

RESOURCES AND TOOLS FOR ADVANCE HEALTHCARE PLANNING (developed by the Albuquerque Action Team – Compassion & Choices)

KEY WEBSITES

www.Compassionandchoices.org – This site has many resources including video clips, news articles and up to date information about work being done in various states.

<http://www.nbcnews.com/video/rock-center/50112401>

www.AGoodGoodbye.com A great website by Gail Rubin who wrote a book of the same name. She also has a Channel 27 TV show and DVD series

<http://www.agingwithdignity.org> An alternate form for expressing advance care planning. Goes into values and ethical desires as well as medical, physical wishes.

www.nrc-pad.org Information for advance care planning for people with mental health issues

www.gundersenhealth.org/respecting-choices Gundersen Lutheran Hospital's program for assisting people with their advance healthcare planning

How to Die In Oregon: Film www.howtodieinoregon.com

www.theconversationproject.org/ Has a variety of information and downloadable brochures including a “conversation starter kit” and how to choose and be a proxy

www.conversationprojectnewmexico.org Affiliated with national Conversation Project” but has more local information and resources

<http://opinionator.blogs.nytimes.com/category/the-end/> Very good essays about people's experiences with families and dying

<http://www.dyingwishmedia.com/> Documentary about hospice patient, Dr. Michael Miller, 80-year-old, retired surgeon with end-stage cancer who chooses to stop eating and drinking in order not to prolong his dying process, to ease suffering and die in grace.

INTERNET LINK TO IMPORTANT/USEFUL DOCUMENTS

Advance directives

www.docs.phs.org/idc/groups/public/@phs/@marketing/documents/phscontent/pel_00133737.pdf In English, may not be able to access unless part of the Presbyterian Health System

www.docs.phs.org/idc/groups/public/@phs/@marketing/documents/phscontent/pel_00133738.pdf In Spanish, may not be able to access unless part of the Presbyterian Health System

5 Wishes www.agingwithdignity.org/forms/5wishes.pdf

Values History Form www.som.unm.edu/ethics/docs/values-history.pdf or www.hscethics.unm.edu/directives/values.html

Medical Orders for Scope of Treatment www.nmmost.org

Emergency Medical Services and Do Not Resuscitate Orders
[www.archive.nmems.org/documents/DNR EMS form.pdf](http://www.archive.nmems.org/documents/DNR_EMS_form.pdf)

OTHER RESOURCES

Healthcare Proxy/Medical Power of Attorney/Care Management- these are some that we have talked with; there are others in the phone book. Please note that we are not recommending any, just providing possible connections.

Guardianship and Care Management Services; Mary Galvez, (505) 480-6541, www.marygalvezguardianship.com; Marygalvez1@hotmail.com

Decisions in Care; Susan Stuart, (505) 237-8181, www.decisionsincare.com

Decades; Nancy Oriola, (505) 345-5529, www.decadesgroup.com

Executive Senior Care Management; Angela Walker, (505) 681-5093

Necessity CMC; (505) 293-5374, necessitycmc@qwestoffice.net

Transitions: Fiduciaries & Care Managers; Margot Keener, (505) 999-7959

Senior Citizen's Law Office (Ellen Leitzer, Ex. Director), 505-265-2300

Lawyer Resources for the Elderly (a project of the NM State Bar), 1-800-876-6657.

Trained advance healthcare planning facilitators are available to help with completing directives at Presbyterian Hospital. Call 505-938-6633 to schedule an appointment. This is available to members of the community, not just Presbyterian Healthcare Plan members.

Documentary: “Extremis” on Netflix, about Dr. Jessica Zitter’s Palliative Care Team and what they go through along with the patients and families they serve

Local volunteer group – provide speakers, help with completion of Advance healthcare Directives: Albuquerque Action Team – contact Elizabeth Armijo, earmijo@compassionandchoices.org :

BOOKS/ARTICLES

Becker, Ernest; *The Denial of Death*; 1997, available on Amazon and at the library. Becker tackles the problem of the vital lie - man’s refusal to acknowledge his own mortality and sheds a light on the nature of humanity.

