

Partnership Guide:

A resource to support children to understand and participate when serious illness decisions are considered

This guide is for those who are supporting a school-aged child with a serious illness. A *serious illness* is a condition that impacts life and daily functioning, with unknowns about the future and/or the condition is difficult to manage in symptoms, treatments, or family stress.¹

When children have a serious illness, there are many decisions to be made as a family. *Making decisions about care and treatment* involves the choices and preferences about the diagnosis, treatment options, and the impact the decisions will have on life. The experience of serious illness decision-making can feel like a maze.² There are many decisions to consider, which can then lead to a series of more decisions to make. This experience is complex and requires ongoing evaluation.

Partnering with children in healthcare decisions supports children to feel valued and empowered. Involving children can help them cope better with treatments and build trust with the hospital environment and the people involved in supporting their health and care.

Goals of this guide

This guide is dedicated to improving the healthcare experience and quality of life for children, youth, and families. The intention is to provide information and activities that will:

- Promote partnership with children through child-focused ways to engage in a serious illness conversation.
- Provide a tool to support children when a serious childhood illness is part of their care.
- Offer approaches to guide conversations between children, their families, and the healthcare team.
- Help families understand the importance of child participation in healthcare decisions by sharing evidence and recommendations from medical literature.
- Provide direction to families to know when they may need help with serious illness conversations and where they can access support.
- Help families talk with children about goals, questions, wishes, and worries when healthcare decisions arise.

The development of this guide was in collaboration with patient and family partners and pediatric healthcare professionals who support families with serious illness conversations.

¹ Ariadne Labs, Inc., (2012). Serious Illness Care Guide <https://www.ariadnelabs.org/areas-of-work/serious-illness-care/>

² Feudtner, C., Schall, T., & Hill, D. (2018). Parental personal sense of duty as a foundation of pediatric medical decision-making. *Pediatrics*,142,133-141.

Partnering with decision-making

- In a shared decision-making process, everyone works together to decide on plans for care management and/or treatments.
- A shared approach considers the views of parents/caregivers, the perspectives of children, and the health care team.
- These three views, like a three-legged stool, provide a sturdy and supportive foundation for everyone.



- This process promotes evidence-based, child-focused decisions that support the best interest of children that balances the risk and benefits with the child/family values and preferences.

YouTube videos: Shared Decision-Making <https://www.youtube.com/watch?v=XPm5IEDEI8Y>
 Shared Decision-Making and Families <https://www.youtube.com/watch?v=9Wo7GQNXEXU>

✓ Research has shown

- **Parents/caregivers and children prefer a shared approach.**
 - Children report a desire and have a right to be involved with conversations that impact their health³. This viewpoint is supported by the Canadian Pediatric Society⁴ and the UN Rights of the Child⁵.
 - Children can express themselves when they feel supported and included. To know what children understand and need, we must ask.
 - Inviting children to participate communicates permission and acknowledges their views and involvement are valued.⁶

³ Moore, L., & Kirk, S. (2010). A literature review of children's and young people's participation in decisions relating to health care: Children's and young people's participation in decisions. *Journal of Clinical Nursing*, 19(15-16), 2215-2225. <http://doi:10.1111/j.1365-2702.2009.03161.x>

⁴ Coughlin, K. W. (2018). Medical decision-making in paediatrics: Infancy to adolescence. *Paediatrics & child health*, 23(2), 138-146. <http://doi:10.1093/pch/pxx127>

⁵ Lansdown, G., Lundy, L., & Goldhagen, J. (2015). The U.N. Convention on the Rights of the Child: Relevance and Application to Pediatric Clinical Bioethics. *Perspectives in biology and medicine*, 58(3), 252-266. <http://doi:10.1353/pbm.2016.0005>

⁶ Davies, A., & Randall, D. (2015). Perceptions of children's participation in their healthcare: A critical review. *Issues in Comprehensive Pediatric Nursing*, 38(3), 202-221. <http://doi:10.3109/01460862.2015.1063740>

- **Children's participation is important.**
 - Some children are cautious about sharing what they think and feel. Parent/caregiver permission and support are essential when including children with decisions in a safe and respectful manner.⁷
 - Shared responsibility for decisions ensures everyone is supported to express important information, feel listened to, and to consider all expressed views.⁸
 - Children are more likely to follow a plan that they helped create. When parents, children, and the healthcare team work together to make a decision, the decision that is made is a fully informed one. This process can lead to a decision that everyone feels comfortable to follow.^{9,10}
- **Children can understand.**
 - When there is a diagnosis of a serious illness, new knowledge and experiences automatically become part of the child's world, which informs them. Whether children are informed or not impacts how well they will adapt and adjust.
 - Children can learn and grow with their serious illness and healthcare experiences. Children learn through guidance from knowledgeable and trusted supporters as well as through social interactions in their environments.¹¹
 - Children are capable of understanding how they feel, knowing what is right and wrong for them, and taking actions based on this knowledge.¹² Sometimes this is referred to as their **autonomy** when children have agency and consent for decisions.
 - The YouTube video: Vygotsky's Social Interaction Theory describes how children learn and grow. This model can be applied to healthcare experiences with parent/caregiver guidance.

