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## Breast Cancer Care: Education and Survivorship

### Breast Cancer Decision Guide – Making Sense of Treatment Options

When meeting with a patient newly diagnosed with breast cancer, Sandhya Pruthi, M.D., used to draw pictures to explain surgical treatment options. Sketches from **lumpectomies** to total **mastectomies** would fill the page.

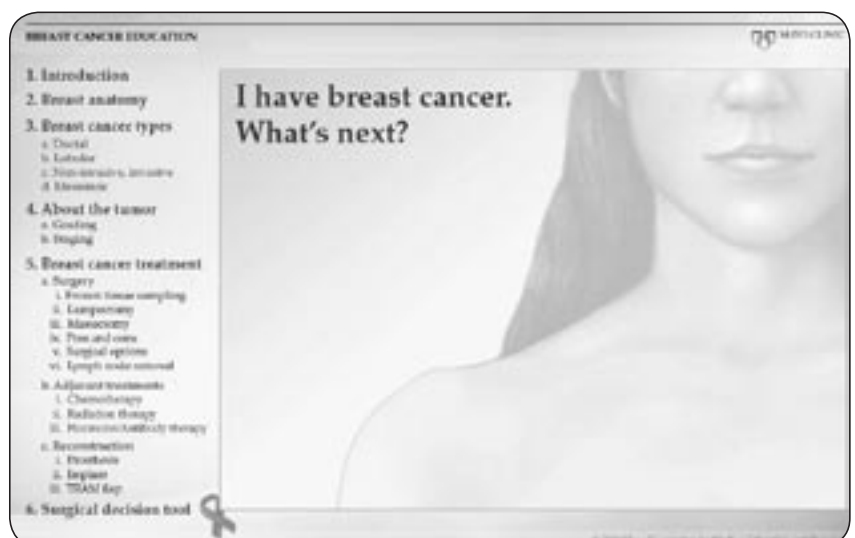
“Many times, patients would ask if they could keep the drawings,” says Dr. Pruthi, director of Mayo Clinic’s Breast Clinic in Rochester. “I always wished I had something to hand them other than my rather messy drawings.”

After some creative thinking, she now has much more than her simple sketches. The Breast Cancer Decision Guide is a multi-media tool that helps patients learn about breast cancer treatment options. Dr. Pruthi created the program, which has audio, video and computer graphic components, with help from Mayo Clinic graphics and technology experts.

“A picture is worth a thousand words, and this program is a picture of the decision-making process women go through when thinking about their treatment options for breast cancer,” says Dr. Pruthi.

Health care providers walk through the decision guide with patients to educate them about their options. Patients also receive a printed version of the guide.

“We compared the experiences of women who were counseled using the program to those who received standard care, and



Introduction screen for the Breast Cancer Decision Guide.

found that women who used the program were more knowledgeable about their options and more confident about their decisions,” says Dr. Pruthi. “In addition, patients whose physicians used the program felt their doctors were more involved in their care.”

The Breast Cancer Decision Guide is being used by Mayo Clinic breast health specialists in Minnesota and Florida, as well as by nurse educators, surgeons and other staff.

### **Continuity Breast Clinic - Minnesota**

Sandhya Pruthi, M.D., had a problem: too many patients, and not enough time to see them all. Her colleagues reported similar challenges. So Dr. Pruthi decided to look for a solution.



*Sandhya Pruthi, M.D.*

“I analyzed my patient load, and noticed that many of the women I saw were coming to me for follow-up care after breast cancer treatment,” says Dr. Pruthi. “They’d finished their course of care and been given a clean bill of health, so were at a point they could be followed by their home physicians. But because we’d developed a relationship over the course of their diagnosis and treatment, they wanted to continue seeing me.”

The solution: the Continuity Breast Clinic, where patients at low-risk of cancer **recurrence** are cared for by **mid-level providers** from the Breast Clinic who work closely with staff physicians. The Clinic also provides ongoing **surveillance**, breast exams and breast imaging to patients who have other breast concerns, such as an increased risk of breast cancer or a family history of the disease.

