Advance Care Planning: Resources and Key Concepts Camille Collett, MD, MPH March 31, 2022

Web sites:

Utah Commission on Aging UtahAging.org https://ucoa.utah.edu/coreissues/directives/index.php

The Conversation Project: https://theconversationproject.org/

Provider Order of Life-Sustaining Treatment: http://POLST.org/

Prepare for your care: https://prepareforyourcare.org

Leaving-Well

The Five Wishes

https://leaving-well.org/
https://fivewishes.org/

POLST Provider Guide

https://health.utah.gov/hflcra/forms/POLST/POLST Conversation Guide.pdf

The 5 Ds of Advance Directives - When to update the AD

Decade, Death, Divorce, Diagnosis, Decline

Also, moving to a Different state or living in 2 Different states.

Summary of the Steps in creating an Advance Directive ("Living Will")

- 1. Choose a Healthcare "Decision Maker" (Healthcare Proxy)
- 2. Decide what matters to you the most in life.
- 3. Decide how much flexibility to give your "Decision Maker"
- 4. Tell them about your healthcare wishes
- 5. Share this information with your doctor and scan the document in your medical record.

Who Can be a Medical Decision Maker or Healthcare Proxy?

- 1. Anyone in your family over 18 years of age
- 2. A friend over 18 years of age

Who can't be the Medical Decision Maker or Healthcare Proxy?

- 1. Your Primary Care Doctor or Medical Provider
- 2. People employed by the hospital: Nurse, Social Worker
- 3. Owners or employees of the facility providing care unless they are your relative.

CHARACTERISTICS	POLST	ADVANCE DIRECTIVES	
Population	For the seriously ill	All adults	
Time frame	Current care	Future care	
Who completes the form	Health care professionals	Patients	
Resulting form	Medical orders (POLST)	Advance directive	
Health care agent or surrogate role	Can engage in discussion if patient lacks capacity	patient Cannot complete	
Portability	Provider responsibility	Patient/family responsibility	
Periodic review	Provider responsibility	Patient/family responsibility	

POLST.org

Books:

"Being Mortal: Medicine and what matters in the end" - Atul Gawande

"The Conversation: A Revolutionary Plan for End-of]-Life Care" - Angelo Volandes

"Can't We Talk About Something More Pleasant" - Roz Chaz

"That Good Night: Life and Medicine in the 11th Hour" - Sunita Puri

"When Breath Becomes Air" - Paul Kalanithi and Abraham Verghese

"Everything happens for a reason: And other lies I've loved" - Kate Bowler

UCoPE: Utah Certificate of Paliative Care: https://medicine.utah.edu/pediatrics/palliative-care/ucope/



Examples of Empathic Responses						
Naming	Understanding	Respecting	Supporting	Exploring	"I Wish"	
This must be Frustrating Overwhelming Scary Difficult Challenging Hard	What you just said really helps me understand the situation better.	I really admire your Faith Strength Commitment to your family Thoughtfulness Love for your family	We will do our very best to make sure you have what you need.	Could you say more about what you mean when you say • I don't want to give up • I am hoping for a miracle	I wish we had a treatment that would cure you [make your illness go away]. *[Remember we do have palliative treatments to offer th patient]	
I'm wondering if you are feeling • Sad • Scared • Anxious • Nervous • Angry	This really helps me better understand what you are thinking.	You (or your dad, mom, child, spouse) are/is such a strong person and have/has been through so much.	Our team is here to help you with this.	Help me understand more about	I wish I had better news.	
It sounds like you may be feeling	I can see how important this is to you.	I can really see how [strong, dedicated, loving, caring, etc.] you are.	We will work hard to get you the support that you need.	Can you say more about that?	I wish the situation were different.	
In this situation some people might feel	Dealing with this illness has been such a big part of your life and taken so much energy.	You are such a [strong, caring, dedicated] person.	We are committed to help you in any way we can.	Tell me more about what [a miracle, fighting, not giving up, etc.] might look like for you?	I wish that for you too. [In response to what a patient or family members wishes, such as a miracle]	
I can see how dealing with this might be • Hard on you • Frustrating • Challenging • Scary		I'm really impressed by all that you've done to manage your illness [help your loved one deal with their illness].	We will be here for you.		I wish we weren't in this spot right now.	