

# **Readings Related to Best Practice for End-of-Life Spiritual Care in South Australian Catholic Aged Care Facilities**

**Roger Porter**

Department of Theology  
Flinders University  
South Australia

## **Abstract**

Best practice for palliative end-of-life spiritual care focuses on supporting both the patient and the family. It attends to their immediate spiritual and psychosocial concerns, extending into the bereavement stage. The literary research offers a diversity of theological, spiritual and pastoral perspectives reflecting a broad based approach to the topic of palliative and hospice care. The diversity of research traces the historical development from the past to contemporary palliative and hospice care for the sick and dying. Central to the research is a narrative advancing notions and practices on the holistic care of people with end-of-life issues. This is viewed within the context of social trends, shifting public opinion, and policy advances.

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**KEY WORDS:** Best practice, end-of-life, care, spiritual, holistic, palliative.

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## **Introduction**

Relative to the question of what is best practice for end-of-life spiritual care in South Australian Catholic Aged Care Facilities, the respective reviews offered reflect a diversity of theological, spiritual, and pastoral perspectives. Accordingly, six 500 word literary reviews are presented.

The six literary reviews address aspects of palliative care relative to historical, pioneering and contemporary developments, namely; (1) historical literary reviews of palliative care trends, (2) pioneering work in palliative care, including Dame Cicely Saunders, and (3) Elizabeth Kubler-Ross, (4) contemporary work in palliative care including, Elizabeth MacKinlay, (5) Allan Kellehear, and (6) Richard Egan.

The diversity of the reviews reveals a development through time from the past to contemporary palliative and hospice care for the sick and dying. Central to the six literary

reviews is a narrative on how ideas and practices around the care of people with end-of-life issues have advanced. This is viewed within the context of social trends, shifting public opinion and policy advances.

### **Historical literary review of palliative care trends**

An appreciation of palliative care commences with the story of hospice. The term 'hospice' derives from the Latin word 'hospitium,' meaning hospitality. During the Middle Ages in Europe and Mediterranean regions the term was used to designate a resting place for travellers and pilgrims, offering hospitality for weary travellers, sick or dying people. For many centuries hospices waned in demand, however re-emerged in the 19<sup>th</sup> century particularly in the United Kingdom and France.<sup>1</sup>

The modern use of the term hospice dates from 1967 with the opening of St Christopher's Hospice, London, established by Dame Cicely Saunders. Saunders work was furthered in the United States by Elizabeth Kubler-Ross and replicated throughout the world. A Canadian surgeon, Balfour Mount, introduced the term 'palliative care' in 1975 due to the poor standing associated with hospice institutions in France.<sup>2</sup>

In Australia, the Australian Hospice and Palliative Care Association was formed in 1990 representing Australian state and territory palliative care organisations, subsequently renamed Palliative Care Australia in 1998. The organisation acts as a national voice and peak body for palliative care providing a platform and forum for common issues in palliative care across the states and territories.<sup>3</sup>

In South Australia the main organisations associated with the history and development of palliative care include; the Southern Hospice Association, Mary Potter Hospice at Calvary North Adelaide Hospital, Philip Kennedy Hospice, Royal District Nursing Society, and regional and rural communities in Whyalla and Mt Gambier.<sup>4</sup>

Palliative Care in South Australia commenced its current form in 1980 when the Southern Hospice Association was established, incorporating the Southern Community

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<sup>1</sup> Stuart Milligan and Shirley Potts, "The History of Palliative Care," in *The History of Palliative Care*, (Oxford, UK: Wiley-Blackwell, 2009), 1-16.

<sup>2</sup> D, Clark, "Palliative Care History: A Ritual Process," *European Journal of Palliative Care*, 7 (2) (2000): 1352-2779.

<sup>3</sup> Palliative Care Australia, "Home Page," <http://www.palliativecare.org.au/> (accessed 06.10.14)

<sup>4</sup> Palliative Care Council SA, "Palliative Care in South Australia," <http://www.pallcare.asn.au/about/history-of-palliative-care/palliative-care-in-south-australia> (accessed 27.09.14).

