End-of-Life Planning

Lisa Brace, MSN, RN, and
Michael Sigelman, MSN, RN
May 17th, 2018
DDA Health Initiative

RESTRICTED RIGHTS LEGEND

Use, duplication, or disclosure is subject to restrictions stated in Contract No. DCJM-2014-C-0019 between the Government of the District of Columbia and Georgetown University

© 2019 Georgetown University Center for Child & Human Development
3300 Whitehaven Street NW, Suite 3300, Washington, DC 20007

Forward

University Center
for Excellence in
Developmental Disabilities
GEORGETOWN UNIVERSITY CENTER FOR
CHILD AND HUMAN DEVELOPMENT

The following training was produced by Georgetown University’s Center for Child & Human Development as part of the the DDA Health Initiative project. This project supports the mission of the District of Columbia’s Developmental Disabilities Administration, and focuses on improving the physical, behavioral and mental health supports that affect the quality of living for people with intellectual and other disabilities.

Except for portions cited, the content of this presentation is copyrighted and protected by Georgetown University's copyright policies.

For questions or additional information on this training and the DDA Health Initiative, or to obtain permission to reproduce this presentation, please visit our website at https://ucedd.georgetown.edu/DDA/ or email:

Lisa Brace, MSN, RN, (RN transition specialist), at lmb270@georgetown.edu

Michael Sigelman, MSN, RN, (nurse educator), at mss311@georgetown.edu

© 2018 Georgetown University Center for Child & Human Development

OBJECTIVES

Nurses will be able to:

1. Describe the TAP (Think-Ask-Plan) process for end of life decisions.
2. Compare and contrast two differences between palliative and hospice care.
3. Categorize quality of life aspects for the people they support given three scenarios.

© 2018 Georgetown University Center for Child & Human Development

Aging, Retirement, and End-of-Life for people with IDD

Video:

https://youtu.be/sR6U0O42fHY

End-of-Life Discussions

Opportunities arise when a person's life progresses or as change occurs in a person's health condition.

© 2018 Georgetown University Center for Child & Human Development

End-of-Life Discussions

Health and Wellness Standard 24:

