

# When a parent is ill: What Will We Tell the Children?

By Lauren Rose

Jenny and Karen\*, 6- and 10-year-old sisters, spent the weekend at their friends' house. It wasn't unusual for these sociable girls to have sleepovers, but this weekend was different because they slept out two nights in a row and the arrangements were made at the very last minute. It seemed strange because their mother always planned everything in advance. And this time she hadn't called to say goodnight.

Most of us have some type of emergency plan in place for our families, but few of us have considered how we would deal with a serious illness — especially when a parent or child needs to be rushed to a doctor or hospital. Who would care for the children? What words would we use to tell them what was happening?

## Financial considerations

This topic usually raises the matter of finances first. We think of looming large expenses such as mortgages and car payments, future bar or bat mitzvahs, college tuitions and weddings. How would we manage if a spouse or child became seriously ill? Issues such as disability and life insurance come up. Could we manage without our spouse's income? What would happen if one working spouse needed to stop working to care for the other?

"For someone who is sick, disability income and long-term care plans are safety nets," explains Rick Blank, an insurance broker at Preferred Services Group in White Plains. "With the exception of your home, your income is your most valuable asset. Where will the money you need come from in the absence of a disability policy if your income ceases?"

Shortly before Joe, Jenny and Karen's father, began experiencing symptoms, he updated all of his insurance coverage. Having adequate benefits enabled his wife, Sue, to take a leave of absence from her job when Joe was first diagnosed with an



aggressive cancer. Just managing the insurance claims, follow-up appointments and multiple prescription pills each given several times a day was a full-time job for Sue, in addition to caring for their daughters and keeping the household running.

## What to tell the children

In an effort to protect her children, Sue had rarely discussed with them the details of the illnesses of friends, extended family members or even people in the news. Joe and Sue were uncertain how to balance open communication against unnecessarily scaring their daughters. They planned what to say (and what not to say). Sue struggled with using words like "tumor" and "cancer" with their negative connotations, but also knew it was better to hear these words from their mother than from another child at school. As a result of the difference in their ages and personalities, Jenny and Karen had different levels of understanding and reactions to their father's illness.

Talking to the teachers at school was also difficult. Sue opted to speak with the lead teacher and guidance counselor and hoped they would spread the word to all involved with the chil-

dren. Julie Wilstatter, C.S.W., program coordinator at Gilda's Club, believes that all schools or programs working with children should consider training at least one staff member (be it a teacher, nurse or guidance counselor) to educate all staff in developing sensitivities to such issues and in supporting and responding to the child. Gilda's Club, with a branch in White Plains, offers such training programs through their "Schools Project".

## The struggles of the children

Just when Sue thought she had succeeded in juggling the many concerns at hand, Jenny and Karen began to act out. Getting ready for school became a struggle, homework a nightmare, and calls from the school nurse were frequent. Children often demonstrate their feelings of distress rather than putting the emotions into words. Regression to more childish behaviors (such as thumb-sucking or bedwetting) may occur. Arguments and tantrums may increase. Somatic symptoms, like headaches and stomachaches, may arise with greater frequency. These may be due to a need for increased attention or an unintentional desire to identify with the ill parent. Children may subconsciously do whatever they think they must to return their home and family to its previous state of normalcy.

Sometimes children work so hard to help at home (whether with siblings, food or emotional support) that their parents forget how young they really are. These "parentified" youths also struggle — in different, subtler ways.

## Finding support

In times of crisis, few can make it through without the support of family, friends and, sometimes, professionals. Family friends drove Jenny and Karen to activities, arranged and delivered meals, shopped for food, fixed garage doors, tended to the cat, and made themselves as available as they could. Communities may provide home-cooked meals to families for weeks on end.

"Knowing there are people whom you can count on for support can help you get through those difficult moments," states Freda, a nine-year breast cancer survivor.

While help is appreciated and often irreplaceable, Freda also emphasizes the importance of returning family life to some semblance of normalcy, saying, "Sometimes it's a relief to be able to involve yourself in the tedium of everyday life."

There are times when the help of family and friends is not enough or just isn't available. Freda's husband notes, "Having the shoulders of friends to lean on is great, but you can't have someone with you all the time. There are so many things you just have to deal with alone." Feeling awkward, family and friends may tread lightly or avoid discussing emotional topics altogether. Often it helps to talk with a professional or others who have been through a similar situation.

### *The toll on the spouse*

Most people don't realize the relentless pressures on the spouse of a sick individual. The caregiver may feel that she must also care for those calling to offer their support. While the patient gets the attention and obvious concern, the spouse may not feel she has the right to express her feelings and may feel selfish or guilty if she does.