Hospice Service in 1983; and the Goode Wing - Kalyra Hospital at Belair, which became Daw House Hospice in 1988.<sup>5</sup> Professor Ian Maddocks of the Flinders Medical Centre was the guiding influence for this development.<sup>6</sup>

Prior to this, the Mary Potter Home at Calvary North Adelaide operated as a customary hospice beginning in 1902.<sup>7</sup> In 1986 it became the Mary Potter Hospice when Calvary Hospital established formal ties with the Royal Adelaide Hospital. In 1989 dedicated palliative care beds were initiated at the Royal Adelaide Hospital.<sup>8</sup>

In 1985 the Philip Kennedy Hospice at Largs Bay was established, however was closed at the end of 2014 due to a funding dispute with the state government.<sup>9</sup> Furthermore, the Royal District Nursing Society has provided palliative care in Adelaide to patients in their homes since 1980, with support from Domiciliary Care services.<sup>10</sup>

Regional and rural communities in South Australia have championed the development of palliative care in their communities since 1988, with metropolitan palliative care services supporting regional nurse and General Practice teams in many country towns and remote areas.<sup>11</sup>

Notably, in 1986 the South Australia Hospice Association formed in 1983 became the South Australian Association for Hospice and Palliative Care. This body was renamed The Palliative Care Council of South Australia in 2010. These actions have ensured that best practices for end-of-life spiritual care are adhered to in South Australia, and offer appropriate guidelines for a dissertation on the topic.

### **Dame Cicely Saunders: Pioneering work in palliative care**

Dame Cicely Saunders (1918-2005) was a renowned Anglican nurse, social worker, physician, writer and pioneer of the modern hospice movement. Saunders is universally

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<sup>5</sup> Current form - prior to 1980 hospices were limited to one location and permanent residency. Since 1980 individuals may be located in a hospital, nursing home or private home with flexible residency.

<sup>6</sup> Palliative Care Council SA.

<sup>7</sup> Customary hospice – refers to the custom / tradition at the time. This was less personal and individual.

<sup>8</sup> The Mary Potter Foundation Inc., “Mary Potter Hospice,” <http://www.marypotter.org.au/about-us/mary-potter-hospice/> (accessed 03.09.14).

<sup>9</sup> ABC News, “Philip Kennedy hospice in Adelaide stops taking new patient,” (2014), <http://www.abc.net.au/news/2014-05-01/philip-kennedy-hospice-stops-taking-new-patients/5424060> (accessed 16 September 2014).

<sup>10</sup> Royal District Nursing Society, “RDNS South Australia,” <http://www.silverchain.org.au/sa/> (accessed 06.10.14)

<sup>11</sup> Palliative Care Council SA.

acknowledged for her contribution to the contemporary hospice movement, and for instituting the discipline and culture of palliative care. In 1967 Saunders founded the St Christopher's Hospice in London, which became the first research and teaching hospice introducing new practices and ethics to palliative care:<sup>12</sup>

In 1958, after qualifying as a medical doctor in London, Saunders took a position at St Mary's School of Medicine directing palliative care at St Joseph's Hospice in Hackney. As David Clark notes in his Forward to Saunders book:

Here she laid down the basic principles of modern hospice care, developing a systematic approach to pain control in terminally ill patients; giving attention to their social, emotional and spiritual needs; and teaching what she knew to other people.<sup>13</sup>

Saunders promptly made plans to establish her own modern hospice. This hospice would focus on three related pursuits - clinical care, teaching and research. Saunders organised a group of supporters to formalise her concepts, then journeyed to the United States and other countries promoting and refining her theories. This culminated with the opening in 1967 of her renowned St Christopher's Hospice in Sydenham, South East London.<sup>14</sup>

Cicely Saunders held a profound Christian faith, with religion playing a crucial role at St Christopher's Hospice. Nevertheless, the intention was as much secular as religious, assuring patients, relatives and friends that they were not alone. Moreover, that despite their terminal condition hospice patients continued to have worth as human beings. Saunders died at St Christopher's Hospice in 2005, an institution that trained more than 50,000 students and spread palliative care programmes globally to more than 120 countries.