<https://www.youtube.com/watch?v=zAcNO14HnEE&list=TLPMQjMwNDIwMjA0u1nV300gA&index=2>

⁷ Scherer, D. G. (2018). Pediatric participation in medical decision making: The devil is in the details. *American Journal of Bioethics*, 18(3), 16-18. <http://doi:10.1080/15265161.2017.1418924>

⁸ Coughlin, K. W. (2018). Medical decision-making in pediatrics: Infancy to adolescence. *Paediatrics & child health*, 23(2), 138-146. <http://doi:10.1093/pch/pxx127>

⁹ Ronis, S. D., Kleinman, L. C., & Stange, K. C. (2019). A learning loop model of collaborative decision-making in chronic illness. *Academic Pediatrics*, 19(5), 497-503. <https://doi.org/10.1016/j.acap.2019.04.006>

¹⁰ Jeremic, V., Sénécal, K., Borry, P., Chokoshvili, D., & Vears, D. F. (2016). Participation of children in medical decision-making: Challenges and potential solutions. *Journal of Bioethical Inquiry*, 13(4), 525-534. <http://doi:10.1007/s11673-016-9747-8>

¹¹ De Clercq, E., Streuli, J., Ruhe, K., & Elger, B. S. (2019). "UNDOING" CAPACITY the capability approach in pediatrics. *Perspectives in biology and medicine*, 62(2), 319-336. <http://doi:10.1353/pbm.2019.0016>

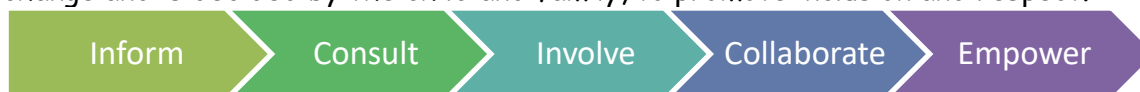
¹² Montreuil, M., Noronha, C., Floriani, N., & Carnevale, F. A. (2018). Children's moral agency: An interdisciplinary scoping review. *Journal of Childhood Studies*, 43(2), 17-30. <http://doi:10.18357/jcs.v43i2.18575>

- The more informed and involved children are, the more able they are to participate with decisions. This ability is a process and increases with development, experience/practice, and/or maturity.¹³



The goal of participation

To provide a process of engagement that has different levels of opportunity, that can change and is decided by the child and family, to promote inclusion and respect.¹⁴



Increasing impact on the decision



- **Participation supports children.**
 - Participation provides ways to:
 - help children understand the situation
 - support children to explore their preferences
 - help children take part in conversations
 - respect children and honour their needs.¹⁵
 - Participation supports children's adjustment to the situation, builds confidence, a sense of control, cooperation with treatments, and manages anxiety.¹⁶
 - Participation provides an opportunity for children to learn and grow with their care decisions.
 - Participation with conversations provides the opportunity for children to process information and time to consider questions for the next discussion.

¹³ Carnevale, F. A., Teachman, G., & Bogossian, A. (2017). A relational ethics framework for advancing practice with children with complex health care needs and their parents. *Comprehensive Child and Adolescent Nursing*, 40(4), 268-284. <http://doi:10.1080/24694193.2017.1373162>

¹⁴ IAP2, International Association for Public Participation (2007). <https://www.iap2.org/page/pillars>

¹⁵ Coyne, I., & Harder, M. (2011). Children's participation in decision-making: Balancing protection with shared decision-making using a situational perspective. *Journal of Child Health Care*, 15(4), 312-319.

¹⁶ Coyne, I. (2011). Participation in communication and decision-making: Children and young people's experiences in a hospital setting. *Journal of Clinical Nursing*, 20(15-16), 2334-2343.

Roles and responsibility in decisions

As a team, children, their caregivers, and the healthcare providers need to consider the information, principles, rights, and responsibilities to make the best decisions together while collectively remaining focused on the child and their best interest.

Parents/Caregivers are responsible for the welfare of their children; to support and guide children, so they can understand, to their ability, and contribute to the decisions that involve their bodies, health, and care.

Healthcare teams have the responsibility to seek the participation of children, by respecting to the extent possible, their developmental ability, and expressed preferences. The healthcare professional's role engages with families and explores how experiences may impact decision-making—supporting the diversity of families by guiding and presenting health care options while respecting their culture, beliefs, and values.

Children have the right to be supported:

- ✓ to understand (to the best of their ability) their condition and care
- ✓ to know what to expect and anticipate
- ✓ to share their preferences and participate in decisions related to their health
- ✓ to be involved in important decisions in meaningful ways, even when they are not the primary decision-maker

YouTube videos: Responsible Decision Making <https://www.youtube.com/watch?v=yWSSPnTB6OY>
Consent for Kids <https://www.youtube.com/watch?v=h3nhM9UJjc>

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Note: Readiness to partner as a family, consider a “goodness of fit” approach.

