kept in contact since. When he told me about the book I knew that he would make a good job of it, but I had no idea of the scope and depth of scholarship until I read the draft. It is a truly unique and multifaceted contribution.

The topic of 'Wellbeing' has moved from the fringes of psychology to be central to the health agenda. This alone makes the book important but it is well known that we are entering into a potentially epidemiologically tricky phase of dementia with our ageing population, which makes the topic of wellbeing in dementia particularly poignant and relevant. Another trend is the need to consider the person suffering from dementia in the context of his or her family and society, rather than from the viewpoint of a medical model, which emphasises the disease and its treatment. Shibley has summarised the complex literature on quality of life and carer burden in dementia through wellness spectacles.

Parallel developments in the medical world have been the improvements in the early diagnosis of dementia and characterisation of subtypes, which again Shibley has dealt with expertly. Decision-making and capacity in dementia are vitally important and clinically relevant to the thrust of this book. Shibley's unique qualifications in medicine and law make him well placed to draw together these disparate strands. A look at Shibley's qualifications might lead the reader erroneously to expect the writing to be dry and academic. Nothing could be further from the truth. The whole book is infused with passion and the desire to make a difference to those living with dementia.

As well as providing a lucid overview of diverse academic topics, the book is a fantastic resource and user guide, covering topics such as communication and living well with dementia, home and ward design, assisted technology, and built environments. Shibley should be congratulated for this unique synthesis of ideas and practice. I am sure that the book will find a wide audience. I shall

certainly be recommending it to professions but particularly to families living with these horrendous diseases.

Professor John R Hodges
Professor of Cognitive Neurology for Neuroscience
University of New South Wales, Sydney
Emeritus Professor of Behavioural Neurology
University of Cambridge
October 2013

Foreword by Sally-Ann Marciano

I feel a tremendous honour that I have been asked to write a foreword to Shibley's outstanding book. I am not an academic but I am a nurse, whose wonderful father died of Alzheimer's in September 2012. Nothing during my training or nursing career could have prepared me for the challenge that came with supporting my mother in my father's journey with dementia. I have never met Shibley in person, which makes being asked to write this even more special. What we do have in common, however, is real passion for raising the profile of dementia and a hope that we can – one day – improve care for all those living with dementia.

Many people with dementia will live for many years after their diagnosis, and it should be everyone's ambition in health and social care to ensure that those living with dementia do so as well as possible for all of the remaining years of their life. Diagnosis is just the start of the journey, and, with that, should come full care and support to allow those with dementia to live where they wish, and with their closest present every step of the way.

Sadly, my father's experience revealed a system where no one appeared to take direct responsibility for his care or support. He was, rather, classified as a 'social care problem', and as a result, he had to fund his own care. Even when he was dying, his care was classified as 'basic' so that he did not even qualify for funded health care. Our only visit was once a year from the memory nurse, and, as his condition declined, my once intelligent, articulate father, who did not even know my name towards the end, needed total care.

Dementia of the Alzheimer type destroyed his brain so badly that my father was unable to feed himself, mobilise or verbalise his needs. He became totally dependent on my mother 24/7. As the condition advanced, my father became increasingly frail, with recurrent chest infections due to aspiration from swallowing difficulties. Each time the GP would be called out, antibiotics prescribed, and so the cycle would begin again. As a nurse, I wanted to see proactive management of my father's condition. The system locally, however, was quite unable to provide this service. I feel that dementia of the Alzheimer

type is a terminal condition, and, as such, should be treated like other similar conditions in care models. What we instead experienced was a 'reactive' system of care where the default option was admission to hospital into an environment where my father would quickly decline.

Dementia awareness and training among staff must be better; many staff within health and social care will come into contact with people living with dementia as part of their everyday work. That is why I am so excited about Shibley's book. It is written in a language that is easy to read, and the book will appeal to a wide readership. He has tackled many of the big topics 'head on', and put the people living with dementia and their families at the centre of his writing. You can tell this book is written by someone who 'understands' dementia; someone who has seen its joy but who has also felt the pain.

My father was cared for at home right up until he died, mostly through the sheer determination of my mother to ensure she fulfilled his wishes. Not everyone is so fortunate, and for these individuals we really need to be their champion and advocate. Everyone should be allowed to live well with dementia for however long that may be, and, with this book, we can go some way to making this a reality for all.

