

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 go 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.

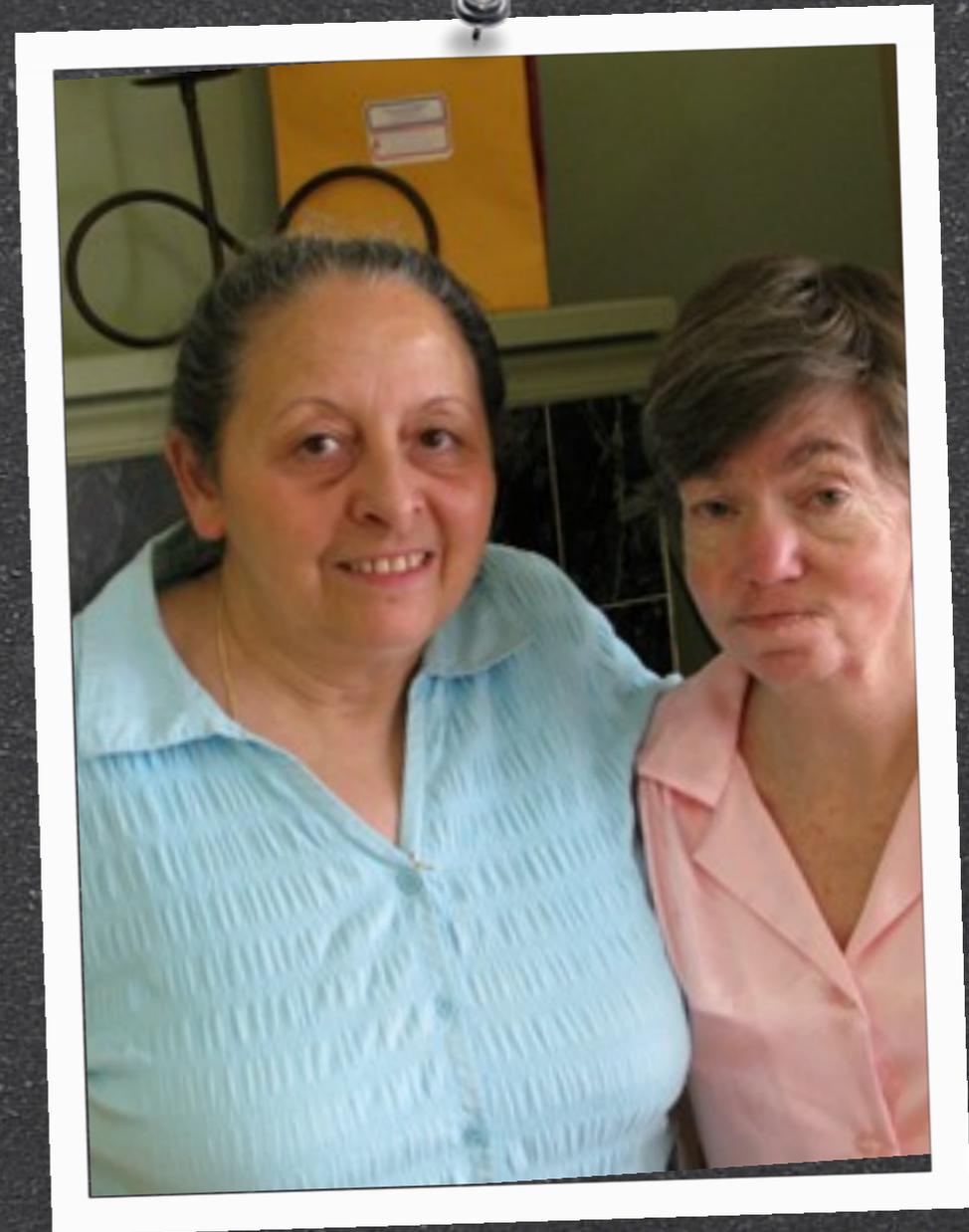
What was the ACP Process Like For Me?

• 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.