- As a family, how are decisions usually made?
- Does your family have experience with medical decision-making?
- At this time, is your child open and ready to participate?
- As parents, what are your views and beliefs?
- Are additional supports needed to support your family with this process of decision making?
- Does the goal of collaboration support your family at this time?
- Does a shared approach fit for your situation?
- Are there ways to modify/adapt processes to accommodate the needs of children, your family, and the situation?
- How can inclusion and well-being with decisions be supported?

If you need additional support to explore these questions, contact members of your healthcare team and/or consult with the clinical ethics department at 604.875.3182.

¹⁷ Mastly, J., & Fisher, C. (2008). A goodness-of-fit approach to informed consent for pediatric intervention research. *Ethics & Behavior*, 18(2-3), 139-160.

Serious illness conversations are difficult

- When healthcare professionals want to talk about the condition/illness and planning, it can be overwhelming. These conversations can and are meant to be meaningful and supportive.
- These conversations are important, and the support for children to participate is available. Situations and reasons may occur that challenge everyone's best intentions. Keep trying to find the time and ways to have conversations.
- It is natural for parents to want to protect children as they often worry about how children will cope. Serious illness requires families to balance the need to support children and help them cope and manage the changes to their health, body, and life.

Note:

- Serious illness conversations with children can be tricky. It may take time and many attempts to find opportunities to facilitate and find the right balance for each family.
- Your healthcare team can help you prepare, provide guidance, and assistance with challenging questions that may arise.

- **For most parents, this situation is a new parenting challenge.**
 - Consider the capability of children and ways to promote their developing autonomy. Help children achieve a developmental understanding of their illness and inform them of what to expect.
 - Ask for and support their perspectives, assess reactions, and explore their acceptance of care.¹⁸
 - Having conversations about serious illness decisions with children is hard, scary, and can be awkward. There may be conversations that you will feel you need help with.
 - Talk to your healthcare team and/or find the supports to assist you with this challenging experience. **This guide can be utilized with your healthcare team.** They are here to help and care for you too.
 - Children think about things even though they may not bring it up. Children often attempt to participate but are confronted with barriers, protect others and may learn to be passive in their care.¹⁹

¹⁸ Katz, A. L., Webb, S. A., & Committee on Bioethics. (2016). Informed consent in decision-making in pediatric practice. *Pediatrics*, 138(2), e20161485.

¹⁹ Coyne, I. (2008). Children's participation in consultations and decision-making at health service level: A review of the literature. *International Journal of Nursing Studies*, 45(11), 1682-1689. <http://doi:10.1016/j.ijnurstu.2008.05.002>

- **Remember**

- Children can communicate in many ways, even if they are not able to talk.
- Feelings are normal and help us know what we need.
- There is no one way to do this or right thing to say.

Note: Prepare and plan for these conversations.

- What would your family like to know about the illness and the next steps?
- What information would help your family make decisions?
- What is important to your family?
- What are your questions and concerns?
- What ways can children participate?

Ways to support the participation of children with conversations

- Offer choices of how children wish to be involved with conversations and decisions. (listening to the conversation, being part of the conversation - part/all of the time)
- Ask how they wish to have information shared with them, how much they want to know, and from whom, when, and where.
- The use of drawings or pencil/paper activities may support children to express their views.
- **Preparing for conversations**
 - Choose a time that is not rushed and a place that feels comfortable.
 - **Ask permission** and **clarify the control of preferences** as it can vary.
 - **Communicate** the shared goal, to connect, understand, and work together.
 - **Decisions change.** Be open to the moment, and try to remain flexible.
 - Provide information in **ways that everyone can understand.**
 - It may be helpful for someone to take notes.
 - It may be helpful to invite a family member or friend to be a support.
 - Keep communication open and plan to talk again.

Ask Permission

Communicating and seeking permission to include children with decisions begins with introducing the opportunities and preparing them for the conversation.

Use opening statements like:

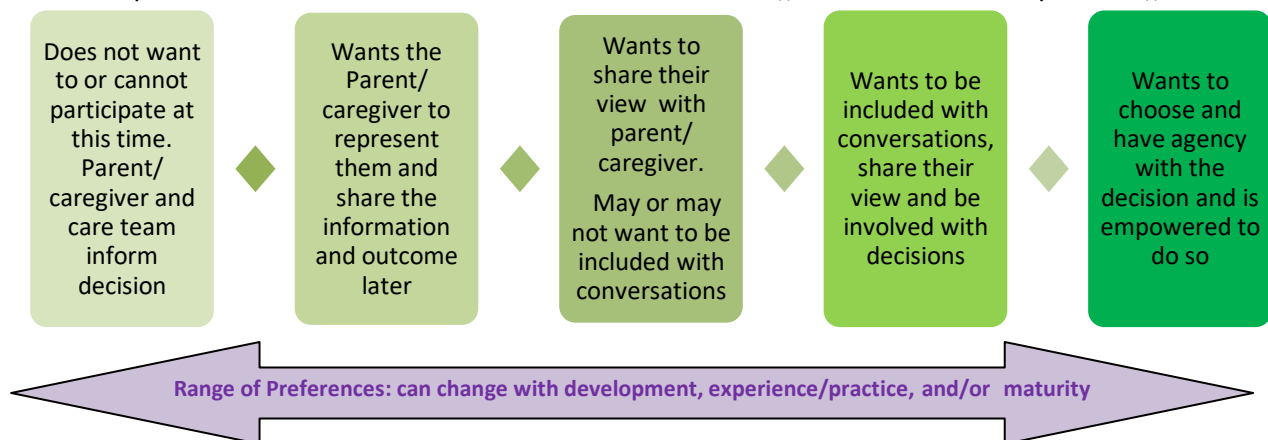
- I am wondering how you are feeling about...
- I am curious to understand your thoughts...
- It would be helpful if I knew what you...
- I am hoping that...

