

**2019 AVENIDAS CARE FORUM CAREGIVER TOOL KIT  
SESSION 3 | JUNE 1, 2019 | [www.avenidas.org](http://www.avenidas.org)**

**WELCOME CAREGIVERS!**

The Avenidas Care Forum is uniquely positioned to benefit family caregivers and their personal support teams. This series of 7 lectures will provide participants with insider information to help family caregivers navigate complex levels of care transitions, minimize stress, cultivate resilience, and thrive!

**“LET'S GET THE CONVERSATION STARTED”!  
CRITICAL CONVERSATIONS FOR THE CAREGIVER DEALING WITH SERIOUS ILLNESS  
by Ellen Brown, M.D. | [www.ellenbrownmd.com](http://www.ellenbrownmd.com)**

**SECTION 1: THE NEED FOR CRUCIAL CONVERSATIONS**

As a society, we tend to avoid discussions concerning end of life treatment options and death. Consequently, these conversations usually take place at the time of a health care crisis, between physicians and stressed family caregivers who may not know their loved one's wishes.

We acknowledge that it can be difficult to initiate conversations on our deeply held values and thus our preferred end of life care options. Here is a compilation of helpful resources for beginning your conversation with loved ones on your values and what matters most.

**WHY HAVE CONVERSATIONS?**

- Goals of care conversations are associated with improved end of life care for patients.
- Lower risk of depression and anxiety in surviving members.
- Sharing your wishes for end of life care can bring you closer to the people you love.

**MORE IMPORTANT QUESTIONS**

- What matters to you?
- What are the important things in your life? What do you do you want to accomplish?

**SECTION 2: NOT ONE THING THAT CAN WORK FOR EVERYONE, THERE ARE MULTIPLE TOOLS AVAILABLE TO GET THE CONVERSATION STARTED**

1. PREPARE <https://prepareforyourcare.org>

2. The Conversation Project <https://theconversationproject.org>

Shared understanding of what matters most to you/your loved ones, makes it easier to make decisions when the time comes.

3. Go Wish cards <http://www.gowish.org>

Effective tool for people of all ages, levels of cognition, literacy. including people with limited literacy and limited English skills.

4. WHEN YOU SIMPLY CAN'T HAVE THE CONVERSATION - The Letter Project - <https://med.stanford.edu/letter/what-matters-letter.html>

## ADVANCE DIRECTIVES

- Advance directives are only as good as the conversations around them.
  - Forms are the symbols of the conversations behind them.
1. **DPAHC - Durable Power of Attorney for Health Care.**  
Appoint a decision maker or proxy to speak for you if you can't speak for yourself.
  2. **LIVING WILL / FIVE WISHES - Five Wishes** <https://fivewishes.org>  
Helps you imagine your vision of a good death
    - My wish for how comfortable I'd like to be...
    - My wish for how I want other people to treat me....
    - My wish for what I want my loved ones to know....
  3. **HEALTH DIRECTIVE FOR DEMENTIA** [www.dementia-directive.org](http://www.dementia-directive.org)

**SECTION 3: POLST -** [https://capolst.org/wp-content/uploads/2017/09/POLST\\_2017\\_Final.pdf](https://capolst.org/wp-content/uploads/2017/09/POLST_2017_Final.pdf)

A POLST is a doctor's order, signed by a doctor, nurse practitioner or physician's assistant and the patient or proxy.

### NO WRONG ANSWER. WHAT IS CONSISTENT WITH YOUR VALUES?

1. **Attempt Resuscitation/CPR or Do Not Attempt Resuscitation (Allow Natural Death)**
2. **WHAT TYPE OF MEDICAL INTERVENTION DO YOU WANT?**
  - **Full Treatment:** with the primary goal of doing everything possible to prolong life. This includes CPR, intubation, ventilators, dialysis, intensive care units.
  - **Selective Treatment:** with the goal of treating medical conditions while avoiding burdensome measures. No CPR, but IV antibiotics, IV fluids, hospitalization utilized.
  - **Comfort focused treatment:** Primary goal is maximizing comfort. Relieve pain and suffering with medication by any route necessary. Use oxygen if for comfort.

## SECTION 4: CRUCIAL CONVERSATIONS WITH HEALTH PROVIDERS

- Talking to your doctor about your goals and what matters.
- Many doctors don't know how to have these conversations.

## HELPFUL TIPS WHEN MEETING WITH DOCTOR

- "I want a realistic picture, so I can plan ". Take notes.
- Bring a friend or relative, ask follow-up questions.
- If they are using medical jargon, ask them to say it more simply so you can understand.

## **KNOW THE TRAJECTORY OF AN ILLNESS**

- What can you expect (if the disease follows its usual course)?
- Can you give me a rough estimate of how much time I have left (years, months, weeks or days)?
- How will you feel?
- How will treatments affect your quality of life?

## **SECTION 5: DISCUSSION OF HOSPICE AND PALLIATIVE CARE**

### **PALLIATIVE CARE**

- Extra level of support, focusing on relieving suffering and improving quality of life for those who are coping with serious illness.
- Other names: supportive care, pre-hospice, pain management.
- You can still be receiving curative treatment.
- A team of MDs, nurses, counselors and social workers, provide medical, emotional and social support needed to cope with the burdens of serious illness.
- Works with your health care team.
- Experts at managing pain, shortness of breath, nausea and fatigue.
- People who receive palliative care:
  1. Spend less time in the hospital
  2. Have less pain and suffering
  3. Enroll in hospice earlier

### **HOSPICE CARE**

A specialized type of palliative care available to people with an incurable illness and a life expectancy of less than 6 months. Focus on caring, not curing. Doesn't hasten death but focuses on living well until you die. Motto: Hope for the best but prepare for the worst. Care provided by a team of MD, nurse, social worker, chaplain, personal aide and volunteer. Treats emotional and spiritual pain in addition to physical pain. Addresses emotional needs of caregivers.

### **MYTHS OF HOSPICE**

- Hospice is a place or building: No, not in the US. It is a type of care that goes to where you live.
- Hospice is care for the last hours of life: No, the benefit meant for those who have up to 6 months.
- Signing up for hospice is like signing your death warrant: No, 15% of people "graduate" from hospice.
- Hospice is expensive: No, it is covered by Medicare and Medicaid and private insurance, but there are gaps.
- Hospice covers around the clock care: No, hands-on bedside care needs to be provided by family, friends or private aides.
- Hospices push morphine and hastens death: No, there is no evidence that hospice shortens life.

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#### **SOURCES FOR TOOL KIT**

- Being Mortal by Atul Gawande 2014
- The Art of Dying Well by Katy Butler 2019