

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 they 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 them 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. Yet...
- 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.

calendar of events

Join Us. Contact Jen Ivanovich at 314-454-5076 to learn more about a specific program or to be included on our mailing list.

Young Women's Yoga

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.

The Young Women's Group

This monthly program offers presentations on a variety of medical, psychological, and family care issues. Invited professionals and young survivors lead the group discussion. The group meets on the **4th Thursday** of the month.

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.

Young Women's Family Day

Our first annual conference for family members of young women with breast cancer will be held in January 2008. Sessions will focus on the needs of spouses, children and parents of young women. Look for additional announcements through our website and by mail.

HUGS (Help Us Give Support)

HUGS is a structured support program for children with mothers or grandmothers with breast cancer. Contact Kathy Jones at 314-362-7844 to register your children for the program. Dr. Teresa Deshields is the director of this program.

Young Women's Peer Network

A young survivor is paired with a young woman recently diagnosed with breast cancer or who has a recurrence. This program is structured to help young women seeking support in a one-on-one setting. Peers are paired using shared clinical and family characteristics.

Contact the program director if you wish to be paired with a young survivor or if you wish to serve as a peer advisor.

About the pictures in this edition.

The beautiful women and their families shown in this edition are members of our young women's breast cancer program.

Our community program is coordinated through Washington University School of Medicine, Siteman Cancer Center and Barnes-Jewish Hospital and is funded in part by a generous grant from the St. Louis Affiliate of the Susan G. Komen For the Cure Foundation.

Check out our new website, ywbcn.wustl.edu for updated program news.

Volume Two: April 2007

The Young Women's Breast Cancer Program

Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine

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A Note From the Director



Dear Friend,

Welcome to the 2nd edition of YWBCP, the annual news magazine of the Young Women's Breast Cancer Program. For this edition, we focus on the impact of a breast cancer diagnosis on the entire family.

Breast cancer takes a great toll on young women. We can lessen this impact by providing support to young women with breast cancer and their families; advocating for greater services for young women; and sponsoring research focused on early onset disease and survivorship. By combining our energy, spirit and resources WE BELIEVE CHANGE IS POSSIBLE.

This change will be brought about by walking this journey together, side by side. We partner with young survivors to determine the program's priorities and implement strategies to meet the age relevant needs of young women. I am pleased to welcome Jennifer Staed as the program's co-director. Jennifer has worked tirelessly to provide support for women with breast cancer. As a young survivor, Jennifer brings an insightful energy and spirit that will enhance our outreach.

I invite you to join any of our monthly or annual programs. Our Calendar of Events lists the program sponsored activities. Check out our new website, ywbcp.wustl.edu for ongoing program news. No matter if you were diagnosed three months ago or 5 years ago, JOIN US. Be a part of this powerful and uplifting movement.

Join us in believing, change is possible.
Jen Ivanovich



Family Focused

Written by Susan Sylvia, Ph.D. St. Louis Children's Hospital

"When I learned I had breast cancer I was in shock. I didn't think something like this could ever happen to me, especially not at 40. I just kept asking myself 'How am I going to get through this? I didn't want to think my children and my husband could be affected too but I couldn't stop worrying about what this was going to do to my family.. I couldn't sleep thinking 'What if something happens to me?' It was so overwhelming to think about taking care of all of us."

Karen, mother of children ages 6 and 10.

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 constant challenge. Most families manage to cope by sharing the burden and taking turns making sacrifices for each other. When cancer enters the family and life becomes even less predictable, many women, like Karen, can become overwhelmed by concerns for themselves, their children and their spouse. They may wonder how the family will cope and how to handle family stress.

When one person in a family is ill, everyone must make changes in order to meet both the demands of the illness and the day to day responsibilities that the ill person is no longer able to manage. A husband whose wife is diagnosed with breast cancer may have to take on additional household chores, more childcare responsibilities, or work to increase his income due to her lost wages. A teenage daughter or son may find themselves cooking dinner for the first time, caring more often for younger siblings or driving their mother to the hospital for treatment rather than driving to soccer practice. This role shift can be stressful for everyone.

Studies have shown that a parent's cancer can impact family functioning and reduce family cohesiveness. Young women and their spouses appear to experience similar levels of distress about the cancer diagnosis, but it is not unusual for husband and wife to cope differently with the stress of illness and be "on different pages at the same time". One person may feel hopeful and want to talk about the future, while their partner is worried and withdrawn. Thus, married couples coping with a wife's cancer are at risk for increased conflict. Sometimes, just acknowledging and accepting coping differences can be helpful.

Family Focused

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. Adolescent females whose mothers have cancer appear to be most susceptible to the stress of their parent's 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
defiance

risk-taking behavior

sleep disturbance
reappearance of "younger" behaviors
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 2-6) 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)

clinical update

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: 2733-43). 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 (Capecitabine) 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 focus of the study. Time to progression was defined 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 long among women receiving both Tykerb and Xeloda (8.4 months) compared to women who received Xeloda alone (4.4 months). Side effects were similar in the two study groups. Cardiac toxicity, a side effect for some women who receive Herceptin,

was minimal in both study groups. The interim study results were so significant, enrollment was ended prematurely 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 gained by using these treatments before cancer progresses. Several studies are ongoing, or are being planned to evaluate the use of Tykerb with standard chemotherapy treatments. These studies will evaluate the effectiveness in using Tykerb at the time of diagnosis rather than using it in response to when breast cancer has advanced.

Ask your healthcare providers about the latest advances in breast cancer treatment at every follow-up evaluation. Keep a copy of your pathology report. Knowing the details of the breast tumor pathology will help you to understand the available treatment options.



yw program news

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 local 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 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.

Kids COLUMN

Emily Maassen, age 14

My life changed after someone, very close to my heart, was faced with a life threatening disease. My mom had breast cancer twice when I was younger. I was only six years old when my mom was first diagnosed. Because I was so young I didn't understand very well about what was going on. I remember nights when she would be in the hospital and my dad would stay with her overnight, so my brother and I would have to stay at a friend's house. I felt fear because I didn't know what was going to happen. Luckily, my mom overcame breast cancer. Unfortunately, four years later, she had a recurrence of her breast cancer. This time it was worse because the chemo was heavier. I remember before she started to lose her hair she went and donated her long hair to "locks of love". This was her way of trying to make it a positive experience. After she lost her hair, I remember always being out shopping and her buying hats to go with all of her outfits. At the same time, my grandpa had stomach cancer, so I was so scared of what might happen. I think experiencing my mom's illness helped me be better prepared for dealing with my grandpa's cancer. But I still feared the possibility that I could lose two people I loved so much. Sometimes I would go to sleep with the horrible feeling that in the morning my mom and grandpa could be gone. I learned to just take one day at a time. Thankfully, my mom recovered and the cancer hasn't shown up since.

What I have learned is how precious life is and how important it is to take care of my health. My brother and I are very conscious of our health and try to eat healthy because of what we experienced. Sometimes I am afraid to be around people who are sick, but I also love to be there and help take care of them. With my mom going through cancer twice, I am ready for almost anything that comes my way. Now, I have scoliosis and I have a surgery scheduled in March. I know that my family and mom will be there for me just like I was for her.

My family and I are so grateful my mom is here today. Some people still ask me how my mom is doing and I'm proud to say that she is healthy and doing great!



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.

my story

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