

THE IMPORTANCE OF HOPE

Holding on to hope may be as important to your child as it is to you. You may not want to share bad news because you fear it will take away hope. One parent described hope almost as a religious belief. But let's remember there is a difference between hope and understanding. A wonderful adolescent I knew who had just learned he had an incurable condition, said to me: "I guess I will have to hope for one thing and prepare for another." How can you help your child to hold onto hope of some kind? Can you help your child notice that she may have several hopes at the same time (as you perhaps do also) that may even be contradictory? For example, a child can hope she is cured, may hope she can stay at home whatever happens, and may hope she can go to her graduation. As your child gets sicker, it may be that some of her hopes are more realizable than others. Your hopes may shift, too. Perhaps you can encourage your child to transfer her hope from one goal, namely being cured, to other shorter-term goals that would give her satisfaction and pleasure in the short run, such as being at home or achieving a particular goal, like going to her graduation.

In the same way, do not be surprised if your child is sometimes able to discuss his likely death and sometimes not— if he appears to be going back and forth between recognizing his medical condition and planning for the future. Just as life would be unbearable if you focused solely on your child's illness and likely death, a brief excursion into the subject of death may be all your child can tolerate or need before returning to the experience of his or her daytoday life. Hope may have a hand when fluctuations like the following occur:

- A teenager plans her funeral one week, and the following week, chooses the courses she wants to take next semester.
- A twelve-year-old child talks in quick succession about his likely death, his worry about how his parents will manage, and the progress of his local baseball team.
- A terminally ill seven-year-old boy describes in a play session how sad a baby dinosaur is because his mother has died, but notes that he will be all right because he will remember his mother and have his father with him. He then ends the intense play session by saying, "That's enough of that. Now let's play a game."

SAYING GOOD-BYE WITHOUT SAYING GOOD-BYE

Some families find meaningful ways to say good-bye— to demonstrate the power of their love—without ever explicitly saying the words.

- An adolescent who rarely spoke of her imminent death bought her boyfriend a cologne called Eternity.
- An eleven-year-old boy asked to have a party for his classmates.
- A ten-year-old boy used his MakeAWish money to buy presents for his family and his friends two days before he died.

For some parents, the quality of your child's life—adequate pain management, being at home, or achieving a particular goal—may be the most important way to express love as your child approaches death. Reminiscing about treasured family moments, recognizing your child's achievements, making a photograph book together, or expressing love verbally or nonverbally may be valuable substitutes for

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explicitly verbally acknowledging with your child his imminent death. You may do these things consciously or unconsciously. And after your child's death, you may be very glad you did them.

In this chapter I have described ways to begin conversations with your child about his condition and his prognosis. You can listen to what she is thinking and take that or an earlier conversation you had together as a starting point. You can give your child openings to talk but not force a conversation. Remember the importance of hope, but also remember that hopes can shift to match a sad reality. Children and adolescents have different styles, beliefs, and attitudes that will influence how they want to face or not face directly their upcoming death. And even if your child can talk sometimes about her likely death, she may be able to have such conversations only in small doses before her focus returns to her current life. If your child is able to speak to others but not you about his likely death, that may reflect his love and wish to protect you from pain, so don't feel bad about it. If you are able to have these conversations, as I said earlier, they may comfort you later, but if you do not, perhaps that is what allows you to be with your child in the way you want. You and your child will be the ones who negotiate the extent and nature of the conversations that feel right for you.