Supporting Families in Advance Care Planning

With thanks to Patricia O'Malley, MD, for her contributions of content and editorial review.

Learning Objectives

After reviewing this Guide you will be able to:

- Recognize the value of advance care planning (ACP) as a tool to enhance communication with families, build trust, engage in shared decision-making, and improve the care of medically complex children
- Consider strategies to introduce families to ACP, and to support them in reflecting on their values and goals throughout the course of the illness (not only at end of life)

Benefits of Advance Care Planning

Advance care planning is a set of communications, in conversation and in writing, between an individual, their family and clinicians as they consider the values, goals and preferences that should guide medical treatment. These communications can be considered an aspect of palliative care for individuals of any age. Advance care planning can be particularly challenging in pediatrics–and especially in the context of a child's complex condition, as many children will not be able to verbalize their wishes and parents can feel the added burden of surrogate decision-making.

While the number of studies of advance care planning in pediatrics is small, there is growing awareness that the process has a positive impact on quality of life for the patient and family, and on clinician fulfillment. This is because ACP:

- Provides information about potential decisions to be made. Even when the information is upsetting, parents want to know their child's prognosis and what might lie ahead. They tend to prefer more information (with exceptions, of course). This prognostic information does not compromise hope and, indeed, appears to support hope even in the setting of a poor prognosis.

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- Encourages understanding of clinical information; supports participatory decision-making and planning. Advance care planning conversations involve the primary caregivers in considering– and, if necessary, reviewing and re-considering–care goals and options. Adolescents often wish to participate in the process when given the opportunity. ACP gives the participants some sense of control, and helps them feel confident that their decisions will be honored.
- Helps the clinical staff to provide care that is consistent with the family's wishes. Written ACPs are beneficial when a child has complex medical needs, especially if there is concern that the needs will not be well understood by clinicians who are unfamiliar with the child.

As conversations and planning have been occurring more purposefully, it appears that:

- More goal-oriented care is realized, with fewer hospitalizations
- Patient and family coping skills are improved and stronger
- Parents experience less decisional regret
- Palliative and hospice care are being introduced earlier, providing additional support to families at home

Initiating Advance Care Planning with Families (When)

Advance care planning may begin right from diagnosis of a serious illness, as it preferably includes multiple conversations over time. Conversations should occur whenever a family initiates or requests one; perhaps with every hospitalization, particularly if there is a recommended change in the treatment course; and/or whenever there is a change in the baseline of the child's health. Planning also is necessary if the prognosis for the child's disease changes and if the child's death seems likely.

Introducing Families to ACP (How)

Communication is about establishing a caring connection between the child, family and healthcare team. Thus, using words not simply to convey information, but also to express empathy and vulnerability is an important skill. Introducing advance care planning to a family can be normalized as part of your practice. There are increasing educational opportunities to learn and practice communication. Here are some ways to get started:

> "With all of my patients I like to make time to think together about what we might face in the future."
>
> "It feels like we are in a new place—can we talk about that?"

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Family members are the only ones who can speak to what is most important to them. Asking permission to explore hopes and worries with the parents and/or the child about what might lie ahead helps establish that there can be a shared understanding of what is occurring and what that future might hold. These conversations open the door to other questions that address what the family may be wondering about:

> "What do you know or have you been told about your child's illness?"
>
> "What are your hopes for their health?"
>
> "What are your worries?"
>
> "May I tell you my understanding?"
>
> "If your child gets sicker, what is most important?"

The answers to questions like these allow you to respond appropriately and meaningfully if the parent or child asks for advice ("what would you do?"). You can use their responses to clearly tie your recommendations to the family's goals and values while demonstrating your respect for them. You might consider language like this:

> "Based on your child's medical condition and what you have told me about your hopes, I recommend..."

Including the Child

No matter their age or developmental stage, children have the ability to sense the emotional state of parents and caregivers. Nonverbal children may still speak with their eyes or their cries or other communication cues. We know that children overhear conversations and observe and interpret their family's reactions. They may imagine things to be worse than what is. Silence and/or not telling can cause a rupture of trust and a sense of loss of autonomy, giving the child no chance to engage in meaningful activities or to make their wishes known. When children are given information in a developmentally appropriate manner, they have an opportunity to talk about their own fears, ask questions about what is being considered, and express their feelings. A family's culture, beliefs and history will also influence these conversations.

Therefore it is important to include the child, as they are able, possibly also involving a child-life specialist or psychosocial clinician. Allowing the child to express feelings through art or play and/or talking may not only benefit the child, but will provide information for caregivers. After it was realized that often teens and young adults want their voice to be heard, the tool Voicing My ChoicesTM was created with their input.

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As ACP conversations move to include end of life planning, even very young, verbal children may be able to share what is most important to them; for example, telling a parent, "I don't want to go back to the hospital." Honest conversations help parents know their child's wishes, which can support their decision-making at end of life. One Courageous Parents Network mother reflects, "Those conversations ended up being my saving grace because then I had no regrets."