“This Clinic is a wonderful option for patients with breast cancer who want to continue to have their follow-up care at Mayo,” says Dr. Pruthi. “They get the same high-quality imaging and evaluation that they’ve had throughout their treatment. They have the comfort of knowing that if anything suspicious is discovered during an exam, they’ll be referred back to the breast specialist who directed their treatment. Patients get exactly the care they need and with timely service.”

Dr. Pruthi says explaining this approach to women early in their diagnosis is important. The bond between patients and physicians can be strong, especially after the extended and often emotional course of cancer treatment. Preparing patients helps ensure they won’t feel abandoned when their treatment ends.

“I tell my patients about this from day one,” she says, adding that when patients are ready, she suggests the options of switching to a home physician or being seen in the Continuity Breast Clinic. “Patients accept the change if they understand it is a standard and positive part of the care process.”

Dr. Pruthi says she will continue to look for new care models, and encourages her colleagues to do the same. “We have to adapt to the changing world and find ways of responding to what patients and referring providers need,” she says. “Mayo’s ability to do this -- and do it well -- is part of what makes us unique.”

### **Breast Cancer Survivor Clinic – Arizona**

The Breast Cancer Survivor Clinic at Mayo Clinic’s Scottsdale campus is for patients with breast cancer after they have completed surgery, chemotherapy or radiation therapy. Monitoring long-term side effects and helping individuals through the maze of physical and emotional changes is a key role health care providers offer. Typical follow-up consists of evaluations every six months for five years and then annually. Patients can access the clinic through a primary care physician referral.

# Where Did I Leave My Keys? Why Can't I Remember Her Name? How Did I Forget to Buy Milk?

By Jill Dowdy, with contributions from Sadhna Kohli, Ph.D.

After cancer treatment, some individuals may experience thinking and memory problems, also known as chemo brain. Chemo brain may also be referred to as chemo fog, cognitive changes or cognitive dysfunction.

Signs and symptoms of chemo brain can include:

- Difficulty concentrating, multi-tasking or finding the right word
- Being unusually disorganized
- Shorter attention span
- Short-term memory problems
- Trouble with verbal memory, such as remembering a conversation
- Trouble with visual memory, such as recalling an image or list of words

These symptoms can begin during cancer treatment and continue for many months and years after treatment. These changes can vary widely and may not be obvious to others.

It is not clear what causes chemo brain. Some cancer-related causes may include chemotherapy, hormone therapy, radiation therapy, immunotherapy and surgery. Complications of cancer treatment, such as **anemia**, fatigue, infection, menopause, poor nutrition and sleep issues, may also trigger symptoms. Emotional reactions to a cancer diagnosis and treatment, such as anxiety and depression, may also contribute to memory and thinking problems.

There is no clear definition of chemo brain, so no test exists to diagnose this condition and no standard treatment has been developed. In most cases, cancer-related memory problems are temporary, so 'treatment' may focus on managing symptoms until they eventually decrease.

Learning to adapt and deal with memory changes may involve:

- **Exercising your brain.** Try crossword puzzles or number games.
- **Learning a new skill.** Learn a second language or start a new hobby.
- **Maintaining a schedule.**
- **Practicing relaxation techniques.** Stress can contribute to memory and concentration problems.
- **Staying organized.** Use calendars or planners. Make lists and maintain an organized work space.
- **Taking frequent breaks.** Divide tasks into manageable portions and take a break each time one part is completed.
- **Exercising your body.** Moderate exercise can help with stress, fatigue and depression.
- **Getting enough rest.**

Chemo brain symptoms can be frustrating and difficult to deal with emotionally and physically. Because symptoms differ from person to person, consider talking with a health care provider to develop an individualized approach.

Remember that memory problems happen to everyone. Try to take time each day to relax and be honest with others about your symptoms. Talk with friends and family members to suggest ways they can help.