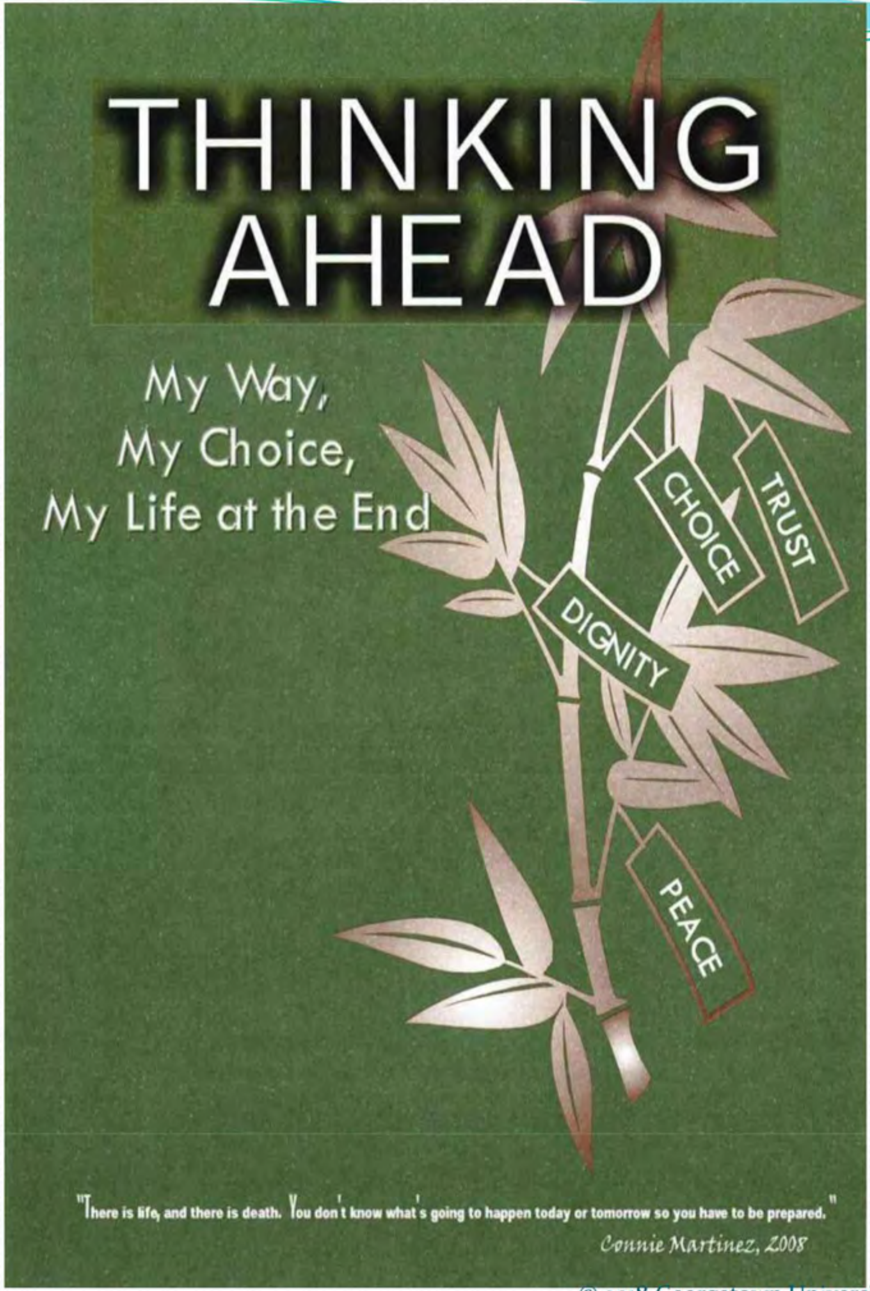
End-of-Life Planning

Obligation to be introduced during the annual ISP meeting.

Healthcare decision maker and person decide on extent of planning.

https://ucedd.georgetown.edu/DDA/HealthWellnessStandards.html

© 2018 Georgetown University Center for Child & Human Development



THINKING AHEAD

My Way,
My Choice,
My Life at the End

"There is life, and there is death. You don't know what's going to happen today or tomorrow so you have to be prepared."

Connie Martinez, 2008

© 2018 Georgetown University Center for Child & Human Development

End-of-Life Terminology

- DNR: Do Not Resuscitate
- DNI: Do Not Intubate
- DNH: Do Not Hospitalize
- COO: Comfort Care Order

© 2018 Georgetown University Center for Child & Human Development

Do Not Resuscitate (DNR)

- DNRs signed in hospital do not apply in the home.
- DNRs signed as part of Advanced Directive, Living Will or Durable Power of Attorney apply in all settings.
- EMS will honor DNR if CCO is signed and present in the home, and bracelet is worn.
  - Obtain bracelet through Department of Health
  - (See H&W Standard 24 for contact information)

© 2018 Georgetown University Center for Child & Human Development

Futility vs. Utility

- Futility: uselessness or absence of any effect (benefit)
    - Does not consider harms of resuscitation

- Utility: usefulness or profitableness, incorporates an evaluation of benefit over cost

© 2018 Georgetown University Center for Child & Human Development

Futility and Decision Making

- Physicians use perceptions of futility when starting or continuing life-supports endeavors.
- Futility is a prediction, and there is no consensus definition for it.

© 2018 Georgetown University Center for Child & Human Development

Futility

1. Physiologic Futility: when a procedure cannot bring about its physiologic objective
   a. Ex: CPR produces no pulse
2. Quantitative estimate of Futility: if it has failed in the last defined number of times attempted
   a. 100 successful attempts as threshold
3. Qualitative component of futility: patient's resulting QOL falls well below the minimal threshold by general professional judgement

© 2018 Georgetown University Center for Child & Human Development

Harms of Resuscitation

1. If unnecessary because person's condition is insufficiently serious to justify
2. If unsuccessful because person's condition is too far advanced
3. If it is unkind because it prolongs a poor quality of life
4. If it diverts resources from alternative health care activities that would bring more benefit to other persons
5. If it is unwanted because it is against the wishes of the person
6. The use of futility as the driver for withholding or withdrawing life-support treatments brings harms of its own

Must consider the balance of benefit and harm that results

© 2018 Georgetown University Center for Child & Human Development

End-of-Life Planning

Code status should not be the only topic of discussion.

- Nutrition
- Activities
- Residential arrangements
- Visitors
- Medical care
- Funeral arrangements

© 2018 Georgetown University Center for Child & Human Development

Nutrition at End-of-Life

Feeding Tube vs Natural Dying Process

- Is it ethically or medically necessary to insert a feeding tube for artificial hydration and nutrition?
- Is it painful to die naturally?
- Why does healthcare look to tube feeding?

