**Serious Illness Care Program-Pediatrics**

*Reference Guide for Inter-professional Clinicians in the Pediatric Setting*

**Key Ideas** for successful discussions about serious illness care across Pediatric care settings:

image1.png**Principles**

##### “Patients” includes the child & and their families as the unit care across settings

##### “Clinicians” includes Physicians, Nurses and other Allied Health professionals

##### Include the child in these conversations when developmentally appropriate

##### “Parents” will be used to indicate the child’s guardians. In reality there are many, diverse family structures and “parents” may refer to grandparents, appointed ministry workers, aunts/uncles and/or a single parent. We will use the word “parents” to represent all of these diverse possibilities for simplicity

##### Parents have goals and priorities besides helping their child live longer; learning about these goals empowers you to provide better care

##### You will not harm your patient or their parents by talking about serious illness, declining function and end-of-life issues

* Anxiety is normal for both families and clinicians during these discussions
* Although difficult to discuss, parents want the truth about their child’s prognosis, disease trajectory and what to expect in the future. Prognostication is complex, especially in the pediatric context
* Titrate conversations based on parent and patient responses (especially anxiety)
* Giving parents and patients an opportunity to express fears and worries is therapeutic
* These conversations may be formal and planned, or informal and unplanned

**image1.pngPractice**

***Do:***

##### Explore parents understanding of their child’s illness and what to expect in the future

##### Discuss prognosis directly and honestly when desired by parents

##### Give a direct, honest prognosis when desired by parents

##### Present prognostic information in a range

**N – Naming**

**U – Understanding**

**R – Respect**

**S – Supporting**

**E – Exploring**

##### Discuss changes that could be expected as the child’s

##### Disease progresses (i.e. functional, cognitive and social)

* Allow silence
* Listen actively
* Acknowledge and explore emotions (NURSE mnemonic)
* Focus on the child & family’s quality of life, fears, and concerns
* Acknowledge that these can be hard conversations and can be had over time
* Make a recommendation (“Based on XX medical situation, YY treatment options, and ZZ important goals and values, I recommend…” **OR** “Based on what I have heard you tell me about what is important to you and your child what your concerns are, I recommend...”)
* Document and communicate the conversation so that it is available to the team

(including patients)

*Do not:*

##### Talk more than half the time

* Give premature reassurance
* Provide factual information in response to strong emotions
* Focus on medical procedures or decisions

**This material has been modified by Canuck Place Children’s Hospice. The original content can be found at** [**https://portal.ariadnelabs.org**](https://www.google.com/url?q=https://portal.ariadnelabs.org&sa=D&ust=1514409130325000&usg=AFQjCNGkMlhAf9pmXQRldPUycuXwnX7X3Q) **and is licensed by Ariadne Labs under the Creative Commons Attribution-NonCommercial- ShareAlike 4.0 International License. Ariadne Labs licenses the original content as-is and as-available, and makes no representations or warranties of any kind concerning the original content or concerning this material, which Ariadne Labs has not reviewed or endorsed. Last modified: Feb 15, 2018**

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**NOTE:** This document is NOT intended for use with patients. It is for your reference in honing end-of-life communication skills or when preparing for a conversation with an individual patient.

