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978-1-107-53599-2 — The Dementia Manifesto
Julian C. Hughes, Toby Williamson
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The Dementia Manifesto

Endorsement for *The Dementia Manifesto*

“I welcome this book which sits squarely alongside my lived experience of dementia and underlines its complexities that are so often overlooked. I wholeheartedly commend the authors’ bravery in applying their wisdom and experience to a book which will, I am sure, contribute towards positive change. Indeed that should be the function of any manifesto worthy of the label. The book is challenging, but so is attempting to live well with dementia, and without challenge nothing will move forward. This book is a very significant step in the right direction.”

**Keith Oliver, Alzheimer’s Society Ambassador, Kent and Medway
NHS and Social Care Partnerships Trust (KPMT) Dementia Service
User Envoy”**

“I loved the case vignettes – true to life, rich in narrative detail, precisely constructed and thoughtfully teased apart to illustrate the application of Values-based practice (VBP) in dementia.

The Dementia Manifesto is in essence a comprehensive and heartfelt refutation of an old idea that dementia represents a loss of personhood. Instead, it proclaims as its first principle: Dementia is a unique touchstone for understanding our humanity.

This book describes the principles of Values-based practice in dementia, as an essential complement to Evidence-based practice, and deeply rooted in the established perspectives – philosophical, scientific, ethical, political, legal, institutional – which shape the thinking of practitioners in the field. Key concepts in VBP include the recognition that ‘objective facts’ are nearly always entangled with values, and the idea of Dissensus – respectful appreciation of the variety of legitimate values at work – as a practical way forward when consensus is impossible.”

Dr Catherine Oppenheimer, Oxford

“In *The Dementia Manifesto*, Hughes and Williamson recognize dementia as a human condition that challenges people to find the ‘better angels of our nature’ and, thereby, never to lose sight of the fact that it is a person who is experiencing what is called dementia. They demonstrate convincingly why it is utterly crucial to recognize that our understanding of dementia and the psychological, social, and pharmacological treatment of people so diagnosed are laden with values and that absent a clear, focused understanding and practice of those values, we shall be treasonous to ‘the better angels of our nature’. The case examples they present illustrate wonderfully the complex value-laden interpersonal relationships that people diagnosed and their care partners experience, their respective rights, and the great sensitivity required to understand people in their

totality so as to provide optimal person-centred care, or Values-Based Practice, in the authors' terms. The values in and the value of human life demand nothing less. Indeed, they behave us to pay especially close attention to what Hughes and Williamson put forth in this volume."

Steven R. Sabat, Ph.D., FGSA
Professor Emeritus of Psychology, Georgetown University,
Washington, D.C.
Associate Editor, Dementia: The International Journal of
Social Research and Practice

"This book makes a timely and unique contribution to the dementia discourse. It brings together theoretical, ethical and practice based knowledge to make the case for a values driven manifesto for people living with dementia. It is infused with a clear commitment to rights and person centredness and foregrounds the importance of relationships, both formal and family and friends, in enhancing well being and personhood. Using vignettes the authors thoughtfully and skilfully illustrate the role and capacity of a values based approach to shift the fulcrum of care towards meaningful, respectful and individualised engagement with different and varied lived experiences of dementia. The book is exquisitely written and captures the reader immediately; it will have wide and refreshing appeal. The authors bring their considerable clinical, policy and research related expertise and knowledge to bear in an imaginative and coherent text that offer a new lens on how we think and conceptualise dementia and support people living with dementia."

Dr Alisoun Milne
Professor of Social Gerontology and Social Work, University of Kent

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The Dementia Manifesto

Putting Values-Based Practice to Work

Julian C. Hughes

University of Bristol

Toby Williamson

University of West London



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Every effort has been made in preparing this book to provide accurate and up-to-date information that is in accord with accepted standards and practice at the time of publication. Although case histories are drawn from actual cases, every effort has been made to disguise the identities of the individuals involved. Nevertheless, the authors, editors, and publishers can make no warranties that the information contained herein is totally free from error, not least because clinical standards are constantly changing through research and regulation. The authors, editors, and publishers therefore disclaim all liability for direct or consequential damages resulting from the use of material contained in this book. Readers are strongly advised to pay careful attention to information provided by the manufacturer of any drugs or equipment that they plan to use.