Sally-Ann Marciano
Project Specialist, Skills Utilisation Project
Skills for Health
October 2013

Foreword by Professor Facundo Manes

A timely diagnosis of dementia can be a gateway to appropriate care for that particular person. While historically an emphasis has been given to medication, there is no doubt that understanding the person and his or her environment is central to dementia care. Shibley's book will be of massive help to dementia researchers worldwide in my view, as well as to actual patients and their carers, and is a great example of the practical application of research. For patients with dementia, the assistance of caregivers can be necessary for many activities of daily living, such as medication management, financial matters, dressing, planning, and communication with family and friends. The majority of caregivers provide high levels of care, yet at the same time they are burdened by the loss of their loved ones. Interventions developed to offer support for caregivers to dementia patients living at home include counselling, training and education programmes, homecare/health care teams, respite care and information technology-based support. There is evidence to support the view that caregivers of patients with dementia especially benefit from these initiatives.

I am currently the Co-Chair of Aphasia/Cognitive Disorders Research Group of the World Federation of Neurology. In this group, we also have a specialist interest in world dementia research. 'Wellbeing' is notoriously difficult to define. Indeed, the World Health Organization (WHO, 2011) indirectly defines wellbeing through its definition of mental health:

Mental health is defined as a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community.

Such a definition necessarily emphasises the potential contribution of a person to society. Some people who participate in research are voluntarily contributing to society. Irrespective of the importance that they assign to their own

wellbeing, it is the duty and responsibility of researchers to protect participants' wellbeing and even to contribute towards it if possible. Participating in research can and should be a positive experience.

I feel that there is much 'positive energy' in dementia research around the world. Dementia research is very much a global effort, and many laboratories work in partnership both nationally and internationally, where expertise can be pooled and more progress can be made through collaborative efforts.

In England, the support and funding of world-class health research in the best possible facilities by the National Institute for Health Research, the Medical Research Council, the Economic and Social Research Council and the Research Charities is vital to the development of new and better treatments, diagnostics and care. Likewise, the 'World Brain Alliance' is working towards making the brain, its health, and its disorders the subject of a future United Nations General Assembly meeting. As part of this effort, a 'World Brain Summit' is being planned for 2014, Europe's 'Brain Year', to create a platform involving professional organisations, industry, patient groups and the public, in an effort to set a World Brain Agenda.

It is certainly appropriate to think these are exciting times, at last, for living well with dementia.

Professor Facundo Manes
Director, Institute of Neurosciences
Professor of Neurology and Cognitive Neuroscience
Favaloro University, Buenos Aires
Co-Chair, Aphasia/Cognitive Disorders Research Group
World Federation of Neurology
October 2013

REFERENCE

World Health Organization (WHO) (2011) *Mental Health: A State of Wellbeing*. Geneva: WHO, available at: www.who.int/features/factfiles/mental_health/en/

Introduction

OPENING REMARKS

Living well with dementia is fundamentally about what an individual can do, rather than what he or she cannot do. For example, on an evening in March 2013, filmmakers and scientists came together at an event hosted by the University of Bristol to increase the public understanding of dementia. A series of short films about dementia, curated by local filmmaker James Murray-White, preceded a discussion with researchers from the University of Bristol and other institutions supported by 'BRACE', a local charity that funds research into Alzheimer's disease and other forms of dementia (BRACE, 2013).

At the start of this book, I begin a long journey into 'living well with dementia', but this is a journey that will only begin in English public health policy really where this book finishes. The main actors of the play are now well known. Wellbeing is more than the absence of illbeing, just as health is more than the absence of disease (Huppert, 2014, citing WHO, 1947). Huppert – only this year, 2013 – remarks, *'Yet it is remarkable how resistant large sectors of the academic, practitioner, and policy communities are to recognising the importance of positive well-being or of positive health.'*

This has been an incredibly challenging book to write, but also an incredibly exciting one. It is a massively complex issue, but an extremely significant one for society. Dementia in the UK is a huge issue, but so is wellbeing; any attempt to write a book on both of these issues is bound to be an ambitious task. I have been fortunate in that I have written this book completely unfunded, with no income in the form of sponsorship even. This means that I can write freely, without any conflicts of interest at all. This book does not give any medical or legal advice, and you are encouraged anyway to read this book in conjunction with other sources of useful information. You are, in particular, advised to be guided by professional lawyers and physicians for aspects of advice that require their expertise (such as capacity-related issues, pain or hydration), but I hope

this book will provide an interesting and thought-provoking introduction to the ever-enlarging field of 'living well with dementia'.