© 2018 Georgetown University Center for Child & Human Development

Feeding Tube at End-of-Life

Disadvantages vs. Advantages

Feeding Tube vs. Natural Dying Process

Alzheimer’s Association’s Position
“The Association asserts that it is ethically permissible to withhold nutrition and hydration artificially administered by vein or gastric tube when the person with Alzheimer’s disease or dementia is in the end stages of the disease and is no longer able to receive food or water by mouth.”

“The Association emphasizes that assisted oral feeding should be available to all persons with advanced Alzheimer’s disease.”

“Neglect in this area should not be tolerated, and concerted efforts are called for to educate and support professional and family caregivers in techniques of assisted oral feeding.”

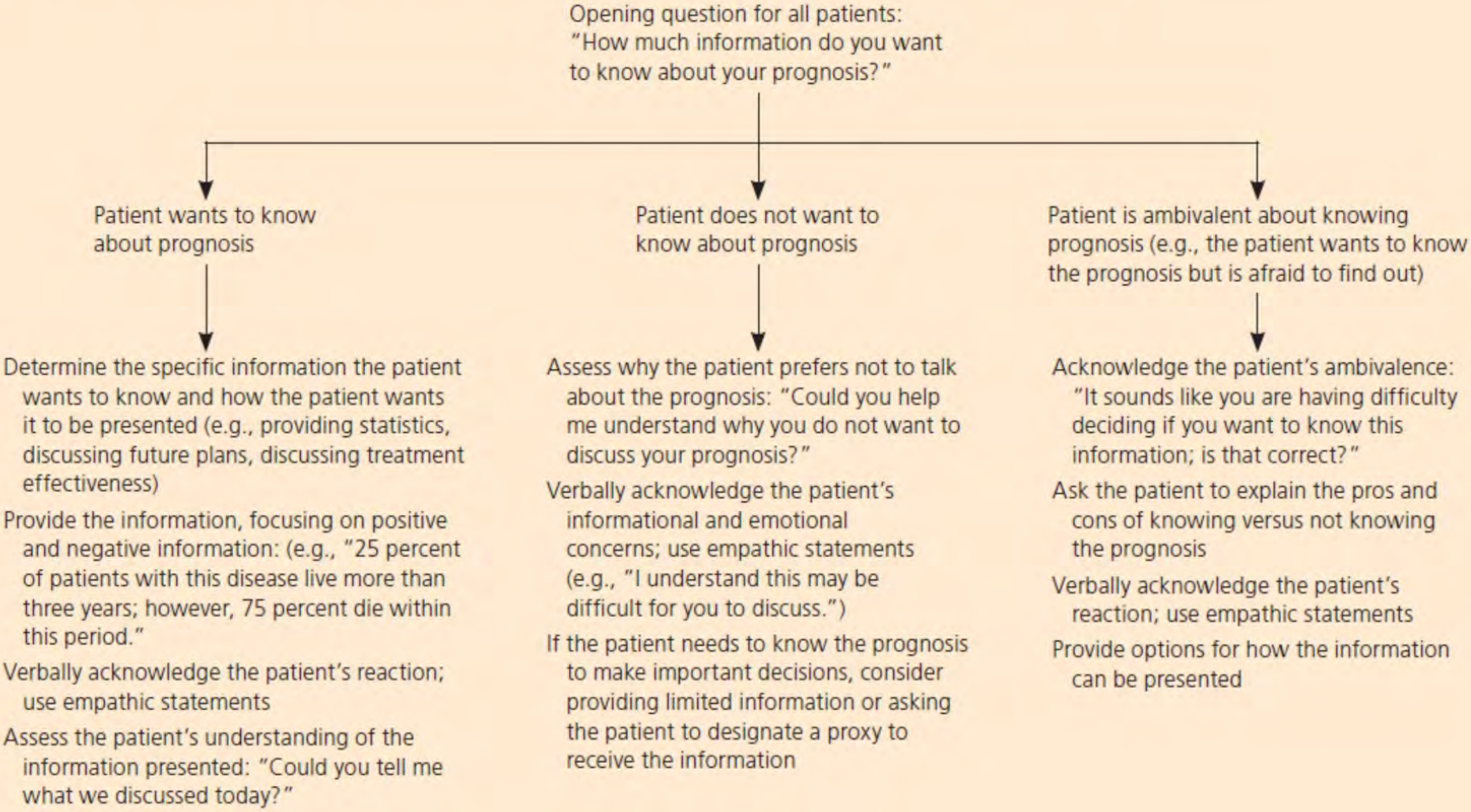
© 2018 Georgetown University Center for Child & Human Development

Guidelines for Patient-Centered Communication

- Progression of disease causes changes from curative care to palliative care.
  - As this change occurs, the goals of care change.
- Support the person and family/caregivers.
- Ask more open-ended questions.

