

ADDITIONAL RESOURCES AND INFORMATION



Susan G. Komen
www.komen.org

Susan G. Komen for the Cure is the world's largest grassroots network of breast cancer survivors and activists working together to save lives.



Young Survival Coalition
www.youngsurvival.org

The Young Survival Coalition (YSC) is an international, nonprofit network of breast cancer survivors and supporters dedicated to the issues unique to young women with breast cancer.



Living Beyond Breast Cancer
www.lbbsc.org

Living Beyond Breast Cancer (LBBC) is a national organization whose goal is to improve quality of life and help women in their recovery or management of the disease.



LIVESTRONG Fertility
<http://bit.ly/2qxgceS>

LIVESTRONG Fertility, a program of the LIVESTRONG Foundation, provides information and support to cancer patients and survivors whose medical treatments present the risk of infertility.



Bright Pink
www.brightpink.org

Bright Pink is the only national non-profit organization focusing on the prevention and early detection of breast and ovarian cancer in young women, while providing support for high-risk individuals.



FORCE
www.facingourrisk.org

Facing Our Risk of Cancer Empowered (FORCE) is the only national nonprofit organization devoted to hereditary breast and ovarian cancer. Programs serve anyone with a BRCA mutation or a family history of cancer.

Support and education

SoulMates

A peer mentor support program providing guidance and support. If you are newly diagnosed and want to be matched to a survivor, or if you are a survivor looking to be a mentor, contact SoulMates at **617-632-6501**.

Facing Forward

Julie Salinger, LICSW

A six session series held twice yearly for patients who have recently completed treatment for early stage breast cancer. For more information, call Julie Salinger at **617-582-8081**.

Metastatic Breast Cancer Support Group

Liz Farrell, LICSW, and Fremonta Meyer, MD | Monthly, 11–12:30pm

For women of all ages with metastatic breast cancer. For more information or to register, call Liz Farrell at **617-632-5606**.

Upcoming events

Living Well After a Breast Cancer Diagnosis: Practical Tips for Young Women

Thursday, July 20, 2017 | 5:00PM–7:00PM, Dana-Farber Cancer Institute

Breast cancer and its treatment can lead to a number of short and long-term physical and emotional concerns. Many young women and their loved ones have questions about what can be done to address these common problems. Presented by Living Beyond Breast Cancer's Young Women's Initiative in partnership with Young & Strong, this program is designed to answer your questions about these issues, provide evidence-based recommendations and practical tips, and to help you manage them to live the best life possible after breast cancer. For more information or to register, please go to www.lbbsc.org/tips4youngwomen.

Young and Strong Walk Team

A Young and Strong Walk Team will once again participate in the Boston Marathon @ Jimmy Fund Walk on September 24, 2017. To prepare, we will continue the traditions of Long Walk Sundays this summer. This group is a great way for young survivors to meet one another and exercise. We are looking for volunteers to lead these walks, so please be in touch if you are interested. You do not have to be a member of the Walk Team in order to participate in the Long Walk Sundays; all are welcome. To learn more or get involved, please visit www.jimmyfundwalk.org/2017/youngandstrong or email youngandstrong@partners.org.

Breast Cancer in Younger Women: A Forum for Patients and Survivors

Friday, October 13, 2017, Joseph B. Martin Conference Center, Harvard Medical School

This annual full day event for our patients and their loved ones includes a patient and survivor panel, an "Ask the Expert" panel including many prominent providers from the Susan F. Smith Center, and small group sessions with our social workers. For information or to register, call Stephanie Cram at **617-632-3916** or email youngandstrong@partners.org.

Celebrating Young and Strong Gala

Friday, October 20, 2017, Boston Design Center

The planning committee is excited to announce the 4th annual Celebrating Young and Strong Gala. This fun-filled evening, established and planned by young survivors, celebrates the courage and strength of all young women who are faced with a breast cancer diagnosis. Proceeds benefit Young and Strong, the Program for Young Women with Breast Cancer at The Susan F. Smith Center for Women's Cancers at Dana-Farber. In addition to a joyful night of food, cocktails and dancing, this event provides a unique opportunity for young women who have been diagnosed with breast cancer. To register, please visit the gala website www.celebratingyoungandstrong.com or email the coordinators (Meghan or Maggie) directly at celebratingyoungandstrong@gmail.com.

Young and Strong®

A PROGRAM FOR YOUNG WOMEN
WITH BREAST CANCER

Volume 8. Issue 1: Spring/Summer 2017



**SUSAN F. SMITH
CENTER FOR
WOMEN'S CANCERS**



A program just for you

Established in 2005, Young and Strong, the Program for Young Women with Breast Cancer at Dana-Farber's Susan F. Smith Center for Women's Cancers, provides comprehensive care and support to young women confronting the challenges of living with and beyond breast cancer. Our mission is to enhance care and education for patients and their families, as well as to advance understanding of the biology of breast cancer and the experience of the disease through ongoing research focused on younger women. More than 3,500 young women have been enrolled to date.