Clarify control of preferences

Once permission has been communicated, children need control of how involved they wish to be with exploring decisions.²⁰ Be clear as to the choice of preferences children have.

Children need to know:

- the decisions they can have control over
- the decisions that will include their view as much as possible
- if there are situations that others will need to make the decisions for them²¹



Acknowledge and communicate that children can change their mind of their preferences

Communicate

Communication helps everyone to know what matters most.

- **Children benefit from having open and honest conversations.** Some parents/caregivers hold back from having conversations with children out of fear of saying the wrong thing. Others may avoid such discussions for doubt that children are too young to understand or will not be able to handle the information.

²⁰ Degner, L. F., Sloan, J. A., & Venkatesh, P. (1997). The control preferences scale. *Canadian Journal of Nursing Research Archive*, 29(3).

²¹ Olszewski, A. E., & Goldkind, S. F. (2018). The default position: Optimizing pediatric participation in medical decision making. *American Journal of Bioethics*, 18(3), 4-9. <http://doi:10.1080/15265161.2017.1418921>

- **Children have great instincts and usually know that something is going on.** Children notice and observe behaviour, overhear information, or bits of conversations. They observe changes that may be happening and may pick up on the stress or feelings of their family members.
- **When children are left without answers to their questions, they may feel left out and/or alone.** Without truthful explanations as to what is going on, children often use their imagination to try to make sense of the situation. Their interpretations can be inaccurate and can cause anxiety about things that are not true.
- **Addressing Questions**
Invite children to ask questions and welcome their inquiry with openness and without judgment. When children ask questions, it can reveal so much about what the child is thinking and feeling, which can guide our efforts to support them.

Before providing an answer to children's questions, explore what they already know, what they think, and what information they are seeking.

Child: "What will happen with my treatments?"

Supporter: "What do you think will happen?"

Child: "I hope that they will help me get home faster."

(Clarification reveals what the child is wondering about and provides an opportunity to explore further.)

- **Be honest as it builds trust.**

Know that it is okay to respond with, "**I do not know**" when you do not have all of the answers as there are some questions in life that do not have answers.

If unsure what to say, it is okay to respond with, "**I need to think about that or I need to ask someone, and will get back to you**" if you need time to think about your response.

Child: "I heard the nurses talking that the treatments are not working, is that true?"

Supporter: "I do not know. Who do you think we should talk to about your question?"

Child: "Maybe you can check with the doctor. I do not know if I want the answer."

(Providing space and time for the child to consider their question can allow them to come to their conclusions)

- **Ask children**

- How do they want to be comforted, and what supports this?
- Who can make decisions for them if they wish not to?
- What do they want the healthcare team to know?
- What makes them feel safe?
- What matters most to them right now?
- What are they interested in knowing about their care?
- What do they understand?

- **Keep explanations clear and concise**

- Respond to what you heard. Provide only the information that the child has asked to know.
- Help the child to understand. Use simple and direct words to help the child understand complex medical terms.
- Use plain language without expressions that may confuse children.

- Provide child-focused explanations. The following is an example of describing cancer (Kids Health, 2015). To learn more visit www.kidshealth.org

"Cancer is a group of many related diseases that all have to do with cells. Cells are the tiny units that make up all living things, including the human body. There are billions of cells in each person's body. Cancer happens when some cells in the body grow differently and spread very fast. Normal body cells grow, divide, and know when to stop growing. Over time, the cells die and make room for new ones. Unlike these normal cells, cancer cells just continue to grow, divide out of control, and don't die when they're supposed to. Cancer cells usually group or clump together to form tumours. A growing tumour becomes a lump of cancer cells that can affect the normal cells around the tumour and damage the body's healthy tissues. This can make someone very sick."

- **Use open communication when having conversations as a family.**

Below are a few videos that provide a quick overview of important communication tools: empathy, non-verbal communication, reflection, active and empathetic listening.

Brené Brown on Empathy <https://www.youtube.com/watch?v=1Ewgu369Jw>

Non-Verbal Communication <https://www.youtube.com/watch?v=SKhsavlvuao>

Modern Family Reflective Listening <https://www.youtube.com/watch?v=95lANl1oeBk>

Everybody Loves Raymond Active Listening <https://www.youtube.com/watch?v=4VOubVB4CTU>

Inside Out Empathetic Listening <https://www.youtube.com/watch?v=t685WMM5R6aM>

Decisions may change

- Preferences may range and change from day to day and from one decision to another.
- Children may shift between wanting to be involved and wanting to rely on others to consult on their behalf.
- Children can be involved in important decisions in meaningful ways, without being the primary decision-maker or having the full capacity of an adult.
- Permission for children to participate always needs to be communicated when revisiting preferences.