© 2018 Georgetown University Center for Child & Human Development

Patient-Centered Communication When Discussing a Bad Prognosis



Opening question for all patients: "How much information do you want to know about your prognosis?"

Patient wants to know about prognosis

- Determine the specific information the patient wants to know and how the patient wants it to be presented (e.g., providing statistics, discussing future plans, discussing treatment effectiveness)
- Provide the information, focusing on positive and negative information: (e.g., "25 percent of patients with this disease live more than three years; however, 75 percent die within this period."
- Verbally acknowledge the patient's reaction; use empathic statements
- Assess the patient's understanding of the information presented: "Could you tell me what we discussed today?"

Patient does not want to know about prognosis

- Assess why the patient prefers not to talk about the prognosis: "Could you help me understand why you do not want to discuss your prognosis?"
- Verbally acknowledge the patient's informational and emotional concerns; use empathic statements (e.g., "I understand this may be difficult for you to discuss.")
- If the patient needs to know the prognosis to make important decisions, consider providing limited information or asking the patient to designate a proxy to receive the information

Patient is ambivalent about knowing prognosis (e.g., the patient wants to know the prognosis but is afraid to find out)

- Acknowledge the patient's ambivalence: "It sounds like you are having difficulty deciding if you want to know this information; is that correct?"
- Ask the patient to explain the pros and cons of knowing versus not knowing the prognosis
- Verbally acknowledge the patient's reaction; use empathic statements
- Provide options for how the information can be presented

© 2018 Georgetown University Center for Child & Human Development

Palliative Care vs. Hospice

- Palliative Care
  - Begins at diagnosis, and at the same time as treatment.
- Hospice
  - Begins after treatment of the disease is stopped and when it is clear the person is not going to survive their illness.

© 2018 Georgetown University Center for Child & Human Development

Palliative Care

- Does not hasten death nor prolong life!
- Take steps to alleviate pain, discomfort, and suffering.
  - Appropriate to withdraw or withhold medical interventions that exacerbate or prolong pain and suffering.

Palliative Care

Symptoms treated:

- nausea and vomiting
- fatigue
- constipation
- diarrhea
- insomnia
- anorexia
- SOB
- hiccups
- anxiety and stress
- depression (hopelessness, isolation)
- anticipatory grief and bereavement
- any other symptoms from disease or treatment

Hospice Care

- Does not hasten death nor prolong life!
- Give supportive care to people in the final phase of a terminal illness.
    - Focus on comfort and quality of life, rather than a cure.
- Used for persons with prognosis of 6 months or less.

© 2018 Georgetown University Center for Child & Human Development

Strategies for Supporting Grief, Loss, and End-of-Life Issues

Funerals

- Encourage invitation and participation.
- Does the person want to go?
- Talk with the person conducting the ceremony ahead of time.
- Be supportive of individual spirituality, religiosity, and expression.
- Plan ahead when someone first starts receiving services.

Depression caused by a loss a year or more ago

- Participate in a group for people grieving.
- Involve other people the person knows to help them.
- Did the person participate in mourning rituals to help bring closure?

© 2018 Georgetown University Center for Child & Human Development

Strategies for Supporting Grief, Loss, and End-of-Life Issues

Loss of home and relationships

- Don’t take choices away from the person without involving them in the planning process as much as possible.
- Mementos might be wanted or needed. Help them make a photo album if they would like one.
- Make the option to revisit the space a possibility.
- Provide emotional support. Keep contact with the person.
- Ensure support staff is on the same page to provide consistency.

Unexpected losses (sudden death in the residence)

- Be sensitive to one another’s feelings.
- Ask for assistance from counselors or helpers who know the person/people involved.
- Call appropriate religious/spiritual leaders, if appropriate.