# Serious Illness Care Program for Pediatrics:

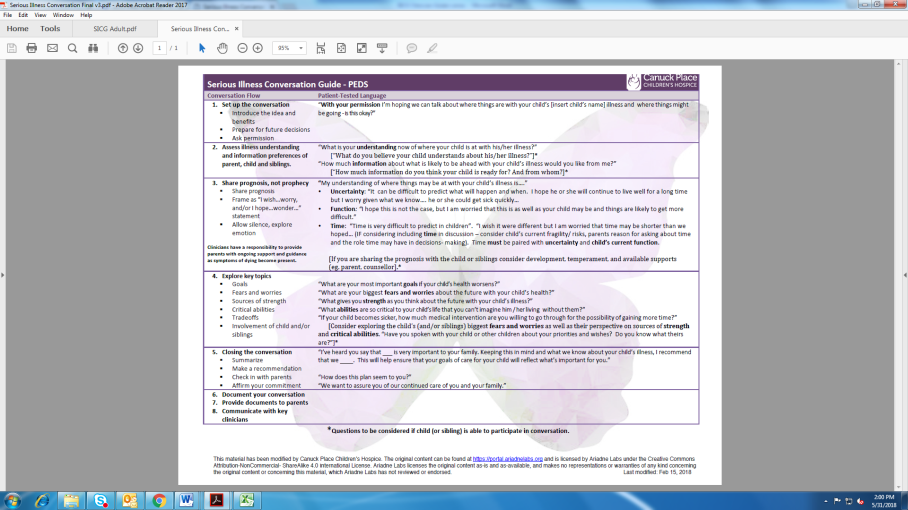
# *One conversation or many?*

# Some conversations are formal appointments or interviews with patients and families. Many allied health clinicians will have these conversations during moments of care – so they may emerge as informal and unplanned conversations. The Serious Illness Conversation Guide and this Interprofessional Clinician Reference Guide can help you have these conversations. Clinicians include physicians, nurses and other allied health professionals.

## Overview of materials

These tools are available to you, the clinician, to help you have successful conversations with your patients about serious illness care goals. Use these tools and the language within them at least 30 times so you become comfortable with the language and flow. Then, you can feel free to ad-lib.

**For clinicians**



**Conversation Guide**

The backbone of this project, the Conversation Guide (version 3), will help you have successful conversations with the families and children you work with. It consists of steps to elicit important information from parents about their goals and values for their child and family: setting up the conversation, assessing illness understanding, information preferences, and sharing prognosis (i.e. what to expect as the disease progresses and/or functional decline is documenting the conversation).

**Conversation Guide** **Modified for use with Pediatric Patients and Families**

This modified Conversation Guide will help you have successful conversations with parents and family members of pediatric patients. It consists of steps to introduce the conversation in patient tested language. Steps include asking permission and assessing illness understanding and information preferences. The guide outlines how to share prognosis (not prophecy) and explore key topics in a family centered way. Strategies to appropriately close the conversation and properly document are also included.

image5.tif**Reference Guide for Interprofessional Clinicians**

[this document]

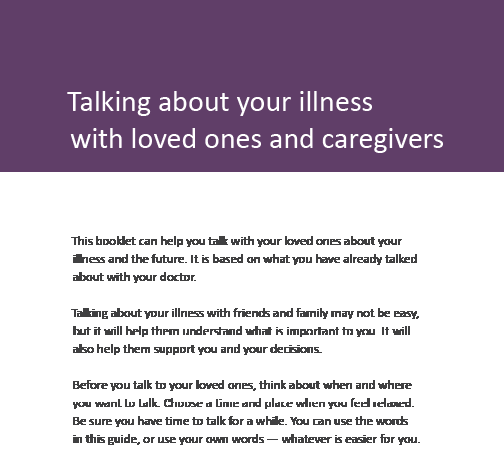
This modified reference for interprofessional clinicians is available to guide you through all aspects of serious illness communication in the pediatric context. It provides detailed information about how to introduce the serious illness conversation, what language to use, and tips for dealing with common patient scenarios. This document addresses common communication scenarios unique to the pediatric context and strategies to address them.

**For patients and families**

###### Pre-Visit Letter (modified version to be created)

This letter is designed to prepare parents and guardians for a serious illness conversation with their child’s clinician. It includes topics for parents to think about in advance, reinforces the importance of the conversation, encourages them to engage family members, and reassures parents that talking about their child’s future will help them have more control over their child’s care. This may be a useful tool in your setting.