For more information about Young and Strong, please contact Stephanie Cram at 617-632-3916, or visit www.dana-farber.org/YoungWomenBreastCancer. You can also follow us on Twitter @YoungStrongDFCI.



Joy Yang faced breast cancer as a young woman with support from her husband, Sam Nathan.

Helping Caregivers Cope

INCREASED ATTENTION is being given to the physical and emotional challenges caregivers face when a loved one is diagnosed with cancer. "Cancer doesn't just happen to one person, it has an impact on the entire family," notes Dana-Farber's Director of Social Work, **Nancy Borstelmann, MPH, MSW, LICSW**, who is the lead investigator of a study focusing on the psychosocial concerns and mental health in partners of women diagnosed with breast cancer at age 40 or younger.

Borstelmann surveyed 289 partners about their psychosocial well-being and maladaptive coping behaviors. Of those who responded, 42 percent reported continued anxiety in the face of managing breast cancer care for their loved one, even several years after the diagnosis.

There was a strong association between those who reported maladaptive coping, such as withdrawing emotionally, increased alcohol intake, blaming others for problems, behaving in an aggressive manner,

and higher levels of anxiety. This study highlights the need for interventions that help caregivers to manage anxiety and develop constructive coping mechanisms.

"We need to start with asking partners how they are doing, and bring them into the conversation earlier," Borstelmann explains. "We need to identify their concerns and their needs, and make sure they have adequate information. Only then can we engage them with resources to address anxiety."

Tips for Caregivers

If you are a caregiver, you may feel frustrated and overwhelmed as you navigate a complex medical system, provide emotional support to a loved one, and maintain other life responsibilities. Caregivers often neglect their own well-being during this time. But it's essential to take care of yourself. Here are some tips from Patrick Steele – whose wife was a Dana-Farber patient – for maintaining your

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Living Well After a Cancer Diagnosis

The diagnosis and treatment of cancer can bring a number of physical and emotional challenges. Below are general tips and guidance for three related areas of great importance to survivors: Nutrition, Physical Activity, and Fatigue Management.

Exercise

Exercise offers far reaching benefits for cancer survivors. It can help reduce fatigue, increase energy, improve quality of life, and even help with certain side effects of treatment. Please speak with your physician before beginning an exercise program. Some general recommendations from the American Cancer Society:

- Every week, get 150 minutes of moderate intensity activity or 75 minutes of vigorous intensity activity.
- Exercise for at least 10 minutes per session, preferably spread throughout the week.

Nutrition and Healthy Living

Nutrition and healthy lifestyle play an important role in cancer prevention and survivorship. Research suggests that eating at least five servings of fruits and vegetables a day, along with regular exercise, may help lower breast cancer recurrence. Below we address some of the hot topics around nutrition and breast cancer.

Soy

Some evidence suggests that the intake of traditional or whole soy foods (such as tofu, edamame, and soy milk) may be linked to lower rates of cancer, heart disease, and osteoporosis.

- Although older studies suggested that high levels of soy may trigger growth of ER+ breast cancer cells, current studies suggest that moderate levels of soy intake appear to be safe for breast cancer survivors.
- Dana-Farber nutritionists recommend avoiding products with high levels of soy, such as soy isoflavone used in some supplements, pills, bars, and powders.



For more information on the topics above and other survivorship resources, visit www.dana-farber.org/survivor or contact the Adult Survivorship Program at **617-632-4LAD** (Life After Diagnosis) or dfci_adultsurvivors@dfci.harvard.edu.

Managing Fatigue

Most patients will experience fatigue during their course of treatment and many will have persistent fatigue afterwards. This experience may profoundly affect quality of life for both patients and their families.

What causes fatigue?

Fatigue in cancer patients has many causes, including anemia (low level of red blood cells), hormone imbalance (levels are too high or too low), inadequate nutrition due to loss of appetite or dehydration, lack of exercise, and sleep disturbance.

How should I be evaluated and treated?

Your medical provider will perform a focused history and physical exam to evaluate your fatigue. You may be advised to have lab work to evaluate for conditions associated with fatigue. Your clinician will work with you to treat any condition causing or increasing fatigue, such as pain, anxiety, depression, poor sleep, poor nutrition, or anemia, and will evaluate you for possible side effects from medications.

What are some strategies for treating and coping with symptoms of fatigue?