# “A Gratitude for Fireworks”

by Sarah A. Christensen

It was an aching knee and the thought of not making it to summer volleyball camp that sent 15-year old Valerie Kimball (Dietrich) to the doctor in 1995. While her knee was not strained from sports, the news was not good. There was a tumor on her left thigh bone. So three days after her 16th birthday, Val was sent to surgery to determine if the tumor was cancer. She knew that if she woke up with a **central line**, she had cancer. “The first thing I said to my mom after the surgery was ‘Do I have it? Do I have it?’ And yes, I did have a central line. I immediately started crying, but my mom told me that ‘the Lord does not give us more than we can handle.’” So her cancer journey with a diagnosis of **osteosarcoma**, a cancer of the bone, began by watching the 4th of July fireworks from her hospital bed.

July 4th had always been a favorite part of Val’s life. Not only was it a special time spent together as a family, but it seemed like a continued celebration of her June 30 birthday. While watching the fireworks from her hospital room that year, Val vowed to never watch fireworks from inside a hospital again.

What followed was nine months of chemotherapy on a clinical research study. Several months into the treatment, Val had surgery to remove the mass from her thigh. As part of the **limb salvage**, six inches of bone were removed and her knee and leg were rebuilt with titanium.

It was suggested that Val spend her junior year of high school being home-schooled. “I absolutely refused. That was the last normal thing I had to hang on to. I was missing out on sports and everything, so I decided that I will go to school if and when I can. If I get held back a year, okay.” In total Val missed 40 days of school but was able to keep up with her classmates.

Val’s mom, Colleen, always encouraged her to be open about her cancer and treatment. “She told me ‘how you present yourself to people is how they are going to respond to you.’” Her cancer became more apparent as the treatment caused her hair to fall out. Val agreed to having her shoulder length hair trimmed short, however, it was not the prom or a school event that worried her; it was making it to see the country music star John Michael Montgomery. “The day of the concert my hair started falling out. I wouldn’t brush it or touch it. It just had to make it through the show.” A few days later Val and her sister, Ashley, began washing Val’s hair and handfuls of hair fell into the kitchen sink. “All I had left was little tweety bird hairs on top of my head.” Val had a wig but found it hot and itchy. Hats became her choice of head covering and she even had her senior picture taken surrounded by her hat collection.

Her biggest goal for her senior year was to get back on the volleyball court. “I really wanted to be a part of things my senior year” and that meant playing volleyball. After receiving a medical release from her physician, and sporting a solid knee brace, Val spent a week training with the team. But at the end of the week the coaches were not convinced that she should be on the court. “That was probably the only downfall in my cancer story.” She did go on to play intramural volleyball while in college and found other ways to remain active.



*A proud high school senior.*



While grateful for the love and support provided by her small town, Val was ready to redefine herself in college. "I wanted to go to school where no one knew me. I have always been open about my cancer. I have a big scar on my leg, but it was so nice that people got to meet me, and not the cancer. I got to just be 'Val.'"

Since elementary school, Val had wanted to be a radiologist. During her treatment scans or x-rays, she would ask the technicians all sorts of questions. However, once she entered college, she knew a related field would be a better fit and the choice was obvious. "Nurses are everything. During my treatment I didn't want to cry in front of my mom, and when she left the room, the nurses would let me sob. They would bring me a drink at 2 a.m. when I needed one. The nurses always knew just what to do or say to make me feel better or to make things seem a little better. I just knew that's what I should be and I hope that's what I give to my patients now."

Since graduating nursing school, Val has worked at Mayo Clinic Rochester as a floor nurse for hematology and oncology. She now works in the outpatient chemotherapy unit. Sometimes she shares her own story with patients, if she thinks it will help. One day a person who was receiving chemotherapy for osteosarcoma became quite agitated. Val tried to calm and reassure her with little success, so she simply rolled up her pant leg to display her scar. The woman asked "You?" to which Val replied "Yeah, I had it too." That sense of connection and caring calmed the patient.