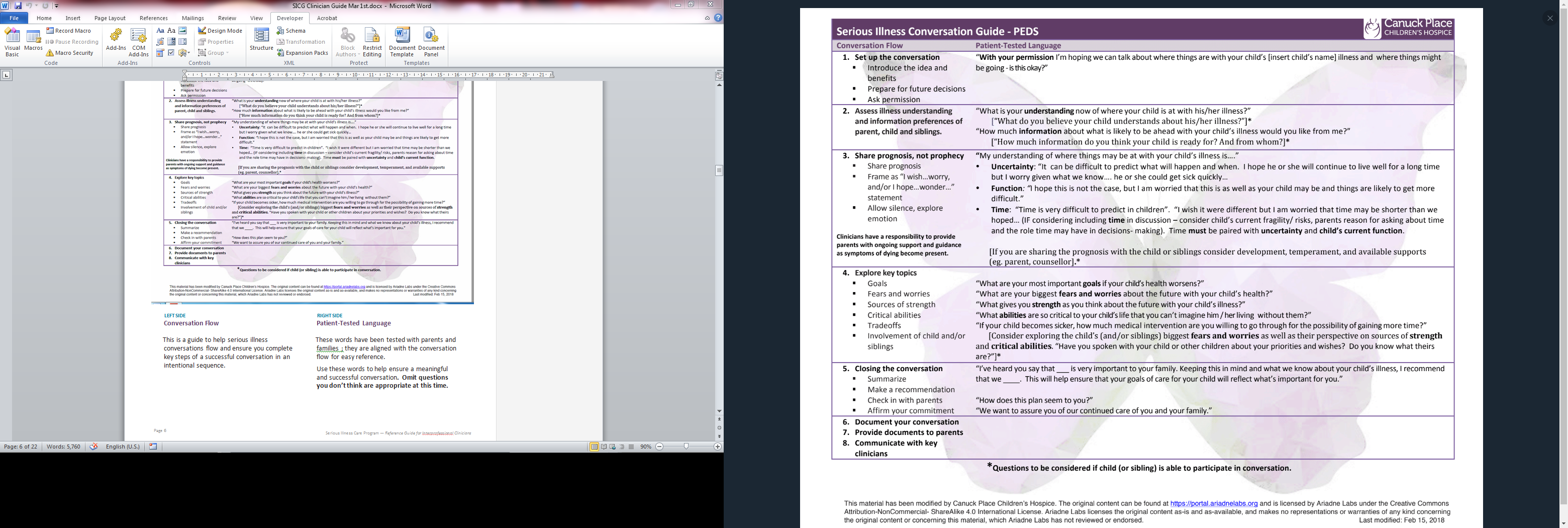
###### Family Communication Guide (modified version to be created)



Designed for the parents use with their family, this guide will help parents talk with their family and friends about the same topics you bring up with them in your conversations. Like the clinician materials, it provides language for the parents to relay information to their extended family and to continue the conversation by exploring their concerns. This document will (has) been modified to include strategies for communicating with siblings, the child's friends and grandparents. We encourage you to remind your parents that this resource is available to them.

# Serious Illness Conversation Guide - Peds

How the guide is organized



**LEFT SIDE**

###### Conversation Flow

###### This is a guide to help serious illness conversations flow and ensure you complete key steps of a successful conversation in an intentional sequence.

**RIGHT SIDE**

###### Patient-Tested Language

These words have been tested with parents and families; they are aligned with the conversation flow for easy reference.

Use these words to help ensure a meaningful and successful conversation**. Omit questions you don’t think are appropriate at this time**

**Initiating the conversation with parents of child**

**WHEN** The ideal time to introduce a discussion of values and goals is when the child is relatively stable and not in a medical or emotional crisis.

**HOW**  Use the ‘Set up the conversation’ prompts to help you remember the optimized sequence of ideas for introducing the conversation with parents. The table below illustrates suggested language that flows from one idea to the next. Before starting the conversation, acknowledge that you will be using the guide: “I may refer to this Conversation Guide, just to make sure that I don’t miss anything important.”

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| **Prompt** | **Purpose** | **Suggested Language** |
| Introduce the idea and benefits | Orient the parents | “***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 this okay?”*  *This is part of the way we care for children at this stage of illness.*  *We like to discuss these issues when children are doing well and we are not in a crisis.”* |
| State benefit and support | *“Talking about it now allows all of us time and space to talk and think these issues through.*  *It means you don’t have to make any decisions if you’d prefer not to, because we have time.*  *We want to help you stay in control of decisions about your child’s care, and to support you in case your family has to make difficult decisions.”* |
| * Ask permission | Give the parents control | *“Is this OK? If not okay, we certainly don’t have to do it today, but I will bring it up again for us to talk about later.”* |

# Strategies for common scenarios

##### Use this content to support your learning in anticipation of conversations with parents, or as follow-up after a challenging interaction.

* KEY IDEAS and STRATEGIES provide a mix of approaches and suggested language.
* The following panels offer guidance for scenarios that can be challenging for clinicians.