A child's inability to participate due to age and/or developmental level places an added mental and emotional burden on the parents ("I wish I knew what she would want."). Still, parents know their child best and clinicians will ideally listen and respect parents' interpretation of what their child is feeling ("I can see he is getting tired" or "I can tell that she doesn't want to fight any more").

Advance Planning for End of Life

While families don't typically initiate conversations about end of life, they may well be thinking about it and be willing to engage. In fact, when the topic is raised parents typically feel relief.

When a family is facing the likely death of their child, advance care planning becomes more focused on helping parents and the child, if appropriate, with decisions regarding preferences for resuscitation, orders for life-sustaining treatment, use of medical technologies and preferred location of death. These are the most sensitive conversations to engage in, and some families may not wish to do so–at least not initially.

The conversations can also become a way for parents to share what they would otherwise carry in silence. Nevertheless, there are fears and assumptions that are potential obstacles. Parents may worry that talking about death will make it happen sooner, that talking about death indicates that they are giving up on their child. Parents generally still want to know treatment options when confronted with any given medical event, even if medical directives have been chosen. They worry that if they ask questions or establish directives they will not have the option to change their mind. They also may be bewildered if offered a list of possible resuscitation interventions that cannot be understood outside the context of their child's medical condition and the family's goals.

> *Note: Specific to resuscitation, some families may assume that these attempts are usually successful (as they see in the movies or on television). Most are unaware that health care providers are bound by law to begin resuscitation attempts unless there is an order instructing them not to do so.*

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Here are some of the other common, often unspoken questions that may be on parents' minds:

- How will I know when we have done enough?
- How will I know whether to stop or change treatment?
- Will others think I am giving up? Will I?
- How will my child die? What will it look like?
- What should I tell my other children about what to expect?
- Will my family survive our child's death? Will I?

These are questions with no easy answers. Having in-depth conversations will be required. It may feel supportive to include palliative care specialists or other specialists trained in supporting families at this tender time.

Conclusion

Although a life-threatening event may occur at any point in our lives, this possibility comes into sharper focus when someone is diagnosed with a serious illness. Advance care planning is hard. Rarely do individuals or caregivers want to think about the "what-ifs." While clinicians are often tasked with beginning the conversation, these discussions and decisions will help ensure that the child receives the best possible care, consistent with the family's beliefs, values and wishes.

Resources for Families

Handouts/Downloadable Guides

Family Meeting: Being Prepared

Over the course of your child's illness there will likely be family meetings proposed by different clinicians. These meetings may be used as a way to present clinical updates, consider decisions about interventions, check in about how family members are coping, and/or address any questions you or the care team might have.
https://courageousparentsnetwork.org/guides/family-meeting-being-prepared/

Understanding Medical Orders

Explains full resuscitation, DNR, DNI, AND and MOLST
https://courageousparentsnetwork.org/guides/understanding-medical-orders

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Understanding Baseline

Over the course of your child's illness there will likely be family meetings proposed by different clinicians. These meetings may be used as a way to present clinical updates, consider decisions about interventions, check in about how family members are coping, and/or address any questions you or the care team might have.
https://courageousparentsnetwork.org/guides/understanding-baseline/

Voicing My Choices

Planning Guide for Adolescents & Young Adults, from FiveWishes.org.
https://store.fivewishes.org/ShopLocal/en/p/VC-MASTER-000/voicing-my-choices

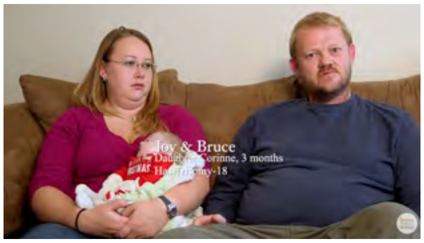
Videos

The Role of Medical Orders: Understanding the Alphabet Soup (MOLST, POLST, DNR, DNI

Brief overview of the role these orders play, with parent voices sharing how they have used them.
https://courageousparentsnetwork.org/videos/understanding-medical-orders-molst-polst-dnr-dni-and-their-role/

"Wait a minute, we're off script."

Parents and their palliative care doctor discuss the last 24 hours of their son's life and the role of palliative care in advocating for them in their moments of fear and sadness.
https://courageousparentsnetwork.org/videos/the-last-24-hours-we-were-not-ready-for-it-wait-a-minute-were-off-script/



"We're going to take one day at a time, enjoy every day, and let nature take its course."

Parents express faith in their child's ability to determine her own path.
https://courageousparentsnetwork.org/videos/2459-2/

"We knew we could revoke [hospice] at any time and go back to the hospital. … and then she said, 'no hospital.'"

Mother remembers the journey from no-hospice to hospice, inspired by her dying daughter's articulation of her own wishes.
https://courageousparentsnetwork.org/videos/a-mom-on-the-decision-to-put-her-daughter-in-hospice-we-knew-we-could-revoke-it-at-any-time-and-go-back-to-the-hospital-and-then-she-said-no-hospital/