Prior to her death Saunders co-founded Cicely Saunders International, a charitable mission promoting research in palliative and hospice care. Among Saunders many awards was the Templeton Prize for Progress in Religion for her holistic approach to care giving.<sup>15</sup>

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<sup>12</sup> British Medical Journal, <http://www.bmj.com/content/suppl/2005/07/18/331.7509.DC1> (accessed 20/08/14).

<sup>13</sup> Cicely Saunders, *Watch with Me: Inspiration for a Life in Hospice Care* (Sheffield UK: Mortal Press, 2003) viii.

<sup>14</sup> Shirley du Boulay, *Cicely Saunders: Founder of the Modern Hospice Movement* (London: Hodder and Stoughton, 1984), 124.

<sup>15</sup> The Guardian Obituary 16.08.05, Dame Cicely Saunders, <http://www.theguardian.com/news/2005/jul/16/guardianobituaries.health>. (accessed 23/08/14).

A critique of Saunders' life and works reveals her interest in the connection between personal biography, spiritual life and ethics of care.<sup>16</sup> Saunders drew upon a range of philosophical and religious influences supported by the underlying inspiration to care for peoples confronting impending death.<sup>17</sup> Saunders pioneered what is considered best practice for end-of-life spiritual care in catholic hospices, and offers a prime source for a holistic dissertation on palliative and hospice spiritual care.<sup>18</sup>

### **Elizabeth Kubler-Ross: Pioneering work in palliative care**

Elizabeth Kubler-Ross (1926-2004) was a Swiss born American psychiatrist, physician, humanitarian, scientist and mystic. A pioneer in death studies Kubler-Ross argued her five stages of death theory. These reversed how physicians traditionally regarded dying patients and lobbied for more compassionate handling of death issues.<sup>19</sup>

Kubler-Ross's most significant work published in 1969 titled *On Death and Dying* became one of the foremost psychological studies of the late twentieth century.<sup>20</sup> The book grew out of Kubler-Ross's renowned interdisciplinary seminar on death, life and transition. The text surveyed her five stages of death; denial, isolation, anger, bargaining, depression and acceptance. Kubler-Ross's work offered an awareness of how impending death affects the patient, professionals, family and all parties concerned. Moreover, how a sense of hope may be conveyed to all involved.<sup>21</sup>

Kubler-Ross published 15 books on life and death studies. Her memoir *The Wheel of Life* is an insightful appraisal of an extraordinary woman.<sup>22</sup> In this poignant memoir Kubler-Ross outlines the events that formed her intellectually and spiritually. These events initiated a belief that death does not exist but is a transformation. This belief stemmed from her work in war-ravaged Poland, counselling the terminally ill, legendary seminars and discussions with people who had been revived after death. These experiences provided her with theories for the enigma of death and dying.

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<sup>16</sup> Personal biography –refers to an individual's life story particularly the spiritual narrative.

<sup>17</sup> Saunders, *Watch with Me*, ix-x.

<sup>18</sup> Cicely Saunders, *Beyond the Horizon: a Search for Meaning in Suffering* (London: Darton, Longman & Todd, 1990), 1-4.

<sup>19</sup> Obituaries- Elisabeth Kubler-Ross, *BMJ*2004;329:627, (2004)

<http://www.bmj.com/content/329/7466/627> (cited 27th august, 2014).

<sup>20</sup> Elisabeth Kubler-Ross, *On Death and Dying* (New York: Macmillan, 1969).

<sup>21</sup> Elisabeth Kubler-Ross, *On Death and Dying*.

<sup>22</sup> Elisabeth Kubler-Ross, *The Wheel of Life* (Great Britain: Bantam Press, 1997).

However, Kubler-Ross's work has not been without controversy. In the late 1970's Kubler-Ross became fixated by mediumship, spiritualism and other ways of attempting to contact the dead. This led to a scandal connected to the Shanti Nilaya Healing Centre she had established in Escondido, California. Kubler-Ross's views on life after death had alarmed both the medical and New Age communities alike.<sup>23</sup> This publicity adversely affected Kubler-Ross's credibility.

