Family Focused (cont.)

Children in both preschool and middle childhood will likely have many questions regarding how the illness will affect them and how their lives may change (e.g., “Who will take care of me?” or “Will I still be able to see my friends?”). Adolescents may be able to grasp fairly complex information about illness. However, individuals vary in the amount of information they desire. Because they have a better sense of the implications of illness for the future, they may worry more about long-term consequences, including the possibility of death. Regardless of the children’s ages, parents can often be stumped by questions their children ask and may benefit from professional consultation regarding how to respond.

What are some basic strategies for helping children cope with the distressing experience of having a parent with cancer?

While each child and family is unique, these general strategies are important to keep in mind:

• Provide basic information about the illness to the child, making sure that the information is consistent with her developmental level. Provide concrete information about what is going to happen (especially what might change or stay the same for the child) in the short term.

• Ask the child to repeat what you have told him to assess how much they understand. Respect the child’s needs for more or less information.

• Always be honest. Don’t tell the child everything will be ok if it is not. Not…

• Provide hope and reassurance when possible. Even when prognosis is poor, it is important to be able to reassure children that they will be taken care of and will have help getting through difficult events.

• Develop a family plan for taking care of children’s basic needs and share that plan with them.

• Maintain routines and usual activities when possible.

• Validate the child’s emotions. Let the child know that it’s ok to feel whatever he is feeling and try to guide him in healthy ways of expressing himself.

• Access other sources of support for the child.

• Seek professional guidance for coping when there are concerning changes in the child’s behavior.

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A health centered program open to all young women with breast cancer. Women engage in low-impact yoga. Group members support one another in maintaining a healthy lifestyle and exercise routine. Yoga is held on the 2nd Wednesday of the month.

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Young Women’s Health
An activity based, health program open to all young women with breast cancer. Activities include walking, hiking, biking, and other health centered activities. The group meets during the third weekend of the month at various parks around the region.

Young Women Living
An ongoing program offered for young women with metastatic breast cancer. A clinical psychologist leads the group as we explore living when breast cancer has spread. We meet on the 4th Thursday of the month.

Annual Symposium
Our annual education symposium is the program’s cornerstone event. Plenary and breakout sessions are held to discuss the diverse nature of living beyond breast cancer at a young age. Future announcements are mailed under separate cover.

Calendar of Events
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Just trying to manage the demands of day to day life – home, work, extra-curricular activities, commitments to family and friends – can be overwhelming for healthy families. Creating a balance is a priority for the well-being of all family members. Children may be particularly vulnerable to the stress of parental cancer. Children with a chronically ill parent often report more symptoms of anxiety and depression than children with healthy parents. Ancient women whose mothers have cancer appear to be more susceptible to the stress of their parents’ illness and strikingly high levels of distress have been reported for these girls. Distress is most apparent when teenage girls take on a number of responsibilities previously managed by their mothers, including care of siblings and multiple household tasks.

While the stress of cancer poses risks to family and child adjustment, some factors have been shown to protect family members from the impact of this stress. Good communication within the family is especially important in helping individuals cope. Talking about cancer and what the family is going through leads to better adjustment than avoidance coping. The psychological health of parents, including the parent with cancer, appears to be particularly important to the adjustment of their children. Thus, while many parents attempt to put the emotional needs of their children first, it is in the best interest of their children for parents to make their own self-care a priority.

Women with cancer often have questions about how to tell when their children are having difficulty coping and what to do help their child and their family cope.

What are the symptoms of distress to watch for in a child?

When faced with a medical crisis in a family member, children may feel a loss of control over events in their lives. Anger and anxiety related to the effects the illness is having on their family may result and children may worry about current and future functioning for their parent and family. Children who are distressed by a parent’s cancer may demonstrate a variety of concerning behaviors, including:

- irritability/anger
- withdrawal
- clinginess
- reappearance of “younger” behaviors
- defiance
- tearfulness

While many of these reactions are normal responses to a crisis, they should not be ignored. People often find it helpful to talk with a professional about strategies for coping.

Are children more susceptible to distress from a parent’s cancer at certain ages?

Children of all ages are at risk for experiencing some distress when a parent is ill, but reactions may vary depending on a child’s age and developmental status, and what the child understands or believes about the illness. Preschool children ages 2-5 typically have a very limited understanding of illness and are likely to talk about it in simple terms that reflect their own personal experiences. For example, a four-year-old whose mother has undergone chemotherapy for cancer might say “cancer is when your hair falls out.” Children typically become more sophisticated in their understanding of illness with age. In middle childhood (ages 7-11), children may think more about various causes of illness. Yet they may still be somewhat “magical” in their thinking. For example, a seven-year-old may wonder if his difficult behavior somehow lead to his mother becoming ill (continued on back page).
In December 2006, Geyer and colleagues reported in the New England Journal of Medicine their study of the use of Tykerb (Lapatinib) in the treatment of advanced breast cancer (NEJM, 2006, 355: 2734-43). The study was a phase 3 clinical trial conducted at multiple centers in the United States and around the World. The goal was to compare the benefit of using both Tykerb and Xeloda (Cisplatin) versus using Xeloda alone in the treatment of metastatic breast cancer.

