Young and Strong®
A PROGRAM FOR YOUNG WOMEN WITH BREAST CANCER
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SUSAN F. SMITH CENTER FOR WOMEN'S CANCERS
DANA-FARBER CANCER INSTITUTE

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.danafarber.org/YoungWomenBreastCancer.

You can also follow us on Twitter @YoungStrongDFCI.

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Living Well After a Breast Cancer Diagnosis

ON JULY 20, 2017 Young and Strong partnered with Living Beyond Breast Cancer (LBBC), an organization that provides information, community, and support to those whose lives have been affected by breast cancer, to present: Living Well After a Breast Cancer Diagnosis: Practical Tips for Young Women. Speakers from Dana-Farber included **Ann Partridge, MD, MPH; Julie Salinger, LICSW;** and two patients—Alexis, who was diagnosed with Stage 4 breast cancer at 33; and Kristen, who was diagnosed with triple negative breast cancer at 40 when she had an infant and toddler twins. Kristen's husband, John, joined the discussion to provide a caregiver perspective, and Janine Guglielmino, senior director of Programs and Partnerships at LBBC, served as host. Below are some highlights from the discussion.

What advice do you have for people who are newly diagnosed and dealing with that initial fear?

Alexis: When I was originally diagnosed, Dr. Partridge had prescribed some anti-anxiety meds. And I remember thinking, "Oh I wonder what these are for," and when I put my head down on the pillow that night I realized, "Oh, that's what these are for." When your friends and family are around, they distract you, but at the end of the day, you have to go to sleep in your own head, in your own body. Sleep meditations were great, but I also turned to Netflix and watched The Office. Find something that will keep your mind quiet at night.

John: Being by myself and alone at times was really, really tough. I purchased every self-help book possible, but I found that facing inward really helped me. I'm not big into yoga, but I did a little 15 minutes of yoga, and it helped me find myself.

How do you weigh whether to continue on a hormonal therapy vs the side effects you may be experiencing?

Ann Partridge, MD, MPH: There are choices. It very much depends on the risk-benefit ratio for a given individual, which has to do with how you feel on the treatment and the risk of the cancer to begin with. Women

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Adherence to Endocrine Therapy

About 60-75% of all breast cancers are classified as estrogen receptor (ER) positive and/or progesterone receptor (PR) positive, collectively known as hormone-sensitive breast cancer (HR+). For women with this type of breast cancer, oral hormonal therapy is recommended to reduce the risk of breast cancer coming back or new cancer ever developing again.

Standard oral hormonal therapy includes tamoxifen and aromatase inhibitors, which are daily pills that are generally prescribed for at least five years. More recent data has shown that taking oral hormonal therapy for up to 10 years may be worth it for some.

Some people just have trouble getting into the routine of taking medication on a regular basis, and this can get in the way of getting the full benefits of therapy. Following are some helpful tips for taking medication regularly:

Get educated

- Understand why you take your medication
- Learn how your medication works and how your medication will benefit you
- Listen, ask questions, and read about the potential side effects
- Know who to call with questions or concerns

Understand your medication instructions

- Medication dose, frequency, and time of day
- Take on an empty stomach? With food? Either?
- Other medications or foods you should avoid
- What to do if you miss a dose

Report side effects (including if you need help with menopausal symptoms)

- If you have side effects, tell your health care team
- Tell your doctor if you have any problems getting your medication
- Cost of medication or co-pay, inability to get to the pharmacy, and other issues can often be addressed; work with your providers and insurance company

Stay organized

- Use a pill box to sort a week's worth of medication
- Start a medication diary or chart to keep track of the pills you take each day
- Plan ahead by checking the number of refills on your prescription. Call your provider's office when you fill your last refill to receive a new prescription

Develop a routine

- Take your medication during an activity that you perform daily, at a consistent time. For example, when brushing your teeth in the morning or before bed
- Set a daily alarm on your cell phone, watch, or email calendar

If you are on endocrine therapy and experiencing menopausal symptoms, there are behavioral and physical ways to help manage them. Symptoms of menopause include hot flashes, night sweats, sleep problems, memory problems, depression or anxiety, and urinary or vaginal symptoms. Following are tips for managing these symptoms:

Hot flashes

- Dress in layers
- Avoid triggers, such as stress, alcohol, caffeine, spicy foods, and hot showers
- Sleep on cotton sheets
- Maintain a healthy body weight
- Practice relaxation techniques, such as yoga, meditation, or breathing exercises

Sleep

- Wake up and go to bed at consistent times, even on weekends. Avoid naps.
- Avoid caffeine late in the day, ideally 4-6 hours before bed.

Anxiety or depression

You may benefit from therapy, medication, or both. Speak to your doctor for more information.

Vaginal dryness

Vaginal moisturizers, which are available in gels, tablets, or liquid beads, provide a smooth layer of moisture that adheres to the vaginal tissue and improves the vaginal pH. The best absorption occurs when used prior to bedtime.

- These moisturizers are non-hormonal and available over-the-counter. Examples include Replens, Luvena, or Hyalo Gyn (these products are also available for sale at the Dana-Farber gift shop!).

Vaginal lubricants provide a temporary protective coating and should be applied in the vagina and around the genitals immediately before sexual activity.

- Petroleum-based lubricants can irritate tissue, may damage condoms and diaphragms, and can increase risk of infection.
- Water-based lubricants without perfumes or other irritants are best and wash away more easily. Examples include products such as Astroglide, Liquid Silk, or Slippery Stuff.

