

1. Set up the Conversation

- Introduce the idea and benefits
- Prepare for future decisions
- Ask permission

"With your permission I'm hoping we can talk about where things are with your child's [insert child's name] illness and where things might be going — is that ok?"

OR

"Talking today will help us get to know you and your child better and help us prepare and plan for the future. Is this okay?"

2. Assess Illness Understanding and Information Preferences of Parent

"What is your understanding now of where your child is at with his/her illness?"

"How much information about what is likely to be ahead with your child's illness would you like from me?"

3. Share Prognosis

- Frame as "I wish ... worry, and/or I hope ... wonder ..." statement
- Allow silence, explore emotion

Clinicians have a responsibility to provide parents with ongoing support and guidance as symptoms of dying become present.

"My understanding of where things may be at with your child's illness is ..."

Uncertainty: "It can be difficult to predict what will happen and when. I hope he or she will continue to live well for a long time, but I worry given what we know (Insert information about illness/condition) ... he or she could get sick quickly ..."

Function: "I see the following (fragility, instability, assessment of function) and I am worried that this represents ..."

Time: "It is very difficult to predict time. Like you, I also want your child to ... But I am worried that time may be shorter than we hope." *If using time in prognosis, it MUST be paired with a statement of uncertainty and with function information.

4. Explore Key Topics

- Goals
- Fears and worries
- Sources of strength

Optional points to explore

- Critical abilities
- Trade-offs (balance of interventions)
- Involvement of child and/or siblings

"What are your most important goals/hopes if your child's health worsens?"

"What are your biggest fears and worries about the future with your child's health?"

"What gives you strength as you think about the future with your child's illness?"

"What abilities are so critical to your child's life that you can't imagine him/her living without them?"

"If your child becomes sicker, how much medical intervention are you willing to go through for the possibility of gaining more time?"

(see reverse)

If involvement of child / sibling is appropriate / necessary, arrange for another meeting to explore (see reverse)

5. Closing the Conversation

- Summarize
- Make a recommendation
- Check-in with parents
- Plan follow-up

"I've heard you say (insert goals/hopes)... is very important to your family and that you also worry about ..."

"Keeping this in mind and what we know about your child's illness, I recommend that ... (e.g.; change the care plan, create ACP, watch and wait)."

"How does this plan seem to you?"

"We will schedule/check-in again in (time frame — days/weeks/month) to ensure ongoing support."

6. Document your Conversation

7. Provide Documents to Parents

8. Communicate with Key Clinicians

Assessing with Parents their Child(ren)'s Understanding/ Involvement

Questions to be considered if child (or sibling) is able to participate in the conversation:

- "What do you believe your child understands about his/her illness?"
- "How much information do you think your child is ready for? And from whom?"

Consider exploring the child's (and/or siblings) biggest:

HOPE "What goals or hopes do you think your child(ren) have?"

FEARS AND WORRIES "What worries or fears do(es) your child(ren) have?"

STRENGTH "What are your child(ren)'s strengths?"

CRITICAL ABILITIES "Have you spoken with your child or other children about your priorities and wishes? Do you know what theirs are?"

If you are sharing or supporting the parents to share the prognosis with the child or siblings, consider stage of development, temperament, and available supports (e.g. parent, counsellor).

Reciprocal/Attuned Responses

NON-VERBAL

- Use of silence, pauses
- Physical space/body positioning

VERBAL

- Inquiry
- Advice (given when asked)
- Reflection (paraphrase words, meaning or circumstance)
- Responding safely to emotion
- Normalizing/acknowledging experience

Assessing Clinical Status to Help with Prognosis Wording

FRAGILITY: degree of risk of a significant deterioration

INSTABILITY: rate of change in child's wellbeing

ROBUST

FRAGILE

STABLE

UNSTABLE

CNS: seizures, increased ICP, hemorrhage

SYMPTOM BURDEN: pain, nausea, feeding intolerance, dyspnea etc.

CVS: heart function, arrhythmia, hemodynamics

CARE NEED CHANGE: feeding, respiratory, transfusion support

RESPIRATORY: central +/- pulmonary

FUNCTIONAL CHANGE: eating, ambulation, interaction/engagement

GI: nutritional status, obstruction

DEVELOPMENTAL CHANGE: loss of or failing to meet milestones

IMMUNE SYSTEM: sepsis

Wish/Worry Framework

RATIONALE

- "I wish" allows for alignment with the parent's & child's hopes.
- "I worry" allows for being truthful while sensitive.
- "I wonder" is a subtle way to make a recommendation.
- "I will" is a direct way of expressing your commitment to ongoing support and care.

Examples:

- "I wish we could slow down or stop your child's cancer/disease and I will continue to look for options that could work for him/her."
- "But I worry that you, your child, and your family won't be prepared if things don't go as we hope."
- "I wonder if we can discuss a plan if symptoms continue to get worse."
- "I will continue to connect with you daily so we can ensure this plan is working."

Goals of Care

SUSTAIN LIVING

SUSTAIN LIVING + COMFORT
CONSIDERATIONS

COMFORT-FOCUSED

Optional Questions to Explore

CRITICAL ABILITIES

Explore if parents have indicated that they are weighing development and abilities in treatment decisions. Listen for subtle inquiries about what is 'ok' to do or not do.

With infants or critically ill children, ask about 'future' abilities and hopes and fears related to those.

With non-verbal children with disabilities, listen for the abilities the parent's value and explore potential losses of those.

TRADE-OFFS — BALANCE OF INTERVENTIONS

Examples of trade-offs are time in hospital vs time at home, increasing respiratory support (bipap, intubation), treatment for potentially reversible causes, or care planning directed at comfort treatments. Provide recommendations about what may or may not be of benefit instead of offering a 'choice' or a menu of options.

INVOLVEMENT OF CHILD/SIBLINGS

(See Assessing with Parents their Child(ren)'s Understanding/ Involvement)

Self-Awareness – Consider your Tendency to...

- Fix, placate or falsely reassure
- Overly identify
- Feel responsible (role or relationship)
- Be triggered by strong emotion
- Avoid difficult feelings or difficult comments from parents
- Be attached to own agenda