Joe told me that at times he felt his illness was actually harder on Sue than on him. He says, "I knew how I was feeling and that I would survive due to sheer determination. But for Sue, there were more unknowns and more burdens. She has far exceeded any expectations I had of her (and I am sure any expectations she had of herself) to handle an extremely stressful situation over a prolonged period of time. My love for her is stronger than ever, and I am fortunate to have her by my side."

Freda concurs that her illness was harder on her husband than on her. Sam felt strongly that he had to shield Freda from much of what their family was going through. He says: "If I needed to break down, I had to do it away from her, while trying to smile and hide from her that this really was a tremendous struggle. I didn't want to make the situation worse for her. The world and all its problems don't stop for you."

### *Learning to cope*

Wilstatter describes the importance of learning to live with cancer: "It is critical for the designated patient and all loved ones to discover what feels supportive to them." Some who need to talk things through can turn to individual therapy or one of the many support groups offered at Gilda's Club or other sites around the county. Others need distraction; attending social events or participating in calming activities like yoga or knitting might help. Some gain support from

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# Cancer...

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hearing the experiences of others. By identifying your coping style, you take a step beyond the early phase of illness and progress toward a more manageable lifestyle.

Another issue faced by grown children in crisis is how to handle parents and in-laws who may feel they better understand how to handle doctors, finances or even the children. In addition to concern for their child's ill spouse, the caregiver's parents worry about *their* child's suffering and the toll that illness is taking on her and the grandchildren. They worry about the financial and emotional future and how they might help.

Coping with a life-altering and perhaps life-threatening illness can have tremendous effects not only on the patient, but also on loved ones, especially the children and the caregiver spouse. It is important to remember these often-silent sufferers and consider *their* needs as well as those of the patient.

\* Names have been changed to respect privacy.

### *Tips on Talking to the Children*

- It can be difficult to decide how to tell a child about a family member's serious illness and what to say (or not say). Consider the help of a professional — your child's pediatrician, a therapist or guidance counselor — prior to the initial conversation and throughout the coming weeks and months.
- Choose a time that is not rushed and when neither you nor your children are tired. Sit down with your children together, and later individually, to tell them about the diagnosis.
- Use words that are age-appropriate, but also integrate some of the terms they may later hear (such as "tumor" and "cancer").
- Give them time to ask questions and answer them truthfully. Be sure to answer what they are asking, not what you think they are wondering. Inquire as to whether you have answered their questions.
- Periodically check in. Ask how your child is doing and if he has any questions.
- Give your child an opportunity to talk about her feelings, draw pictures or make a card.
- Watch for signs of depression including mood swings, poor sleep

patterns, decreased/increased appetite, melancholy, regression, poorer grades and social isolation. Be aware of increased aggressive or acting-out behaviors towards peers, siblings or others. These may indicate a need for professional help.

## RESOURCES

### Local Support Groups

- Gilda's Club  
(914) 644-8844
- Westchester Medical Center  
(914) 4-CANCER

### Websites

- Cancer Care: [www.cancercare.org](http://www.cancercare.org)
- National Cancer Institute: [www.cancer.gov](http://www.cancer.gov)
- The Brain Tumor Society: [www.tbts.org](http://www.tbts.org)
- The Cancer Hope Network: [www.cancerhopenetwork.org](http://www.cancerhopenetwork.org)
- Cancer Information and Counseling Line: [www.ame.org](http://www.ame.org)
- Candlelighters Childhood Cancer Foundation: [www.candlelighters.org](http://www.candlelighters.org)
- Gilda's Club Worldwide: [www.gildasclub.org](http://www.gildasclub.org)
- The Leukemia and Lymphoma Society: [www.leukemia-lymphoma.org](http://www.leukemia-lymphoma.org)
- St. Jude Children's Hospital: [www.stjudes.org](http://www.stjudes.org)

### Books

- *Cancer in the Family: Helping Children Cope with a Parent's Illness*, by Joan F. Herman, Katherine V. Bross, Sue P. Heiney
- *Can I Still Kiss You?: Answering Your Children's Questions About Cancer*, by Neil Russell
- *Helping Your Children Cope with Your Cancer: A Guide for Parents*, by Peter Van Dermoot, Madelyn Case
- *When a Parent Has Cancer: A Guide to Caring for Your Children and Becky and the Worry Cup: A Children's Book About a Parent's Cancer*, by Wendy S. Harpham
- *Navigating the Strange Land*, by Tricia Ann Roloff
- *The Hope Tree: Kids Talk About Breast Cancer*, by Laura Numeroff, Wendy Schlessel Harpham, David Mc. Phail
- *Our Mom Has Cancer*, by Adrienne Ackermann and Abigail Ackermann
- *Tickles Tabitha's Cancer-tankerous Mommy*, by Amelia Frahm, Elizabeth Schultz
- *Because Someone I Love Has Cancer: A Kid's Activity Book*, by the American Cancer Society

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