Use soap and bubble baths sparingly, as they can dry the vaginal tissue.

Medication

Sometimes, medications can also be helpful with managing symptoms.

Talk to your doctor about this if you are struggling.

Consider social support for help

- Join a group for peer support
- Speak with a counselor

Finally, communicate with your care team if you are having trouble taking your hormonal therapy, whatever the reason. Remember, they are there to help you!

Spotlight

Survivorship Nurse Practitioners

Tara Roy, NP, MSN (left) and Tricia Nutting, NP, MSN

Tricia Nutting, NP, MSN, and Tara Roy, NP, MSN, are nurse practitioners for the Adult Survivorship Clinic at Dana-Farber. Both have an extensive background working in the oncology setting and have been with the survivorship program for more than two years. As Survivorship Nurse Practitioners, Tricia and Tara are available to work with patients as they are transitioning out of active cancer treatment and into the survivorship phase of their care. They are here to help you find expertise, education, and support in managing the issues related to surviving cancer. This includes managing the risk of second cancers, understanding the long-term effects of treatment, and addressing social, physical, or psychological concerns.

Tricia and Tara will also work with you and your primary care provider to develop a treatment care plan to summarize your cancer treatment and help you navigate your care moving forward.

You do not need to have been treated at Dana-Farber to be seen in our Adult Survivorship Program. To make an appointment or find out more about the Adult Survivorship Program, please call **617-632-4523** or email: **DFCI_adultsurvivors@dfci.harvard.edu.**

Living Well After a Breast Cancer Diagnosis

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are afraid of the side effects of the hormonal therapy. The fact is that most women are going to be okay from the side effects of the hormonal therapy. Getting over that hump and saying, "Okay, I'll try it, and if I am miserable, we will come up with another plan"—I think that is the important message to communicate.

Julie Salinger, LICSW: Often people are starting hormonal therapy right after they've finished active treatment for breast cancer. It's sometimes hard to tease out where the anxiety and depression are coming from. What is important for people to understand is that when you finish active treatment for breast cancer, often you can be more anxious and depressed than you were going through it. Be open and talk to your care team.

Did you share your diagnosis with friends, family, and colleagues?

Alexis: I did. It was a process. You have no control in this situation. What little control you have is so important. You'll be really surprised by the people who show up when you're going through this—peripheral people in your life. On the flip side of that, some good girlfriends then might not show up. So it's managing the people who are coming forward and managing the people who are taking a step back. My sister always says, "If you don't show up now, when do you show up?"

Kristen: John and I are very private people by nature. I felt like after my diagnosis I opened up to family and friends immediately because I felt like we needed the support. It really could be neighbors, friends, and colleagues there for you more than anyone else.

How do you deal with controlling parents who just want to be involved in your cancer journey every single day?

Julie: Being honest is really important. Parents feel helpless and want desperately to do something. What we often tell people is to tell your parents what they can do to help you. That may be: "Don't call me once a day, but twice a week." Sometimes that's just being able to say, "What I need now is to feel independent like I have for the past five years. Please try to give that to me."

Imagine that you are talking to a young woman who has just been diagnosed with breast cancer. What is the one thing that you would want her to know?

Alexis: There is no right or wrong way to go through this process. It's whatever feels right to you. I think the number one thing is trying to deal with anticipation. I worried and I anticipated chemotherapy, and that experience was different than what I was worrying about. Try your best to manage it day by day.

Kristen: It's absolutely normal to be devastated and in disbelief, "How did this happen? Why did this happen to me?" You ask yourself all those questions. You as an individual have to find what's best for you. However you feel, express those feelings, either with yourself or someone else. Don't go through it alone.

John: If you have the ability as a caregiver, just be there and be by her side. When Kristen was losing her hair we decided to shave it together, and she had asked me, "Do you mind shaving my head?" and I said, "That's fine; you can shave mine." We went through it together, and I found it was the best way to cope.

Julie: Drop the word 'should' when you're going through cancer treatment. There is no should. You feel what you feel. There is no right or wrong as you go through this.

Ann: Be patient with the process. For those who are newly diagnosed,

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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/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**.

Young Women's Telephone Support Group

Robin Raider, LICSW

For young women who are within the first year of diagnosis looking to connect with others who understand the impact of living with and beyond breast cancer. Sessions offered twice a year. For more information, contact Stephanie at 617-632-3916 or youngandstrong@partners.org.

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

Dating Workshop

Saturday, March 31, 2018 | 10:00am–12:00pm

If you are single and have been treated for cancer, join us for a discussion with Sharon Bober, PhD, Director of Dana-Farber's Sexual Health Program, and Christopher Recklitis, PhD, MPH, Director of Research at the Perini Family Survivors' Center, about the emotional effects of cancer and relationships. Please email youngandstrong@partners.org to register.

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or into survivorship, or living with chronic disease, it really is a process, but you will get through it.

What if you really don't feel like you have social support around you?

One way to find support near you is to call LBBC's Breast Cancer Helpline (888-753-LBBC), a service that lets you talk by phone with a trained volunteer who has been diagnosed with breast cancer. They can provide you with emotional support, share practical information, and give comfort. All calls are completely confidential. The Young and Strong Program also has a phone support group for young women with breast cancer that is offered twice a year and facilitated by a Dana-Farber social worker. Please email youngandstrong@partners.org for more information or to register.

You can view the entire Living Well After a Breast Cancer Diagnosis: Practical Tips for Young Women program at http://bit.ly/2y0OJtG.

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