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| Parent says: “I don’t want to talk about it” | |
| **KEY IDEAS**  Exploring why a parent does not feel able to talk about these issues can provide valuable information that helps you provide good clinical care.  Many parents are ambivalent about receiving information. They may want it but are scared of what they will hear about their child’s prognosis. Your steadiness and calming approaching these issues will help the parents feel that talking about it is possible.  There is a “differential diagnosis” of not wanting to talk about it that includes:   * + Parent has intense fears about their child’s future and about their child’s death that are overwhelming — if this is the case, finding a way to gradually introduce the subject may help the parents be better prepared for reality.   + Parents need more support (e.g., from a family member, faith group) to address these issues.   + This is a bad time because of other difficult events/stressors   (e.g., child having major surgery, other life stressors).   * + A parent has an anxiety disorder that makes it difficult to tolerate the anxiety of a discussion. | **TRY THESE STRATEGIES**  •Explore parents’ reasons for not wanting to discuss this:  *“Help me understand the reasons you would prefer not to talk about this.”*  •Elicit information about how parents think about planning for their child’s future:  *“I’d like to understand what kind of thinking and planning you would find helpful as we think about what may lie ahead with your child’s illness.”*  •Ask about the positives and negatives of discussing these issues.  •**Remind parents that the goal is to initiate discussions, not necessarily to make decisions.**  •**If a parent is ambivalent, “name" the ambivalence and acknowledge how difficult the situation is:**  *“I hear you saying you know it is important to do some planning and also that you worry this process will be too overwhelming.”*  •If parent expresses intense anxiety about their child dying, acknowledge the difficulty of the situation and explore specific concerns using "tell me more” statements  •**Use “I wish” statements (e.g. I wish that things were better so we didn’t need to talk about this).**  •**If requested it may be appropriate to defer the discussion until supports can be present for the discussion (family members, faith groups, counsellors)**  •**Acknowledging parent stress and a plan to return to these issues later can be helpful.**  •**If parents express more global anxiety, explore their experience of anxiety and mood in a non-threatening way and consider mental health referral:**  *“Are you someone who lives on the anxious side of life?”* |

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| **Parent says “Our child is going to beat this”** | |
| KEY IDEAS  “Beating this” has many meanings. Explore them using “tell me more” statements.  Clinicians have the power to reframe the meaning of “beating” the illness.  Parents who are insistent that their child will “beat” a progressive illness are usually terrified and may be living in denial of the severity of the illness.  Help parents focus on additional hopes beyond survival.  If the child is in a particular crisis that may get better, it is often better to avoid addressing denial in that moment. Wait until the parents are in a less stressed frame of mind to address their denial.  Consider strategies to reduce anxiety (e.g. relationship building, encouragement of including family members) which may make future discussions less anxiety producing. | **TRY THESE STRATEGIES**   * Align yourself with parents by using “I wish” statements:   *“I wish that we could, with certainty, beat this illness, but I worry that we may not. Our job is to ensure that your child receives the best care possible while we navigate the uncertainty ahead with you*.”   * **Show respect for the child and family’s fighting spirit:**   *“No matter what happens with your child’s illness, your child and family have the capacity to continue to be fighters. By supporting fundraisers and advocacy group you can continue to fight for the positive outcomes we all hope for and support families like yours*.”   * Focus on the parent’s strengths:   *“I can see what a strong force you are for your child. There is a lot you can do to help them through this awful situation by helping to prepare them and we will walk with you.”*   * Acknowledge parent’s desire for their child to beat their disease, but persist in exploring issues common in worsening disease and moving the conversation forward:   *“We should hope for the best and prepare for the worst”* |

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| Parent is not ready to make a decision | |
| **KEY IDEAS**  Parents need time to absorb and integrate information and to prepare to make decisions.  Reassure the parents that decisions are not urgent and encourage them to talk with their child and each other. This might be an excellent time to provide the Family Communication Guide.  For children who are declining rapidly, sharing information (including the clinician’s concern), and emphasizing that decisions are best made soon, may help the parents move forward in considering these issues. | **TRY THESE STRATEGIES**   * **Reassure parents there is time to think things through:**   *“I brought up these issues early so that you would have time to think about what’s important to your child and your family. I’m not worried that anything will happen in the coming weeks.”*  **Let the parents know you will bring this up again.**   * **Encourage discussion with child, siblings & family as appropriate:**   *“These are difficult decisions. I recommend discussing it with your child and other family as appropriate and then us talking about it again at your next visit.”*   * **If the child is declining rapidly, acknowledge this and focus on providing care aligned with child’s and parent’s wishes:**   *“I am worried your child’s disease is getting worse. I wonder if walking through some of the decisions you may be faced with soon would be helpful.”* |

