

Helping a Child Who Is Dying

by Alan D. Wolfelt, Ph.D.

A child you care about is dying. You want to offer your love and care, but you are not sure how to go about it. Whether you are a parent, friend or caregiver, this article will guide you in ways to turn your cares and concerns into actions.

When a Child is Dying

Children aren't supposed to die. We all believe this in our hearts, yet unfortunately children do die. Confronting this difficult reality for yourself is the first step you can take to help the dying child.

You will probably come to accept the fact of the child's impending death over time, and it may not be until the child actually dies that you fully and finally acknowledge the reality. This is normal.

For now, though, try to accept the reality of the child's medical condition, if only with your head. You will later come to accept it with your heart.

Don't Underestimate the Child's Capacity to Understand

Children have the capacity to understand more than we often give them credit for. Like adults, they deserve our respect and compassion-and our honesty. Sometimes adults, in an effort to protect themselves, assume that children are incapable of understanding or should be protected from the truth. They don't talk directly to dying children about their prognoses, which can leave them feeling alone and isolated.

Children can cope with what they know. They can't cope with what they don't know. Dying children deserve an atmosphere that creates open, two-way communication. Many terminally ill children will go back and forth between wanting to know details about their illness and not wanting to acknowledge they are even sick. It is critical to follow the lead of the child. Always listen first as you support open dialogue about any feelings, concerns or questions they might have. If they ask something and you don't know the answer, simply say, "I don't know."

Be Honest with the Child About Her Coming Death

As the child comes to comprehend her illness and its severity, explain to her that she will likely die-in language she will understand. This may be the hardest thing you have ever done. But honest love is what the dying child needs most.

Depending on her age and developmental maturity, she may not immediately (or ever) fully understand what this means. But she will begin to incorporate the notion of death into her remaining life and will have the opportunity to think about it and ask questions. She will also have the privilege of saying goodbye.

Do not try to protect the child by lying to her about her condition. The dying child who is told she will get better will notice the disparity between this false hope and the way those around her are acting. She will be confused, frustrated and perhaps angry.

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We show our love and respect for all children by being honest and open with them. We show our love and respect for dying children by helping them understand that they are dying.

Encourage Open Communication, But Do Not Force It

As caring adults we should encourage honest communication among the child, caregivers, family and friends. However, we should never force it. Children will naturally "dose" themselves as they encounter the reality of the illness in their life. They aren't able to take in all the information at once, nor will they want to.

Answer only what is asked in the child's terms. Don't over-respond out of your own anxiety. Remember-children will determine with whom they want to share their pain. Often, the child wants to protect his parents or other close adults and will adopt a "chin up" attitude around them. This is a normal response and should be respected.

Watch for the Child's Indirect Communication

Children, particularly seriously ill children, are not always direct about their thoughts and feelings. They may make statements, display behaviors or ask questions that indirectly suggest their understanding or awareness of a situation. These cues reflect underlying needs and deserve loving responses. Pay special attention to the child's non-verbal means of trying to communicate any needs or concerns.

What the Dying Child May be Feeling

Aside from the considerable physical toll terminal illness can take, dying also affects a child's head, heart and spirit. While you wouldn't want to prescribe what a child might feel, do be aware that they may experience a variety of emotions. Fear, anxiety, anger, sadness and loneliness are just a few of the emotions they may feel-one at a time or simultaneously.

These feelings are a natural response to serious illness. Perhaps you can be among those who enter into the child's feelings without thinking they have to help the child "get over" these feelings.

Helping the Dying Child Live

Terminal illness presents human beings with an exceedingly difficult and contradictory challenge: you are dying, you know you are dying, yet it is your nature to want to live. Dying children often feel this tension, too. If the adults around them have been honest, they understand that they will soon die, but they still want to live and laugh and play as often as they can.

Help the dying child live happily. Do what is in your power to make him comfortable. Create special, memorable moments for him. Don't completely abandon his normal routine (this may make him feel out-of-control and unprotected), but do work to make each remaining day count.

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Above all, spend time with him. See that the people who mean the most to him are around him as often as possible.

Peer relationships are very important to children, and the illness will likely create some social and physical barriers to these friendships. As an adult, you can see that friendships continue to be nurtured when possible. Arrange a special party for the dying child. Make play dates with the child's one or two best friends. Help the children write letters back and forth when personal contact isn't possible.

Help the Child Take Advantage of Resources for the Dying

Local hospices are well-staffed and trained to help both the dying child and the dying child's family. Their mission is to help the dying die with comfort, dignity and love, and to help survivors cope both before and after the death. Other organizations, like the Make-A-Wish Foundation, help dying children find joy in their short remaining lives.

Support Parents and Other Important Adults in the Child's Life

A child's terminal illness naturally impacts everyone who loves the child. Not only should you be supportive of the child, you should also be available to support and nurture other family members and close friends. The adult response to the illness will influence the child's response. So, in supporting adults you are supporting the child.

Perhaps you can be a caring companion to the family and help in practical ways. Offer to provide food for the family, wash clothes, clean the house. Listen when they need to talk. Sit with the ill child to give parents a break. Help with other children in the family.

While words may be inadequate, your supportive behavior will be remembered forever.

Don't Forget Siblings

Take special note of the dying child's siblings. Because so much time and attention is being focused on the dying child right now, his brothers and sisters may feel emotionally abandoned. Go out of your way to ensure their needs are being met, as well.

Embrace Your Spirituality

If faith is part of your life, express it in ways that seem appropriate to you. During this difficult time you may find comfort and hope in reading spiritual texts, attending religious services or praying. Allow yourself to be around people who understand and support your religious beliefs.

A Final Word

All children, terminally ill or not, have the right to be nurtured, to be children and to make choices that impact their lives. There is nothing more difficult for families than confronting the

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death of a child. As caring adults, we have a responsibility to maximize the quality of life for the child, the family and friends.

About the Author

Dr. Alan D. Wolfelt is a noted author, educator and practicing grief counselor. He serves as Director of the Center for Loss and Life Transition in Fort Collins, Colorado and presents dozens of grief-related workshops each year across North America. Among his books are [Healing Your Grieving Heart: 100 Practical Ideas](#) and [The Healing Your Grieving Heart Journal for Teens](#). For more information, write or call The Center for Loss and Life Transition, 3735 Broken Bow Road, Fort Collins, Colorado 80526, (970) 226-6050 or visit their website, www.centerforloss.com.

Related Resources

- [Healing Your Grieving Heart: 100 Practical Ideas](#) (book)

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