Note:

- Parents/caregivers know their children best.
- Trust that children are capable and will lead you as to what supports them.
- Children often know more than we think.
- Be patient if children do not want to talk, let them know you are there when they are ready.
- Connecting, giving children permission and providing support ensures they are not coping alone.

Ways to explore that everyone can understand

Supporting children and their families with serious illness conversation is different from supporting adults.

- **Explore goals, hopes, fears, worries, and strengths**
 - It may be difficult for children/youth to share their thoughts and wishes in words.
 - When we do not have the words, finding different ways to express ourselves can be supportive and helpful to externalize thoughts and feelings.
 - Expressing emotions can help people cope better and understand the problem more fully, which can assist in moving forward with the next steps.
 - The needs will be different based on your unique situation and the child.

Activities

- The following pages will provide you with some ways to explore together as a family and help build your confidence in approaching serious illness conversations with children.
- The activities are only suggestions as to ways to engage and explore together. All family members can use them.
- The different activities may not be a fit for everyone, but they are all ways to support understanding and participation if desired.
- The information shared with these activities is personal and confidential. To share with others requires permission from the person who shared it.
- Activities provided can help explore:
 - Goals and hopes
 - Fears and worries
 - Strengths
 - Making decisions

❖ Goals and hopes

- The 4 W's
- Question jar - (sentence completion)
- Past, Present, and Ponder²²

The 4 W's: wish, worry, wonder, will

I wish...	I worry...
I wonder...	I will...

A way to explore thoughts and preferences

- Fold a 8x11 paper in half then half again
- Unfold the paper, there will be creases outlining 4 boxes
- Write in each box a W to consider (see diagram)
- Pose the question that is being considered
- Provide drawing and writing materials
- Invite the child to write /draw their thoughts
- Provide time and sit quietly while witnessing their work
- When the child is finished, invite them to share. Sharing is a choice.

²² Søndergaard, E., & Reventlow, S. (2019). Drawing as a facilitating approach when conducting research among children. *International Journal of Qualitative Methods*, 18. <https://doi.org/10.1177%2F1609406918822558>

Question Jar - (sentence completion)

I feel the happiest when...	I wish...
I wonder...	I feel sad when...
Something that makes me nervous is...	I need...
Others can help me by ...	I worry...
What gives me strength is...	Something that scares me is...
The hardest thing for me right now is...	I feel comfortable when...
I wish others knew...	I feel angry when...
I know that I can...	Usually, I feel...

Sentence completion to prompt exploration of thoughts and feelings

- Above is a list of sentence starters. You may use these or your family can create your own.
- The child and/or members of the family can choose statements to complete to explore thoughts and feelings together about a situation.
- Provide time for everyone to complete their statements. Do not put names on the statements
- Use a container (jar, basket, hat, bowl) to place completed statements in.
- You can take turns to read out the statements and discuss.
- These statements can also be shared with your healthcare team.

Past, Present Ponder

Past	Present	Ponder

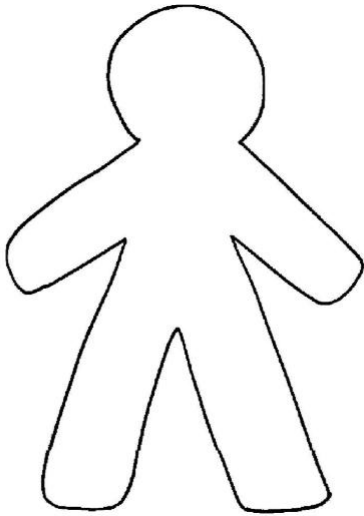
A way to explore and reflect on goals, situations, and hopes

- Fold a 8x11 paper into 3 parts, then unfold
- In each section write one word to consider (see diagram) Past - Present - Ponder
- Consider a topic (e.g. our family, health, hopes, goals)
- Provide drawing and writing materials
- Invite the child to write /draw their thoughts about the topic in the past, now in the present and anything to ponder
- Provide time and sit quietly while witnessing their work
- When the child is finished, invite them to share
- These thoughts can be shared with your healthcare team

❖ Fears and worries

- Colour how I feel²³
- My heart: mad, sad, scared, worried
- Visual distress scale²⁴ (0-none to 10-high) rate difficulty

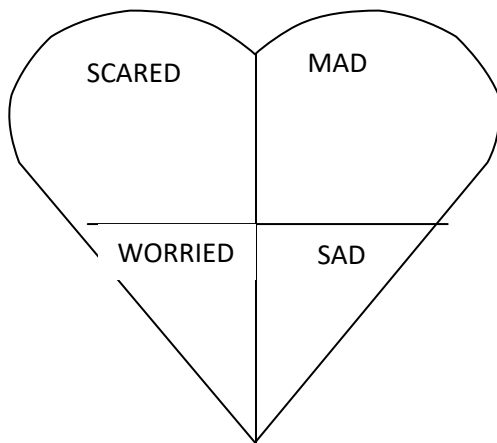
Colour how you feel



A way to identify with experiences and express feelings

- Provide drawing and writing materials
- Draw an outline of a person on the paper (see diagram)
- Invite the child to think about the feelings they have about the situation or decision.
- Ask the child to identify the feelings and pick a color for each feeling they identify to represent the feeling.
- Invite the child to color in the body to show how much of each feeling they are feeling (eg. if the color yellow was picked for happy and the child feels happy most of the time they would use the yellow color most)
- Provide time and sit quietly while witnessing their work. When the child is finished, invite them to share their feelings, for how long they last and what helps them cope with their feelings.