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| **Parent expresses intense emotion (tears)** | |
| **KEY IDEAS**  Dealing with emotion is often a precondition for effectively addressing serious illness decisions.  Tears and other strong emotions are natural when discussing serious illness issues.  When parents express strong emotion, it is therapeutic for you to listen and acknowledge the difficulty of the scenario. Don’t try to “fix” an “unfixable” situation.  Titration based on parent responses with gentle guidance allows forward movement without the parents being overwhelmed.  Sometimes, backing off is a good temporary strategy. Stay calm and remember to breathe before speaking. Filling silence with false reassurance is not helpful.  Parents are often frightened of alienating their clinician by crying – reassurance and staying present can mitigate this.  Most people feel better when they have a chance to express feelings. | **TRY THESE STRATEGIES**   * + Allow silence for parents to express feeling.   + **Name the feeling.**   + **Provide non-verbal support.**   Offer tissues, or put a hand on a shoulder.   * + **Ask parents to describe what the tears are about:** *“Help me understand what is making you so sad/upset/scared.”*   + Explore feelings:   *“Tell me more.”*   * + Express empathy:   *“I am sorry that this is so sad/upsetting/scary for you.”*   * + Provide support and encouragement:   *“I know this is a hard conversation to have, but I think it is important and that it will help make sure that we have a back-up plan in case we need one.”*   * + Obtain permission to proceed:   *“I would like to discuss possible scenarios with you - is this ok?"*   * + Demonstrate and express respect for parents’ (and child as appropriate) emotional strengths:   *“I can see you are a person who feels things strongly and I have a lot of respect for your strength in staying with this hard discussion”*   * **If necessary, offer to take a break and proceed later:** *“I can see that this is a really tough conversation for you. Let’s take a break for today and revisit at our next appointment.”*   + If emotion is very intense and persistent, explore whether a mental health referral would be helpful.   + **Avoid giving false or premature reassurance to contain patient distress.**   + **Avoid offering information that is not explicitly sought.** |

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| Parent expresses anger | |
| **KEY IDEAS**  Stay calm.  Anger in this setting is usually about the message (e.g., “your child is getting sicker”) rather than directed at you personally.  Giving parents an opportunity to talk about their anger, and responding non-defensively, tends to be therapeutic. | **TRY THESE STRATEGIES**  • “I wish” responses are helpful:  *“I also wish this cancer (disease) had responded to the treatment.”*   * + Explore angry feelings, but use less intense language:   *“I can see this is really frustrating. Tell me more about the frustrations you’ve been experiencing.”*   * + Allow parents an opportunity to explore what it means to them to be talking about these end-of-life issues:   *“I am bringing up these issues because I want us all to be prepared for what is ahead. But what is it like for you to have me bring them up at this point?”*   * + Encourage patient to say what is on their mind:   *“As hard as it is, I want to learn as much as I can about what this is like for you and your child, including about your frustrations.”*   * + Respond non-defensively:   *“I am hearing that you feel let down after promising treatments stopped working. I want you to know we are still committed to the best possible care for your child & family.”* |

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| **Parent is reluctant to stop disease-modifying treatment** | |
| **KEY IDEAS**  Once it is clear there is no benefit from evidence-based interventions, it is important to discuss the option of stopping disease-modifying treatment.  Parents may not want to stop treatments that are directed at their child’s underlying disease because they fear loss of relationship with their team, worsening disease, or immediate death.  Poor functional status is a key prognostic  indicator of limited life expectancy and  warrants discussion of stopping disease-  modifying treatment.  Do not hedge (“Well, it might…”); evidence suggests that parents and families hear and remember positive but not negative messages. | **TRY THESE STRATEGIES**   * + **Explore fears about stopping active treatment:** *“Can you tell me what your concerns are about stopping treatment X (e.g. chemotherapy, milrinone, etc.)?”*   + Be clear that more treatment may not mean more time:   *“Some studies suggest that stopping chemotherapy/treatments may not shorten time, and your child may feel better.”* Check family’s understanding, as this information may be counterintuitive to them.   * + If clinically indicated, make a clear, direct recommendation against further disease-modifying treatment.   + **Reassure patient and family that you will continue to be their doctor:** *“I will continue to be your doctor if you choose to stop active treatment.”*   + Don’t say you can reconsider disease-modifying treatment later if you can’t. |