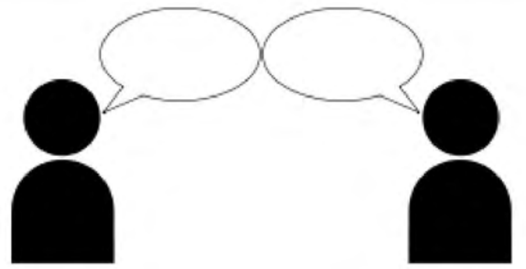
Strategies for Supporting Grief, Loss, and End-of-Life Issues

Loss of roommate or housemate

- Give honest information.
- Encourage maintenance of existing relationships.
- Share past stories/experiences.
- Develop a group scrapbook for home.
- Involve the roommates/housemates when looking for a new resident.

In a day program

- Communicate with staff at a day program; everyone should be kept informed.
- Memorial services, making memorial cards, educatic and group discussion.



© 2018 Georgetown University Center for Child & Human Development

Strategies for Supporting Grief, Loss, and End-of-Life Issues

Saying goodbye

- Don’t leave without saying “Goodbye”.
- Is “I’ll see you later” an appropriate thing to say?
- Can you encourage contact during birthdays and holidays? Establish an Alumni Network.

Thinking about their own aging process

- Relate it to your own experiences.
- Use language that is understood.
- Keep in mind religious beliefs and cultural choices when talking about aging.
- Educate person and staff what to expect during the aging process.

© 2018 Georgetown University Center for Child & Human Development

Strategies for Supporting Grief, Loss, and End-of-Life Issues

When grief is acted out behaviorally

- Look at this on a case by case basis when you address the situation.
- Listen!
- Provide age-appropriate books about death and dying.

Develop an agency response

- Develop a grief response team.
- Help people remember positive traits and stories.
- Establish a memorial place, rock garden, or memorial tree.
- Weekly/periodic conversations.
- Use “Memorial Day” as a day to commemorate friends/loved ones who have died (or choose a date).
- Have a memory box for people to visit when they want to see pictures or mementos, or touch something that belonged to the person.

© 2018 Georgetown University Center for Child & Human Development

Strategies for Supporting Grief, Loss, and End-of-Life Issues

Helping families stay proactive

- Communicate and plan ahead for the unexpected.
- Be honest with families and explain why it is important to talk about end-of-life preparations.
- Respect the family and try to be on the same page as them.
- Work with them, not against them.

Supporting people with dementia

- Develop strategies for re-orienting people to time, place, and person.
- Use visual and audio cues (picture albums, music, scrapbooks).
- Re-teach fundamentals and ADLs.

© 2018 Georgetown University Center for Child & Human Development

Strategies for Supporting Grief, Loss, and End-of-Life Issues

Supporting people with autism

- Have a plan in place to talk about loss, keeping in mind how the individual person processes information.
- Ask if they have questions and answer them honestly.
- Ensure you will be available if they have questions at a later time.

Dealing with grief and HIPPA

- It is acceptable to talk about someone who has died, but do so without confidential details.
- When people are asking questions, find out what they know, and help them talk more about what they know or think about the situation.
- Help others talk about their feelings instead of discussing confidential information.

© 2018 Georgetown University Center for Child & Human Development

Strategies for Supporting Grief, Loss, and End-of-Life Issues

When someone is in the hospital

- Educate hospital staff that people with I/DD experience loss and grief.
- Help the person not be afraid (ex-balloons in the hospital room with personal traits to share).
- Access the hospital staff (clergy), if necessary, to help with conversations and funeral arrangements.

Supporting someone who is dying in the near future

- Be with the person as much as possible and as much as they request.
- Ask them who they want to be there with them, and proactively work to get them present.
- Explain at an appropriate level.
- Respect feelings, culture, and spirituality.
- Help them feel comfortable by providing items they like or activities they enjoy doing.

© 2018 Georgetown University Center for Child & Human Development

T-A-P Planning Process

- Think-Ask-Plan (TAP) process
  - 3 step process
  - Compiled for guardians to make decisions for persons unable to express their end-of-life care

(https://ucedd.georgetown.edu/complex/tap-planning-process.php)

© 2018 Georgetown University Center for Child & Human Development

T-A-P Planning Process

- Step 1: Think
  - Ethics Workup Case Analysis
    - What are the facts?
    - What is the issue?
    - Frame the issue
    - Identify and weigh alternative courses of action and then decide
    - Critique