Julian dedicates this book to
his wife
Anne
with love and gratitude.
Toby dedicates this book to
his wife and his mum
Jane and Karina,
and to family and friends, past and present,
with love and gratitude.
Together we dedicate this book to
all those people,
especially those we have known,
who live and have lived with dementia
and to those who support or have supported them.
For people living with dementia today and in the
future and those who support them,
we hope it contributes to their rights as citizens
and sustains their wishes, feelings, beliefs, and values
as people,
and their lives as human beings and members of
society.

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Foreword

When Julian Hughes and Toby Williamson approached me about their plans for a Values-based dementia manifesto I was initially sceptical. A timely editorial, perhaps, I wondered, or maybe a ‘thought piece’ for an academic journal, but was there really a whole book in this?

Just how wrong I was is evident throughout this inspiring and highly original work. From its thoughtful theoretical underpinnings, through a series of insightful chapters on key aspects of dementia care, to its clear conclusions, Hughes and Williamson’s *Manifesto* consistently comes good on its promissory subtitle in *Putting Values-Based Practice to Work*.

There is much talk nowadays about ‘values based this’ and ‘values based that’. We are all required to have and to evince ‘the right values’. But the Values-based Practice underpinning Hughes and Williamson’s Manifesto is not of this kind. It is rather about building the skills and other resources required to support balanced decision-making where, as in living with dementia, the operative values are complex and conflicting.

As developed recently in Oxford, the focus of Values-based Practice, so conceived, has been on areas of acute clinical care such as surgery and radiology. Hughes and Williamson’s Manifesto brilliantly extends Values-based Practice to the perhaps even greater challenges presented by long-term complex conditions. They are the first to do this. Page after page illustrates how Values-based Practice supports working with people living with dementia, those with dementia and their carers, in ways that are both humane and at the same time deeply practical.

But there is more even than this in their book. In working out the implications of Values-based Practice for dementia care, Hughes and Williamson have greatly enhanced our understanding of Values-based Practice itself. Human Rights are a case in point. In marking itself out as a process- rather than outcomes-focused way of working with values, Values-based Practice has sometimes ended up appearing to be anti-ethics. Hughes and Williamson’s nuanced use of Human Rights principles (derived from disability studies), working always alongside the personalisation of decision-making supported by Values-based Practice, nicely exemplifies the essential complementarity between these two approaches.

There is thus no one-size-fits-all when it comes to working with values. The challenges of dementia care illustrate the vital importance of being ready to draw appropriately on the full range of resources available from the ‘values tool kit’. The significance of the tool kit runs indeed well beyond the remit of the Manifesto. In highlighting the importance for dementia of rights alongside values, the Manifesto innovatively links these to wider notions of personhood and citizenship. Hughes and Williamson’s Values-based Dementia Manifesto thus becomes a touchstone for understanding the human condition as a whole.

Bill (KWM) Fulford
St Catherine’s College, Oxford
November 2018

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Preface

We all see dementia as a challenge. Indeed, many are frightened by the very prospect of it. This is not unreasonable, because more of us throughout the world are getting it as we live longer. And it's a serious and sometimes devastating condition. The biology and psychology of dementia, its medical and behavioural management, are all dealt with elsewhere. In this book we want to pause to reflect on other aspects of dementia because, as we shall argue, despite everything else about it, dementia is also a way of seeing more clearly the human condition. In the face of a threat to our lives and to our standing as persons with relationships and a sense of dignity and worth, we would argue that it's quite natural to ponder on some of the deeper aspects of our being in, or engagement with, the world. These ponderings are pertinent to us all, not just to those of us who will get or are already living with dementia.

Moreover, there is a particular aspect of the human condition which we wish to consider. It is the pervasiveness of values and the implications of this for dementia and for dementia care in particular. The challenge of the human condition is, in part, the challenge of living out our values in a world of diverse values. Values-based practice (VBP), the topic covered by this series of books, is all about negotiating the world of values. In the context of dementia, it is also a way – amongst other ways – of understanding what we are doing and why: a way to work out what might be for the best. Given that dementia and the problems it can throw up will elicit different value judgements, thinking about dementia can give us a particular values-based way of seeing the world. But seeing the world in this light, as a world replete with intersecting, converging, and diverging values, is also to see dementia differently. It's not solely a condition (and it would be odd given the reality of the human condition if this were the case) describable by facts: dementia is shot through with evaluative judgements.