THE SCALE OF THE 'CHALLENGE'

According to the Department of Health's *Improving Care for People with Dementia* (2013a), there are around 800 000 people with dementia in the UK, and the disease 'costs' the economy £23 billion a year. By 2040, the number of people affected is expected to double – and the costs are likely to treble. There is no doubt, therefore, about the scale of the societal issue, and it needs the finest minds in showing leadership on how to enable individuals with dementia to live better, and indeed to live well. **The Prime Minister's Dementia Challenge** ('Challenge') (Department of Health, 2012) sets out a renewed ambition 'to go further and faster' on substantial progress in previous policy, building on the work of the National Dementia Strategy, so that people with dementia, their carers and families essentially get the services and support that they need. This Challenge wished to address in particular certain issues, such as the observation that the number of people with dementia is increasing, that currently the diagnosis rates are thought to be relatively *low*, and that there is sadly a lack of awareness and skills needed to support people with dementia and their carers. While it is possibly difficult to find a 'miracle cure' for dementia, it is a reasonable aspiration for individuals with dementia (and their immediates) to have as best a quality of life as possible, and it is not necessarily the case that subtle but significant improvements in quality of life will '*cost the earth*'.

It is intended that this book should be *not* just of interest in the UK, as the problems in healthcare are relevant to all jurisdictions. This story will be of interest to patients, families, friends, geriatricians, psychiatrists, nurses, students, social workers, economists, lawyers, managers, leaders, journalists, public health professionals, GPs, commissioners, politicians and many more. Thinking about how society should respond inevitably does pose some jurisdiction-specific issues; for example, this book refers to legislation in the UK such as the **Equality Act 2010** or the **Mental Capacity Act 2005**, or regulations in health and safety relevant to building design in the UK. However, a consideration of the global issues in public health leads one quickly to appreciate the complexity of the economic case for improving wellbeing in individuals in dementia and their immediates, and that there are many people who are genuinely interested.

RESPONDING TO THE 'CHALLENGE'

While indeed there has been a lead through the Prime Minister's Dementia Challenge (Department of Health, 2012), previous administrations in England have latterly decided to prioritise dementia as a public health priority (e.g. the

National Dementia Strategy, *Living Well with Dementia*, 2009). The 'ecosystem' of interested parties is large, and it is striking that there are so many passionate '#dementiachallengers' on Twitter daily, for example, who are always a source of contemporary information, enthusiasm and innovation. There are currently huge advances being made in research and policy, and it is only possible through dementia communities 'working together' to keep abreast of them all. For that reason, this book has necessarily had to include electronic references, and I have tried to maintain links as correct and up to date at the time of publication. However, please feel free to look for any related information anywhere, and please do not use this book as an authoritative source of information to rely on necessarily. This book is intended simply as an introduction to a vibrant field, and certainly please be guided by healthcare professionals regarding individual care. The text of this book provides general principles, which I hope you might find interesting.

THE NICE QUALITY STANDARD ON 'SUPPORTING PEOPLE TO LIVE WELL WITH DEMENTIA'

The original clinical guidance by the National Institute for Health and Clinical Excellence (NICE) for dementia (CG42) was published as far back as 2006, and yet the importance of wellbeing in dementia is clearly seen even then. This in part has been driven by a relative lack of strong neuropharmacological interventions in early dementia of the Alzheimer type, perhaps. As recently as April 2013, NICE published its **Quality Standard 30** on '**supporting people to live well with dementia**'. This quality standard was intended to cover the care and support of people with dementia. It applies to all social care settings and services working with and caring for people with dementia.

NICE quality standards are supposed to describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing guidance, which provide an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

The areas covered in this '**quality standard**' include:

- **Statement 1**, Chapter 12. People worried about possible dementia in themselves or someone they know can discuss their concerns, and the options of seeking a diagnosis, with someone with knowledge and expertise.
- **Statement 2**, Chapter 10. People with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support.
- **Statement 3**, Chapter 10. People with dementia participate, with the involvement of their carers, in a review of their needs and preferences when their circumstances change.

