



Seattle Children's
HOSPITAL • RESEARCH • FOUNDATION

The Decision-Making Tool

Information for Families

Hope. Care. Cure.™

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The Decision-Making Tool: An Introduction for Families

Children with serious health conditions and their families have a great deal of information to consider and many decisions to make regarding care. Regular discussion and care planning with their care team can be very helpful. Seattle Children's Hospital staff might suggest a Pediatric Advanced Care Team consult. This meeting helps to make sure that your family is at the center of the decision making and care planning for your child, and that your care team can best hear and respond to your child's needs. The meeting can include your child, family members, hospital staff, your pediatrician, home care nurses and therapists, alternative health care providers, school personnel, spiritual advisors, and any others you wish to invite. It can be used when your child is diagnosed with a new condition, when you have decisions to make about treatment options, planning for discharge, or how to approach your child's care in the future. A member of The Pediatric Advanced Care Team will take notes and assist with the discussion to make sure that all aspects of your child's care and situation are discussed. The Decision-Making Tool ("the DMT") is a form that is used as a discussion guide.

What are the benefits of a DMT care-planning meeting?

- It provides a structure to talk about yesterday and tomorrow, not just the usual problem-oriented approach of addressing today's situation.
- Your family's voice is directly heard – it asks about your belief systems, questions, expectations, plans – what is important to you and your child. Your care team won't have to assume what you want, how to work with you, or how to best care for your child.
- The DMT structure provides the staff with a much larger picture about your child and his or her care than they might otherwise get – it includes much more than just the medical picture.
- You get to tell your story and know someone is listening and sharing information with the rest of your care team. The DMT form is reviewed by you and then distributed and placed in your child's chart.
- It gives you a structured way to reconsider and update the plan when changes happen. You can track changes when reviewing a series of DMTs – each one gives a "signpost" – a way to see what you were basing your decisions on at that time. You and your care team can review those signposts to see how your child's condition has changed and to make changes in his or her care.

What do families say about the DMT?

"We went from being very scared and not knowing what to do, to having a roadmap for what could happen in the different possible situations, and feeling very confident about the possibilities."

"The DMT helped define things – helped us make decisions, understand the choices and options."

"The DMT gave all the providers something concrete to work with. We could communicate our expectations."

"The DMT allowed discussion in a non-threatening way. It gives you a structure to talk about difficult things."

"The DMT helps all the people in the care team be on the same page. They all know what my husband and I would be choosing in a given situation. The clarity is a positive. It brings some options out that we wouldn't have considered otherwise, and we get more information on them."

"It is extremely helpful to sit down and break down all the issues little by little. We are able to identify what would help and what we should do... It is helpful to review step by step what you've done to help your child. Otherwise you lose track of what you've done to get here."

Decision-Making Communication Tool (Explanation)

Patient Name: _____ **Prepared by:** Person recording the discussion **First DMT**
Date: _____ **Present:** Names of all participants, with titles, **Update**
Length of Visit: _____ for future reference
Physician of Record: Primary or specialist
Care Coordinator: At clinic and/or at home

History of Present Illness

In this section, a brief description of your child's medical history and present symptoms and status is recorded.

Medical Indications

This box contains information about your child's diagnoses, symptoms and treatments. Each diagnosis or symptom is described, and each treatment option discussed in the meeting (either currently used or possible) is listed, along with the risks and benefits for each one.

- Description of diagnosis or symptom #1:
Treatment option(s):
Benefits:
Risks:
- Description of diagnosis or symptom #2:
Treatment option(s):
Benefits:
Risks:

Patient Preferences

This box contains your child's and family's preferences and goals and choices. This includes how you prefer to be informed by the care team, how you like to be involved in the decision making, and your goals for this discussion. It also includes your preferences and current thoughts or decisions about each of the specific treatment options discussed in the Medical Indications box.

If your child is too young or unable to express preferences, or if you have decided that they will not be a part of the care planning meeting, you will state your understanding of your child's preferences and your own preferences.

Quality of Life

The things that give value and meaning to your child's life are written in this box. What does your child love to do? What gives your child comfort? Think about:

- Important activities
- Important relationships
- Important possessions
- Important goals and hopes
- Things that make your child who he or she is
- Things that contribute to your child's emotional well being
- Things that contribute to your child's spiritual well being

Also listed here can be the things your child does not like.

Contextual Issues

The physical, social and spiritual parts of your child's and your family's daily life are written here. This includes all the non-medical information that affects your child's health and health care.

- Home environment
 - Who lives in your home, their names and ages?
 - Are there physical restrictions in your home: for example, are there stairs your child cannot climb?
- Who is your child's primary caregiver?
- What extended family and friends make up your support system, and in what ways do they help?
- How do your cultural and spiritual beliefs and needs affect how you make decisions?
- How do financial issues and insurance coverage affect your child's health care?
- Is there any family health history related to your child's condition?
- Does your child receive alternative health care therapies?
- What are the various needs and opinions of your family members and professional caregivers?
- Who are the members of your child's health care team?

Decision-Making Communication Tool, Page 2 (Explanation)

Patient Name:

Date:

Discussion

This section documents the discussion between the health care team, your child and your family. It will describe how the things in the boxes above were discussed, what things were decided in the meeting, and what issues you might still be considering or have questions about. It will show how your child's and family's preferences, goals, and all the aspects of your life lead you to the decisions you are making about your child's care. This section can contain the plan of care that is decided upon, with details to follow below.

Plan

The plan of care can change as your child and family's needs change. It can be updated when you request, and/or when your child's medical situation changes, when your family's situation or decisions have changed, or when your child's care team has new information for you. Each action item is written, along with the person who has promised to do it and when they should have completed the action. You will review the DMT once it is written, making any corrections necessary. Then your child's physician signs the DMT, each member of the team receives a copy, and it is placed in your child's medical chart.

Action:

Who will do:

By what date:

Physician Signature _____

Date _____

Decision-Making Communication Tool

Patient Name:

Date:

Length of Visit:

Physician of Record:

Care Coordinator:

Prepared by:

Present:

First DMT

Update

History of Present Illness

Medical Indications

Patient Preferences

Quality of Life

Contextual Issues

Decision-Making Communication Tool, Page 2

Patient Name:

Date:

Discussion

Plan

Action:

Who will do:

By what date:

Physician Signature _____ Date _____