

BASIC APPROACHES TO DECISIONS

When children are sick, their parents sometimes have to make choices about what plan of treatment is best. Parents work with the doctors and nurses to get information. The staff suggests what treatments can be used. Then parents are asked to approve a course of treatment that is right for their child. Usually everyone agrees about what to try. Sometimes it is not clear what is right.

This booklet talks about some important ideas for decision-making and three ways to think about difficult decisions. These ideas are especially useful when discussing choices with the other people involved. These people may include the child, other family members, and your child's health care team. Especially when parents are not sure what is right, it is good to take the time to use some tools to think about what is best.

Background for decision-making

Parents are decision-makers for their child

Young children cannot completely understand their medical condition and tell us what they think is best. For that reason parents are usually the decision-makers for their child. The parent's job is to get the best information they can and to think carefully about the life goals that are possible for their child. The child's viewpoint should be included as much as he or she can understand and give opinions. Looking at things from the child's point of view, we ask the parent to tell us what they believe is best for their child. The health care team will make recommendations, but the parents guide us and give permission for the treatment their child should receive.

Starting where you are

Every family brings its own beliefs and background to decisions. We always want to start where you are. Talking clearly about these beliefs among yourselves and with the health care team makes decision-making clearer. Sometimes a crisis makes you question long held beliefs. Talking about this can be a useful part of your discussion.


These beliefs come from many places including:

- your cultural and family background
- your own religious or spiritual beliefs
- your extended family's religious and spiritual beliefs and what you grew up with
- your personal experience and approach to life
- your experiences within your family, friends, and life with illness and difficult decisions
- what you encounter in reading, news, movies, and discussions

Each family brings a different set of beliefs and background, and we encourage you to talk with us about your views, and then to see how the ideas presented below fit in with your views.

Hope

Hope is something we always want to hold on to, and never want to give up, especially in relationship to our children. It is also a word with different meaning to different people. Two different but important meanings sometimes get mixed up.



One meaning of hope is what we wish for. We may wish that the disease would just go away or that the medical problem never happened. A second meaning of hope is what we expect will really happen. We expect medicine to work or that there will be some improvement. Often the two meanings get confused with each other. A doctor may say, "We hope to see a response to this drug tomorrow." Does the doctor mean "wish" or "expect"? We would all hope, for example, that a disease will just vanish, but we don't necessarily expect it. As you talk with people, and as you think about things, it is important to be clear about what sense of hope you mean.

It's also important to think about what we can realistically hope for. Changing what we hope for or giving up certain hopes doesn't mean we are abandoning all hope or giving up on a child. Because hope has two meanings, we continue hope when we think about both what we wish for and what is realistic to expect.

Treatment as a bridge to achieve health

One important idea is whether a treatment will be a bridge to health or something that will be a permanent need. This is especially important if the treatment is invasive or painful. We accept a lot of treatments that are painful- surgeries, medications with side effects, ventilators, if they return us to good health. Using those treatments long-term or permanently becomes harder if they will put off death for a while but not give a good quality of life or a return to health. It is always reasonable to ask about whether a treatment will be a bridge to better health or a permanent situation.

Realistic life goals

As you start thinking about each decision, it is good to think about what are realistic life goals for your child. Each person is different. What we want and what we can do in life is different. Good decisions about medical treatment take into account who each person is and what is possible for their life. We all start out with many hopes and dreams for our children, and as time goes by we learn what is possible, what is likely, and what is not possible. Part of good decision-making is understanding what is possible and setting goals that both get us as far as we can but are realistic. This is hard when we talk about medical conditions and life-and-death issues for children. Choices about treatment, however, need to be made with understanding about the life-goals parents have for their child.

The child's point of view

As you think about what is best, spending some time to look at the world as your child experiences it is important. Your child's experience of their body (movement, mastery, pain, basic functions like breathing and going to the bathroom), their thoughts and feelings about themselves and their world (confidence, fears, happiness, worries), and their interactions with others (being comforted, feeling loved, feeling lonely, having friends and family around) are all important aspects of experience.

The family as a whole

Children are always part of families, and taking into account how your child is part of your family is important. This means both how your family helps your child, but also how the medical decisions you make affect your family. Things like child's excitement and joys, what they bring to you and any brothers and sisters, and how the medical care you choose affects brothers and sisters and parents are an important part of the decision. Things like nurses in your home, numbers of doctors appointments, the time it takes to do treatments, expenses of treatments and appointments all need to be taken into account and planned for along with the opportunities for joy, loyalty, helping another person, and embracing life.