A critique of Kubler-Ross's life and works suggests there are supporters and opponents of her movement and activities. Her supporters continue endorsing her concepts, reviewing the emotional aspect of the dying process and adapting Kubler-Ross's model of grief and bereavement to other purposes, such as divorce and adultery. However, Kubler-Ross's opponents assert her model and practices are contentious, indistinct, and lacking perspective. Moreover, her five stages of grief notion was challenged in later years, and her approach viewed as overly linear.<sup>24</sup>

### **Elizabeth MacKinlay: Contemporary work in palliative care**

Elizabeth MacKinlay is a professor, registered nurse and priest in the Anglican Church of Australia. MacKinlay is currently Director of the Centre for Ageing and Pastoral Studies at St Mark's National Theological Centre, Canberra, within the School of Theology at Charles Sturt University.<sup>25</sup>

MacKinlay is a prolific author on spirituality, ageing and pastoral care with twenty publications to her name.<sup>26</sup> MacKinlay's seminal work *Aging, Spirituality and Palliative Care* addresses end-of-life spiritual issues for elderly people in hospice situations.<sup>27</sup> The time when a person approaches death is viewed as problematic both for the patient and caregiver. MacKinlay focuses on this situation by outlining best practices in palliative care, and attendant spiritually diverse needs.

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<sup>23</sup>Karen G. Jackovich, "Sex, Visitors from the Grave, Psychic Healing: Kubler-Ross Is a Public Storm Center Again," (October 29, 1979), (cited 27 August, 2014).

<sup>24</sup> API Healthline, "Elisabeth Kubler-Ross: The Significance of Her Work."(2012), <http://api-healthline.net/2012/04/elisabeth-kubler-ross-the-significance-of-her-work.html> (Cited 23 August, 2014).

<sup>25</sup> Charles Sturt University School of Theology, <http://www.csu.edu.au/faculty/arts/theology/staff/profiles/academic-staff/elizabeth-mackinlay>. (accessed 23/08/14).

<sup>26</sup> Goodreads, "Books by Elizabeth MacKinlay" (2014), [https://www.goodreads.com/author/list/2030644.Elizabeth\\_Mackinlay](https://www.goodreads.com/author/list/2030644.Elizabeth_Mackinlay) (cited 18 September, 2014).

<sup>27</sup> Elizabeth MacKinlay, *Aging, Spirituality and Palliative Care* (Binghamton, NY: Haworth Pastoral Press, 2006).7-9, 11-24.

Accordingly, MacKinlay addresses issues relating to ageing and spirituality, particularly across faiths and cultures of Western society. MacKinlay's edited book titled *Ageing and Spirituality across Faiths and Cultures* is an assembly of essays noting ageing in the framework of the many faiths and cultures in Western society, together with the awareness required to convey sensitive and suitable care to peoples of all faiths.<sup>28</sup>

Similarly, MacKinlay addresses the spiritual dimension of aging in her book *The Spiritual Dimension of Aging*.<sup>29</sup> This text is a definitive source for health and social care professionals, and has had varied impact because the issues are universal. MacKinlay focuses on matters confronting infirm, isolated or institutionalised older persons and their sense of self. Particularly, what makes later life meaningful?<sup>30</sup>

Subsequently, MacKinlay's findings demonstrate how older people attain meaning and support in discovering and exploring their spirituality, regardless of challenges such as mental or physical ill health, loneliness, depression, and loss of dignity. For individuals working with the elderly MacKinlay proposes methods for evaluating individual spiritual needs and procedures for enabling spiritual reminiscence, transcendence and support in the dying process.

A critique of MacKinlay's works reveals a local diversity of theological, spiritual, and pastoral perspectives. MacKinlay advances an appreciation of spirituality that facilitates consideration of the spiritual dimension of ageing, and how it promotes well-being and health in later life. MacKinlay's works are informative texts for nurses, care workers, pastoral support professionals and individuals working with or caring for older people. Hence, MacKinlay's contribution to a dissertation on palliative care is substantial, particularly from the standpoint of an academic, priest and nurse.

### **Contemporary work in palliative care: Allan Kellehear**

Allan Kellehear is an Australian Professor of Community Health at Middlesex University, London. Kellehear is a medical and public health sociologist with a long-standing interest in human behaviour and end-of-life experiences. Kellehear is a designer and advocate

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<sup>28</sup> Elizabeth MacKinlay, *Ageing and Spirituality across Faiths and Cultures* (London: Jessica Kingsley Publishers, 2010), 8-9.