The new view of dementia, the person-values perspective, enables us to see dementia differently, but, more importantly, it helps us to approach some well-recognized problems associated with living with dementia afresh. In order to do this, we cannot be sectarian. We have to grasp the whole of what it is to be a human person living in the world. This includes, then, the reality of our physical state – a physical state which is at risk of (and will inevitably succumb to) disease. Dementia is a disease which needs to be understood at a pathophysiological level. The biology and relevant pharmacology of dementia are important. But dementia is also a disability with which people live. And people with disabilities have rights as citizens to expect certain sorts of regard. They must be treated; but this treatment is not primarily (foundationally one might say) biomedical treatment, nor indeed is it simply a matter of adding in psychosocial treatment. At a foundational level, it's the treatment that we all expect and deserve as citizens: treatment with respect and courtesy as free people bound together by the deep ties of humanity. The interconnections and interdependencies that constitute our solidarity are preserved in the citizenship of people who live with dementia. Furthermore, this citizenship provides us all with rights. So our standing in the world as citizens is shot through with rights, just as it provides a scaffold for the richness of our shared and diverse values.

This book, we hope, will make explicit how useful a VBP approach can be for dementia care. In part, this will be achieved by showing the pervasiveness of values. In addition, it will be achieved by looking at the particularities of cases. We shall show how the VBP framework fits and is beneficial in considering different issues in dementia care. These will include issues around relationships and team work, as well as around diagnosis, behaviour that challenges, truth telling, the end of life, legal matters, communication, stigma, and social policy, to name but a few. In addition, however, we shall show how VBP must be cognizant of, and work in partnership with, the rights-based approach to dementia which emphasizes our standing as citizens.

So dementia – living with dementia and helping others to live well with dementia – and all of the challenges that go with dementia can be usefully approached via VBP. At the same time we must keep in mind both the standing of dementia as a disease and its standing as a disability to which the rights of citizens attach. Meanwhile, by understanding the contribution of VBP to dementia, as well as how the challenge that dementia poses can enhance VBP, we can understand something more about the human condition. Our Manifesto is that we should understand dementia as epitomizing the human condition, as both a disease and a disability, and as a reality for which VBP presents a practical approach bolstered by rights. Moreover, seeing dementia as value-laden, as we must if we see the human condition aright, makes VBP a natural path to follow in trying to deal with the moral, legal, social, and political issues that arise in connection with dementia. If this book achieves even a small part of this ambition, then we shall be able to claim that it has sparked a revolution, perhaps only at an individual level, but with the potential to revolutionize our whole approach to dementia.

Acknowledgements

We would like to express our sincere gratitude to the following:

First and foremost, Bill Fulford for his support and encouragement. It's true that without him this book would not have been written, but more than that, he has remained a guide, inspiration, and friend to both.

Colleagues at the Collaborating Centre for Values-Based Practice in Health and Social Care, St Catherine's College, University of Oxford.

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Toby would like to express his deepest thanks to Julian for agreeing to co-author this book in the first place; his idea of making it a manifesto; his expertise, experience, advice, comments, and support; and his willingness to see it through to completion.

Julian would like to thank Toby for his unwavering tolerance, fairness, common sense, inspiration, perception, and the knowledge and many insights that he has conveyed through the process of writing this book, and for being such a pleasure to work with.

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Authors' Note

All the people featured in the vignettes in this book are fictional but are based upon the authors' collected experience of working with people with dementia, family carers, and practitioners.

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Abbreviations

ACP	Advance care planning
AD	Alzheimer's disease
ADRT	Advance decision to refuse treatment
aMCI	Amnesic mild cognitive impairment
ANH	Artificial nutrition and hydration
CPN	Community psychiatric nurse
CPR	Cardiopulmonary resuscitation
CSF	Cerebrospinal fluid
DEEP	Dementia Engagement and Empowerment Project
DLB	Dementia with Lewy bodies
DoLS	Deprivation of Liberty Safeguards
DOR	Dementia-orientated reality
EBM	Evidence-based medicine
EBP	Evidence-based practice
ECHR	European Convention on Human Rights
GP	General practitioner
LPA	Lasting power of attorney
MCA	Mental Capacity Act 2005
MCI	Mild cognitive impairment
MDTs	Multidisciplinary teams
MMSE	Mini-Mental State Examination
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NSF	National Service Framework
PD	Parkinson's disease
PEG	Percutaneous endoscopic gastrostomy
PSA	Prostate-specific antigen
QoL	Quality of life
RCT	Randomized-controlled trial
RO	Reality orientation
SPECIAL	Specialised Early Care for Alzheimer's
UCDS	Urban Community Dementia Care Services
UK	United Kingdom
UKCEN	United Kingdom Clinical Ethics Network
UN CRPD	United Nations Convention on the Rights of Persons with Disabilities
USA	United States of America
VBP	Values-based practice

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