Provider Language

to support the family

Diagnosis

When a family has just learned of a new diagnosis, it may be helpful for them if you name the feelings that you have seen other parents undergo. This will help normalize the abnormal for them. You might say something like:

- **Anticipatory grief**
  “Even though your child has not been changed by this new diagnosis—she is the same child she was before the diagnosis—what have changed are your dreams and imagined future for your child. These have had to undergo a tremendous change. It is so much to get your mind around. It is typical for parents to experience a range of feelings, including anger, sadness, fear, guilt.

“If it would be helpful for you to listen to other parents describe their feelings after diagnosis, or to hear a psychologist talk about it from a professional standpoint, then I would recommend going to the Courageous Parents Network website. It is a professional website featuring videos of parents talking about this, and you will see that you are not alone.”

- **Disorientation**
  “I have heard other parents describe how disoriented and overwhelmed they feel. They describe landing in a strange land and feeling totally lost. They talk about being afraid they might not be able to manage everything. They worry they will lose control. They worry they will let their family down. They also don’t know what help they need. and they worry they will have to reach for help in ways they never have had to before. If these are things that you have been feeling, you need to know that this is normal common experience and that you are not alone.

“I think you might find it helpful to watch some videos of other parents who have had to deal with this. These videos also include tips from them for how to navigate the hospital culture.”

“We offer a community of other parents experiencing similar experiences.” (CPN trailer)

“We help parents of seriously ill parents understand their emotions.” (CPN trailer)

Palliative Care

You might use language like this for describing palliative care and introducing CPN videos.

“May I talk with you about something I have been thinking about for (your child)? I have been seeing how she is having a harder time with (x,y,z) and that you and I are having more difficulty finding the best choices for her. It feels as if the decisions are just getting more complicated. I know a pediatric specialist at the hospital who helps families think through what is most important when choices are just getting harder. This person is part of the palliative care team. Have you heard of palliative care before? Many people have not heard of palliative care and some who have often think it is just for end of life. They think it is hospice. But that’s not what it is: it’s for families whose child has a serious medical diagnosis involving difficult decisions and a future that holds a lot of uncertainties. I have heard from other families how helpful it has been to talk with a palliative care specialist at this stage you are in.

“Perhaps you would like to hear from some other families that have teamed with palliative care. There is a website where you will find other parents talking about how it helped their child and family. These families have helped me consider when it could be helpful. I think their words may be even more persuasive than mine to reassure you of why I think it’s a good idea to introduce palliative care early. As one of the doctors says, pediatric palliative care is not the end of hope, it can be the beginning of finding your way. You may find other parts of the website really helpful as well. You could start with this intro video.”

“This is my child. This is what we care about. This is what we hope for."

Decision Making

Julie Hauer, MD speaks about our role as offering guidance, asking permission, and then creating a space for family member to reflect and revisit. So, in supporting a family member facing medical choices for their medically complex child, you might say, “It feels as if we are in a new place/beginning a new stage with [your child]. It would be good to review together whether what is most important to you has changed because of what we know now. I have seen other families worry about making the right choices as their child’s condition declines. They don’t know if doing more is the right thing or not. Sometimes doing more feels right and then sometimes it’s the opposite, where doing less feels like the right thing. Can we talk about this? Would it be helpful to see how other families have thought about difficult medical decisions?”

Supporting the Family

When a parent voices concerns about how to support their other children (the siblings) or how to navigate a difference in how they and their spouse/partner is coping, or other family issues, you can help by first normalizing these concerns and then offering the resources of CPN as a way to hear from fellow parents who have been there too.