- **Statement 4**, Chapter 7. People with dementia are enabled, with the involvement of their carers, to take part in leisure activities during their day based on individual interest and choice.
- **Statement 5**, Chapter 6. People with dementia are enabled, with the involvement of their carers, to maintain and develop relationships.
- **Statement 6**, Chapter 6. People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.
- **Statement 7**, Chapter 14. People with dementia live in housing that meets their specific needs.
- **Statement 8**, Chapter 13. People with dementia have opportunities, with the involvement of their carers, to participate in and influence the design, planning, evaluation and delivery of services.
- **Statement 9**, Chapter 11. People with dementia are enabled, with the involvement of their carers, to access independent advocacy services.
- **Statement 10**, Chapter 11. People with dementia are enabled, with the involvement of their carers, to maintain and develop their involvement in and contribution to their community.

OVERVIEW

The aim of this book was not to provide a prescriptive text for this quality standard, but to make occasional reference to it where appropriate. I am hoping especially that the book will be interesting to what I have called ‘immediates’ – by which I mean people who are close to an individual with a diagnosis of dementia, which might include a friend or relative. It is, therefore, extremely hard to find all this information ‘in one place’, and it is hoped that this book will help to provide a much-needed overview and to build bridges between different ‘silos’ of thinking.

The approach of the **national dementia strategy *Living Well with Dementia*** (Department of Health, 2009) devotes the whole of its chapter 5 to the issue of living well with dementia. In the preceding chapter in this strategy, chapter 4 on early diagnosis, the approach described is obviously inclusive:

From our consultation, and based on a successful DH pilot and the DH cost-effectiveness case, it appears that new specialist services need to be commissioned to deliver good-quality early diagnosis and intervention. Such services would need to provide a simple single focus for referrals from primary care, and would work locally to stimulate understanding of dementia and referrals to the service. They would provide an inclusive service, working for people of all ages and from all ethnic backgrounds.

A 'timely diagnosis' is only of benefit, it is felt, if there is a 'useful' intervention in dementia or appropriate support can be given in keeping with the wishes of the patient. The diagnosis has to be correct, and appropriate to the patient at that particular time. This is described in the strategy's **chapter 4** as having three essential components: (1) making the diagnosis well, (2) breaking the news of the diagnosis well to the individual with dementia and his or her immediates, and (3) providing directly appropriate treatment, information, care and support for such individuals. The present book is part of a drive to dispel the notion that '*nothing can be done*' in the context of management of dementia, even if current pharmacological therapies might have limited efficacy. This book is an overview of the field, describing what 'wellbeing' actually means, and why it is important in the context of national policy.

This book quickly establishes the importance of the 'person' in discussing dementia care, including independence, leisure and other activities, and, in the final stages, end-of-life care, which is an unavoidable discussion. No individual with dementia should be abandoned in relation to his or her environment, and, indeed, there is much evidence to support the idea that the environment can be optimised to improve the wellbeing of an individual with dementia and the people who are closest to him or her. Considerations include home and ward design, the use of assistive technologies and telecare, and the 'built environment'. A constructive interaction of an individual with his or her environment is clearly vital, and this includes understanding communication issues, how to champion the rights of an individual living well with dementia through independent advocacy, and the way in which 'dementia-friendly communities' can be supported.

CHAPTER HEADINGS

1. Introduction
2. What is 'living well'?
3. Measuring living well with dementia
4. Socio-economic arguments for promoting living well with dementia
5. A public health perspective on living well with dementia, and the debate over screening
6. The relevance of the person for living well with dementia
7. Leisure activities and living well with dementia
8. Maintaining wellbeing in end-of-life care for living well with dementia
9. Living well with specific types of dementia: a cognitive neurology perspective
10. General activities that encourage wellbeing
11. Decision-making, capacity and advocacy in living well with dementia
12. Communication and living well with dementia
13. Home and ward design to promote living well with dementia
14. Assistive technology and living well with dementia

15. Ambient assisted living well with dementia
16. The importance of built environments for living well with dementia
17. Dementia-friendly communities and living well with dementia
18. Conclusion

CHAPTER SYNOPSES

It is possible to read each chapter in this book independently, and, indeed, each chapter is independently referenced. However, I feel the book makes much more sense if read from beginning to end – not at one go, obviously!