Braun, Pietsch; *Cultural Issues in Decision Making*; 2000

Butler, Katy; *Knocking on Heaven's Door, the Path to a Better Way of Death*; 2013; available at library. A very moving story about how a family coped with a father's stroke and the struggle with the medical community to disable a pacemaker.. It explores such questions as when does death cease being a curse and become a blessing and where is the line between saving life and prolonging dying

Byrock, I; *Dying Well: Peace and Possibilities at the End of Life*; 1997.
***The Four Things that Matter Most: A Book About Living*; 2004**
***The Best Care Possible*; 2012**

Callahan, Maggie & Kelley, Patricia; *Final Gifts; Understanding the Special Awareness, Needs, and Communication of the Dying*; 1997. Using many personal anecdotes of patients they've cared for, the authors give an insight of patients' reactions to their dying, how they communicate both literally and figuratively, and give very practical ways to talk with one's family and friends who may be at life's end. Easy to read and understand.

Chast, Roz; *Can't We Talk About Something More Pleasant?*; 2014, available at library. Rob Chast and her parents were practitioners of denial: if you don't ever think about death, it will never happen. This is the story of an only child watching her parents age, well into their nineties, and die. In this account longtime New Yorker cartoonist Chast combines drawings with family photos and documents chronicling that "long good-bye."

Chell, Byron; *Aid in Dying the Ultimate Argument: The Clear and Ethical Case for Physician Assisted Death*; 2014, available at Amazon and at the library. Chell examines all the objections to aid in dying and clearly explains why states will and should continue the movement towards aid in dying. He addresses the decision of the dying individual, the role of the physician, and the fears people have of the consequences of permitting aid in dying.

DeSpieler, L.A. & Strickland, A.L.; *The Last Dance: Encountering Death and Dying*; 2011

Dunn, Hank; *Hard Choices for Loving People*; 2001/2009, available through various online sites. *Hard Choices* clarifies issues surrounding end-of-life decisions in an easy-to-read format in language that is easily understood. The book covers the most common medical treatment decisions faced by those who are living with a life-threatening illness: CPR (resuscitation efforts), artificial hydration and nutrition (artificial feeding tubes), hospitalization of an ill person, shifting to a hospice approach, ventilators, dialysis, antibiotics and pain control, and more.

Gawande, Atul; *Being Mortal; Medicine and What Matters in the End*;2014; available at library. The author is devoted to geriatric practice and tells stories from his own experience with innovative facilities and people's choices.

Genova, Lisa; *Still Alice*; 2007; available at library. This is the story of a college professor, wife and mother who was diagnosed with early-onset Alzheimer's Disease and how it progressed. Although not directly related to death and dying, it describes family and social dynamics, once such a diagnosis is made and how differently people can face end-of-life issues.

Gibson, Joan; *Pause: How to Turn Tough Choices Into Strong Decisions*; 2013; available via Amazon. Think of the last time you faced a tough decision. Using tough choices we may face in our daily lives, *Pause* shows you how you, your families, neighbors and others can come together to make strong

decisions, especially when perspectives and values collide. This book, with its step by step practical guidance, helps us get there

Kubler-Ross, Elisabeth; *Death, The Final Stage of Growth*; 1975, not found in library catalog although many others by her are available. Kubler-Ross was a psychiatrist and a world-renowned authority and counselor on death. She has written many books considered classics in the field. Other books by her include *On Death and Dying*, *Questions and Answers on Death and Dying*, and *Living with Death and Dying*.

Lembke, Janet; *The Quality of Life: Living Well, Dying Well*; 2003; available at library. This book intermingles the author's research on dying and interviews with people with terminal diagnoses with her own experiences with loved ones. Very engaging while making very good points.

Mangalik, Aroop; *Dealing with Doctors, Denial, and Death*; 2016. It is a book which empowers patients and families to make decisions that are best for themselves, when they are faced with a life-changing or life threatening illness.

Nuland, Sherwin; *How We Die, Reflections on Life's Final Chapter*; 1993, available at Albuquerque/Bernalillo County Library. More academic book about how various diseases and symptoms affect the body, causing death. Less about the emotional/psychological.

Ware, Bonnie; *The Top Five Regrets of the Dying*; 2011, available at library. A caretaker reveals her philosophy about death while relating several of her clients' stories.

Zitter, Jessica, MD; *Extreme Measures*. This moving book tells Dr. Zitter's story as a Palliative Care Physician as she moves through the lives of her patients, their families and her Palliative Care Team. It gives a slightly different perspective of the healthcare providers who put quality of life over quantity.