Married in October 2008, Val and her husband, Ryan, enjoy walking their dogs and staying active. "I've never been skiing but I can still snowmobile." She also enjoys using her elliptical machine because it is easy on her knee. Ryan is very supportive of Val, and they wonder what is in store for them as the questions of chemotherapy late effects await them and as the notion of children presents. The one thing Val insists that they do every year is go someplace to watch fireworks on the 4th of July. "I will work a day shift just so I don't have to be in the hospital during the fireworks. Last year we were so close to the display that Ryan was worried our hair would catch on fire from the falling embers. 'No,' I told him, 'This is awesome!'" Watching the fireworks each year could be a painful reminder of her cancer journey, but Val has chosen to feel gratitude for life and its pleasures.

"Someone told me during my treatment that some day I'd look back on this experience and given the choice, I would choose it again. Now I know it's true. It's changed my personality, led me to my job, and added to everything about me. It made me who I am today."



*Starting her new job as a Mayo Clinic nurse, surrounded by her family.*

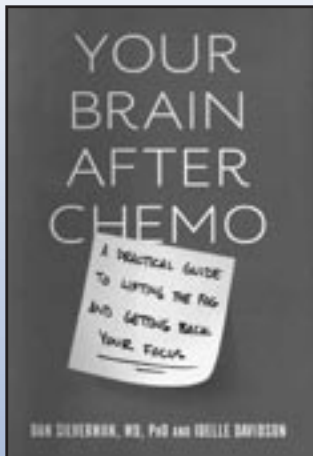


# Cancer Terms

<b>Anemia</b>	A condition in which the number of red blood cells is below normal.
<b>Central line</b>	A tube surgically placed into a blood vessel for the purpose of giving intravenous fluid and drugs. It also can be used to obtain blood samples. This device avoids the need for separate needle insertions for each infusion or blood test.
<b>Limb salvage</b>	A type of surgery primarily performed to remove bone and soft-tissue cancers occurring in limbs in order to avoid amputation.
<b>Lumpectomy</b>	Surgery to remove abnormal tissue or cancer from the breast and a small amount of normal tissue around it. It is a type of breast-sparing surgery.
<b>Mastectomy</b>	Surgery to remove the breast (or as much of the breast tissue as possible).
<b>Mid-level provider</b>	A clinical medical professional who provides patient care under the supervision of a physician. Mid-levels include nurse practitioners (NP) and physician assistants (PA).
<b>Osteosarcoma</b>	A cancer of the bone that usually affects the large bones of the arm or leg. It occurs most commonly in young people and affects more males than females. Also called osteogenic sarcoma.
<b>Recurrence</b>	Cancer that has come back, usually after a period of time during which the cancer could not be detected. The cancer may come back to the same place as the original tumor or to another place in the body.
<b>Surveillance</b>	In medicine, the ongoing collection of information about a disease.

Definitions obtained from [www.cancer.gov](http://www.cancer.gov). Defined terms are in bold in the newsletter.

## Book Review




### **Your Brain After Chemo: A Practical Guide to Lifting the Fog and Getting Back Your Focus**

By Dan Silverman, M.D., Ph.D. and Idelle Davidson, Da Capo Press, 2009. 284 pp.

*Your Brain After Chemo* is a guide, based on scientific evidence, for individuals with cancer who have undergone chemotherapy and are experiencing chemo brain, or thinking and memory problems. The possible link between chemo brain and symptoms commonly related to a diagnosis of cancer including depression, anxiety, insomnia and fatigue are discussed. Additional chapters highlight specific signs and symptoms with suggestions to help alleviate them. The second half of the book describes the authors' nine-step program of strategies to improve memory and focus through a modification of diet, lifestyle, and frame of mind. Inspiring survivor stories are included throughout the book.

# Care for the Caregiver: Don't Forget About Yourself

By Jeri Lensing, American Cancer Society Patient Navigator



Being a caregiver can mean seeing to the daily personal needs of a loved one. It may also include taking on additional roles such as organizing medications, managing finances and medical bills, home maintenance, child care, laundry, grocery shopping and meal preparation. With these added responsibilities, in addition to possibly working and taking care of your own family, caregiving can easily become overwhelming. A caregiver may feel stress or become exhausted which can lead to personal health concerns. As a caregiver, you may be tempted to skip meals, forego exercise, and generally ignore your own health. You may feel that the needs of the person you are caring for should be your primary focus.