<sup>29</sup> David E. Vance, Review of *Ageing and Spirituality across Faiths and Cultures*, by Elizabeth MacKinlay (ed.), *Journal of Religion, Spirituality & Aging*, and 25:3 (26 June, 2013): 282-285.

<sup>30</sup> Elizabeth MacKinlay, *The Spiritual Dimension of Aging* (London: Jessica Kingsley Publishers, 2010), 7-9.

of public health approaches to palliative care promoting community agency, resilience, education, partnerships, support for the dying, the bereaved and their caregivers. Kellehear's interests include community and family provision for palliative care in an international context, particularly in Eastern Europe and South Asia.<sup>31</sup>

From 1998 to 2006 Kellehear was Professor of Palliative Care at La Trobe University in Melbourne, Australia. Accordingly, Kellehear has a balanced perspective on palliative care as a medical and public health sociologist through his Australian and international experience. Kellehear has authored nine books and 100 articles.<sup>32</sup> Kellehear's edited book *Death & Dying in Australia* was published in the year 2000 and was the first major scholarly interdisciplinary book on death and dying in this country. Contributors were drawn from a broad range of disciplines and professions such as; sociology, philosophy, church history, nursing, medicine, law, journalism, pastoral care, psychiatry, and palliative care.<sup>33</sup>

Kellehear's later works of importance to end-of-life spiritual care included; *A Social History of Dying* (2007), *A Study of Dying: From Autonomy to Transformation* (2009), and *The Inner Life of the Dying Person* (2014). In these publications Kellehear reviews human and clinical science literature on human dying, and what it is like to die. *A Social History of Dying* takes a wide-angle view of the human story of endings, identifying and describing the major patterns of dying throughout history.<sup>34</sup> *A Study of Dying: From Autonomy to Transformation* is a collection of twelve essays addressing the question of 'What it is like to die?' Here, the varied authors examine the physical, psychological, behavioural, social, cultural and spiritual aspects associated with the experience of dying. *The Inner Life of the Dying Person* recounts the experience of facing death from the dying person's perspective.

Accordingly, Kellehear's long-standing research interests reside in three distinct areas with Australian and international context; (1) the study of personal conduct and experiences at the end-of-life; (2) public health, health promotion, and community development approaches to end-of-life care, (3) international end-of-life care policy and practice.<sup>35</sup> Hence, Kellehear's

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<sup>31</sup> Professor Allan Kellehear, <http://www.mdx.ac.uk/aboutus/staffdirectory/allan-kellehear.aspx>. (Accessed 31/05/14)

<sup>32</sup> Professor Allan Kellehear, accessed 25.08.14 – <http://www.nourfoundation.com/speakers/allan-kellehear-phd/Print.html>

<sup>33</sup> Allan Kellehear (ed.), *Death & Dying in Australia* (Melb., Australia: Oxford University Press, 2000).

<sup>34</sup> Allan Kellehear, *A Social History of Dying* (Port Melbourne, Vic.: Cambridge University Press, 2007).

<sup>35</sup> The Association for the Study of Death and Society, "Allan Kellehear (President)," [http://www.deathandsociety.org/pages/council-member-profile.php?member\\_id=100122](http://www.deathandsociety.org/pages/council-member-profile.php?member_id=100122) (cited 19 September, 2014).

research and works are suitable to a thesis on end-of-life spiritual care in a South Australian catholic hospice.

A critique of Kellehear's works shows how Kellehear brings research from several disciplines to the topic of dying, and how cultural influences, social conditions and personal choices shape the end-of-life experience. Kellehear's career has a multinational perspective bringing an international, Australian and Australasian perspective to his work. Accordingly, Kellehear's work offers a balanced social and spiritual aspect to a dissertation on global end-of-life spiritual care.

### **Richard Egan: Contemporary work in palliative care**

Richard Egan is a lecturer in health promotion for the Cancer Society Social and Behavioural Research Unit at the University of Otago in New Zealand. Egan has a PhD in Preventive and Social Medicine.<sup>36</sup> Egan's research interests include psycho-social-spiritual cancer care, health promotion, spirituality, hospice and palliative care.