Chapter 2 is an introduction to the whole book. It introduces the concept of what is like to 'live well with dementia'. Investigating wellbeing has broadened the scope of previously overly narrow approaches to healthcare in measuring outcomes. This chapter also introduces the idea that it is grossly unfair to consider 'dementia' as a unitary diagnosis, as in fact the term is a *portmanteau* of hundreds of different conditions at least. There has been an incorrect growing trend that 'dementia' and 'memory problems' are entirely synonymous, and this has added unnecessary noise to the debate. Dementia care is currently undertaken in a number of different settings, and assisted living may be of increasing relevance in a drive to encourage individuals to live well independently with dementia.

Chapter 3 presents the formidable challenges of how 'living well' might be measured in general. There are issues about how quality of life measures change as a dementia progresses, what the relationship might be between wellbeing and physical health, and how wellbeing in dementia could be measured accurately at all.

Chapter 4 looks at the current socio-economic arguments for promoting a wellbeing approach in dementia. There are a number of converging cases for considering wellbeing, such as the economic case, the ethical case and a case based on social equality. While resources are always limited, serious considerations have to be made as to which interventions are truly cost-effective, including, of course, the assistive technologies and ambient-living innovations.

Chapter 5 presents the background for dementia as a public health issue in the UK. There is also a very active debate as to whether one should 'screen' for dementia, although the general consensus at present is that screening for dementia as a whole would be inadvisable. A core aim of the national dementia strategy *Living Well with Dementia* (Department of Health, 2009) is therefore to ensure that effective services for early diagnosis and intervention are available for all on a nationwide basis. It is argued, in this strategy, that, '*the evidence available also points strongly to the value of early diagnosis and intervention to improve quality of life and to delay or prevent unnecessary admissions into care homes.*'

Chapter 6 considers how and why being a 'person' has become so central to living well with dementia in academic and practitioner circles. In a way, the

approach of 'person-centred care' is a historic one, but it has been a consistent strand of English health policy, developing into contemporaneous views of integrated and whole person care. This chapter also introduces 'personhood', and the approach of 'dementia care approach'.

Chapter 7 addresses the specific rôle of leisure activities for an individual with dementia. Leisure activities are generally considered for many to be beneficial for the mental and physical wellbeing of individuals with dementia, and there are specific problems to be addressed, such as the reported levels of relative inactivity in care homes.

Chapter 8 details how wellbeing is relevant also to end of life in dementia. This chapter considers the importance of support for carers, for the wellbeing of individuals with dementia and their carers. This chapter considers where optimal care could be given for individuals with dementia, the contribution of medication, and how it is vital to address specific issues in advanced dementia that have a direct impact on wellbeing (such as pain control). This is of course an extremely complicated professional area, with deeply rooted ethical issues, and this chapter only at best skims the surface of this huge sub-discipline from a general perspective.

Chapter 9 further elaborates the idea that it is impossible to consider dementia as a unitary diagnosis, and that specific forms of dementia can present their own formidable demands and issues. This chapter considers in detail how and why memory problems can be a presenting feature of dementia of the Alzheimer type, and the implications for interventions in wayfinding that could rationally improve wellbeing in such patients. The chapter also includes recent elegant work about the distributed neuronal networks that are hypothesised to be important in behavioural variant frontotemporal dementia, and proposes an initial view of how this 'social context network model' fundamentally affects our notion of wellbeing in such individuals.

Chapter 10 introduces 'general activities that encourage wellbeing'. Certain memories, once revived, can be particularly potent in the dementia of the Alzheimer type, and, while the 'jury is possibly out' on the experimental robustness of reminiscence therapy, the chapter discusses the possible benefits of the CIRCA project on the wellbeing of individuals with dementia. Other activities are also considered; how they may help wellbeing, such as dancing, exercise and music.

Chapter 11 takes up an important theme in living well with dementia – that is, empowering the individual to make decisions, the law relating to capacity, and how independent advocacy services have a beneficial rôle to play. Independent dementia advocacy is a critical area of a statement in **NICE QS30**, and this chapter reviews types of advocacy (and its relevance to wellbeing and person-centred care), the current mental capacity legislation, and the crucial importance of diversity and equality in policy.

