

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'.

Dementia Lead,  
Housing Learning & Improvement Network (Housing LIN)

VIVIEN LYONS

*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.*

doi:10.1017/S0144686X18000399

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

in the past 20 years. As I read the book, I kept wondering how it could be that I had never encountered Emily Abel's work before now.

In many respects, the book appears to serve as a companion for Abel's previous work, *The Inevitable Hour: A History of Caring for Dying Patients in America* (2013), which focused on changing practices in death care from the late 1880s to the mid-1960s. *Living in Death's Shadow* extends the time period to the present day through an examination of the experiences of friends and family who are caring for their loved ones at the end of their lives. In both books, Abel's scholarship is meticulous, deep and expansive, and her writing is elegant, accessible and frequently moving. Abel's work is particularly timely in light of the 'tsunami of ageing' faced by much of the world today. This demographic shift will challenge governments, policy makers, social services and especially families, as they struggle to care for the rapidly growing number of seniors and the frail elderly. This challenge is exacerbated by the fact that most people in the West now die of chronic illnesses – often from multiple conditions. As Abel writes, '[b]ecause degenerative, chronic conditions have replaced acute diseases as the major cause of mortality, large numbers of people live in death's shadow for months or years'.

I learned first-hand what living 'in death's shadow' for an extended period looked like. When my father was diagnosed at the age of 92 with a terminal blood disorder, I anticipated a predicable end much like my sister's death from cancer five years earlier. One year and countless emergency room trips later, his doctor estimated he wouldn't last the summer. In the fall, my father was still stepping out for supper, buoyed by regular blood transfusions, I must have sounded like I was 'crying wolf' when I warned my students that I might have to cancel class at any moment because my father was dying.<sup>1</sup>

In *Living in Death's Shadow*, Abel draws extensively upon '105 narratives by family members of people who died from chronic disease after 1965'. These memoirs provide powerful, sometimes wrenching testimony of the near impossible task of providing support, care, hope and solace for their loved ones throughout the process of diagnosis, treatment and death. The memoirs enable the author to bring to light stories that have previously been passed over by scholars of death and dying – the experiences of family care-givers. The use of personal narratives gives the book an appeal to an audience far beyond the academy. People are drawn to stories in which they can see their own lives projected. Emotionally gruelling as some of the narratives can be – particularly the memoirs written by parents of young children – readers can also find companionship in their own medical journeys. Abel acknowledges that the memoirs may not be entirely representative of the broader population, since 'the authors of these narratives were overwhelmingly white, well educated, and relatively prosperous'. Given that writing a memoir of any sort requires a high degree of literacy, as well as the time, skill and access to publishing resources, this limitation is probably inevitable.

Through her examination of family memoirs, Abel challenges popular images of dying and death, expanding beyond the discussions of DNR (do not resuscitate) orders, ‘pulling the plug’, and the right to medical aid in dying. Abel demonstrates that the decisions faced by family members are infinitely more complex than these discussions suggest. Furthermore, Abel challenges three widespread assumptions about dying: that patient autonomy is a universal good; that acceptance of one’s death is a prerequisite for a ‘good death’; and that a home death is always preferable. She suggests that these assumptions have come to dominate discussions to such an extent that they seem to dictate how we *should* die. It is a remarkable accomplishment that Abel succeeds in achieving these goals in under 140 pages (plus 24 pages of wonderful discursive endnotes!). I highly recommend this book to researchers, practitioners and general readers interested in exploring care-giving, death and dying in the 20th and 21st centuries.

#### NOTE

- 1 My father lived another full year. See Katherine Arnup. 2015. *I Don’t Have Time for This! A Compassionate Guide to Caring for Your Parents and Yourself*. Life Changes Press, Ottawa.

Carleton University, Ottawa, Canada (retired)

KATHERINE ARNUP