Making Tough Decisions About End-of-life Care in Dementia

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At a time when talking about end of life is slowly becoming less of a taboo and more and more of us are advocating for care and support for it, Anne Kenny presents insightful perspectives, thoughts, stories and advice from her time supporting patients and their loved ones with dementia at the end of life, as well as her own experiences caring for her mother. As a nurse myself who has looked after many patients at the end of life and who has conducted research into talking about end of life, I am a huge advocate for the power of stories and narratives. Kenny has used narratives and stories not only to share her experiences but to introduce, highlight, emphasise and illustrate the decision-making process at the end of life in dementia.

The book works through the potential journey of end-of-life care in dementia, each chapter discussing a different aspect. Chapter 1 – 'Understanding the End and the Need for Letting Go' – is a good introductory chapter as it describes in detail the stages of dementia and what may happen in the later stages of dementia. Kenny illustrates the progression through the story of John who moved in with his son and daughter-in-law, Bart and Inga, when his dementia had reached moderate levels of severity. It describes how John would potter about the house during the day and when they all sat around the dinner table, they would discuss one another's workdays and John would discuss the jobs that he had done at home. As John's dementia progressed further, Inga felt it was time for Bart to let someone else do the care-giving. Kenny describes how she knew that Bart accepted this:

> My confirmation of Inga's impressions brought tears to Bart's eyes as he acknowledged his father's journey had entered a new phase. I knew Bart understood when his questions shifted from how could he keep John safe on his feet to how could we accommodate John's inability to walk safely? (p. 21)

Further chapters discuss the need to understand the end is coming and how to deal with this, through the legal and medical aspects, to making decisions and the changes that may occur, and finally to the process of dying and the aftermath. Each chapter discusses the topic illustrated with stories and narratives, and at the end highlights points to remember and provides an action plan as well as additional reading and resources. Throughout, Kenny discusses the importance of communication and looking after each other; whether that be within the family unit or between friends or as an individual carer. For example, she discusses how through time and understanding, families that have had complete opposite opinions or

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barely been able to sit in the same room as each other have eventually been able to sit around a table and discuss things amicably, and come to a decision for the benefit of their loved one. There is a huge emphasis on how the feelings and mental and physical health of loved ones and carers are very important and how this needs to be included in the care of the individual with dementia.

There is an emphasis that all emotions, be it love, disappointment, frustration, should be expected and respected, and there are many signposts to other resources to help people deal with this. Kenny also tactfully discusses issues surrounding abuse by explaining the prevalence of abuse and providing examples. Decision making with regards to treating dementia and other chronic conditions during end-of-life care is discussed, highlighting that, despite the situation, the comfort and care of the person with dementia should remain paramount.

The main audiences of this book are the families and loved ones of those with dementia, but also health-care workers and students would gain a good insight from this book. Overall, the book is well written, if a bit jagged at times where the narrative shared does not quite flow with the particular point, therefore making it feel a little like a list of stories next to a point. The narratives and stories mostly are very relatable although at times they do focus on what she has achieved through her work which some may find distracts from the point a little.

For readers outside the United States of America (USA), it is important to remember that much of the practical advice and scenarios are American, so it is important to think about how replicable they are in your country, particularly the chapters regarding accessing treatment and legal processes where medical and care insurances and probate scenarios are discussed. But the author does acknowledge that, for instance, probate processes differ across the different states of the USA alone.

The language used throughout the book is non-medical but there is no hiding the truth. Kenny presents the full picture of death and dying, and the conversations and scenarios that may be faced, to the reader. When discussing the time when her own mother reached the latter stages of life, she tells a story of finding her in a beauty parlour:

> Her hospice nurse had heard of Mom's recent changes and was on the spot … She turned to me, grasped that I also knew the end was near – and then we both began to laugh at the absurdity of the dying woman in the beauty parlor. Giggling, we acknowledged that her hair looked great. It was my mother's way. (p. 175)

Making Tough Decisions About End-of-life Care in Dementia is definitely a sound and interesting, always informative, sometimes humorous, sometimes poignant read that explores and challenges many aspects of end-of-life care in dementia in an insightful and caring way.

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