

Reviews

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Verena Rothe, Gabriele Kreutzner and Reimer Gronemeyer, *Staying in Life: Paving the Way for Dementia-friendly Communities*, transcript Verlag, Bielefeld, Germany, 2017, 289 pp., pbk £31.66, ISBN 13: 978-3-8376-3890-5.

The clue is in the title: this challenges our view of the hopelessness of dementia and the institutional models of caring for people living with dementia; championing the development of inclusive, dementia-friendly communities so that people living with dementia do not merely stay alive despite the ‘burden’ of their dementia, but remain engaged with their communities, living a fulfilled and enjoyable life.

The book brings together the experiences from 78 projects which have developed throughout Germany and which, although very different in just about every way: size, scope, activity, funding arrangements and operation, have a core philosophy of transforming the environment of people with and without dementia into ‘places of human warmth’ by challenging the orthodoxy of professional practice in ‘dealing with’ dementia.

The book is divided into three parts, each written by one of the authors who are all involved with Aktion Demenz (Action Dementia), a German charitable association which promotes inter-disciplinary research, co-operation and dialogue to improve the social participation and wellbeing of people living with dementia, their families and carers, and which works to tackle the fear, negative stereotyping and stigma around dementia.

Reimer Gronemeyer, the first and current chair of Aktion Demenz, is a theologian and sociologist, and authors the first part of the book analysing the challenge of dementia in an ageing society and outlining the background to the development of Aktion Demenz and the concept and realisation of dementia-friendly communities. He uses metaphor, folk stories and Greek legends to illustrate how Western society has come to view people living with dementia (or ‘PwD’, as Gronemeyer points out ‘people with dementia have thus been reduced, disturbingly so, to an abbreviation; p. 24) in such a negative way. He points out that Western society is pre-occupied with activity – ‘event-centre culture’ (p. 19) – consumerism and search for information and innovation. Anyone living in such a society, who cannot keep up with the frenetic pace, who has no interest in the incessant outpourings of the media or does not participate in the online world, is a pariah. The person living with dementia epitomises society’s view of this outcast or ‘loser’. He throws down a further admonishment to the medical profession: ‘first, they [doctors] promote longevity, then they care for the helpless (not without earning handsomely from them), and, finally, the question forces itself to the forefront as to whether an end should be put to this

“life grown devoid of all sense” or to this “unbearable suffering” (p. 19). He reveals that euthanasia of those living with dementia is a growing phenomenon in those countries in Europe which permit it, with the consent of relatives supported by medical, legal and ethical professionals.

Aktion Demenz developed as a counterpoint to the perspective that ‘dementia is a tragedy of modern society’ (p. 21), that ‘we act relentlessly as though it were a problem to be solved, if only we try hard enough’ (p. 21) and that professionals have created a ‘dementia bureaucracy: ‘The medical–social dementia complex develops its own dynamic, which carries the risk of being interested primarily in its own growth’ (p. 24).

Aktion Demenz sought to inspire communities to develop the ethos and practice which would (re-)develop a sense of neighbourliness where everyone felt a sense of responsibility for one another. Dementia-friendly communities are about breaking down barriers and enabling co-operative working across public and private sectors and the third or voluntary sector, listening to people living with dementia and making it possible to shape new ways of living based on compassion, mutual appreciation and respect.

The second part of the book is written by Verena Rothe, a sociologist who is the Managing Director of Aktion Demenz. It forms the bulk of the book as it details how Aktion Demenz implemented the programme to fund local projects across Germany. The overarching objective of the programme was to fund projects which had dementia within their remit and to implement civil society activities aimed at supporting people with dementia to enable their participation in society. This would help to create communities in which people with dementia, their friends and families could live comfortably and would be included in lived reality not just in theory.

There were three funding cycles across a total of 78 projects of every possible size and scope, in urban and rural communities, with very different activities and foci. As Rothe says: ‘Living diversity is an important guiding principle’ (p. 52). Projects covered every sphere of life: sport; arts and wider culture; medicine; faith and the media. The range of individuals and organisations involved was even wider, from central and local government organisations to shops, sports facilities, office workers, police and fire departments, churches, arts and community centres, and involved paid staff, volunteers, young and older people, migrant and minority ethnic communities, people living with dementia and those who did not have the condition. Details of a wide range of the projects are given: how the projects were set up and selected for funding; how they developed, and the difficulties encountered, the tensions, surprises and joyful achievements made. All projects are listed at the end of the book for further reference.

The final chapter, by Gabriele Kreutzner, a cultural and media scientist who is the Co-Chair of Aktion Demenz, analyses the amorphous question as to what Aktion Demenz has achieved. The difficulty here lies in the fact that Aktion Demenz was/is not about reaching a pre-determined goal or delivering a measurable outcome. Instead, it is about involvement in

real life, exploring new questions and ultimately about open-ended change. This chapter, too, challenges the framing of so many strategic approaches to 'dealing with dementia' which contain narrowly defined objectives and delineate rigid inputs and outputs. Again, the reader is confronted with the possibility of taking a different view of what constitutes 'achievement'.

The chapters are helpfully sub-divided and well signposted with sub-headings and fully referenced with notes at the end of the book. This, together with an abundance of uplifting quotes, highlighting of key points, and a number of attractive photographs and illustrations, make it a pleasurable read for the lay reader as well as the professional. It is certainly a book that encourages the reader to dip in and out and balances fact, authoritative narrative with an imaginative and unstuffy style. It would be easy to dismiss the programme and projects as so peculiar to German systems and culture that it would not be transferrable elsewhere (certainly in the United Kingdom (UK)). In any event, we've embraced the concept of dementia-friendly communities (in the UK) haven't we? However, the book gives us the opportunity to think again, to be creative and allow innovation to flourish.

Staying in Life is a provoking read for those of us working in the 'dementia bureaucracy', wedded as we may well be to our strategies and too mired in the strains of juggling competing priorities and struggles with securing funding to have time to contemplate change. But what a delight it is to discover refreshing, new ways of thinking about dementia, of how one could change one's own practice and to take up the challenge of imagining and developing co-operative communities which enable us all not simply to stay 'alive' but 'in life'.

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With over 40,000 subscribers, the Housing LIN is a sophisticated network bringing together housing, health and social care professionals in England and Wales to exemplify innovative housing solutions for an ageing population.

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Emily K. Abel, *Living in Death's Shadow: Family Experiences of Terminal Care and Irreplaceable Loss*, Johns Hopkins University Press, Baltimore, Maryland, 2017, 182 pp., hbk \$39.95, ISBN 13: 978-1-4214-2184-1.

When I agreed to review this book, I had no idea that I might be the ideal reader. Like Emily Abel, I am an historian, and, in my research and writing, I have focused on social history, including medical, legal and family studies. As I approached senior citizenship, I began to write about care-giving, illness, death and dying – experiences that have come to dominate my life