Review

Toy, E., O'Neill, C., & Jackson, S. (2018). *Terminal Illness: Caring for Yourself and Others*. Chawton: Redemptorist Publications, 53 pp. (pbk). ISBN: 9780852315217.

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As practising clinicians, these authors seek to share some insights into the challenges associated with terminal or “life limiting” illness, while offering a practical and supportive guide to those “whose view of their future has been dramatically changed”. A stated aim is to provide reassurance regarding the help and support that is available, to “ensure that life with a terminal condition can be lived to the full”, and that when the end of life comes it can be a “dignified and peaceful experience”.

The book is divided into five parts, comprised of three chapters followed by a short selection of prayers and readings, with a concluding resource page listing helpful websites and further reading.

Chapter 1, “Terminal illness: A definition”, swiftly and helpfully introduces the concept of life limiting conditions, thereby reframing and offering an alternative emphasis to the commonly used language of “terminal illness”. The authors move briskly into the realm of the practical, ranging from observations on receiving a diagnosis, seeking a second opinion, side effects and symptoms of treatment, to the wisdom of avoiding hospital parking, taking a book to outpatient appointments and managing the number of visitors in accordance with your energy levels as an inpatient.

The content within the chapter intensifies, progressing from questions addressed to the healthcare team and sources of support, to a discussion of prognosis, disease progression, advanced care planning and advanced decisions to refuse treatment. The pages addressing the question “what is dying like?” and reflecting on managing symptoms at the end of life are very helpful, the kind of thing that a healthcare chaplain might wish relatives and friends of the dying to be familiar with. The physical, emotional and spiritual impact on those who experience grief is honestly acknowledged, in a tone that feels consistently open, sensitive and practical throughout.

Chapter 2, “For the person affected”, considers the emotional and practical impact of a diagnosis of a life limiting condition, along with the adjustments that follow. The individual and “non-linear” nature of the response to such news is helpfully noted. Practical considerations of work and finance are balanced with a liberating reflection on some of the less helpful language and outlooks around life limiting conditions. Talk of “battling” an illness or “not letting it beat you” are challenged with the recognition that:

In accepting that it will never go away, the emphasis switches to accommodating the illness, and lack of certainty that goes with it, to establishing a “new normal” and to living in the moment.

In the sections entitled “Simply talking” and “Talking about the illness”, the authors recognize how difficult, yet important, conversations can be. Acknowledging the emotional discomfort and untidiness involved, the authors convey not just an understanding of the dynamics in play, but also reassurance for those affected by them. An example of this might be the observations on the differing impacts of, and responses to, such conversations among the wider family, including children and adolescents.

Chapter 3, “For those who care”, continues to emphasize the importance of open and honest conversations, acknowledging the obstacles and sensitivities involved. Citing the value of Ira Bycock’s four integral themes of intimate conversation at the end of life (“thank you”, “forgive me”, “I forgive you” and “I love you”), the authors’ gentle encouragement towards clear and careful communication is summarized when they quote Lesley Fallowfield, a psycho-oncologist: “Truth may hurt, but deceit hurts more”.

The book maintains a balance between down-to-earth practical information, helpful observations (in this chapter around dealing with visitors, accepting help, being involved in the care of the sick person) and genuine concern for others. “Caring for a loved one can be all consuming. It can be a huge privilege but may also be accompanied by feelings of overwhelming fatigue, duty, guilt or a need to prove oneself to be capable and strong.”

Carers are invited not to underestimate the physical, emotional or spiritual impact of caring or the need to “recharge your battery” and ultimately “be gentle with yourself”.

This compact book manages to condense and concisely capture a vast and formidable topic. The authors convey not simply that they are aware of the various processes an individual may encounter, but also that they “know the ground” surrounding life limiting conditions, appreciating through experience the impact and effect on those involved.

The “Personal story” sections interwoven throughout the text serve to further personalize and ground the themes, nicely bridging concepts and discussion with human awareness and experience. The assorted quotes scattered through the text, along with the “Prayers” section of the book, will appeal or repel according to personal taste.

Overall, this feels like a “to the point”, while sympathetic, guide for all those facing the dilemmas and complexities of life limiting conditions. The format is clear and the content concise. The tone conveys warmth towards those finding themselves caught up in a potentially overwhelming landscape. A consistent softening of expectation offers the reassurance to face distressing and confusing situations with honesty and kindness towards self and others.

The text affirms the contribution of health and social care chaplains within the context of life limiting illness, implicitly raising the opportunity (and challenge) for them to recognize and inhabit their place, working collaboratively with other healthcare professionals in this area.

Reference to doulas, trained companions who are not healthcare professionals but who support another individual through a significant health-related experience, suggests a potential area of exploration, study and research for health and social care chaplains. To what extent, and in which ways do these respective roles inform, complement or stand in conflict with one another?

Occasionally, the intrusion of religious themes unbalances the otherwise broad and inclusive tone of the text. The helpful recognition of legitimate spiritual themes deserves gentler handling, and can feel devalued by theological assumptions. For example, the bold, almost blunt, introduction of “hope”, in Chapter 2, reduces the impact of an otherwise helpful acknowledgment of an aspect of spirituality. The fault line recurs elsewhere. Having deftly commended chaplains as a resource for contexts where individuals wish to express guilt or “a yearning to put things right”, the authors go on to potentially marginalize or alienate readers in the “Dying God and prayer” section, which feels theologically abrasive and particularly religious.

The closing section of the final chapter (under the heading “When death happens”) also disappoints. The message feels undermined by the medium, when the authors’ intention to comfort or inspire is delivered in an unhelpfully heavy-handed quote, stating, “Without fear or anxiety, expect in the quiet confidence that God’s will, will emerge in the confusion ... You will always be supported.”

Some may experience such statements, arising from the authors’ apparent faith/belief perspective, as helpful. Others, contrary to the writers’ intent, may hear them as detracting from the otherwise positive material offered, or as disconnected from their own experience.

In conclusion, this book is a predominantly helpful resource for individuals affected, directly or otherwise, by life limiting conditions. Health and social care chaplains, appreciative of the concise style, practical and exemplified content, might appropriately recommend it, not least for its sympathetic acknowledgment of, and sensitive approach to, the complex emotional dynamics of such situations.