

Young and Strong®

A PROGRAM FOR YOUNG WOMEN
WITH BREAST CANCER

SUSAN F. SMITH
CENTER FOR
WOMEN'S CANCERS



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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 4,000 young women have been enrolled to date.

For more information about Young and Strong, please contact the Young and Strong team at 617-632-3916, or visit www.danafarber.org/YoungWomenBreastCancer.

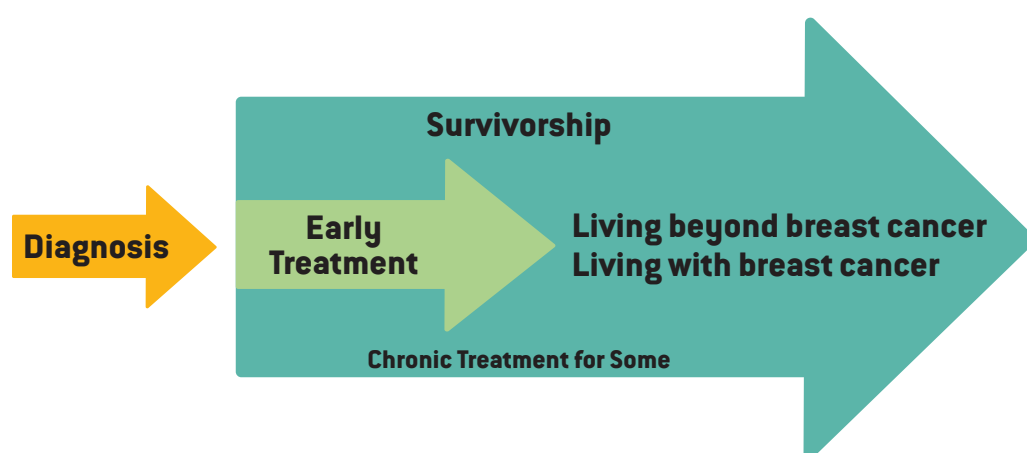
You can also follow us on Twitter @YoungStrongDFCI.

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The Cancer Care Trajectory

Cancer survivorship begins at diagnosis. Individual needs may vary and often depend on where you are in your journey. The Young and Strong Program is here to support you along the way!



Diagnostic Phase | The Young and Strong Coordinator introduces you to the program and resources and makes referrals as needed.

Early Treatment | You develop and follow a treatment plan (chemo, radiation, surgery, etc.) with your care team.
The Young and Strong Coordinator reaches out to you periodically.

Follow-Up and Long-Term Care | The Young and Strong Coordinator contacts you to coordinate a Survivorship Appointment at Dana-Farber. During this visit, a provider meets with you to outline the details of your cancer treatment and develop a plan with you to enjoy and maintain your health.
The Young and Strong team will send you emails and newsletters alerting you to new research, educational opportunities including in-person events, and supportive resources.

The Young and Strong Coordinator is available for you to reach out to for additional support and resources throughout your care.



with you from diagnosis, through treatment, and beyond...every step of the way.

Too Many Sleepless Nights?

Has this ever happened to you? You get into bed and then all the worries of the day come rushing in, leaving you tossing and turning, and unable to fall asleep? Or, you wake up in the middle of the night and struggle to fall back asleep? You're not alone.



While a night or two of poor sleep can happen to anybody, many cancer survivors experience insomnia. Insomnia is a sleep disorder in which a person has difficulty falling asleep or staying asleep. People with insomnia may also wake up too early. The rate of insomnia is much higher in cancer survivors than in the general population. And the condition may persist even after active treatment has ended. In fact, insomnia can continue for years if it is not properly treated. Chronic sleep difficulties can have a major impact on your health. They can affect your memory and concentration, hinder your ability to manage your emotions, and decrease your immune functioning.

How Are Cancer and Sleep Linked?

There are several reasons why sleep difficulties are more common in cancer survivors:

- The emotional distress of being diagnosed with cancer can make it very difficult to fall asleep at night.
- Cancer treatments can contribute to sleep difficulties. For example, some side effects of chemotherapy, such as

nausea and fatigue, can negatively affect your sleep. For people recovering from surgery, the pain and discomfort caused by surgery can make getting a restful night of sleep even more difficult.

Once you've had a night or two of poor sleep, you may start to change your sleep behaviors to try to manage the disruption that it causes in your life. For example, after a bad night of sleep, you might try to limit your activity the next day or take a nap to recover. Or, if you are experiencing anxious thoughts at night, you may try to distract yourself by falling asleep with the TV on. While these strategies might help you to cope with feeling tired or stressed in the moment, they may actually cause your sleep problems to persist, or even worsen in the long run.

What Can You Do to Improve Your Sleep?

For many cancer survivors, insomnia treatment involves prescription or over-the-counter medication. However, these are not meant for long-term use, and using them long term can create psychological and physiological dependence. The gold standard of insomnia treatment for adults is cognitive behavioral therapy for insomnia (CBT-I). CBT-I is different from cognitive behavioral therapy for other disorders, such as anxiety or depression. CBT-I targets the maladaptive sleep behaviors and thoughts that disrupt good sleep. As part of CBT-I, cancer survivors track their sleep using sleep logs, develop a consistent sleep "window," learn to avoid sleep-impairing activities in their bedroom, initiate behaviors that improve sleep, address the thoughts that can make it more difficult to fall asleep or stay asleep, and learn relaxation exercises.

If you are concerned about your sleep, you should speak to your doctor who may refer you to a sleep specialist for a thorough evaluation. It may be that your sleep difficulties are due to another medical condition or even another sleep disorder, such as obstructive sleep apnea.