© 2018 Georgetown University Center for Child & Human Development

T-A-P Planning Process

- Step 2: Ask
  - Guided Interview for Decision-makers
    - Used prior to meeting with health care professionals to talk about treatment and care.
    - Reflect on the following:
      - What you know about the person
      - Everyday experience
      - What gives pleasure
      - Causes of pain
      - Optimal functioning
      - Level of assistance with ADLs
      - Level of medical care required

© 2018 Georgetown University Center for Child & Human Development

T-A-P Planning Process

- Step 3: Plan
  - Quality of Life Considerations tool to assess medical decisions and impact of decisions.
    - Strength and direction of what you think is in the best interest for the person.
      - Definitely want treatments that might keep the person alive.
      - Probably would not want treatments that might keep person alive.
      - Unsure of what to do.
      - Probably would not want treatments that might keep person alive.
      - Definitely do not want treatments that might keep person alive.

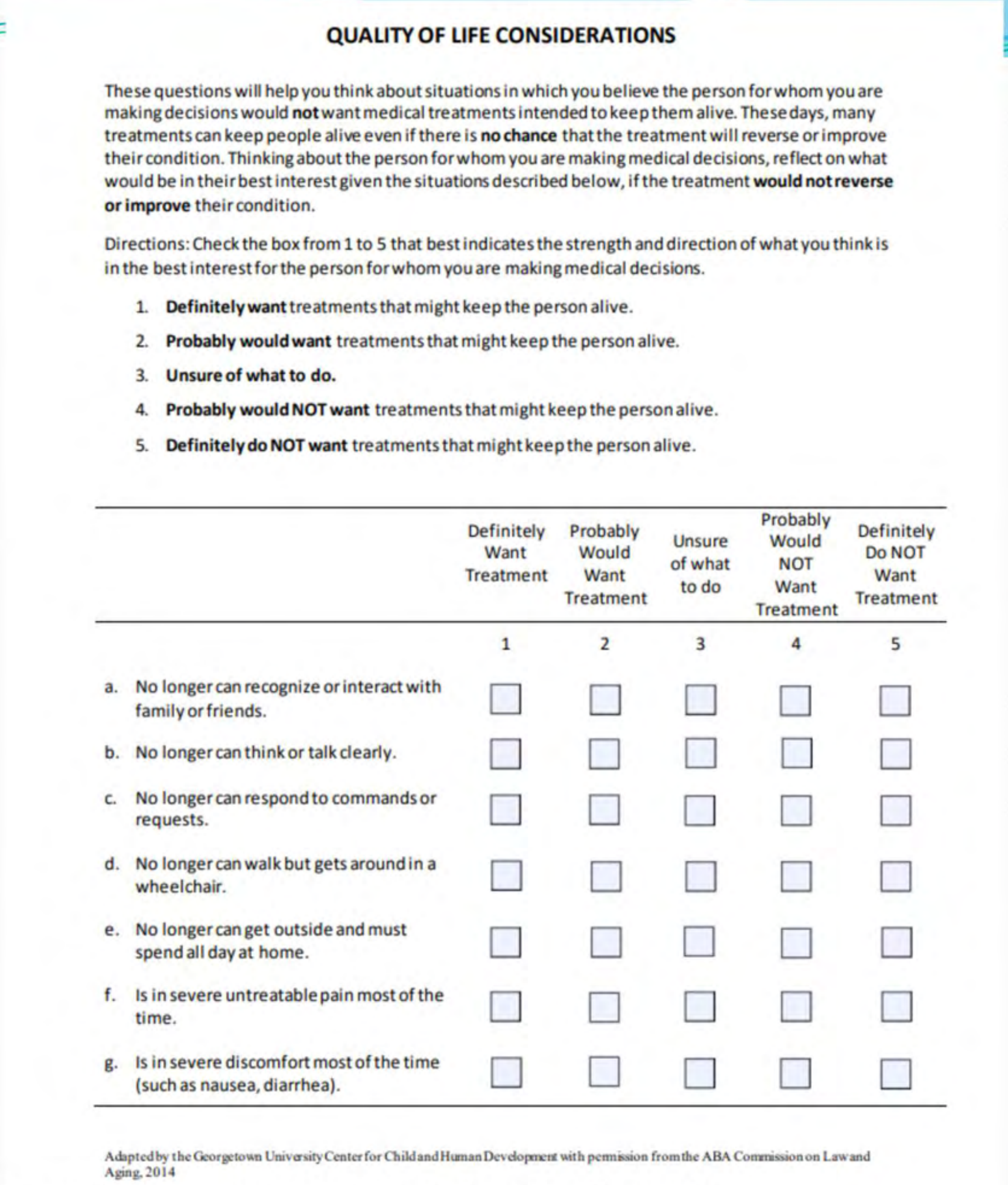
© 2018 Georgetown University Center for Child & Human Development

