

Advocacy for Self and Others

Presented by:

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“.....we know conversations, connection, and learning about death and dying can improve the quality of one’s life and create a sense of community around a profound experience we all share.”



What does *Living Well* and
Ending Well mean to you?

Objectives

Understand the role of advocacy for self and community

Recognize challenges and barriers

Explore practical approaches

Being and Doing Advocacy

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Why Advocacy Matters

Advocacy is the ability to “speak” up for oneself or another’s needs, hold presence, make informed decisions, and ensure your “voice” is central to your or another’s end of life experience

Your Voice and Presence Shapes Your Care

Advocacy is about having agency. It ~~guarantees~~ enables a person's values, needs, and rights are prioritized in the decision-making process.

Psychosocial Barriers to Advocacy

Personal Perspective:

- ❖ Fear of speaking up or challenging authority
- ❖ Lack of health literacy or confidence
- ❖ Cultural beliefs and stigma around illness or death
- ❖ Emotional distress, anxiety, or depression¹²
- ❖ Limited support from family or community
- ❖ Ageism

Healthcare Perspective:

- ❖ Time-limited appointments and rushed communication
- ❖ Power imbalances between providers and patients
- ❖ Complex insurance and billing systems
- ❖ Bias, discrimination, or inequities in care
- ❖ Lack of integration between medical, social, and community supports
- ❖ Access to care

Sharing Past Health Care Experiences

- ❖ What happened?
- ❖ How did you feel (especially about not being heard)?
- ❖ What do you wish had been different?
- ❖ Can you describe a time when you didn't feel your concerns were listened to?
- ❖ How did that affect the outcome of your care or your trust in the provider?
- ❖ What would you have wanted to hear or experience instead?
- ❖ How have you advocated for yourself or a loved one in healthcare?
- ❖ What challenges did you face, and how did you address them?

EXAMPLES

- ❖ Consider Release of Information (ROI)
- ❖ Take list of questions with you
- ❖ Practice asking questions or communicating what you want before the visit
- ❖ Take someone with you to take notes or ask questions on your behalf
- ❖ Role play
- ❖ Ask to record the visit
- ❖ Knowing an appointment is time limited, write up a brief summary of your concerns and/or questions that you can give to the nurse or medical assistant (MA), before the doctor sees you
- ❖ Send message before the scheduled appointment. Ask for confirmation that the message was received and delivered to the provider
- ❖ Make sure or have someone you trust make sure information is up to date (UTD) in your electronic health record (EHR/EMR)
- ❖ Review the after-summary visit to confirm it contains what was discussed and captured your questions or concerns accurately. Send clarifying message if the notes do not reflect what you heard or said during the visit.

Neighbor-to-Neighbor

“Stranger-Friend”

“We do not have to be caregivers to be caring.”

Ikigai (生き甲斐) “a reason for being” or
“that which makes life worth living.”

“You are not alone,” may be part of their reason for being and letting go. Ikigai is not only individual, it can be communal.

“What is your story? It is all in the
telling....”

The Faraway Nearby, Rebecca Solnit

SILENCE BETWEEN THE STORIES

Four Questions

What am I not saying that needs to be said?

What am I saying (in words or actions) that is not being heard or seen?

What is being said, that I am not hearing

How am I complicit in creating the conditions I do not want?

“If we talked as honestly and openly about death as we do pregnancy and childbirth, we might live differently.”

THANK YOU!

Get in contact with us

www.northcoasteolcollective.com

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