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978-1-107-53599-2 — The Dementia Manifesto
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Excerpt
More Information

Introduction

Manifestos, Dementia, Values, and Rights

This is a book about dementia, but we are calling it a Manifesto because we want to change dementia care and the way dementia is understood by society in general.

We recognize that all the different health conditions that come under the umbrella term of dementia are real illnesses affecting millions of people worldwide, causing many people experiencing them or providing care genuine distress and debilitation. We fully acknowledge that as a progressive, terminal disease, without cure or evidence-based universally effective treatments, a dementia diagnosis may come as a devastating blow. We also recognize the importance of evidence-based approaches in trying to find causes, treatments, good care, and perhaps even cures for dementia.

But we have written this book because we also believe that dementia needs to be seen and understood as something much more than a collection of diseases requiring health interventions and other forms of support. Dementia is an issue about our common humanity – who we are, how we relate to each other, where we fit in society, and how society supports us when we experience difficulties. All forms of dementia have defied attempts to find a cure or truly effective treatments that stop the condition from advancing. Forty-seven and a half million people worldwide have some form of dementia, and because it is closely associated with ageing, this number will increase exponentially as people live longer and populations grow. Partly because of the fear and stigma that dementia invokes, having high-quality care and support is necessary but not sufficient to ensure those people can remain part of society and enjoy a good quality of life as much as possible, for as long as possible.

Our Manifesto builds on the work of others before us and tries to be inclusive of several different perspectives. We want to provide a kaleidoscopic yet clear view of what we believe to be important in the way people with dementia, their families, and their friends live in society and are supported. The dominant view of dementia is largely based upon a biomedical disease model. We do not reject this but stress the fundamental importance of also understanding it in terms of disability. People with dementia need care and treatment, but they also need to have their rights as citizens upheld, irrespective of the severity of the disease. We support the use of facts and evidence-based interventions where right and wrong are usually fairly clear. But much of this book focuses on *values*, on which we might disagree, where the language of right and wrong is usually not very helpful. Where a disease has no existing cure and the effectiveness of treatments is limited; where it has profound effects upon a person's ability to understand, communicate, remember, and many other basic human functions; where it is frequently described by phrases such as ‘living death’ (presumably making people with the disease the walking dead), under such conditions values must be addressed.

Values-based practice (VBP) is an approach that has been developed for health and social care practice to provide both a crucial counterpoise and partner to evidence-based practice (EBP). This book describes VBP and is the first book that applies it to dementia. But, call us foolhardy or brave, we wanted to do more than write a VBP guide for dementia. There are several reasons for doing this, but one that we wish to emphasize here is the importance of rights-based approaches for improving public services, including health and social care. A rights-based approach does not exclude or conflict with VBP, but VBP cannot afford to ignore rights. Rights are expressions of values but have solidity, because they are in the form of laws and legal conventions with processes enabling enforcement and challenge.

Structure of the Book

By realigning the values associated with dementia to focus on identity, agency, relationships, community, and rights, rather than a narrow focus on disease, dysfunction, despair, and ultimately, death, we hope this book can bring about change. Chapter 1 sets the scene, first by giving an overview of dementia and then by giving a summary of VBP. In Chapter 2, we describe how dementia really challenges VBP and present a growing emphasis on people’s rights, including human rights, which we believe are of crucial importance. When we talk about values we are talking about action-guiding words for people. By realigning the values associated with dementia and incorporating a focus on rights, we are led to our Manifesto in Chapter 3. It’s a very short and simple manifesto, but we believe that’s what good manifestos should be, though we explain in the chapter some key themes that underpin it.

The book emphasizes that a focus on values, in partnership with evidence and rights, can really help develop and improve everyday practice in dementia care. By applying VBP, we believe some of the challenges and distress caused by dementia can be significantly mitigated. As well as being a Manifesto, the book is therefore also a guide to using a VBP approach in dementia care. Chapters 4–13 describe how VBP can be applied in practice. But we try not to lose sight of the Manifesto, so there are three layers to our book: people and dementia on top, supported by VBP beneath, and then underpinned by the Manifesto as a foundation.

Manifestos Again

So the book aims to change or influence practice as well as perceptions of dementia and provide guidance on how this can be achieved. Manifestos are often associated with change – perhaps the most famous manifesto, the Communist Manifesto written by Karl Marx and Friedrich Engels, was the source of considerable change, both good and bad. But manifestos can also describe ways of conserving and protecting what already exists. The Conservative Party in the UK produces manifestos before elections, and their ideology contains a strong emphasis on continuity and tradition rather than change. This is an apt reminder of how values may be immutable or deeply held by people, and, certainly, the task of dementia practitioners is not to change the core values, beliefs, or personality of a person with dementia or family carer they are working with. So this Manifesto also emphasizes continuity – of people, of relationships, of what makes us human. Finding ways of helping someone with dementia to preserve their identity, to continue to be able to communicate what's important to them, their likes and dislikes, their wishes, feelings, beliefs and values is an important task for dementia practitioners, as well as family carers. This can also be challenging, but there is plenty of evidence to indicate the importance of engaging and supporting the person, not just treating the dementia, even in the later stages of the illness. This is why we believe that it is crucial to understand dementia in terms of a social model of disability and in terms of rights, including human rights.