QUALITY OF LIFE

Subjective and unique to that individual

Hard to measure and difficult to predict

© 2018 Georgetown University Center for Child & Human Development



QUALITY OF LIFE CONSIDERATIONS

These questions will help you think about situations in which you believe the person for whom you are making decisions would **not** want medical treatments intended to keep them alive. These days, many treatments can keep people alive even if there is **no chance** that the treatment will reverse or improve their condition. Thinking about the person for whom you are making medical decisions, reflect on what would be in their best interest given the situations described below, if the treatment **would not reverse or improve** their condition.

Directions: Check the box from 1 to 5 that best indicates the strength and direction of what you think is in the best interest for the person for whom you are making medical decisions.

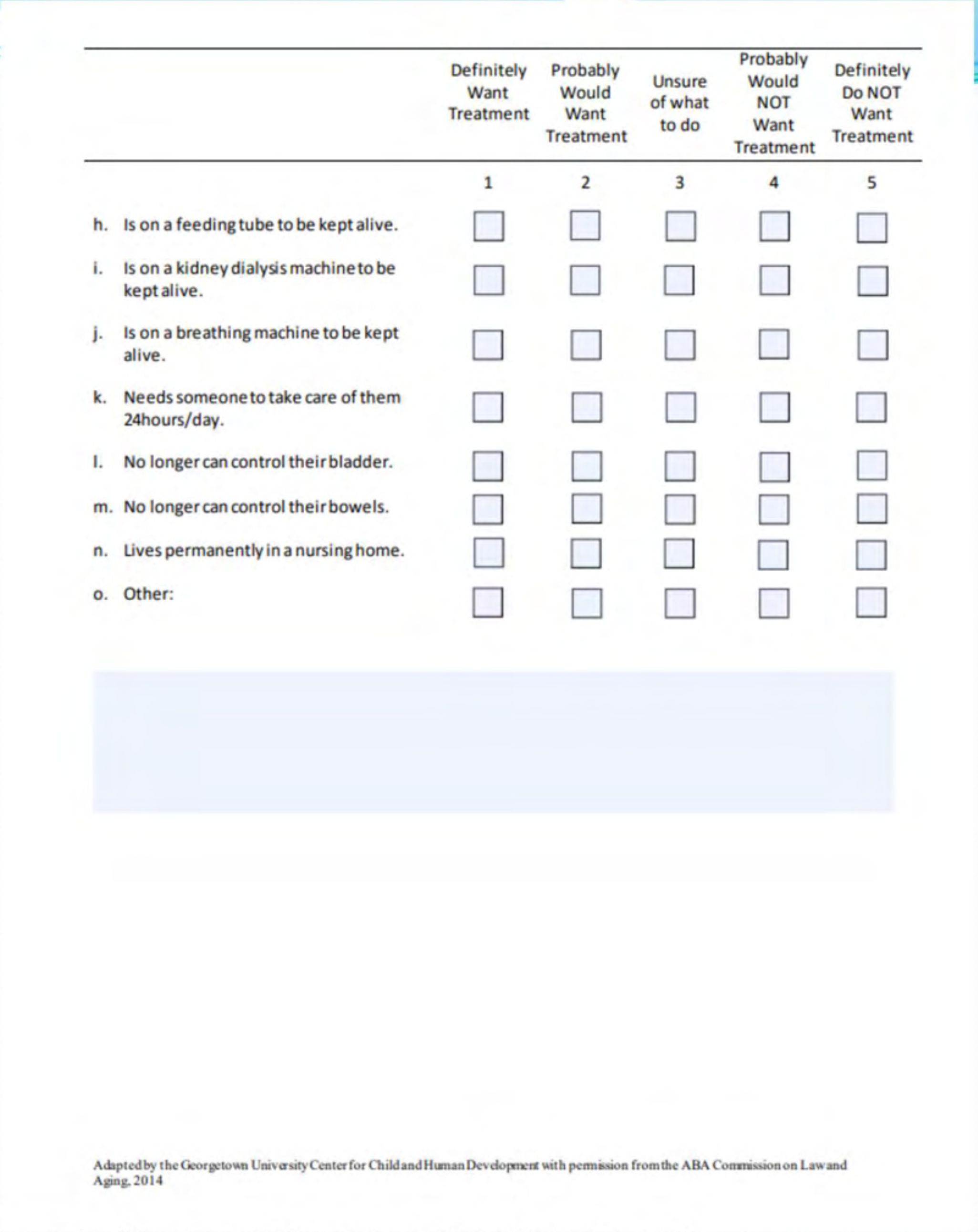
1. **Definitely want** treatments that might keep the person alive.
2. **Probably would want** treatments that might keep the person alive.
3. **Unsure of what to do.**
4. **Probably would NOT want** treatments that might keep the person alive.
5. **Definitely do NOT want** treatments that might keep the person alive.

