

YOUR CHANGING REACTION OVER TIME

You may notice over time that your thoughts and feelings change a lot, a little, or hardly at all. You will likely have been absorbing the news in your own way— and there can be many different ways— as you continue the extraordinarily difficult task of supporting your child as he gets sicker.

You may notice any or several of the following reactions as time goes by:

You begin to acknowledge to yourself that your child is likely to die. Perhaps you needed time to absorb the news and needed the evidence of your child becoming weaker and sicker before you could recognize this. But do not be surprised if the focus of your attention still goes back and forth. You may notice the focus of your thoughts and your emotions fluctuate between acknowledgment, sadness, new or changing hopes, other family concerns and activities, and reassessing what is happening. These fluctuations in focus might last all the way up until the time your child dies; in fact having ever-changing feelings may be what help you keep going. Few people can bear a relentless truth without some reprieves.

“You need to be told only once your child is going to die. It’s not something you forget.” You may have immediately acknowledged that your child’s death is likely once the doctor told you it was a probable outcome. Some parents take in the bad news right away, but they compartmentalize it to allow other things to occupy their mind and heart. You might find that you focus on something besides your child’s impending death, such as a short-term objective like getting your child home for Thanksgiving or a new potentially curative treatment you read about on the Internet. Sometimes you may still find yourself hoping for a different outcome or praying for a miracle. As I said earlier, it is true that some children do defy the odds and their doctors’ expectations. The human spirit can use that knowledge to endure the darkest times. This division between your rational mind and your hopes may sustain you and allow you to enjoy the time with your child. As another parent said, *“I cannot think of him dying right now, I want to be fully present and available to him right now.”*

You may want as much information as possible about what is happening and what will happen. You want to know about the way your child is likely to die in order to prepare yourself.

“I can’t believe I’ve planned his funeral already, but I know I won’t be able to do it when the time comes.” You may notice you have done some advance planning for your child’s death. You may have thought about the funeral home you want to use (hospital staff can help here), who you want in the hospital with you and how to reach them, how you will get home afterward, and even whether or not you want your child to have any kind of postmortem— often a doctor is obliged to ask you about this if your child has been on an experimental protocol after your child has died. Some parents say no immediately but might have said yes if the reasons were explained beforehand and they were told then that the results could benefit others. If you are a planner, these are all decisions that can be made in advance that may spare you pain and effort later.

“I don’t want to be so sad that I cannot enjoy whatever time I have left with him.” “I’m not going to grieve for one second longer than I have to or before I have to.” You may understand that your child is likely to die but want to protect yourself from experiencing emotionally what that means because you want to be sure you can be emotionally available to your child.

“Once I start crying, I’m afraid I won’t be able to stop.” You may be afraid to cry because you fear that you will be overwhelmed by grief and will not be able to support your child.

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On the other hand, you may be a parent who deliberately makes a space in your life where you can feel some anticipatory grief and you find that releasing some of the emotional sadness and tension you are carrying inside you helps you continue to function. *“When I’m driving home from work, that’s when I let myself cry. Then I’m ready to face my family again.”* Or you may select a time or place where you can express your feelings. *“I need to talk to you today. I’ve got to have a safe place where I can cry.”*

“The doctors kept telling me he was going to die. I just did not believe them. I don’t know why.” You may continue to deny the information entirely over time, perhaps because you fear at some level that if you allow the knowledge in, you will not be able to protect yourself from the incapacitating emotions that could follow.

“How can I be there for Jane when I feel so devastated that I cannot look at her without crying?” Or you may be so grief stricken that it becomes very hard to visit or be with your child. Sometimes strong emotions can be overwhelming and negative thoughts can take over. I will talk below about the importance of getting help immediately in this situation.

You may have moments of thinking you will not be able to go on living if your child dies. Many parents have fleeting thoughts or questions about this and wonder how they will continue to live without their child. I will also say more about this later.

ARE YOU RECOGNIZING REALITY?

It is often a process. You may be taking some conscious steps to prepare yourself for your child’s likely death. But you also may be taking unconscious steps that you don’t even realize you’re taking that help you prepare yourself. You may notice any of the following:

You have acknowledged to yourself that your child is likely to die even if you find the strength of that acknowledgment waxes and wanes. You may notice that you still go back and forth in what you are thinking about and focusing on between your child’s likely death and other hopes, preoccupations, and activities. One week you may want to talk with the doctors about your child’s imminent death and the next week about the possibility of his returning to school. This is perfectly normal, and indeed this back-and-forth process may be exactly what helps sustain you and allows you to be with your child in the way you want.

You are gradually adjusting your hopes for your child— from hopes for a cure to hopes that your child will be able to be part of a particular family event to hopes that his death will be peaceful and pain free.

You have done some advance planning for your child’s death. You have taken positive steps to help yourself when the time comes and when you fear you will feel incapacitated, yet you are still able to be with your child and be a source of strength for her.

Even if you may still not consciously believe what the doctors are telling you, you may hear it at some level but not want to acknowledge it consciously to yourself or to the doctors while you are unconsciously preparing yourself, as Frankie’s mother appears to have been doing.

So what hints suggest you may be unconsciously preparing yourself? Be aware of dreams you have about friends or relatives who have died. Or notice if you suddenly think about other families who have lost a

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child and you feel an urge to contact them. Follow that urge. These experiences may be preparing you at some level for your child's death and may buffer you somewhat against the shock when it happens.

Also know that if you do not appear to be taking in the seriousness of the news, the doctors will likely become worried about you and continue to repeat the bad news. If this repetition is very hard for you to hear, you can always tell the doctors you have heard what they said but that you believe there will be a miracle and will deal with a contrary outcome if or when it happens. You can add that until then, the hope for a miracle is what is sustaining you and allowing you to support your child in the way you want.

But if you really have not recognized that your child's death will occur, you could feel completely blindsided and your grief path will be affected by how you react afterward. If you can, like Iris, say, "I helped him die without fear," that will be a comfort. If you accept your child's death as "God's will" and manage not to be angry with God because of that but still find your faith a comfort, you will ease your grief path. But the next section mentions other factors that can make this attitude more complicated and may require you to get help before or after your child dies.