Chapter 12 explains why good communication is so crucial in the setting

of individuals living well with dementia, and this is not simply restricted to healthcare professionals. This appears to be in terms of not only providing information about the condition locally but also face-to-face communication with people living well with dementia. This chapter looks in detail at both verbal and non-verbal methods of communication, with a view to raising awareness of their impact on living well with dementia.

Chapter 13 analyses the importance of home and ward design for improving wellbeing in dementia. ‘Therapeutic design’ is a central philosophy of good design, and this chapter has as its focus a number of different settings. This is a philosophy that has been warmly embraced by a number of different stakeholders, ranging from the King’s Fund to the Royal Institute of British Architects, the professional body for architects in this jurisdiction. General principles for the improvement of wellbeing through careful design of certain parts of the house (such as balconies, bathrooms, bedrooms, living rooms and dining rooms) are described, and this chapter considers some basic neuroscience of sensory considerations at play (e.g. in lighting and vision, and sound and hearing.)

Chapter 14 is the *first* of two chapters on ‘assistive technologies’ in dementia, providing an overview of this important area for living well with dementia. This chapter explains what ‘assistive technology’ is, what its potential limitations are, the INDEPENDENT project, the importance of ‘telehealth’ (and important ethical considerations), and the design of ‘smart homes’.

Chapter 15 is the *second* of two chapters on ‘assistive technologies’ in dementia, looking specifically at an approach called ‘ambient assisted living’ (AAL). The rationale behind the use of AAL in improving wellbeing is explained, as well as the general issue of how to encourage adoption of innovations in an older population. Detailed examples of specific AAL projects in improving wellbeing are described, including SOPRANO, COACH and NOCTURNAL.

Chapter 16 introduces the general emphasis on the ‘built environment’ setting, and how inclusivity still drives this area of work in living well with dementia. Ageing presents its own challenges, including opportunities and threats, but this chapter focuses on the remarkable initiatives that have recently taken place in improving the outside environment for individuals with dementia. The chapter details the I’DGO project, and highlights the especial importance of inclusive design for furthering wellbeing in dementia outside environments. The chapter concludes with an evolving theme in the research that the quality of wellbeing of an individual with dementia is a highly personal affair. It is very much dependent on that person’s unique interaction with his or her environment.

Chapter 17 considers how an individual with dementia lives as part of the rest of a community and society, and policy initiatives that have sought to address this. The discussion is unexpectedly problematic about a need to define what a ‘community’ might be, but the chapter includes domestic and

international approaches to the 'dementia-friendly community', including the RSA's 'Connected Communities' and the World Health Organization's 'age-friendly communities' initiatives.

As a central policy plank that is thought to be critical for developing wellbeing in individuals with dementia and their immediates, this chapter considers why dementia-friendly communities are worth encouraging at all, why there is a societal need to involve individuals with dementia in their communities, what aspects individuals with dementia wish from such communities (including the 'Four Cornerstones' model), and the benefits of 'resilient communities'.

Chapter 18 completes my thesis. It concludes with a review of some of the themes that emerge in this book, but puts especial focus on the language of the debate regarding 'prompt diagnosis' or 'timely diagnosis' and tries to put current policy on living well with dementia into a realistic and achievable perspective.

FURTHER INFORMATION

You are advised to look at specialty websites that are devoted to all the dementias (such as medical charities), which often have useful information fact sheets and booklets.

Also, the Department of Health and their 'Dementia Challenge' website is an impressive source of information (2013b). You are also advised to consult the National Health Service (NHS) website (www.evidence.nhs.uk), which has access to a number of useful contemporaneous clinical evidence sources. Online medical journals are also an excellent source of peer-reviewed research, such as the *BMJ*, the *Lancet*, and the *New England Journal of Medicine*. You are also strongly recommended to become familiar with the output of the King's Fund, the Royal College of Physicians and the Royal College of Psychiatrists, which have all produced interesting contributions in this field.

In the references, I have decided to include some **electronic references**, but only where I feel this would really help, given the problems that these links may become dead 'in due course'. All links are to citations that were accessible on the internet at the time of submission of the manuscript, on 1 August 2013. I apologise if you are unable to find links as updated, although it might be worth using a search engine to discover whether links have been relocated. They are, by and large, important documents that are unlikely to be taken 'off the internet'.

