

Talking with Children About a Parent's Serious Illness

Commentary by PARAG BHARADWAJ, MD; NISHA SANDESARA, MD; and SANDRA E. STERNBERG, CCLS, CPE Cedars-Sinai Medical Center, Los Angeles, California, and BARBARA L. JONES, PhD, MSW, University of Texas School of Social Work, Austin, Texas

Case scenarios are written to express typical situations that family physicians may encounter; authors remain anonymous. Please send scenarios to Caroline Wellbery, MD, at afpjournal@aafp.org. Materials are edited to retain confidentiality.

A collection of Curbside Consultations published in *AFP* is available at <http://www.aafp.org/afp/curbside>.

Author disclosure: No relevant financial affiliations.

Case Scenario

A 45-year-old woman is admitted to the hospital with severe pancreatitis. She reports rapid and significant weight loss over a period of one month. Tests reveal that she has metastatic pancreatic cancer, and the prognosis is poor. She is married and has two children five and 14 years of age. She receives a palliative care consultation immediately. After a discussion with the woman and her husband, it is recommended that she be referred for hospice care. Some of the staff members involved in the patient's care believe that the children should not be exposed to their mother's illness and death, and suggest that they not be allowed to see their mother in her final days. Is it appropriate to talk to this patient's children about her illness and impending death? To what degree should the children be involved in her final days?

Commentary

It is not uncommon for children to have parents who have cancer.¹ Although parents may be understandably apprehensive about discussing a serious illness, children want and need to know what is happening.² It is strongly recommended that children be involved and informed in the illness and death of a parent. A parent's illness disrupts children's daily routine and creates fear of the unknown.³ Just as the patient needs a plan of care that incorporates physical, emotional, spiritual, and cultural needs, there should be a plan for the patient's family, particularly for the children as appropriate to their age and developmental stage. Parents and spouses may have difficulty accepting the diagnosis, prognosis, and treatment plan; as a result, children often become part of that process of acceptance. The entire family needs the proper tools to cope with the

diagnosis. If patients have preschool-aged, school-aged, or adolescent children, it is vital to involve social workers and child life specialists (i.e., professionals who are trained to work with children and families to help them cope with illness and hospitalization). These professionals are trained in the most appropriate ways of supporting children who are facing a parent's illness.

In these challenging and painful circumstances, children need simple, honest answers to their questions.⁴ These answers should be given by the most important adults in their lives, namely their parents or caregivers. Unfortunately, parents may underestimate their children's degree of distress.⁵ Teaching parents to talk with their children about their feelings has been shown to have positive outcomes for children and parents facing illness.⁶

As in this case scenario, family members and health care professionals often worry that allowing children to visit critically ill parents may be detrimental to their well-being. It is a common misconception that children may not have the emotional capacity to understand the situation. Although children must be presented the information in different ways based on their maturity level, research has shown that allowing children to visit loved ones who are ill decreases negative behavioral and emotional responses.⁷ Evidence demonstrates that children with a parent in the intensive care unit feared their parent's death, and that these fears lessened when they were allowed to visit.⁸ Children's responses to a family member's critical illness may include emotional turmoil, minor illnesses, and difficulty sleeping and eating. These effects have been found to decrease with more visits to the sick family member.⁹ ►

Table 1. How to Talk with Children About a Parent's Serious Illness

Explain that Mom or Dad is seriously ill, but the child did not cause the disease
Mention the name of the disease, and reassure the child that he or she can't "catch" it
Provide Mom's or Dad's best understanding of what may happen
Reassure the child that he or she is loved and will be kept safe
Emphasize that all feelings are acceptable
Explain who will help take care of the child

Information from reference 12.

Age and developmental level play a key role in preparing children for processing a parent's serious illness and treatment plan. Children three to six years of age may have difficulty separating fact from fiction. They may fear a parent's hospitalization is a type of punishment for something they did or thought. Physical and emotional regression to earlier developmental stages is common in younger children, causing them to potentially abandon recently acquired skills. Children in this age group need short and simple explanations using pictures, models, and actual medical equipment to decrease their unrealistic thoughts and to promote trust. With regard to the end of life, children at this age often confuse death with separation or sleep, and do not see it as permanent. Straightforward words and phrases like "The body doesn't move. It doesn't breathe. The heart doesn't beat. There is no hurt, no pain, no life," may help explain death.¹⁰ The key is offering reassurance that nothing the child did caused the parent's illness.

