Disclosing a diagnosis to children: Tell or not tell?

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As a professional oncology social worker specializing in helping children affected by cancer, I often work with parents whose first and most pressing question is, “What should I tell my children?” As health care professionals, you may find yourself posed with this question as well. Sharing news of a cancer diagnosis with children can be difficult, but disclosing a diagnosis honestly and early on in the treatment process can strengthen communications and help children cope with the uncertainty of a cancer diagnosis better.

Professional oncology social workers, available through most hospital/treatment center settings and organizations such as CancerCare (www.cancercare.org), help patients and families cope with the emotional, financial, and practical considerations of a cancer diagnosis. Social workers can also help parents determine the best way to communicate with their children and come up with a plan. There are some key points to keep in mind that will make you better equipped to answer this delicate question should a patient or caregiver ask it.

Children are intuitive. Patients and caregivers should keep in mind that children often already know when something is “going on.” They possess a knack for detecting a fluctuation in their family’s routine, even when they cannot pinpoint just what that difference is. So even when not told of a parent’s diagnosis, a child can still note that things seem amiss. This can be frustrating, especially to a younger child whose understanding of feelings, emotions, and language skills are limited.

I recently worked with a CancerCare client who had decided to tell her teenage children about her diagnosis, but not her 7-year-old son. The client noted that every time her son entered the room, she and her daughters would abruptly stop the conversation and a hush would ensue. This greatly confused her son and created anxiety in the home for everyone. There was a hypervigilance in the atmosphere as they strived to prevent her son from hearing the word cancer and learning the truth. Although I greatly respected my client’s strength and determination to shield her son from pain and worry, I encouraged her to disclose her diagnosis to her son. After doing so, she reported that, although it was a difficult conversation, she felt an immediate sense of relief that her family was now all on the same page.

Explain things simply and truthfully. Answering children’s questions as directly and accurately as possible is best. Assure children that nothing they did caused the diagnosis, and tell them not be afraid to say the word cancer. Children will hear this word at some point, so hearing it used by trusted family members is better.

Explaining the treatment plan and how it will affect their lives is also helpful. Prepare children for any physical changes they might observe during treatment (eg, hair loss, fatigue, or weight loss). Letting them know that their needs will continue to be taken care of will also go a long way (such as, “Daddy will take you to soccer practice instead of Mom for a while”).

When helping children cope with a cancer diagnosis, being prepared for every situation

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Remind parents that if they do not know the answer to a question, it is okay to say, “I don’t know.”

People with cancer sometimes ask if I think telling children they will be cured is a good idea. Life has no guarantees, and parents should always give children honest and accurate information but consider sharing it as optimistically as possible. For example, explain hair loss in a different light: losing your hair means the treatment is working hard to help your body fight the cancer.

**Include the child in caregiving** Suggest that patients allow their children to participate in their care. Having age-appropriate tasks, such as bringing their parent a glass of water or an extra blanket, can make children feel more involved in their parents’ care.

**Extend the support network** Encourage patients to build a support network that extends to close friends or school teachers. You can help by directing patients to organizations, such as CancerCare, that provide free professional counseling and support groups for parents and children. Kids Konnected (http://kidskonncet.org) offers face-to-face support groups throughout the United States for children affected by cancer. The American Cancer Society (www.cancer.org) and the National Cancer Institute (www.cancer.gov) also have information on helping children affected by cancer on their respective Web sites.

Cancer can impact a family greatly, but that does not mean that there is no more room for fun. Kids (and parents) still need to laugh and decompress from the stresses of cancer. Families that can tap into humor might find a renewed resilience. Suggest watching a favorite movie together, or even turn up the music in the house for an impromptu sing-along.

Perhaps most importantly, parents and caregivers should always show their children a lot of love and affection. Letting children know that they are loved and will continue to be cared for can go a long way toward giving them—and their parents—some peace of mind during this challenging time.

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