My heart



A way to explore big feelings

- Provide drawing and writing materials
- Draw an outline of a heart on the paper and divide into 4 (see diagram) label feelings.
- Starting with **MAD** invite the child to think about the feeling.
- Invite the child to write or draw about what that feeling feels/looks like for them.
- Repeat process, next to **SAD**, then **WORRIED** and last **SCARED**.
- When the child is finished, invite them to share. Sharing is a choice.

²³ Ziffer, R. L., & Shapiro, L. E. (1992). *CSRPI: Children's Self-report and Projective Inventory*. Psychological Assessment Services

²⁴ Wiener, L., Battles, H., Zadeh, S., Widemann, B. C., & Pao, M. (2017). Validity, specificity, feasibility and acceptability of a brief pediatric distress thermometer in outpatient clinics. *Psycho-oncology*, 26(4), 461-468.

Visual distress scale



0 No Distress ————— 10 Distress ++



Using the vertical line, please mark your current level of distress on the line below.

A way to rate experiences, reactions and coping

- Ask the child to indicate on the scale below the number between 0 and 10 that best describes how they are feeling. A zero (0) means no distress and a ten (10) means the most distress.
- A way to ask children to rate how they are feeling (mood, anxiety, fatigue, pain etc.)
- Explore and inquire as to the reason for their rating.
- Can be used when we notice signs that the child may be having difficulty, but having a hard time talking about what is happening for them.

❖ **Strengths**

- Things that I "**CAN**" (abilities)
- Name anagram (what is important to me)
- Trust target (who supports me)

Things that I "**CAN**"



Name Anagram

F - Fun

A - Accepting of me

M - My support system

I - Interesting adventures

L - Loving

Y - Yummy food

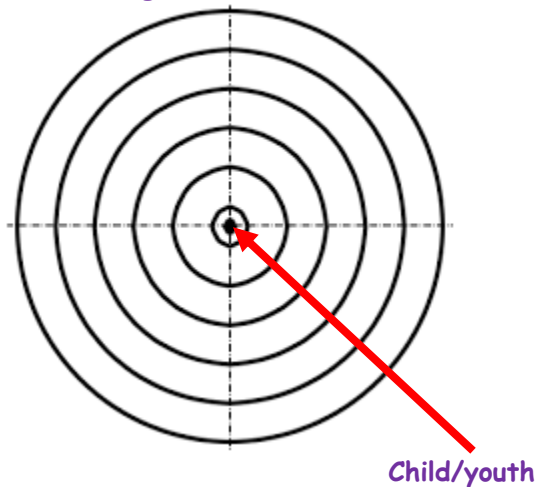
A way to identify and affirm important abilities

- Provide drawing and writing materials
- Draw an outline of a tin can on the paper (see diagram)
- Invite the child to decorate the can with pictures, words, objects that describe the abilities that are most important to them (you can use collage/magazines if preferred)
- Provide time and sit quietly while witnessing their work
- When the child is finished, invite them to share what they have identified and why.
- These thoughts can be shared with your healthcare team.

Use the child's name to explore the abilities/things important to them

- Provide drawing and writing materials
- On a piece of paper invite the child to write their name along the left side of the page (see diagram of the word **FAMILY**)
- Ask them to think of words that begin with each letter of their name (you can use a few words to describe as long as one word starts with the letter)
- Provide time and sit quietly while witnessing their work
- When the child is finished, invite them to share their thoughts.

Trust Target



This is a way to identify people in the child's life and to consider the support and/or the trust in the relationship.

- Provide drawing and writing materials
- On a piece of paper invite the child to draw a target and to put their name in the middle.
- Invite the child to think about all the different relationships they have in their life (make a list).
- Consider one name at a time and invite the child to consider where to write that name on the target.
- The names closer to them in the middle are relationships that they trust and support them most. As names move away from the middle are relationships that may not be as close and are people that they trust less.
- When the child is finished, invite them to share what they have identified and why.

❖ Making decisions

- Thumbs up, thumbs down
- Pros and cons
- Control of Preferences Cards

Thumbs Up/ Thumbs Down



This is a way to indicate attitudes or views towards different situations and experiences.

- People can indicate their preferences in many ways (smile/frown, nods up/down, blink once/twice)
- Thumbs up/thumbs down provide a simple way to indicate a positive or negative view on something.
- Preferences can still be determined without the use of words.

