

When Your Child's Treatment Does Not Work

Sadly, some children do not get better. A child may lose his battle very shortly after a diagnosis or many years later after a long series of treatments when doctors finally tell you that they have no more options for cure. Doctors may speak to you about continuing to treat your child's symptoms in order to keep him as comfortable as possible, and perhaps will tell you they may be able to help him live a little longer. But, if you are reading this section, the heartbreaking truth is that your child is one of those unlucky ones for whom a cure cannot be found.

These were the words you hoped, above all else, that you would never hear, and they may feel like a physical blow to your stomach that leaves you stunned, immobilized, and terrified. Your challenge will be how to absorb this terrible news in a way that still allows you to be there for your child and continue to function in a suddenly bleak world. Be understanding with yourself. Your thoughts are likely to spin in every direction. You may well be struggling hard to manage your emotions. Your immediate reactions may be instinctive and protective and not immediately under your conscious control. As time goes on, you may find that your method of dealing with the news slowly changes or you may not. You may experience any of a range of possible reactions immediately and over time.

A RANGE OF REACTIONS

Nothing challenges the mind and heart quite like having to absorb such painful information about your child and then trying to continue to live your life as normally as you can for the sake of your child. People have very different styles of dealing with terrible news and living with the reality afterward.

So do not be surprised if initially:

- You do not believe the news. Your mind may search desperately for alternative ideas, views, options, and scenarios. Perhaps you demand a second opinion or spend hours on the Internet researching experimental treatments for your child's condition. Your efforts to explore these alternatives may give you energy, hope, and comfort. You will also be doing everything you can to try to save your child— and taking every possible action may bring you comfort later. Or you may turn to other sources of comfort and hope such as your faith in God and the belief that God will not let your child die. You may want to talk with your priest or minister or the hospital chaplain and share your reactions with that person.
- You hear the news and acknowledge its likely accuracy given the present state of medical knowledge, but immediately hope that some other cure will appear or that your child somehow or other will beat the odds. Hope buffers you against the blow. And you can remind yourself, accurately, that occasionally a child does recover contrary to the doctor's predictions.
- You start preparing yourself immediately. You want a great deal of information about why this has happened, what will happen next and how. You question your child's medical team intensely and look up information on the Internet. You want to know the details of what you and your child will be facing in order to get ready.
- You and your partner become angry with each other for having different ways of reacting. For example, you may believe the news right away and want more information while your partner does not believe the news and wants to hear no details. Understand that you are each trying to cope with the news in your own way and may need other family members or friends to talk to as well as having separate meetings with the doctors for some time.

- You or your partner becomes angry with the doctor, especially if he or she was initially quite positive about the outcome of treatment. The messenger who gives bad news has a long history of being reviled. The doctor will understand, but remember that he or she 1) has a responsibility toward both you and your child, 2) knows parents want to make decisions in their child's best interest, 3) wants you to be in a position to make informed decisions about your child's care, and 4) wants to give you the option of having a treatment plan that is more focused on comfort than on intensive measures, which could have long-term benefits for your child and for you. There is some evidence that parents who have earlier discussions with their doctor about their child's likely death are more satisfied with the endoflife care their child receives.¹ If you do continue to feel angry over several months with your doctor and this is impacting your communications, consider whether you would be more comfortable working with someone else who you could trust more to walk with you through this agonizing time.
- You are irritated with your other children for behaviors and actions that you would normally tolerate. You are under great stress and may need to explain that to your child's siblings.
- You find yourself resenting other children who are healthy and are not having to endure what your own child is enduring. Indeed, they are not.
- You feel enormous rage that comes on unexpectedly, even toward people who are unconnected to your child. Anger and sadness are closely related emotions, and some people feel easily enraged when they are very sad.