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| **If timing is right for a code status conversation** | |
| **KEY IDEAS**  Discussion of code status should always follow a broader discussion of prognosis and values and goals.  Parents and families are often overly optimistic about the outcomes of CPR.  In-hospital CPR survival, overall1   * Immediate survival: 30-45% * Survival to discharge: 11-17%   The above statistics have not changed in 40 years.  In hospital CPR survival for cancer patients2:   * Overall survival to discharge: 6% * Localized disease: 10% * metastatic: 5% * ICU: 2%   Withholding an intervention like CPR can make families feel abandoned. Describe of all the things you will do (i.e. intensive symptom control, emotional support for them and their families, etc.).  **1Peberdy MA et al. Ressuscitation 2003**  **2Reisfield GM et al. Resuscitation 2006** | **TRY THESE STRATEGIES**   * Introduce the concept of code status decision in context of values and prognosis:   “*We’ve talked about some of the key issues that are important as your child gets sicker, and I think it would be helpful to get a bit more specific about the types of treatments that do and don’t make sense in your child’s situation.”*   * Explore parents’ understanding about CPR:   *“One of the questions we should figure out is whether cardiopulmonary resuscitation makes sense for your child. What have you heard about CPR?”*   * Describe CPR: * Correct misunderstandings * Describe what it is, the risks and benefits, and possible outcomes * Share data about possible outcomes (if desired)   *“CPR is a procedure for patients who have died in which we use machines to try to restart the heart or breathing. In patients with a serious illness, its effectiveness is extremely low – and even those who can be brought back initially have to be kept alive on breathing machines and almost never leave the hospital.”*  “*Based on your child’s current condition, and knowing that we have no more treatments to stop the progression of your child’s illness, and that CPR would not likely be appropriate due to the fact that even if we restart his or her heart, their underlying condition will remain and they will continue to deteriorate.”*   * Check for patient agreement:   *“How does this plan sound to you?”*   * Share the conversation with the child’s primary care providers (family physician, pediatrician) and care team * Emphasize the care that will be provided to the child:   *“I want to make sure you know that we will monitor your child carefully, provide and arrange for the best possible support for your child and your family.”*   * Do not say “We will just give your child comfort care.” * **Do not offer CPR if it is not clinically indicated:** Inform parents that they are not a candidate for CPR because it will not be effective and ask them to affirm your decision. |

**Discussing the child’s prognosis**

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| **Functional prognosis** | |
| **KEY IDEAS**  For many conditions, it is impossible to predict how much time a child is likely to have, but it is possible to predict their level of function, which may provide them with useful information for planning and goal-setting.  Providing functional prognosis — outlining what is and is not likely to improve in the future - helps parents understand what their child’s lives will be like in the future, and allows them to make trade-offs that align with their values and the goals of their child  Clinicians have a responsibility to provide parents and siblings with ongoing support and guidance as symptoms of dying become present. This includes physical, emotional , and spiritual changes in the child and instruction and choice for family members to participate with the care. | **TRY THESE STRATEGIES**   * **Provide information on what is likely and not likely to improve:**   *“Following a severe brain injury it is unlikely that your child will be able to see or hear, he/she will feel your touch and presence”*   * **Support hope:**   *“I think that your child will continue to have good times with your family and take pleasure in small daily things.”*   * **Affirm commitment to optimizing function:**   *“We are going to continue physical therapy to give your child’s body the best chance possible to regain some strength. And we’re going to keep looking for other options that can help him/her feel as well as possible.”*   * **Share what you are seeing and what may be next:**   “Right now your child is still eating and drinking well. We are not seeing many symptoms. As these things change, we will know more about what to expect.”  “As the body gets weaker, it can give us signs that time is short. We will make sure we share with you our assessment of changes (such as more sleeping, less intake and breathing changes) to help you understand what is happening. Right now, I am seeing this…..what are you seeing?” |

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| **Uncertain / unpredictable prognosis** | |
| **KEY IDEAS**  Pediatric conditions can remain stable, slowly deteriorate over time, or bring sudden and life-threatening crises. Potential scenarios should be communicated to parents. This allows families to consider their values and preferences within this context, and to prepare. | **TRY THESE STRATEGIES**   * **Provide clear information about potential trajectories:**   *It can be difficult to predict what will happen with your child’s illness. Children can live well for years, but sometimes things can happen quickly. I think we need to be prepared for a crisis, or sudden event, in which we may be confronted by some difficult decisions.*   * **Use hypotheticals:**   *If your child’s**illness was to suddenly worsen, he or she may not be able to return to where they are now or might need to be hospitalized or consider intensive treatments.*   * **Hope for the best, plan for the worst:**   *Even though this is difficult to think about, I am hopeful that your child will have a lot of good time ahead and that doing some planning together can help you have a safety net* ***OR*** *a Plan B, in case things don’t go as we hope.* |