Children seven to 12 years of age are aware that death is real, final, universal, and inevitable. They may feel the most vulnerable to severe stress, and may display a variety of emotional and behavioral responses. However, studies show that young children who know about a parent's disease and its treatment are able to respond and receive support in developmentally congruent ways.¹¹ It may help to explain the parent's disease in simple terms and encourage the children to express their feelings. By maintaining contact, the healthy parent may help decrease the amount of anxiety the child experiences. Children find it reassuring to know who will care for them, and to discuss any changes in routines. Children in this age group need opportunities to say goodbye to the parent who is ill, and they should be included in family rituals. When appropriate, children should be encouraged to make cards, assist with care, or voice their wishes. The most important tool is to give children as much choice and control as possible, and to avoid forcing them to do something they are not comfortable doing. Children have their own pace, and this is particularly true with end-of-life issues.

Adolescents want detailed information, so the healthy parent should answer their questions fully and honestly. It is particularly helpful to make sure there is someone outside the immediate family with whom an adolescent can talk, such as a school counselor, an extended family member, or a member of the clergy. Teenagers need a safe arena to vent their feelings and frustrations. Preparation and opportunities for teens to say goodbye to parents should be provided, whether in the hospital, a hospice, or at home.

Regardless of age, there are certain issues that must be discussed to help children successfully cope with a parent's serious illness (Table 1¹²). Children can often sense when something in their family is different. Their imagination can be far more frightening than the truth. Even in the face of ultimate tragedy, children can be prepared, weather the trauma, and emerge whole, healthy, and ready to go on with life. On the other hand, children who are not prepared and who do not receive the kind of support and understanding they need can be permanently scarred by a parent's medical crisis, even if the parent survives and returns to full health.¹²

Address correspondence to Parag Bharadwaj, MD, FAAHPM, at paragbharadwaj@hotmail.com. Reprints are not available from the authors.

REFERENCES

1. National Cancer Institute. Surveillance epidemiology and end results. SEER cancer statistics review, 1975-2009 (vintage 2009 populations). http://seer.cancer.gov/csr/1975_2009_pops09/index.html. Accessed January 21, 2013.
2. Jones BL, Tesh M. Children, adolescents, and grief in medical settings. In: Pomeroy EC, Garcia RB, eds. *Children and Loss: A Practical Handbook for Professionals*. Chicago, Ill.: Lyceum Books; 2011:120-144.
3. Brenner A. *Helping Children Cope with Stress*. Lexington, Tex.: D.C. Heath and Company; 1984.
4. Webb NB. *Helping Bereaved Children: A Handbook for Practitioners*. 2nd ed. New York, NY: Guilford Press; 2002.
5. Welch AS, Wadsworth ME, Compas BE. Adjustment of children and adolescents to parental cancer. Parents' and children's perspectives. *Cancer*. 1996;77(7):1409-1418.
6. Lewis FM. Therapy for parental cancer and dependent children. In: Watson M, Kissane DW, eds. *Handbook of Psychotherapy in Cancer Care*. Chichester, West Sussex, UK: Wiley-Blackwell; 2011:225-234.
7. Crider J, Pate MF. Helping children say goodbye to loved ones in adult and pediatric intensive care units: certified child life specialist—critical care nurse partnership. *AACN Adv Crit Care*. 2011;22(2):109-112.
8. Craft MJ, Cohen MZ, Titler M, DeHamer M. Experiences in children of critically ill parents: a time of emotional disruption and need for support. *Crit Care Nurse Q*. 1993;16(3):64-71.
9. Cullen L, Titler M, Drahozal R. Family and pet visitation in the critical care unit. *Crit Care Nurse*. 1999;19(3):84-87.
10. Grollman EA. *Talking About Death: A Dialogue Between Parent and Child*. 3rd ed. Boston, Mass.: Beacon Press; 1990.
11. Blumberg B, Flaherty M, Lewis J; National Cancer Institute Office of Cancer Communications. *Coping with Cancer: A Resource for the Health Professional*. Bethesda, Md.: U.S. Department of Health and Human Services, Public Health Service, National Institutes of Health, National Cancer Institute; 1980. DHHS publication no. (NIH) 80-2080.
12. McCue K, Bonn R. *How to Help Children Through a Parent's Serious Illness*. 1st ed. New York, NY: St. Martin's Press; 1994. ■