Women with advanced breast cancer who had a HER2 positive breast tumor and who were previously treated with Herceptin (Trastuzumab), were eligible to participate.

The primary study end-point was the time to progression. The study end-point is defined as the primary feature/characteristic that is measured at the end of the study. It is the main... as the time when a woman began the trial to the time when the disease progressed or the woman died from breast cancer.

The early analyses showed the combined therapy was associated with a significant reduction in the risk for disease progression. The average time to progression was nearly twice as... and the results were reported early.

Herceptin is a first line therapy for breast tumors which are HER2Neu positive. It works by blocking the HER2 receptors, located outside the cell. In contrast, Tykerb works by blocking the receptors found inside the cell.

Intensive research evaluating the effects of combined therapy, like the use of Tykerb plus Xeloda, to treat metastatic breast cancer, are underway. Yet, the greatest advances may be made... with breast cancer? Was the program in place or did you start it? Does your program have formal funding to support it? Tell us about your program. Contact Jen Ivanovich at 314-454-5076 or by email at jen@ccadmin.wustl.edu with information about your local young women's breast cancer program. Let us begin to work together.

The Young Women's Breast Cancer Research Program is actively inviting women diagnosed with invasive breast cancer 40 years of age or younger to participate in a research study. The goal of the study is to identify the genetic factors which contribute to breast cancer at a young age. Women from around the country are participating in this study. We wish to invite 5,000 women to participate in the research program. The Barnes-Jewish Hospital Foundation and the Celebrate-Fitness Program at the Siteman Cancer Center currently support this research program. Contact Jen Ivanovich at 314-454-5076 or by email at jen@ccadmin.wustl.edu to learn more or to participate. Additional studies are planned with the ultimate goal to improve the medical care of young women with breast cancer.

Clinical update

The Young Women’s Breast Cancer Program is expanding by extending our outreach beyond the St. Louis region. We recognize the benefits from structured programs which meet on a regular basis and which are easily accessible to young women and their families. Meeting face-to-face with women of the same age who have experienced breast cancer first hand can be supportive at a time of medical crisis. For this reason, we are working to establish a national network of programs partnering to provide support to and advocacy for young women with breast cancer and their families. Do you participate in a support or education program tailored for young women with breast cancer? Was the program in place or did you start it? Does your program have formal funding to support it? Tell us about your program. Contact Jen Ivanovich at 314-454-5076 or by email at jen@ccadmin.wustl.edu with information about your local young women’s breast cancer program. Let us begin to work together.

The Young Women's Breast Cancer Program is...
When I think of my breast cancer diagnosis I immediately think of the well-meaning ladies at my former job. Upon hearing my announcement they gathered around me to tell me exactly what I could expect to go through, based on their own experiences and those of their mothers or grandmothers.

As much as I appreciated the advice, in no way did it prepare me for what I actually went through. I have since spoken with several young women who have recently been diagnosed and I refrain from telling them what they are going to go through, mostly because I don’t know what their experiences will be. I believe it is different for every woman, depending on their beliefs, experiences, marital status and economics. It cannot be the same for every woman.

That being said, I am happy to share my own experience and hope some women will benefit from what surviving breast cancer has taught me. The most important lesson: you are not alone.

It is easy to feel sorrow, anxiety, fear and loss of power against the disease. I certainly did. I lost contact with friends and family who did not know how to cope or how to help. But I did gain a renewed strength in my faith in God and a reinforced love and support of my immediate family. It brought us closer together. One of my two sons, mother or my brother always accompanied me to chemotherapy, which was crucial to me. I also became especially close to my niece, who had tears when my hair fell out. She now styles my hair on the weekend.

A cancer diagnosis is very stressful and can be difficult to deal with on your own. Once I came to terms with the realization I had cancer, I sought the support of family, friends and caring professionals. Of course, there are all the psychological aspects too.

Taking care of your family doesn’t usually stop with a cancer diagnosis. Life goes on even when you are fatigued, nauseated, irritable and having trouble concentrating, not to mention the feelings of sadness and depression you may have. You may feel vulnerable. You may fear not being there to raise your children or missing special occasions in their lives. I talked openly with my sons and my brother, who know more about breast cancer and breast reconstruction than any man ever wanted to know, but I consider them to be enlightened males who are empathetic to the issue.

I believe being African American presents a different aspect to having breast cancer. The American Cancer Society reports death rates from the disease are higher in African-American women than Caucasian women. Studies also show African-American women do not get treated as promptly and don’t always receive high quality care. Access to insurance, healthcare and health education plays an important role. There are economic and social gaps as well, but there are steps that can be taken. Research your family history, make and keep appointments for tests and screenings. Try to adopt a healthier lifestyle. For those willing to seek answers, knowledge is extremely powerful.

It can be a confusing and life changing time. There are strategies for coping. Help is available, arm yourself with information. Support groups can be extremely helpful, find a mentor and become a mentor. Draw support from family members if possible. Have age-appropriate conversations with your children.

In my opinion, there is no right path for healthy survivorship. It can be a challenge trying to balance work, family and illness. I believe finding peace and personal empowerment are important goals to strive for. My hope is to gain support and join together to continue to fight this disease. We are all in this together.

Remember, you are not alone. Unity is strength, knowledge is power, and attitude is everything.

Your sister in survival,
Pamela Evans