Knowing for sure

One thing that makes decisions hard is that we all want to be sure we are doing the right thing. In medical decisions, as in other decisions for our child and family, we are only human beings. We can not see the future, and can not be absolutely sure. We still need to make decisions, because that is our job for our children. The amount of

time we have for decisions also varies. Ask how quickly a decision must be made before more problems might come up if we wait. All we can really be sure of is that we did our best for our child at the time. That is why we want you to talk carefully with your doctors and health care team. Get all the information you can, ask lots of questions, talk to the people who know you and your child, and think about the decision carefully. As parents we can not be perfect, but we can do our best. That is what we should expect of ourselves, and what our children expect of us.

Three ways to think about hard decisions

1. One way to think about a course of treatment, and about each single treatment, is to ask about the harm and benefit it brings to the child. Every treatment has both a harm and a benefit.

Sometimes the harm is small; for example it tastes bad, or it is inconvenient. Other times the harm is in-between or large; side effects can damage other organs or cause a risk of bleeding. They may even be life-threatening.

Benefits come in the same way: small, in-between, or large. A new medicine might make a small difference in lab values, but not really change the overall situation. Or it might have a chance to make a big difference for the child. Ask your health care team to help you sort out the possible harms and benefits.

It is also important to ask if the benefits and harms are certain or uncertain. Often in medicine we don't know for sure what will happen, so you have to decide even though it is not clear. Again, ask your health care team about how likely each harm or benefit may be.

You also need to ask about who gets the harms and benefits. We always start by asking about the patient. Harms and benefits to the patient are most important, but you also need to think about other members of your family, for example brothers and sisters. Sometimes even other children taken care of at the hospital are affected. Especially for things you don't know about or understand, you can ask the doctors and nurses about harms and benefits. That helps you make the best choice for your child.

It can often help to write down the harms and benefits:

	Harms	Benefits
Doing the treatment		
Not doing the treatment		

2. Doing the right thing as a parent

How can I be the best parent for my child? Most parents ask this about choices they need to make. The answer is often unclear because the harms and benefits are unclear. Every parent wants to do what is best for his or her child. The problem is knowing what is best.

One thought many people have is that a good parent should do everything for their child, and that the doctors should do everything. But sometimes a treatment or our technology and machines can not really make children better and can cause more suffering than cure. Rather than thinking of doing everything, it makes sense to think about doing all the right things.

Many people think about this based on how their parents did things. They may want to do things the same way or do things differently than their parents. That is an important kind of information, but there are many other places to get information on this question. Talking to family or trusted friends, reading, and talking to your child's health care team can all help. The important thing is to do your best to understand and make sense of the choices you are facing.

Most people agree that a good parent should do their best to know what is right for their child. The parent tries to understand the harms and benefits, and to make the best decision they can. Sometimes we cannot know for sure what is right, but we can know that we did our best to try to understand it and see it from our child's point of view.

3. Doing to and doing for

When treatments and decisions get complicated there is a question that can be helpful. "Does this treatment do something for my child, or do something to my child?" This question recognizes that sometimes a treatment may be medically possible, but doesn't really help the child overall. For example, it may be possible to straighten a child's bone, but if they will never use their arm or leg for other reasons, the surgery may not make sense. With each treatment, in addition to asking about harms and benefits, you can ask if it is doing something for or to your child.

Working together

There are other ways to think about decisions, but the three ways we talk about here are a good place to start. Your health care team will want to talk with you about any ways you have of thinking about things. Be as clear as you can about what is important to you and what you are thinking.

Collaborative decision-making

Parents are given a lot of medical information. They also bring important information about what is important to their child and their family. Parents are the experts in their child's life, and also learn a lot about their child's medical care. Health care teams ask parents to guide us about what is best for their child. But parents are not alone in these decisions. The doctors will let you know what is possible and should make recommendations about what they believe is best.

You should ask as many questions as you need to about how your child's doctors and health care team understand your child's condition. Understand that you remain the person guiding the direction of treatment. Your job is to do the best you can even when we don't know for sure what will happen or what is right. Working together, you and your child's health care team will be able to arrive at what is best for your child.

The Ethics Committee and the Office of Ethics at Children's Hospitals and Clinics of Minnesota are resources to families and caregivers to discuss these issues further or provide additional consultation. Please feel free to contact us at (612) 813-6159 for further information or discussion.