LOOKING TO THE FUTURE

There are, of course, no '*right answers*' to many issues, and a wise person is a person who knows where to find relevant information. However, the sense of optimism and goodwill is a genuine one in UK health policy, regarding

dementia. While there will often be difficult debates regarding dementia – such as ‘How willing should a GP be to make a diagnosis of dementia when a patient has only gone to see his GP because of a sore throat?’ or ‘Should we look to research a drug that can immunise people against dementia?’ – the fact there are so many bright people in the UK working in areas relating to dementia is a real credit to English health policy, as it faces formidable challenges of its own.

Developments in neuroscience and cognitive neurology have helped to shape this policy, but also there are formidable converging strands of thinking in social care, bioengineering, general medicine, economics, social and cognitive psychology and innovation management, to name but a few. The impact of the English law – for example, in equality and mental capacity – cannot be underestimated either, and helps to see some of the policy elements as enforceable rights rather than well-meant aspirations. Understanding how elements of this jigsaw all produce a coherent picture of living well in dementia is certainly challenging, but undeniably rewarding.

Dr Shibley Rahman
Queen’s Scholar, BA (1st Class Honours),
MA, MB, BChir, PhD (all Cambridge); MRCP(UK);
Graduate Diploma in Law and LLB(Hons) (BPP Law School);
LLM (with commendation) (College of Law of England
and Wales); MBA (BPP Business School); BPP Postgraduate
Diploma in Legal Practice; FRSA
October 2013

REFERENCES

- BRACE (2013) *An Evening of Short Films about Dementia*, available at: www.alzheimers-brace.org/events/evening-short-films-about-dementia
- Department of Health (2009) *Living Well with Dementia: A National Dementia Strategy; Putting people first*. London: The Stationery Office, available at: www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf
- Department of Health (2012) *The Prime Minister’s ‘Dementia Challenge’: Delivering Major Improvements in Dementia Care and Research by 2015*. London: The Stationery Office, available at: www.gov.uk/government/policies/improving-care-for-people-with-dementia
- Department of Health (2013a) *Improving Care for People with Dementia*. London: The Stationery Office, available at: www.gov.uk/government/policies/improving-care-for-people-with-dementia
- Department of Health (2013b) *The Dementia Challenge*. London: The Stationery Office, available at: dementiachallenge.dh.gov.uk
- Huppert, F. (2014) The state of well-being science: concepts, measures, interventions and policies. In: Huppert, F.A., and Cooper, C.L. (eds) *Interventions and Policies to Enhance Wellbeing*, vol. 6. Oxford: Wiley-Blackwell. pp. 1–49.
- National Institute for Health and Clinical Excellence (NICE) and Social Care Institute for

- Excellence (2006) *CG42: Dementia*. A NICE–SCIE Guideline on supporting people with dementia and their carers in health and social care, available at: www.nice.org.uk/CG42
- National Institute for Health and Care Excellence (NICE) (2013) *Supporting People to Live Well with Dementia (QS30)*, available at: <http://guidance.nice.org.uk/QS30>
- UK Government. *Mental Capacity Act 2005*, available at: www.legislation.gov.uk/ukpga/2005/9/contents
- UK Government. *Equality Act 2010*, available at: www.legislation.gov.uk/ukpga/2010/15/contents
- World Health Organization (WHO) (1947) *The Constitution of the World Health Organization*. Geneva: WHO.



ASSISTIVE TECHNOLOGY

Assistive technology (AT) can be defined as

an umbrella term for any device or system that allows an individual to perform a task they would otherwise be unable to do or increases the ease and safety with which the task can be performed (Cowan and Turner-Smith, 1999).

An alternative definition, which emphasises the rôle of AT in maximising the independence of older people, is:

AT is any product or service designed to enable independence for disabled and older people (The King's Fund, 2001 – see website references).

The technologies embraced by these definitions include devices that might form part of 'telecare' and 'telehealth' service packages (that is, assistance devices linked to response teams via a person's telephone, such as community alarm services, detectors or monitors of fire, gas or falls). The definitions also embrace a range of technologies from low-level to high-tech devices, however. These may also include more general technologies (such as access to the internet) that might have a rôle in promoting the independence and wellbeing of older people.

