

Living Well with Dementia:  
The Importance of the Person and  
the Environment for Wellbeing

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Radcliffe Publishing  
London • New York

# Contents

	<i>Foreword by Professor John R Hodges</i>	v
	<i>Foreword by Sally-Ann Marciano</i>	vii
	<i>Foreword by Professor Facundo Manes</i>	ix
	<i>Acknowledgements</i>	xi
1	Introduction	1
2	What is 'living well'?	13
3	Measuring living well with dementia	29
4	Socio-economic arguments for promoting living well with dementia	55
5	A public health perspective on living well with dementia, and the debate over screening	67
6	The relevance of the person for living well with dementia	101
7	Leisure activities and living well with dementia	121
8	Maintaining wellbeing in end-of-life care for living well with dementia	133
9	Living well with specific types of dementia: a cognitive neurology perspective	147
10	General activities that encourage wellbeing	161

11	Decision-making, capacity and advocacy in living well with dementia	175
12	Communication and living well with dementia	197
13	Home and ward design to promote living well with dementia	213
14	Assistive technology and living well with dementia	233
15	Ambient assisted living and the innovation culture	253
16	The importance of built environments for living well with dementia	269
17	Dementia-friendly communities and living well with dementia	285
18	Conclusion	301
	<i>Index</i>	311

# 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**  
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**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**  
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*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*

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