Hence, Egan's doctoral thesis *Spirituality in New Zealand Hospice Care* is ideally linked to the research question, "What is basic practice for end-of-life spiritual care in a South Australian Catholic hospice?" The findings of Egan's thesis indicated explicit spiritual care was inconsistent. This inconsistency related to spiritual care in the study presenting a varied approach to issues of spiritual assessment, support, training, policy and associated matters.<sup>37</sup>

The study samples revealed spirituality to be broadly but not specifically understood. The study's participants had varying spiritual practices and beliefs, including spiritual needs and issues necessitating improved spiritual care. The majority of participants had diverse beliefs in God, the afterlife and paranormal occurrences.<sup>38</sup>

Relative to hospice spiritual care, Egan notes that contemporary spirituality, characterised by fragility for real existence, impacts on ideas about death and end-of-life spiritual care. The dying process can be a meaningful experience despite perceptions of pain, indignity, apprehension, ambiguity and technological complexity. Moreover, the hospice approach mandates spiritual care, hence transforming the dying process.<sup>39</sup>

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<sup>36</sup> Dr Richard Egan, Cancer Society Social and Behavioural Research Unit, [http://dnmeds.otago.ac.nz/departments/psm/research/sbru/staff/egan\\_richard.html](http://dnmeds.otago.ac.nz/departments/psm/research/sbru/staff/egan_richard.html). (Accessed 27/08/14)

<sup>37</sup> Richard Egan, *Spirituality in New Zealand Hospice Care*, A thesis submitted for the degree of Doctor of Philosophy at the university of Otago, Dunedin, New Zealand, July 2009.

<sup>38</sup> Richard Egan, *Spirituality in New Zealand Hospice Care*, <http://otago.ourarchive.ac.nz/handle/10523/442>. (cited 27/08/14).

<sup>39</sup> R. M. M. Egan, (2010) *Spirituality in New Zealand Hospice Care* (Thesis, Doctor of Philosophy). University Otago. Retrieved from <http://hdl.handle.net/10523/442>.

Egan's thesis is the first national study of spirituality in New Zealand end-of-life care that is centred on hospices. As a model study, Egan's thesis addresses issues informing and possibly advancing spiritual care for individuals receiving palliative care in New Zealand.

Egan's findings indicated an inconsistent approach to end-of-life spiritual care. For example, the most convincing evidence for unmet spiritual needs were structural disparities, such as deficiency of spiritual assessment, staff support, training and policy. The role of spiritual care professionals was shown to be indispensable. As Egan notes:

A structural spiritual audit tool revealed room for improvement in all hospices surveyed. This is not a criticism of the compassionate individuals working in hospices, but a challenge for the whole organisation.<sup>40</sup>

Moreover, the findings indicated the approaches to spiritual care were widely canvassed and a range of methods detailed.

A critique of Egan's works suggests dying from cancer offers opportunities for spiritual growth, with the need for an enhanced spiritually conducive hospice environment at a local level. Moreover, Egan's findings may be applied beyond cancer to other end-of-life situations, hence enhancing the mounting international data confirming the importance of spirituality at end-of-life. Egan's thesis is suitable to a dissertation on end-of-life spiritual care due to location and correlation of content.

## **Conclusion**

In conclusion, the six literary reviews presented on end-of-life spiritual care in a palliative/hospice context reflect a broad based approach to the topic. The selected authors display a diversity of social, theological and pastoral perspectives on palliative and hospice care. The reviews address the needs of the dying, their relatives and friends, and those who provide support and care from a local and international perspective.

The reviews suggest a number of emerging palliative care trends. These trends relate to multiculturalism, changing attitudes to religion and spirituality, spirituality as a non-religious pursuit, and heightened medical interest in the topic. Furthermore, the reviews reflect a trend to an enhanced interest in end-of-life issues, and the benefits of individual personal biographies. Accordingly, the reviews offer suitable preliminary research for a dissertation around the question of basic practices for end-of-life care in South Australian catholic hospices.

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<sup>40</sup> Richard Egan, *Spirituality in New Zealand Hospice Care*, (thesis) IV.

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