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| **Time-based prognosis - ALWAYS INCLUDE UNCERTAINTY WITH USE OF TIME** | |
| **KEY IDEAS**  Many parents and families want our best estimate of how much time their child may have given their stage of illness as this can help with planning. Cancer may have a more predictable prognosis; less so for other pediatric conditions. Parents do not expect precision, but they expect to give them time to prepare for what may come. Remember prognosis is not prophecy. | **TRY THESE STRATEGIES**   * **Discuss prognostic information as a range:**   *Days to weeks, weeks to months, months to years*   * **Acknowledge prognostic uncertainty:**   *It could be shorter or longer.*   * **Support hope:**   *I am hoping it will be on the long side of this range.* |

**Clinician changes focus to making a decision**

For example, the clinician observes that the parents are “reluctant to stop disease-modifying treatment”, or “timing is right for a code status conversation”.

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| **Talking about making a decision** | |
| **KEY IDEAS**  Either the child, family or clinician has become involved in a conversation that is about making a decision (a treatment decision). Here we remind ourselves that we are trying to facilitate a listening conversation – reroute the conversation along the lines of the conversation guide (i.e. move discussion to ask questions about worries, strengths, fears).  How you make a recommendation can influence the parents’ choice and reaction. | **TRY THESE STRATEGIES**  **Have you followed the guide?**  **Where did you get off track?**  *Try to use the guide to find your place in the conversation.*  **Be clear about their understanding of their child’s disease and prognosis (i.e. more treatment may not mean more time):**  *“Some studies suggest that stopping chemotherapy may not shorten time, and you may feel better.”*  *Check parent understanding, as this information may be counterintuitive to families.*  **Explore key topics (i.e. parent fears about stopping active treatment):**  *“Can you tell me what your concerns are about stopping treatment X (i.e. chemotherapy, milrinone, etc.)?*  **Make a recommendation to have ongoing conversations with the patient’s Physician or Nurse Practitioner and ensure any discussion is documented and communicated with them directly.** |

**When it is time to make a plan**

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| **Making a recommendation** | |
| **KEY IDEAS**  Make recommendations only after you’ve had a chance to summarize a family’s values, goals, and priorities that reflects what they have told you.  How you make a recommendation can influence the parent’s choices and reactions. | **TRY THESE STRATEGIES**   * **Recommend next steps that are based on prognosis, medical options and family’s values and priorities:**   *“Based on the rapid progression of your child’s illness despite intensive treatments and your wishes for them to be at home, I recommend that we discuss discontinuing medications that require admission to hospital and explore community supports.”*   * **Be direct in making your recommendation:**   *Say “I recommend….” Rather than using a “menu” approach of options.* |

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| **Talking about family/sibling involvement** | |
| **KEY IDEAS**  Parents often look to clinicians for guidance on how to discuss a child’s illness with siblings.  Preferences about child and sibling involvement in decision-making vary a lot.  Sibling involvement helps them prepare for the child’s death. Preparation is associated with better bereavement outcomes. | **TRY THESE STRATEGIES**   * **Explore:**   *“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?”*  *“Have you spoken with your other children about your priorities and wishes? Do you know what theirs are?* |

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| **Talking about child involvement** | |
| **KEY IDEAS**  Preferences about child involvement in decision-making vary a lot.  Consider exploring the child’s (and/or siblings) biggest fears and worries as well as their perspective on sources of strength and critical abilities.  Professionals are available to help parents communicate with their children about difficult end of life questions, including play/art therapists, in a developmentally appropriate way.    If children are asking questions about their health, parents should be coached and encourages to explore those questions.  Clinicians will not lie to a child if they ask about their health condition. | **TRY THESE STRATEGIES**   * **Explore:**   *“Have you spoken with your child about your priorities and wishes? Do you know what theirs are?”*   * **Encourage the parent to involve and prepare the child if developmentally appropriate** * **Explore:**   *“If your family has strong wishes about your care that are different from yours, how would you like us to decide on your care?”* |