Pros and Cons

PRO	CON
2	1
1	2

A way to compare two choices/decisions

- Provide drawing and writing materials
- On a piece of paper invite the child to divide the paper into four boxes (see diagram)
- Identify each choice/decision #1 and decision #2
- For each choice/decision consider the **PROS** (positive/desirable/wanted outcomes)
- For each choice/decision consider the **CONS** (negative/undesirable/unwanted outcomes)
- List the pros and cons on the table to compare and consider.
- Discuss together as a family.
- You may discover that you need more information.
- It may be helpful to review and come back to as you consider the options.

Control of Preferences Cards



Informed by: The Control of Preferences Scale (Degner et al., 1997) & The Public Participation Framework (IAP2, 2007). The following cards have been developed by Susan Poitras and illustrated by Zoe Schmidt.

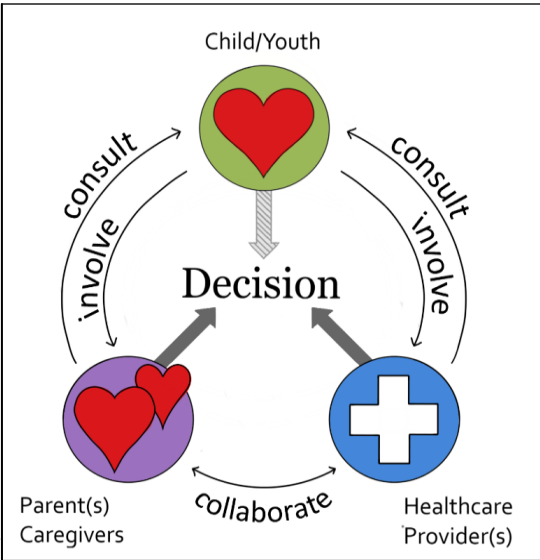
Provides a visual way to indicate how involved an individual wants to be in the decision making process.

- Each card represents different roles and ways to participate.
- The degree of control can be revisited and reaffirmed quickly with the child/youth.
- Offers an opportunity for children to express their preference about their participation when decisions are being made.
- Cards can be used at any time, to indicate how involved children wish to be during meetings, appointments and with discussions
- Cut the cards out, fold, glue the two sides together and use.

Fold on the perforated line

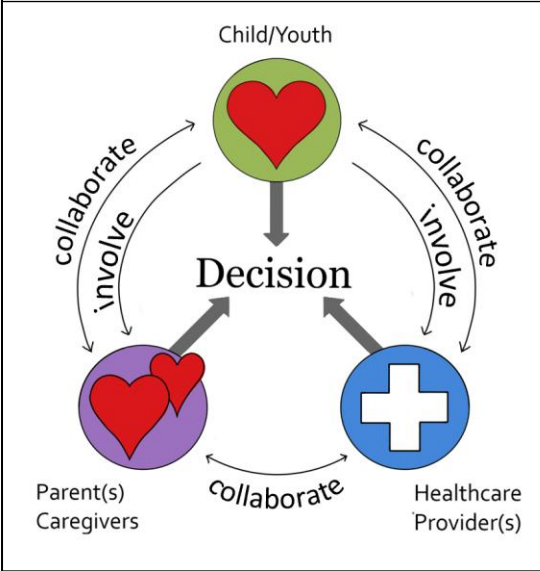
<p>Child/Youth</p> <p>Parent(s) Caregivers</p> <p>Healthcare Provider(s)</p> <p>Decision</p> <p>represent</p> <p>collaborate</p>	<p>Child/Youth does not want to or cannot participate at this time. Parent(s)/Caregiver and Healthcare Provider(s) inform decision.</p> <p>Child: “Please represent me”</p>
<p>Child/Youth</p> <p>Parent(s) Caregivers</p> <p>Healthcare Provider(s)</p> <p>Decision</p> <p>inform</p> <p>represent</p> <p>collaborate</p>	<p>Child/Youth wants the Parent(s)/ Caregiver to represent them and share the information and outcome later. Parent(s)/Caregiver and Healthcare Provider(s) inform decision.</p> <p>Child: “Please represent me and let me know”</p>





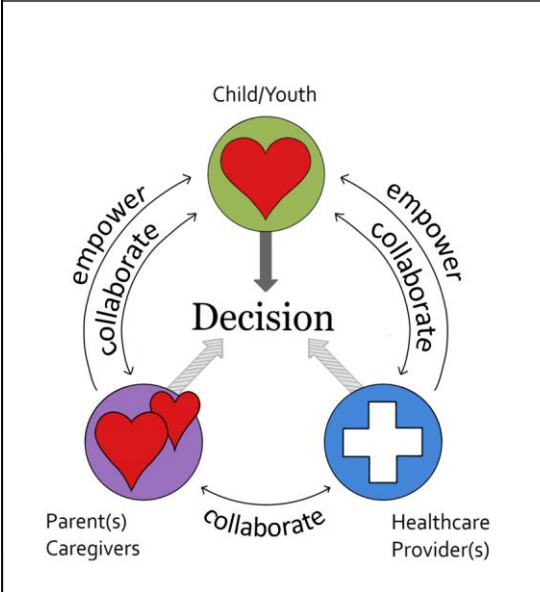
Child/Youth wants to share their view with Parent(s)/ Caregiver/ Healthcare Provider(s). May or may not want to be included with conversations.

