

FURTHER READING

In the course of writing 'A Hospital Bed at Home', I discovered many books and internet-based resources that I wish I had known about when I first became a caregiver. This list contains those that I found most enlightening, moving and informative, plus some more I've added since publishing the book.

Personal stories

Addison, S 2001, *Mother Lode: Stories of home life and home death*, University of Queensland Press, St Lucia, Queensland.

Passionately and poetically written, this memoir tells the life and death of Susan Addison's teenage son.

Brennan, F 2007, 'A doctor's notebook', *Griffith Review*, Edition 17 – Staying Alive, at <http://www.griffithreview.com/edition17/78-memoir/124-brennan17.html>

A collection of Dr Frank Brennan's moving tales of his work as a palliative care specialist.

Garner, H 2008, *The Spare Room*, Text Publishing.

In this novel heavily based on her own experiences, Garner provides a searingly honest portrait of a caregiver's thoughts and reactions.

Hender, M 2004, *Saying Goodbye – Stories of caring for the dying*, ABC Books, Sydney.

Portrays the experiences of ten caregivers with a focus on the positive and spiritual aspects of the situation.

Lloyd, V 2008, *The Young Widow's Book of Home Improvement: A true story of love and renovation*, University of Queensland Press, St Lucia, Qld.

About love, loss and grief – and putting your house in order.

Palliative Care Australia 2005, *A Journey Lived: A collection of personal stories from carers*, PCA, at <http://www.palliativecare.org.au/Portals/46/resources/AJourneyLived.pdf>

Eight brief accounts of supporting a loved one towards death with the help of palliative care services.

Rieff, D 2008, *Swimming in a Sea of Death: A son's memoir*, Simon & Schuster, New York.

David Rieff, the son of Susan Sontag, says he felt impelled to be his mother's chief cheerleader as she forced herself through a series of gruelling, futile treatments in order to avoid dying.

Rose, P 2001, *Rose Boys*, Allen & Unwin, Sydney.

An award-winning family memoir about suffering, devotion, dependence and mortality.

Valenta, T 2007, *Remember me Mrs V? Caring for my Wife: Her Alzheimer's and others' stories*, Michelle Anderson Publishing, Melbourne.

Former journalist Tom Valenta describes his own and others' experiences of caring for a loved one with Alzheimer's disease.

Wyndham, S 2008, *Life in his Hands: The true story of a neurosurgeon and a pianist*, Pan Macmillan, Sydney.

The true story of controversial neurosurgeon Dr Charlie Teo and one of his most high-profile and tragic cases, young pianist Aaron McMillan.

Informative

Advance Care Directive Association Inc, *My Health, My Future, My Choice: An Advance Care Directive for New South Wales*, at

<http://www.advancecaredirectives.org.au/AdvanceCareDirectives-my-health-my-future-my-care.html>

Combines a workbook with the form, and explains the issues and terms in a way that a layperson can understand.

Anastasios, Andrew 2007, *Dying to Know: Bringing death to life*, Pilotlight Australia, Prahan, Victoria.

A delightful, thought-provoking little book of illustrations, epigrams and wisdom.

Barbato, M 2002, *Caring for the Dying*, McGraw-Hill Sydney.

Written by a doctor with forty years of experience in palliative care, this handbook is a fount of clear, useful information and an insightful guide to the emotional aspects of caring for people as they are dying.

Barnard, D, Towers, A, Boston, P & Lambrinidou, Y 2000, *Crossing Over: Narratives of palliative care*, Oxford University Press Inc, New York.

Richly detailed case studies of particular patients and their families, written by palliative care researchers.

Carers Australia 2007, *Carer's Handbook: A practical Australian guide to caring for people who are sick, elderly or have a disability*, Dorling Kindersley Australasia, Camberwell, Vic.

Published in conjunction with St John's Ambulance Service, a fully illustrated guide with comprehensive advice on all aspects of home-based caring.

Four Corners – A Good Death program web site:

<http://www.abc.net.au/4corners/content/2010/s2810506.htm>

Contains the video and transcript of this excellent ABC TV documentary about palliative care, as well as many links to further information.

Herbert, Lisa 2013, *The bottom drawer book : the after death action plan*, Tamworth, illustrated by Phillip Judd.

Contains lots of practical information and space for you to write down your wishes. Its brightly coloured illustrations and humorous text encourage thinking and planning.

Home Hospice web site: <http://www.homehospice.com.au>

Home Hospice runs a community-based mentorship program that supports people caring for a dying family member at home.

Marriott, H 2006, *The Selfish Pig's Guide to Caring*, Time Warner Books, London.

A humorous, irreverent look at some of the taboo subjects of caregiving, including resentment, sexual frustration, incontinence and the occasional desire to push your loved one down the stairs, written by a man whose wife deteriorated over many years from Huntington's disease.

Palliative Care Australia web site: <http://www.palliativecare.org.au>

The peak national organisation working to foster and promote the delivery of quality care at the end of life.

Palliative Care Australia 2004, 'The hardest thing we have ever done': Full report of the national inquiry into the social impact of caring for terminally ill people, PCA, Canberra, at <http://www.palliativecare.org.au/Portals/46/The%20hardest%20thing.pdf>

The first section highlights the challenges and difficulties faced by family carers; the second section analyses public submissions from individual carers, service providers and support organisations.

Wakely, M 2008, *Sweet Sorrow: A beginner's guide to death*, Melbourne University Press, Carlton, Victoria.

Mark Wakely embarks on a personal crusade to explore the issues, practices and customs surrounding the end of life.

World Health Organization 2007, *WHO definition of palliative care*, at <http://www.who.int/cancer/palliative/definition/en/>

The World Health Organisation's definition of palliative care.

Zuger, A 2008, 'A fight for life consumes both mother and son', *The New York Times*, January 29, at <http://www.nytimes.com/2008/01/29/health/29book.html>

A penetrating review of David Rieff's memoir by a medical doctor who says Susan Sontag set a new benchmark for 'a bad death'.