- Clinical trials consistently show that regular exercise will reduce fatigue. Although it may not seem logical to exercise when you are tired, gradually increasing exercise will improve endurance and energy over time. Try to build up to 150 minutes a week of moderate activity, such as fast walking, swimming, or cycling, or use your Smartphone or a pedometer to count steps with a goal of 10,000 steps per day.
- Meet with a nutritionist who can work with you to ensure that you are getting enough calories, fluids, protein, and other nutrients.
- Try to avoid caffeinated beverages after noon.
- Cognitive behavioral therapy programs can also reduce fatigue. This type of program is typically administered by a psychologist or therapist and can help you to develop a mental training program to overcome fatigue.

Organic Foods

- There are no epidemiological studies in humans that demonstrate whether organic foods affect cancer incidence, recurrence, or progression. The decision to eat organic foods is a personal choice.

Preliminary research suggests that excess insulin can promote tumor cell growth. Limit your intake of sugar-sweetened beverages (such as soda, sports drinks, and fruit drinks) and high-sugar foods (such as pastries, candy, and sugar-sweetened breakfast cereals).

Sugar Intake

- Sugar does not feed cancer, but it lacks many nutrients that offer health benefits. It can also promote weight gain and, if eaten in excess, may lead to undesirable changes in insulin production and regulation.

Drink Only in Moderation, If at All

Research shows a link between drinking alcohol and the risk of developing some cancers. It is recommended that you limit your alcohol intake to one drink or less per day for women and two or fewer drinks per day for men.

Recommended Resources

- Find more information online at Nutrition Services at Dana-Farber: www.dana-farber.org/nutrition
- Foods that Fight Cancer, by Richard Beliveau, PhD, and Denis Gingras, PhD
- The Cancer Lifeline Cookbook, by Kimberly Mathai, MS, RD, with Ginny Smith
- “Ask the Nutritionist” smartphone app: Recipes and more. www.dana-farber.org/nutritionapp
- Dana-Farber’s Registered Dietitians and Licensed Nutritionists provide education programs and individual consultations for patients. For more information, call **617-632-3006**.

Helping Caregivers Cope

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own physical and emotional well-being during this stressful time.

*Nancy Borstelmann, MPH, MSW, LICSW
Director, Patient/Family Support and Education at Dana-Farber*



Pay attention to your needs

- **Take a break.** You can’t solely be a caregiver and face losing your other identities as a partner and individual.

Don’t be afraid to ask for help

- **While it may be hard to ask for help, family members and friends are often eager to offer assistance.** Accept it, and don’t shy away from delegating specific tasks, such as picking children up at school, getting groceries, or driving your loved one to an appointment.

This second piece of advice came from a dear friend. She told me that if something needed doing that I was not able to do, I had to find someone who can, without delay. That was my responsibility as a caregiver.

Share

- **I belonged to a caregiver support group.** I was a new member once, and then I was able to offer comfort to new caregivers with their own worries.

Keep Your Bodies and Minds Active

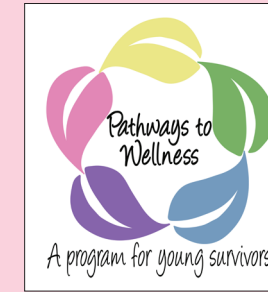
- **I made sure we kept our bodies and minds active.** We exercised together at the gym or at home. We practiced mindfulness meditation, yoga, and group healing. We went to acupuncture. Some days, it was time for rest, and plans had to change.

Spotlight

Pathways to Wellness: A Program for Young Survivors

Dana-Farber, in collaboration with the University of California Los Angeles and Johns Hopkins

University, is conducting a study that focuses on wellness after breast cancer. Researchers are looking to compare two groups, a mindfulness meditation class and



survivorship education class, and their impact on meeting the common needs of young survivors.

You may be eligible to participate if you:

- were diagnosed with breast cancer before age 45
- are within five years of your diagnosis.

Classes will meet for six weeks (one, 2-hour class per week) and will be held at the Dana-Farber Cancer Institute in Boston, MA. There are also three in-person appointments that include blood draws throughout the duration of the study. If you are interested in participating or would like more information, contact the study staff at: **617-582-9706** or PathwaysToWellness@partners.org.

Do What You Do Best

- **I made delicious, healthy food.** We bought a juicer, so we could get more vegetables into our daily diet. My recipe has kale, beets, berries, carrot, celery, apple, parsley, lemon, and ginger.

Get organized and plan ahead

- **I stayed up to speed with my wife’s treatment.** I took notes when she met her oncologist and study nurse. I put her appointments in my calendar. I brought her meds and coffee every morning.

There are many great caregiver resources available through the Dana-Farber website, including a toolkit on Taking an Active Role as a Caregiver. Visit www.dana-farber.org/caregivers. Dana-Farber’s division of Social Work offers regular daytime and evening support groups for caregivers of Dana-Farber patients, and select patient support groups are also open to caregivers. Visit the online calendar for upcoming sessions. Breastcancer.org also has an online forum, created by and for people with cancer and their families: <https://community.breastcancer.org/forum>.