Child: **“Please include my view with the decision chosen”**



Child/Youth wants to be included with conversation, share their views, and be involved with decisions.

Child: **“Please support and work with me as we make the decision together”**



Child/Youth wants to choose and have agency with the decision and is empowered to do so.

Child: **“Please support and work with me as I make the best decision for me”**

Exploring, understanding, being/doing



Mindfulness practices can help manage stress

- Thoughts feelings and sensations inform, influence and impact parents/caregivers.
- Invite intentional awareness of yourself in the present moment, without judgment.
- Helps with focus, actions are more intentional and supports a calmer mind.
- Can affect the brain areas that regulate memory, empathy and stress.
- Mindfulness has many health and wellness benefits.

Mindfulness Resources

- How Mindfulness Empowers Us: An Animation Narrated by Sharon Salzberg
<https://www.youtube.com/watch?v=vzKryaN44ss>
- Stress and Thinking: The mind/body connection
- <https://www.youtube.com/watch?v=KYcLfBf-T9c&list=PLjJ+OP3StIuXFJ3jjjR3THLhHNMrFFJkM&index=8>
- Mindful Parenting: https://www.youtube.com/watch?v=XIryQI2m_oE
- 3 Keys to Mindful Parenting: <https://www.youtube.com/watch?v=ffFxSNFJyFo>
- Everyday Mindfulness:
- <https://www.youtube.com/watch?v=QTsUEOUaWpY&list=PLjJ+OP3StIuXFJ3jjjR3THLhHNMrFFJkM&index=1>
- The Samurai and the Fly:
- <https://www.youtube.com/watch?v=R5-HNXxc5kk>
- Headspace: <https://www.headspace.com>
- BreathR: <https://keltymentalhealth.ca/breathr>
- Calm: <https://www.calm.com>

Tools and Resources (Best Access with Google Chrome Browser)

Family

- Family Support Institute of BC <https://familysupportbc.com>

Making Decisions

- Kids' Health: Child and Youth Health
<http://www.cyh.com/SubDefault.aspx?p=255>
- Six Steps of Shared Decision Making. © 2012 by Informed Medical Decisions Foundation
https://www.healthit.gov/sites/default/files/nlc_shared_decision_making_fact_sheet.pdf

Serious Illness

- Serious Illness Care <https://www.ariadnelabs.org/areas-of-work/serious-illness-care>
- Institute for Healthcare Improvement (2017) Pediatric starter kit: Having the conversation with your seriously ill child. <https://theconversationproject.org/starter-kits/#pediatric-starter-kit>
- My Wishes/Voicing My Choices <https://fivewishes.org/five-wishes/individuals-families/individuals-and-families/children-and-adolescents>

BC Children's Hospital:

- Resource Center and Library <http://www.bcchildrens.ca/our-services/support-services/resource-centre#About>
- Clinical Ethics <http://www.bcchildrens.ca/our-services/support-services/clinical-ethics>
- Decision-Making Tool for Patients and Families Facing Difficult Healthcare Decisions <http://www.bcchildrens.ca/aboriginal-patient-liaison-site/Documents/Goals-of-Care-Framework-2017.pdf>
- Voice <http://www.bcchildrens.ca/our-services/support-services/transition-to-adult-care/youth-toolkit/voice>
- Child Life Services <http://www.bcchildrens.ca/health-info/coping-support/child-life>

Your experience is important

We invite your feedback and anything you wish to share about your family's story navigating serious illness conversations.

The embedded link below will connect you with a brief voluntary quality improvement survey to continue to learn and improve the care of families in similar situations as you.

Thank you in advance for your time and consideration. Please click on the link to provide your feedback. <https://surveys.vch.ca/Survey.aspx?s=33d920b94f7a41f1b4b1b0698abe034f>

Acknowledgements

We acknowledge all the families whose lives have been impacted by complex, serious illnesses. With the challenges, you must move through; we hope that you find partnership with your process.

Thank you to the children, youth, and their families whom we have had the privilege to support and learn from their stories.

We extend gratitude to BC Children's Hospital and Canuck Place Children's Hospice for the support to develop this guide and their work with children and families

The Partnership Guide is an initiative developed by Susan Poitras, under the ChildKind Project, making comfort a priority and dedicating to the humane treatment of children.

Parent/Caregiver Feedback

"I believe it is a guide that can be utilized at several times throughout the healthcare journey."

"The guide is informative and gives families permission to discover how best to recognize and include their children on a level they may not have pondered previously."

"An excellent guide for both families and healthcare providers to utilize."

"I like that the guide is meeting the child where they are at."

"The guide provides ideas and activities on how to have these conversations with children."

"Having gone through this experience with my child, the partnership guide would have helped ALL involved in her life...and ultimately, would have contributed to her quality of life."

"Parts of the guide I could read with my child and ask how she felt. Explain why we are going over this and tell her we want her to choose what makes her most comfortable."

"It is reassuring as parents and children that whomever the healthcare team is that they are here going through this journey with you. You are not alone."