The CARES Toolkit

End-of-Life Cases and Resources:

An Interprofessional Toolkit for Health Science Students

Facilitator Notes

Case Title

Directions

- Develop a series of questions and answers that address specific discussion points.
- Develop 1-2 different scenarios (with questions and answers) that change or add discussion points.
- Develop a list of needed community/healthcare resources and support services.

Possible Discussion Points (See Pages 8-10 for Example Questions):

- Difficult Conversations
- Ethical / Legal Considerations
- Patient Goals, Preferences and Values
- Medical Decision-Making Capacity
- Social Determinants of Health
- Advance Care Planning
- Community Resources/Access to Care

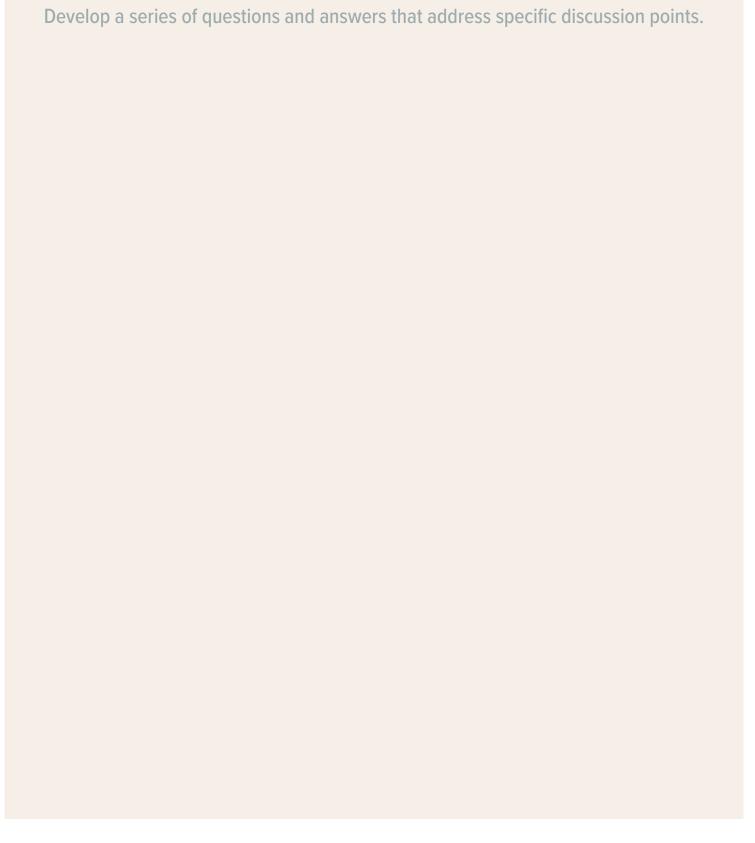
- Cognitive Impairment
- Health Literacy
- Sensory Deficits
- Ageism, Gender or Other Bias
- Cultural Humility / Diversity / Spiritual Considerations
- Family / Caregiver Concerns
- Limited English Proficiency
- Public Policy

Questions

Develop a series of questions and answers that address specific discussion points.

Domain	Example Questions for Older Children, Adolescents, and Young Adults	Example Questions for Younger Children*
Knowledge	Tell me what you understand about your illness. What are your care options? What do you understand might happen in the future?	How is your body feeling today? What's going on with your (child's name for their illness)? What have you heard?
Information Sharing	How much information do you find helpful about your diagnosis and potential complications? Whom do you prefer to receive information from? Whom do you want present when information is shared?	Do you want to hear updates or news from the doctors? Or from your parents? Or both?
Culture and Family	How do your personal values or community values impact your preferences for receiving information? Do you openly talk about your health and your future with those you love? How does your role in your family impact your readiness to discuss certain health topics? How do your family members' preferences about discussing medical information impact your ability to access information?	Who can you talk to about how you are feeling?
Emotions	Can you tell me about any worries that you have about your illness or the future? Can you tell me what it feels like to talk about your illness or the future?	What made you happy today? Yesterday? Lots of boys and girls like you have worries. What are you worried about right now? What other types of feelings are you hav- ing?
Hopes	What do you hope for with your current medical care? These hopes are meaningful. If these hopes do not come true, what else would you hope for?	If you had three wishes, what would they be? What are you hoping for?
Quality of Life	What does living well (a good day) look like for you? What is important for you?	What makes today a good day? What would make tomorrow a good day? What helps you feel better/your best?

Questions



Scenario 1 and Questions

Develop 1-2 different scenarios (with questions and answers) that change or add discussion points.

Scenario 2 and Questions

Develop 1-2 different scenarios (with questions and answers) that change or add discussion points.

Resources and Support Services for the Patient / Family

Develop a list of needed community/healthcare resources and support services.		

Example Questions for Discussion Points

DIFFICULT CONVERSATIONS

- What is the specific communication/conversation skill(s) that is needed for this case? (e.g., Best Case/Worse Case framework; Serious Illness Conversation)
- · How would you begin the conversation?

ETHICAL / LEGAL CONSIDERATIONS

- Are there any ethical/legal considerations that need our attention?
- Do they have a medical power of attorney?

PATIENT GOALS, PREFERENCES AND VALUES

- How do you ensure you know/understand the patient's care preferences and values?
- What strategies would you use to assess the patient's goals, preferences, and values?

MEDICAL DECISION-MAKING CAPACITY

- Decision-Making capacity is always related to a specific medical decision. Capable patients have the legal and ethical right to make their own treatment decisions.
- Does the patient have decisional capacity? What more would you need to know?

COMMUNITY RESOURCES / ACCESS TO CARE

 What community or healthcare resources or services would help the patient and/or family?

SOCIAL DETERMINANTS OF HEALTH (SDH)

• How would you address any known SDH issues? (food, housing or transportation insecurities; childcare, utility, legal, or education needs; financial resources; employment instability).

ADVANCE CARE PLANNING

- What do you see as the important decisions that the patient/family are facing?
- What specific knowledge is needed to provide the best of care? (e.g., definition of palliative care vs. hospice benefits).

COGNITIVE IMPAIRMENT

Does the patient have any cognitive impairment?

HEALTH LITERACY

• Can the patient understand and navigate health-related issues? Note: health literacy is different from general literacy.

SENSORY DEFICITS

• Does the patient have any sensory impairment (hearing, vision)?

AGEISM, GENDER OR OTHER BIAS

- Can you identify any overarching bias?
- Can you identify any possible assumptions one might make about this patient? Note: Ageism occurs for people of ALL ages.

CULTURAL HUMILITY / DIVERSITY / SPIRITUAL CONSIDERATIONS

- How does the patient's culture influence our approach to care?
- What terms may be misunderstood because of cultural definitions?

FAMILY / CAREGIVER CONCERNS

- Does the patient have a caregiver?
- What is their relationship?
- Does the patient live with the caregiver?
- If not, does the caregiver live close-by or are they a long-distance caregiver?
- How is caregiver handling the stress of being a caregiver?
- Do they need support/resources?

LIMITED ENGLISH PROFICIENCY

- How do you identify if someone has limited English proficiency?
- When do you know you should bring a translator into the conversation?
- How do you access a translator?

PUBLIC POLICY

What information about this patient might inform public policy or regulatory action?