# The “Wish/Worry/Wonder” framework

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| **I wish…I worry…I wonder….** | |
| **KEY IDEAS**  “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. | **TRY THESE STRATEGIES**  **Align with parent & child’s hopes, acknowledge concerns, then propose a way to move forward:**  *“****I wish*** *we could slow down or stop your child’s cancer/disease and I promise that I will continue to look for options that could work for him/her.”*  *“But* ***I worry*** *that you, your child, and won’t be prepared if things don’t go as we hope.* ***I wonder*** *if we can discuss a Plan B today.”* |

**Managing the conversation:** *Practical challenges*

##### Time pressures can be a barrier to effective end-of-life conversations.

* Plan for enough time to have a meaningful conversation or plan to take up the conversation at another time, as needed.
* SIC are iterative, repetitive, and require a team-based approach over time, where you may be involved at a point in time but that your conversations contribute to an overall shaping of a child’s illness journey.
* Plan to have the right people present or to have a plan to communicate conversations with other care team members (documenting to other members of the team, inviting resident/physician, family, etc.).
* Use these strategies to make the best use of your time with each child and family.

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| **Keeping parents on track** | |
| **KEY IDEAS**  Parents wander when they are anxious or have other high priority issues to discuss.  Parents usually recognize that you have an agenda and need to fulfill it within a limited time frame, if reminded. | **TRY THESE STRATEGIES**   * **Acknowledge that this is a tough conversation, and gently bring parents back to topic:**   *“I know this is hard to talk about, but I’d like to see if we can clarify a couple of things about what your worries are about the future.”*   * **Remind patient of time constraints:**   *“I wish we had more time to talk about your new dog, but I would like to get back to thinking about some future planning that I think we need to do.”*   * **Interrupt gently:**   *“Mrs.& Mr. Smith, we need to get back to my question about your goals if your child’s time is getting short.”* |

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| **Managing your time** | |
| **KEY IDEAS**  The conversation can still be effective when spread over several visits. | **TRY THESE STRATEGIES**   * **Discuss ahead about distributing the questions to other health care providers.** * **Consider going through 2 questions per visit** * **Make sure everyone documents the discussion in the patient’s medical record.** |

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| **Documenting the conversation** | |
| **KEY IDEAS**  Avoid using the computer while talking to the patient. | **TRY THESE STRATEGIES**  •**Make notes on the guide if you need to remember specific things the patient says.**  **•If you must document while talking, make frequent eye contact with patient.** |

**Parents say says: “He or she is having a terrible day I, what ifshe never feels better than this?"**

**KEY IDEAS TRY THESE STRATEGIES**

# Unplanned/Informal conversations: Using the Guide in the Process of Care

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| **Parents says: “He or she is having a terrible day, what if he or she never feels better than this?** | |
| **KEY IDEAS**   * “In the moment”, use the guide to have a listening conversation that helps the team understand the parents perspective more clearly. * Be prepared to move “in” and “out” of the SIC, especially if it occurs in the process of care, i.e. you may need to move “out” of the listening conversation to deal with problems that arise in the process of care and during the SIC. | **TRY THESE STRATEGIES**  •**Deal with present and urgent issues** (i.e. give pain medication, finish dressing change) **and then moving back “in” and focus on the serious illness conversation:**  “I think we were discussing your fears, could we get back to that now? I think this is a really important conversation for us to have today.” |

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Useful tools for difficult conversations

* <http://www.health.gov.bc.ca/library/publications/year/2013/MyVoice-AdvanceCarePlanningGuide.pdf>
* [Speak Up](http://www.advancecareplanning.ca/): <http://www.advancecareplanning.ca>
* CPR Decision Aids: (<http://www.advancecareplanning.ca/resource/cpr-decision-aids/>)
* CPR Decision Aid: ([http://thecarenet.ca/docs/CPR%20Decision%20Aid%20revised%20to%20PDF%20brochure%20Nov%203%202009.pdf](http://thecarenet.ca/docs/CPR%252520Decision%252520Aid%252520revised%252520to%252520PDF%252520brochure%252520Nov%2525203%2525202009.pdf))
* Ottawa Personal Decision Guide: (<https://decisionaid.ohri.ca/docs/das/OPDG.pdf>)
* The Conversation Project: (<http://theconversationproject.org>)