

Planning Your Last Journey – End of Life Decisions

RESOURCE GUIDE

note: * denotes videos we watched in the workshop

** is something added since the 1st class

This guide is also available on uuse.org under learning/adult programs so you can use hyperlinks to go directly to the websites

End of Life Medical Treatment Decisions (see also Patty Albrecht's recommendations p.5)

“*Being Mortal*” Atul Gawande - book and *[PBS Frontline video that can be viewed online](#) (we watched 3 short segments from this video in the 2/7/16 workshop; full video is 1 hour.)

“*The Better End – Surviving (and Dying) on Your Own Terms in Today’s Modern Medical World*” Dan Morhaim, MD – easy, interesting, informative read; contains good resource appendix

“*Knocking on Heaven’s Door: The Path to a Better Way of Death*” Katy Butler

[Imagine a Medicare part Q for Quality at the End of Life](#) NYT article by Katy Butler

[VA Home based primary care program](#) Great resource for veterans and a model for a Medicare part “Q” (Quality)

[Nurse with fatal breast cancer says end of life discussions saved her](#) Washington Post article - Interesting take on limiting curative care in favor of comfort care – sometimes comfort care extends life.

[The Slow Medicine Group on Facebook](#) Administered by Katy Butler; “explores shared, nonrushed medical decision-making, palliative care, and comfort-giving treatment, especially near the end of life.”

Tools for Planning and Communicating Your Wishes including an Advanced Directive

** [US Living Will Registry](#) You can register your Advanced Directive here so it will be available to any medical providers anywhere. Site says Directives are generally honored in other states than the one where it was prepared. There is a \$59 charge to register.

[Compassion and Choices CT](#) Organization that is helping guide legislation that will make aid in dying accessible to terminally ill residents of Connecticut. Includes excellent resources for

end of life planning, documents and a phone line for consultations and questions. Superb “Good to Go” Toolkit.

[Departing Decisions End of Life Resource Guide](#) Another useful online website

[Stanford “What Matters Most” Letter](#) this is the letter we used in the 2/7/16 workshop – website has fillable form, letters in other languages, and a registry of letters so you can share yours or see what others have written. Note: I had some difficulty entering text & downloading the form. Internet Explorer worked somewhat better than other browsers.

[The Conversation Project](#) Similar to Stanford letter – Starter kit for having conversations with important people in your life about your values and wishes.

[Everplans](#) A comprehensive online service for End of Life planning and advice. The website’s free “Resources & Guides” section is very helpful.

[Honoring Choices Massachusetts](#) a 3-step online guide to making a healthcare plan; the documents are Massachusetts specific but the planning steps are useful for anyone. Also has other highly useful resources including videos of local diverse clergymen discussing their spiritual assessment of palliative treatment choices. It would be nice to have a website like this for Connecticut!

Funerals and Burials:

**** [alkaline hydrolysis - more ecofriendly than cremation](#)**

[Funeral Consumer’s Alliance of CT](#) non-profit organization providing end of life planning information, especially on funerals, to help consumers make informed, cost effective decisions.

Error! Hyperlink reference not valid. sets standards, rates the “greenness” of cemeteries and burial grounds, and has green burial provider locator. Locator for CT: [Find-a-provider/Connecticut](#)

[White Eagle Memorial Preserve](#) Lovely, brief video on a natural burial site in WA State.

*[A Will for the Woods](#) 2 minute trailer from the documentary about green burial preserves (which we watched at the 2/7/16 workshop)

**** [Buy a Bios Urn](#)** and come back as a tree! For real! This is not a fake story on NPR’s “Wait, Wait, Don’t Tell Me”

****[Burial Pods](#)** Here's another way to come back as a tree. I hope to be a European Beech, preferably a Socialist one.

[Shared sorrows](#) Good resource for pre-planning and for survivors including a "Time of Loss" checklist and help in planning cost effective funerals. Their [EternaPlan](#) is a useful tool for planning your own or a loved one's funeral.

[CT laws on funeral charges](#) CT laws governing funeral charges & very helpful checklist for funeral shopping

[CT State law on Custodian of Remains](#) which governs who decides what happens to the body if the deceased does not specify

[CT law help / prepaid funeral contracts & burial plots](#) Legal Aid guide to prepaid funeral contracts in CT

Consumer Law Project for Elders (CLPE) Call: 1-800-296-1467 (will review prepaid funeral contracts for you). (No website)

Recording your memories

[NY Times- Preserving family history one memory at a time](#) Great article about digital businesses that make it easier to collect memories from family members.

[Storyworth.com](#) The online service featured in the above NYT article.

[Record Your Family's Oral History before It Dies](#) helpful blog on recording family memories

****[National Public Radio's Story Corps](#)**

****[NPR's Story Corp App for smart phones](#)**

Organ and Body Donation

[How to donate a body to UConn Medical Center](#)

[Organ Donation in CT](#)

[Organ Transplants – understanding death](#) Excellent information on the hows and whys of organ donation

Political/Social

[NY Times / Dying at home when you're poor](#) Eye-opening article on Racial Disparities in Dying

Digital Legacy

[Everplans](#) A comprehensive online service for End of Life planning and advice. You can invite “Deputies” to your Everplan who can access all your electronic documents and accounts. The websites free “Resources & Guides” section is very helpful.

[Digital-assets-checklist from Everplans](#)

[How to close online accounts and services when someone dies](#) Another great resource from Everplans website – An alphabetical listing of over 140 services with instructions on how to close them.

[The four most popular password managers](#) These programs manage your passwords so you only need to remember, update (and pass on) one master password.

[Pew research-What happens to your digital life after death](#) short, informative article

[The Digital Beyond](#) An online list of services to help you plan for your digital afterlife

[Access to decedent’s electronic mail account](#) Text of the CT law governing this

[Is Apple evil for not giving Ipad password to widow?](#) Good article on the issue of convenience v. security

General

[New York Times Category - The End](#) Lots of fascinating articles on what we are discussing; have Kleenex handy

[Cleveland Clinic video on empathy for healthcare providers](#) ... but moving and inspiring for anyone

*[Cindy Chang video - "Before I Die I Want to"](#) 6 minute video we watched in the 2/7/16 workshop

**** Bibliography of Patty Albrecht (of VNHSC who spoke on Medical Treatments, 3/13/16)**

“Hard Choices for Loving People”, Hank Dunn. Addresses CPR, artificial feeding, comfort care etc., clearly and concisely.

“Lifetimes: A Beautiful Way to Explain Death to Children”, Bryan Mellonie

“A Hand in Healing: The Power of Expressive Puppetry,” Marge Schneider

“The Four Things That Matter Most: A Book About Living” Ira Byock M.D.

“And a Time to Die: How American Hospitals Shape the End of Life”, Sharon R. Kaufman

“How We Die: Reflections of Life's Final Chapter”, Sherwin B. Nuland

“Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying”, Maggie Callanan and Patricia Kelley

“Let Me Die Before I Wake: Hemlock's Book of Self-Deliverance for the Dying”, Derek Humphry