

TOOL 2 – DECISION MAKING

Making decisions and planning care

While there are many things we cannot control, there are important choices that can be made about the care of a child with a life-threatening illness. Parents share the difficult task of making these decisions with the help of doctors, nurses, and other health professionals. Parents know their children better than anyone else. Doctors and the rest of the care team bring experience and specialist knowledge.

It is often helpful to think about and discuss what the best approach would be if your child were to deteriorate suddenly. This is called advance care planning. Sometimes doctors and parents are unsure how to raise the question of decision making. Signaling to your child's doctor that you are ready to talk about some of the more difficult aspects of the illness and its treatment can help facilitate important discussions.

What decisions will I be asked to make?

What is the overall goal of care?

When a child cannot be cured of their illness, or when a cure is extremely unlikely, the focus of care may shift. This may involve attempting to prolong the child's life for as long as possible, or to ensuring the time that remains is as full of life and happiness as it can possibly be. Sometimes there is a choice to be made between length of life and quality of life.

Prolonging life or pursuing a cure when this is unlikely nearly always comes at a cost, and parents can find themselves torn. Do you leave no stone unturned in the search for a cure or do you ensure your child does not suffer? These can seem impossible choices and different families may make different decisions when faced with identical circumstances.

It is important to know that palliative care, including the management of pain and other symptoms, can be combined with ongoing efforts to cure your child's disease or prolong their life, if such efforts are considered to be in the best interests of the child.

What treatments are and are not appropriate?

There may be many treatments that are possible. But distinguishing between what **could** be done and what **should** be done is important. What are the benefits and burdens of the various treatments? Only the individual child or those who know and love them can know what is a burden and what is a benefit to them. For example, some children feel frightened and distressed when they are in hospital, while others feel safe and may even enjoy the activities on offer there.

The process of decision making

The key word here is 'process'. Where circumstances allow, take time to seek information, to think, and to talk with experts and with friends and relatives.

Gather as much information as you can

Meet with the health professionals involved in your child's care and ask questions. You may need to ask the same question a few times to fully understand the answers. It may also be helpful for you to see blood test results or scans.

Ask yourself some key questions

- What are the most important things to you and to your child?
It can be hard to distinguish between what you may want for your child and what they might want for themselves. Even if your child is very young, it may be helpful to think what they might say if they could speak for themselves.
- If time was limited, what would make this time the best it could possibly be?
- Ask your child some key questions. An older child may not be able to participate fully in decision making but may be able to offer a perspective on how they experience their illness and treatment.

What is most important to them?

What are their hopes?

What are their worries?

Talk together as parents. You may not always see things the same way at the outset so it is important to respect each other's views and continue talking.

Seek support from family, friends, and from your spiritual or cultural community. There may be key individuals who are of special value. It's okay to ask if they can be included in discussions with the care team.

Once a decision is made

Once important decisions are made, it's crucial that everyone involved or likely to be involved in your child's care is informed. Many hospitals and palliative care services have documents where these decisions are recorded. This does not necessarily mean the decision is legally binding. Decisions will need to be reviewed as your child's condition changes.

A word on hope

Even in circumstances where there seems to be no hope for a child's survival, many parents find they simply cannot accept it. In their head they understand, but in their heart hope remains. This is okay and hoping for the best while preparing for the worst may be a helpful way to approach the situation. Hope can also be refocused on goals such as going home, comfort, or time.