And if the parent doesn't raise these issues directly with you, they will often be grateful when you ask about them yourself and give them an opening to discuss:

- "I know under these difficult circumstances that parents often worry about the healthy siblings—how are they doing?"
    - Then, based on the parents' response, introduce CPN: "Worry about the other siblings is a universal concern for parents in your situation. You may find it helpful to hear how other parents have wrestled with this natural concern, including how they talk to the kids about their sibling's condition and prognosis, how they include the siblings in the care, how they make time for them, how they feel guilty when they don't."
- "I know under these difficult circumstances that parents often must divide tasks, and sometimes feel isolated, disconnected from, or resentful of each other—how are you two managing?"
    - Then, based on the parents' response, introduce CPN: "Managing the partnership and your spouse/partner can be a big issue. It is really common for people to respond differently, and this can make a tough situation feel harder. You may find it helpful to hear how dozens of other parents have wrestled with the relationship dynamic."

- "What do your other family members know about what is going on? Have they been helpful or has it made it harder to include them?"
    - Then, based on the parents' response, introduce CPN: "Extended family, like grandparents, can play a big role—sometimes for good, sometimes not. This website has resources for extended family, including some grandparent videos and a Guide with tips on how they can be helpful that you may even want to share with family members."

The more you can demonstrate understanding and empathy and can anticipate family concerns and dynamics, the more healing your care will be.

Advanced Care Planning

Introducing advance care planning to a family can be normalized as part of your practice; e.g., “With all of my patients I like to make time to think together about what we might face in the future,” or may be occasioned by a change in health status or treatment option: “It feels like we are in a new place—can we talk about that?”

The particular words we use as providers are likely not as important as simply asking about goals and values, indicating your willingness to hold this space for a family and enter it with them. A template like the Framework for The Difficult Decisions, adapted from the Serious Illness Checklist, asks permission to explore hopes, worries, and values for their child’s future before opening discussion. This helps establish that there is a shared understanding of what is going on and what that future might look like. Family are the only ones who can speak to what is most important to them, and we cannot know what that is unless we ask. Our medical recommendations need to be shaped by their goals and values.

When providers engage in advance care planning, they may be asked by family, “What would you do?” While many providers dodge this question with the truthful reply that they do not know, it is possible to support the family by providing suggested tools for decision-making.

We can explore how they make decisions, what they use as their navigational tools. For instance, do they consult family, elders, spiritual advisors, prayer? Is there something that they must stay loyal to, no matter how tough it gets, that guides their choices? If the choices all appear equally to lead to loss, is there a choice that will reduce regret? The following list of questions provide a different way to think about decision-making.

Personal dignity: What do you want medical providers to know about your child and you, as a person and as a family, in order to help you make the best plan of care?

- Information preferences: How much information do you want and can your child handle about what is likely to be ahead with this illness?
- Decision-making: What are the touchstones you use to make these difficult decisions? What could help you feel that you have made the best decisions you could for your child? What do you feel your child is telling you? Do you see any difficult medical decisions ahead? How will you know if it is time to consider stopping treatments?
- Goals: If your child’s health situation worsens, what are your most important goals, for your child, and for your family?
- Fears/worries: What are your biggest fears and worries about the future given your child’s condition?

- Hopes: Given what you know about what might happen, and what your child is up against, what are your hopes for your child and family?
- Tradeoffs: If your child becomes sicker, how much do you think it makes sense to have him/her go through different treatments for the possibility of gaining more time with you and your family?
- Function: Are there specific life conditions or states that you would not find acceptable for your child to be in? For example, being on a ventilator for the remainder of her life.
- Family: How much have you, your family, and your child talked about these issues? Would you like help talking with other family members about these difficult issues?
- End of Life: If it must be that your child will die, where would you and your family want your child to be when dying? Is there the possibility of a "good death" for your child, and what would it look like, for you, your family, and your child? Is there anything that you or your medical team could do that might make you less fearful of your child's death?

Asking the family if it would be helpful if you made a recommendation may support them at a time when they may be feeling overwhelmed. When that recommendation is clearly tied to their values, it reflects your respect for those values: "From what you have said about how important it is to you that your child be at home and avoid hospitalizations, I would recommend that we explore hospice as a way to make that happen."