A word of caution: many of the challenges posed by dementia arise because the evidence and knowledge currently available about many aspects of the condition are still limited. The causation of most forms of dementia, finding more effective treatments than are currently available, and the subjective experience of the person with dementia as it becomes more severe over time are three of those challenges. Being aware of values and understanding them is useful in most situations but can be particularly important where evidence is more limited. VBP provides a process for doing this, but in some situations there may be no clear answers or simple solutions. Manifestos also have to take into account unknown or unpredictable factors since they are about the future – they rely partly on a willingness to believe, see, and do things differently. Tolerance of uncertainty, the unknown, and the unresolvable are useful adjuncts or skills to have (or cultivate) as ways of approaching those aspects of dementia involving limited knowledge or experience.

Calling a book a manifesto sets the bar very high in terms of ambition. We also think it's a new, positive, and stimulating way of thinking about dementia. VBP draws upon some philosophical thinking. Still, we concur with a quote from one of the authors of perhaps the most famous manifesto, Karl Marx, who wrote in his *Eleventh Thesis on Feuerbach*: 'The philosophers have only *interpreted* the world. The point however, is to *change* it' (the line also appears as an epitaph on his grave in Highgate Cemetery). This book describes the changes we aspire to in the world of dementia, but also some of the challenges – we hope that it will help readers work out how to address the challenges and change that world.

How This Book Was Written

We wrote this book as a joint endeavour but took responsibility for writing different chapters. We shared each chapter we wrote, sometimes on several occasions, and made suggestions and comments. It was a positive, constructive experience, and we both valued each other's expertise and experience enormously. The reader will notice differences in style between the chapters, but we decided that this was of potential benefit to the book and to the experience of reading it. Most importantly, we believe that our message is consistent, and how we apply the principles and practice of the Manifesto is the same throughout.

It may be useful for readers to understand our different backgrounds. Toby is an independent health and social care consultant working in the fields of adult mental health, dementia and disability, mental capacity, rights, and inclusion. He has worked in and managed frontline mental health services and has research, practice and service development, and policy expertise working at a national level in the UK, together with family experience of dementia. Julian is a consultant in old age psychiatry who has worked in multidisciplinary teams in various parts of the National Health Service in the UK

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looking after older people with a full array of mental health problems. He originally trained in general practice. He has been involved in a wide range of research but has a focus on philosophy and ethics in relation to ageing and dementia. His clinical and ethical interests are combined in his research on palliative care for people with dementia.

A Note on Terminology

In the book we generally use the term 'people' or 'a person with dementia'. On occasions, we use the term 'service user' or 'patient' where it makes the most sense in the context we are describing. We are aware that different people like some terms and dislike others, and we do not wish to offend or upset anyone. 'People' or 'person with dementia' is our preferred term because, first and foremost, this book is about people.

We often use the term 'carer' to denote family members or friends of a person with dementia who are also providing unpaid care and support to them. We fully recognize that family members and friends are people too and their relationships with a person with dementia they care for usually go far beyond just a caring role. 'Professionals' and 'practitioners' are the terms we use most to describe people in paid roles, though we appreciate there are staff and volunteers working in a wide variety of roles and settings doing invaluable jobs caring and supporting people with dementia, who might not use these terms to describe themselves. Wherever possible we try and be more specific about who a person is, but sometimes 'carer' and 'practitioner' are the terms that make the most sense.

Finally, we use the terms 'disease', 'illness', and (health) 'condition' fairly interchangeably to describe dementia (we also recognize that 'dementia' is itself an umbrella term). These terms can mean slightly different things, but our use of them is partly to differentiate them from describing dementia as a 'disability'. This is an important theme in the book, although we do not argue that they are mutually exclusive. However, we have always tried to use the term 'disability' in the context of a rights-based, social model of disability (which we shall describe in more detail later). 'Disability' in this sense refers to how wider society disadvantages, discriminates against, and excludes people with impairments, such as those caused by dementia. 'Impairments' describes the characteristics, features, or attributes within an individual which are long-term and may be the result of disease or injury, potentially causing pain and distress, but may also be deemed by society to be the grounds for excluding or rejecting the individual.