	Definitely Want Treatment	Probably Would Want Treatment	Unsure of what to do	Probably Would NOT Want Treatment	Definitely Do NOT Want Treatment
	1	2	3	4	5
a. No longer can recognize or interact with family or friends.	☐	☐	☐	☐	☐
b. No longer can think or talk clearly.	☐	☐	☐	☐	☐
c. No longer can respond to commands or requests.	☐	☐	☐	☐	☐
d. No longer can walk but gets around in a wheelchair.	☐	☐	☐	☐	☐
e. No longer can get outside and must spend all day at home.	☐	☐	☐	☐	☐
f. Is in severe untreatable pain most of the time.	☐	☐	☐	☐	☐
g. Is in severe discomfort most of the time (such as nausea, diarrhea).	☐	☐	☐	☐	☐

Adapted by the Georgetown University Center for Child and Human Development with permission from the ABA Commission on Law and Aging, 2014

https://ucedd.georgetown.edu/complex/documents/Worksheet-Considerations.pdf

© 2018 Georgetown University Center for Child & Human Development



	Definitely Want Treatment	Probably Would Want Treatment	Unsure of what to do	Probably Would NOT Want Treatment	Definitely Do NOT Want Treatment
	1	2	3	4	5
h. Is on a feeding tube to be kept alive.	☐	☐	☐	☐	☐
i. Is on a kidney dialysis machine to be kept alive.	☐	☐	☐	☐	☐
j. Is on a breathing machine to be kept alive.	☐	☐	☐	☐	☐
k. Needs someone to take care of them 24hours/day.	☐	☐	☐	☐	☐
l. No longer can control their bladder.	☐	☐	☐	☐	☐
m. No longer can control their bowels.	☐	☐	☐	☐	☐
n. Lives permanently in a nursing home.	☐	☐	☐	☐	☐
o. Other:	☐	☐	☐	☐	☐

Adapted by the Georgetown University Center for Child and Human Development with permission from the ABA Commission on Law and Aging, 2014

https://ucedd.georgetown.edu/complex/documents/Worksheet-Considerations.pdf

© 2018 Georgetown University Center for Child & Human Development

Ethics Workup Case Analysis

- Scenario #1: 50 year old female with CP and CVA
- Scenario #2: 40 year old male Down's and Dementia
- Scenario #3: 65 year old female with ESRD
- Scenario #4: 85 year old male with stage 4 lung cancer

© 2018 Georgetown University Center for Child & Human Development

References

Alzheimer's Association. (no date). "Assisted oral feeding and tube feeding."

American Geriatrics Society. (2013). "Feeding tube in advanced dementia position statement."

Ardagh, M. (2000). "Futility has no utility in resuscitation medicine". Journal of Medical Ethics. 26: 396-399.

Boggs Center. (2013). "Ideas from your peers: strategies for supporting grief, loss, and end of life issues compiled from strategy planning groups at the Boggs Center's grief, loss, and end of life workshops".

DDA Health Initiative. (2017). "Emergency medical treatment for people on comfort care".

Keene, S., Samples, D., Masini, D., Byington, R. (2006). Ethical concerns that arise from terminal weaning procedures of a ventilator dependent patient a respiratory therapists perspective". The Internet Journal of Law, Healthcare and Ethics. 4 (2); 1-6.

Ngo-Metzger, Q., August, K., Srinivasan, M., et al. (2008). End-of-life care: guidelines for patient-centered communication. American Family Physician. 77, (2): 168-174.

Perkin, R., and Resnik, D. (2002). "The agony of agonal respiration: is the last gasp necessary?". Journal of Medical Ethics. 28: 164-169.