Several publications discuss the importance of taking time for yourself and provide a helpful list of ideas such as going to a movie with a friend, shopping or spa days. While these suggestions are helpful, it can be frustrating or difficult to put these steps into action. Simple things that can be done on a daily basis are usually more manageable.

Some ideas include:

- Redefining “three square meals a day” - eat small, frequent meals.
- Try energy boosting snacks like 100% fruit juice, cheese and crackers, raisins, peanuts, granola bars, fruits and vegetables.
- Carry small, healthy snack items with you.
- When friends ask, request prepared meals that can be refrigerated or frozen for future use.

- Keep track of your weight and make note of any changes (gains or losses) and discuss significant changes with your health care team.
- Exercise or find ways to be physically active, even in small doses.
- Include appropriate stretching and strengthening exercises that can be built in to daily tasks.
- Maintain a regular sleeping schedule, if possible. Adequate diet and regular exercise will help improve sleep quality. For some, a fifteen-minute nap can refresh better than napping for an hour or two.
- Try relaxation techniques such as listening to music, creating art, reading, meditating, or praying.
- Accept or request help from others. Caregiving does not have to be your sole responsibility. It is okay to rely on others' help and accept guidance and support.

Keep in mind that by taking care of yourself you are also ensuring your ability to take care of your loved one. It is not selfish to focus on your own needs and desires.

For information or resources related to caring for the caregiver, caregiver support groups, relaxation, nutrition, exercise, or other topics please contact your American Cancer Society patient navigators located at Mayo Clinic in Minnesota by calling 507-266-9288 or visit [www.cancer.org](http://www.cancer.org) and click on 'Caregivers'.



Jeri Lensing



Angela Young

# Calendar of Events

## March

### *Daffodil Days*

American Cancer Society  
800-227-2345  
www.cancer.org

### *National Colorectal Cancer Awareness Month*

Prevent Cancer Foundation  
800-227-2732  
www.preventcancer.org/colorectal

## May

### *8-9 Living with a Blood Disease Symposium*

Mayo Clinic  
Rochester, Minn.  
507-288-5620  
www.mayoclinic.org/blood-patient-workshop

## May

### *21 Stay Out of the Sun Run*

Rochester, Minn.  
www.sosrun.org

## June

### *6 23rd Annual National Cancer Survivors Day*

Rochester area  
Mayo Civic Center  
Rochester, Minn.  
507-424-4602  
www.ncsdf.org

## Distinguished Service in Cancer Education

The Mayo Clinic Cancer Center Education Network (MCCEN) is proud to announce the recipients of the 2009 Distinguished Service in Cancer Education Awards for Professionals and Patient Volunteer-Advocates. Nominations for these awards come from Mayo Clinic Rochester, Arizona, Florida, the Mayo Health System, and the American Cancer Society.

**Jeri Lensing**, Mayo Clinic Rochester, has been selected as the Professional Award recipient. Ms. Lensing is an American Cancer Society (ACS) Patient Navigator located at the Stephen and Barbara Slagie Family Cancer Education Center. Ms. Lensing has made significant contributions in a variety of roles in advancing cancer education and consistently provides high quality care with compassion. She is continually furthering her own knowledge of cancer and available resources. Jeri has presented at local and national cancer programs and has volunteered for multiple events in community, state and national locations.

**Elizabeth L. Canan**, Mayo Clinic Rochester, has been selected as the Patient Volunteer-Advocate Award recipient. Ms. Canan, along with three other mothers of children diagnosed with cancer, created Brighter Tomorrows, an organization that encourages families touched by childhood cancer to gather, communicate, learn and gain strength from one another through shared experiences. She is described as a woman with passion, perseverance and strength whose efforts have changed the landscape of pediatric cancer support.



Liz Canan, Jeri Lensing

# together

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**together** newsletter provides educational information for cancer patients, their family, caregivers and friends. Physicians, staff and cancer patients write the articles.

To submit story ideas, provide feedback or unsubscribe, call 507-266-9288 or e-mail [canceredprog@mayo.edu](mailto:canceredprog@mayo.edu).



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