

<p>1. Set up the Conversation</p> <ul style="list-style-type: none"> • Introduce the idea and benefits • Prepare for future decisions • Ask permission 	Set up	<p>“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?”</p> <p>OR</p> <p>“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?”</p> <p><small>*Denotes an infant, child, or teen</small></p>
<p>2. Assess Illness Understanding</p> <p>Assess Information Preferences</p>	Assess	<p>“What is your current understanding of where your child is at with his/her condition, diagnosis, or symptom?”</p> <p>“How much information about what is happening or what might be ahead would you like from me?”</p>
<p>3. Share Prognosis</p> <p>Provide your understanding based on the child’s function, test results, body systems</p> <p>Frame as “I wish ... worry, and/or I hope ... wonder ...” statement</p> <p>Allow silence, explore emotion</p>	Share	<p>[Use one or two of the following categories to be explicit with the family about what may be ahead.]</p> <p>Function: “I see the following (fragility, instability, assessment of function) and I am worried that this represents ...”</p> <p>Uncertainty: “It can be difficult to predict what will happen and when. I hope he /she will continue to live well for a long time, but I worry given what we know (Insert information about illness/condition) ... he/she could get sick quickly ...”</p> <p>Time: “It is very difficult to predict time. I too hope your child will improve or do well for a long time... But I am worried that time might be shorter than we hope.”</p>
<p>4. Explore Key Topics</p> <ul style="list-style-type: none"> • Goals • Fears and worries • Sources of strength <p>Optional points to explore</p> <ul style="list-style-type: none"> • Experiences/activities essential to life • Trade-offs of risk vs benefits (balance of interventions) 	Explore	<p>[Given this [prognosis] it will be helpful for me to ask you some more key questions...]</p> <p>“What are your most important goals/hopes if your child was to get sicker?”</p> <p>“What are your biggest fears or worries related to your child’s health?”</p> <p>“What gives you and your family strength?”</p> <p>“What activities or experiences give meaning or are essential to your child’s life?”</p> <p>“If your child was to have a setback, what interventions do you think may help or be of benefit?”</p> <p>“Are there interventions or treatments that you feel may cause burden or discomfort?”</p>
<p>5. Closing the Conversation</p> <ul style="list-style-type: none"> • Summarize • Make a recommendation • Check-in with parents • Plan follow-up and close 	Close	<p>“I’ve heard you say (insert summary of parents words).... is very important to your family and that you also worry about ...”</p> <p>“Keeping this in mind and what we know right now, I recommend. that we...(e.g. meet again, change the care plan, document goals of care, watch and wait).”</p> <p>“How does this plan seem to you?”</p> <p>“So next steps or follow-up will include” “Thank you for meeting with me today”</p>

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/EXPERIENCES “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

ROBUST

FRAGILE

CNS: seizures, increased ICP, hemorrhage

CVS: heart function, arrhythmia, hemodynamics

RESPIRATORY: central +/- pulmonary

GI: nutritional status, obstruction
Immune System: sepsis

INSTABILITY: rate of change in child's wellbeing

STABLE

UNSTABLE

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

CARE NEED CHANGE: feeding, respiratory, transfusion support

FUNCTIONAL CHANGE: eating, ambulation, interaction/engagement

DEVELOPMENTAL CHANGE: loss of or failing to meet milestones

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

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