Research Study to Get Help for Sleep:



If you are 25 years of age or younger and struggling with insomnia, there is a current research trial at Dana-Farber Cancer Institute of a web-based insomnia treatment program. You can find out more information by

calling **617-582-8260** or visiting:
clinicaltrials.gov/ct2/show/NCT03279055.

Spotlight: The Adult Survivorship Program at Dana-Farber Cancer Institute

Tips for Getting Better Sleep

There are also some things you can do on your own to improve your sleep. Keep in mind that these tips are not overnight fixes; they require consistency on your part to see improvements.

- Wake up at the same time every day (yes, seven days a week, even on weekends). Having a consistent wake time is more important than having a consistent bedtime.
- Use the bed only for sleep and sex. Restrict other activities to outside the bed. This includes “trying” to sleep. If you are having trouble falling asleep, get out of bed, and only return when you feel sleepy.
- Create an environment made for sleep. Keeping your room dark at night, quiet, and at a cool yet comfortable temperature helps your body relax in bed.
- Limit naps. If you must nap, keep it to less than 30 minutes and don’t nap within 8 hours of bedtime.
- Limit technology use before bed. That means no cellphones, television, or computer screens before bed – two hours is best. Don’t bring your phone into bed with you. Use a separate alarm clock to wake you up in the morning.
- Pay attention to your daily habits. Avoid caffeine and alcohol six to eight hours before bed. Exercise regularly, but not right before bed.
- Talk about your worries or fears during the day, not right before bed.

Remember, using these strategies every day is critical for them to work. If you aren’t consistent, you will be continuing the disruptive strategies that contributed to your poor sleep in the first place. Implementing these tips can be very difficult in the beginning, and you may even feel sleepier at first. However, over time, these strategies can help improve your sleep and day-to-day functioning.

MYTH: Survivorship care is only for people who are 100% cancer-free.

FACT:

The Adult Survivorship Program is available to all Dana-Farber patients, including those who are receiving treatment.



Our mission is to improve the health and quality of life for people living through and beyond a cancer diagnosis by providing clinical care, education, counseling, and by conducting innovative, patient-centered research. The program utilizes a personalized approach to follow-up cancer surveillance, prevention, management of late and long-term effects, behavior modification, and coordination of care.

Below are the services available through the Adult Survivorship program:

Survivorship Specialty	Providers	Scheduling Information
General Survivorship	Patricia Nutting, NP	To schedule appointments with any of these providers, call: 617-632-4LAD (Life After Diagnosis)
General Survivorship	Tara Roy, NP	
Internal Medicine for Cancer Survivors	Larissa Nekhlyudov, MD, MPH	
Onco-Cardiology	John Groarke, MD	
Onco-Cardiology	Anju Nohria, MD	
Onco-Endocrinology	OP Hamnvik, MD	
Onco-Nephrology	Albert Lam, MD	
Onco-Nephrology	Shveta Motwani, MD	
Onco-Fertility Counseling	Lauren Czapla, NP	
Sexual Health	Sharon Bober, PhD	
Sexual Health/Gynecology	Caryn Dutton, MD	
Sexual Health/Gynecology	Sandy Falk, MD	
Sexual Health and Sleep	Eric Zhou, PhD	
Exercise and Nutritional Services	Leonard P. Zakim Center for Integrative Therapies and Healthy Living	
		617-632-3322

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.lbbc.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/2qxgcS>

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 mentoring program providing guidance and support to women with early-stage (0-III) breast cancer. 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**.

Young Women's Telephone Support Group

Robin Raider, MSW, LICSW | Thursdays, Oct. 4 - Dec. 8, 12 - 1 p.m.

The fall session of our biannual phone support group will be starting on the first Thursday in October and will run for 8 weeks. These weekly group calls, facilitated by a breast oncology social worker, give young patients and survivors an opportunity to discuss a variety of topics relevant to younger women with breast cancer – such as careers, sexual health, and managing relationships.

This group is best suited to women who were diagnosed with stage 0-III breast cancer before age 45 and are within 12 months of the diagnosis; women living with metastatic breast cancer, please contact us for more resources.

To register, please e-mail youngandstrong@partners.org or call **888-814-3324**.

Facing Forward

Julie Salinger, MSW, LICSW

A six-session series held twice yearly for patients who have recently completed early-stage (0-III) breast cancer treatment. For more information, call Julie Salinger at **617-582-8081**.

Metastatic Breast Cancer Support Group

Liz Farrell, LICSW, and Fremonta Meyer, MD | Monthly, 11 a.m. - 12:30 p.m.

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

Upcoming Events

Celebrating Young and Strong

Friday, Oct. 26 | Artists for Humanity Epicenter, Boston, MA

The planning committee of Celebrating Young and Strong is excited to announce their 5th annual gala. This fun-filled evening, established and planned by young survivors, celebrates the courage and strength of all young women facing a breast cancer diagnosis. Celebrating Young and Strong is a fundraiser with proceeds benefitting the Young and Strong Program. 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 gather for support, love, and encouragement. For more information or to get involved, please visit <http://celebratingyoungandstrong.com>.

Dr. Bober's Sexual Health Workshop for Couples

Nov. 13, 2018, 6 - 7:30 p.m. | 450 Brookline Ave., Yawkey Center Room 306, Boston, MA 02215

You and your partner are invited to join Dr. Sharon Bober, Director of Dana-Farber's Sexual Health Program, as she explores the common challenges faced by patients and their partners after a cancer diagnosis.

Light dinner and complimentary parking will be provided.

Please email youngandstrong@partners.org for more information or to register.

WEBCAST: Survivorship 101

Ann Patridge, MD, MPH | Wednesday, Jan. 23, 2019, 12 - 1 p.m.

More information and registration link will be shared throughout December and January.