Thinking Ahead

Advance Care Planning for People with Developmental Disabilities
Objectives

- Review principles and importance of ACP
- Describe the steps of the ACP process
- Describe the role of patient, proxy, clinician, and others
- Identify pitfalls and limitations in ACP
Principles of ACP

ACP is an ongoing conversation between the patient, family members, friends, and providers to ensure treatment plans are aligned with the individual’s goals and values.

The goal is to support the individual in making well-informed treatment choices from among the full range of options for their care—whether life-prolonging, or entirely comfort-focused, or something in-between.

The desired outcome is documented decisions about goals and wishes, medical treatments, desired location of care, and alternate decision-maker.
Why is ACP Important?

- All persons have a right to be active participants in their healthcare.
- ACP ensures that persons are able to express their wishes, and make decisions for themselves.
- ACP articulates a person’s wishes and fears and also what supports are needed to have a meaningful quality of life on their own terms.
ACP Steps

- Introduce the topic.
- Engage in discussions.
- Document the person’s preferences.
- Review, update based on change in circumstances.
- Apply directives when need arises.
Introduce the Topic

- Assess person’s readiness to discuss ACP
- Reflect on what you know about the person.
- Gather any needed information about the person.
- Try a test question to assess person’s readiness to discuss ACP.
- Determine need to include appropriate representative in the discussion.

Start the discussion

“Talking about death and dying is hard, but thinking ahead will let you make your own decisions about your care during your final days.”
Engage in Discussions (1)

Assess person’s current understanding of their health and their disease trajectory.

Discuss the importance of choosing the right person to speak for them when they cannot speak for themselves.

Ideal scenario is for the designated health care proxy to be present for discussions about ACP.
Engage in Discussions (2)

- Discussion should include familiar care examples, scenarios, or videos to assist in discussion and decision making process.
- Discuss treatment and care options.
- Elicit individual’s values and goals.
Document Person's Preferences

- Advance directive information should be documented on a proper form.
- Form should be completed fully, including the mandatory individual signature and witness signature.
- Designated Health Agent should be identified and contact information should be included in advanced directive form.
- Additional care wishes should be documented on the form.
ACP: Review, Update, Change

- Review document periodically.
- Review with major life events.
- Discuss impact of life events and document any ACP changes.
Apply Directives

- Determine applicability of ACP to current situation.
- Read and interpret the advance directive.
- Consult with the proxy if person is unable to speak for self or requires assistance with decision-making.
- Call for ethics consult if there are disagreements on treatment plan.
- Carry out treatment plan.
Roles in ACP

- **The Role of the Patient:**
  - To express values and goals and engage in discussion and make choices about care.

- **The Role of the Proxy:**
  - Entrusted to speak for the patient.
  - Involved in the ACP discussions.
  - Willing able to take the proxy role.

- **The Role of the Clinician:**
  - Educate the patient and proxy on medical terms, facilitate discussion, illicit individual’s values and goals.

- **The Roles of Others:**
  - To bring additional relevant information to the discussion to assist individual in their decision making process.
ACP Pitfalls and Limitations

- Failure to plan
- Proxy absent for discussions
- Unclear patient preferences
- Focus too narrow
- Communicative patients are ignored
- Making assumptions
Answers to Important Questions
Why Do I Think ACP is Important?

It is important to me because:

- It gives me reassurance that when the time comes, my family and friends know what I want at the end of my life.
- I have everything written up about what I want so my family doesn’t need to worry about what they think I might want.
It’s important for people with developmental disabilities to express their thoughts on what they want all the way through their life even at the end. It is a right as well as a responsibility for us to be involved.
How has ACP helped me plan for the future?

People know what I want. Some examples:

- I am writing out my own Obituary.
- I know what I want to be said on my stone.
- I made a list of who I want my belongings to do to.

How does it make me feel to plan for the end of my life?

- It makes me feel secure knowing that my family and friends have all my information on what I want done at the end of my life.
- It’s a comfort that my family and friends already know what my choices and decisions are so no one would argue about it.
- Putting my family and friends at peace is important to me.
What was the ACP Process Like For Me?

- **Good Thoughts:**
  - My responsibility
  - Not leaving people worried
  - Having a voice

- **Bad Thoughts:**
  - It made me feel uncomfortable
  - I did not know what my needs and wants were right away
  - I did not want to think about what might happen to me someday
What Do You Need To Know To Help Me with ACP?

- Our voice is important.
- The people that we trust to make decisions in our lives may not be who you think it is.
- Start asking questions and work with us ahead of time.
- Become familiar with publications designed to help us with the conversation on end of life issues.
- Honor our wishes.