Such technologies clearly require more analysis, and they raise important ethical issues about empowering patients at the risk of potentially making them more 'socially excluded', definitely an 'unintended consequence'. ATs, including ambient assisted living, are discussed in **Chapters 14 and 15**, in particular in relation to what might constitute a 'successful innovation' for an individual with dementia.

WHERE TO NEXT?

The next chapter considers that, if you think observing wellbeing is a worthwhile activity, how should wellbeing be measured?

WEBSITES

- 'Dementia MKN website' can be accessed on the Scottish NHS site: www.knowledge.scot.nhs.uk/dementia.aspx
- 'Enhancing the Healing Environment', an initiative from the King's Fund: www.enhancingthehealingenvironment.org.uk

REFERENCES

- Audit Commission (2000) *Forget Me Not: Mental Health Services for Older People*. Abingdon, Oxon; Audit Commission Publications, available at: archive.audit-commission.gov.uk/auditcommission/nationalstudies/health/mentalhealth/pages/forgetmenot.aspx.html
- Banerjee, S. (2009) *The Use of Antipsychotic Medication for People with Dementia: Time for Action; A report for the Minister of State for Care Services*. London; Department of Health.
- Banerjee, S. (2010) Living well with dementia: development of the National Dementia Strategy for England. *Int J Geriatr Psychiatry*, 25(9), pp. 917–22.
- Banerjee, S., Samsi, K., Petrie, C.D., et al. (2008) What do we know about quality of life in dementia? A review of the emerging evidence on the predictive and explanatory value of disease specific measures of health related quality of life in people with dementia. *Int J Geriatr Psychiatry*, 24(1), pp. 15–24.
- Brayne, C. (2012) 'Rooted in evidence: a public health perspective to dementia', available at: www.cam.ac.uk/research/news/rooted-in-evidence-a-public-health-response-to-dementia.
- Brayne, C., Bayer, A., Boustani, M., et al. (2013). Rapid response to 'There is no evidence base for proposed dementia screening' (27 February 2013): 'A rallying call for an evidence based approach to dementia and related policy development', available at: www.bmj.com/content/345/bmj.e8588/rr/633370
- Burns, A., and Robert, P. (2009) The National Dementia Strategy in England: a 'smorgasbord' of evidence, economics, and obligation, *BMJ*, 338: b931.
- Cohen-Mansfield, J., Theina, K., Dakheel-Alia, M., et al. (2010) The underlying meaning of stimuli: Impact on engagement of persons with dementia, *Psychiatry Res*, 177(1–2), pp. 216–22.
- Cornwell, J., Sonola, L., Levenson, R., et al. (2012) *Continuity of Care for Older Hospital Patients: A Call for Action*. London: King's Fund, available at: www.kingsfund.org.uk/publications/continuity-care-older-hospital-patients
- Cowan, D., and Turner-Smith, A. (1999) The role of assistive technology in alternative models of care for older people. In: Tinker, A., et al. (eds.) *Alternative Models of Care for Older People: Royal Commission on Long Term Care Research Volume 2*. London: The Stationery Office. pp. 325–46.
- Day, K., Carreon, D., and Stump, C. (2010) The therapeutic design of environments for people with dementia: a review of the empirical research, *Gerontologist*, 40(4), pp. 397–416.
- Department of Health (2009) *Living Well with Dementia: A National Dementia Strategy*. London: The Stationery Office, available at: www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy
- Department of Health (2012) *The Prime Minister's 'Dementia Challenge': Delivering Major Improvements in Dementia Care and Research by 2015*. London: Department of Health, available at: <http://media.dh.gov.uk/network/353/files/2012/11/The-Prime-Ministers-Challenge-on-Dementia-Delivering-major-improvements-in-dementia-care-and-research-by-2015-A-report-of-progress.pdf>
- Easton, M. (2006) *Britain's Happiness in Decline*, BBC website, 2 May 2006, available at: http://news.bbc.co.uk/1/hi/programmes/happiness_formula/4771908.stm
- Green, E. on behalf of the MRC Institute for Environment and Health (2000) *Health and Wellbeing: Does our Environment Matter? A report of an open seminar organised by the MRC*