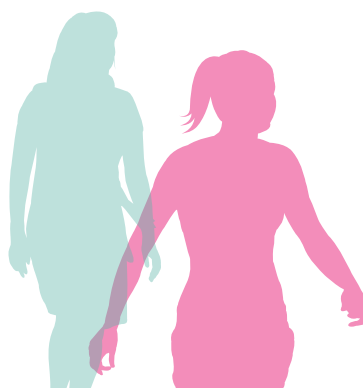


Young and Strong®

A PROGRAM FOR YOUNG WOMEN
WITH BREAST CANCER

Volume 10. Issue 2: Fall/Winter 2019

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 5,000 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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Sexual Health: No, It's Not "Frivolous"

A note from Sharon Bober, PhD, Director of DFCI Sexual Health Program

"I know I am supposed to be grateful..." I can't tell you how many times I have heard this phrase at the start of a consultation about sexual health and cancer. I am often struck by this particular sentence, which seems to convey the message that women feel unsure if it's ok to be distressed about something as "frivolous" as sexuality or body image in the shadow of something as serious as cancer. As if concerns about sexual problems must mean that they are not adequately appreciative just to be alive. Before we say a word about sex, I find myself acknowledging the reality that we humans can be grateful and distressed, appreciative and frustrated with the profound side effects of treatment, including those that impact sexuality.



Sharon Bober, PhD

Even though 'quality of life' is now commonly referenced in the world of cancer care, it is striking how talking frankly about sexuality is still not part of routine care for many women both during and after breast cancer. Although patients are regularly asked about other side effects such as nausea or pain, many women are not routinely asked about (or when asked, are uncomfortable discussing) common changes in sexual health such as vaginal dryness, loss of desire, pain with or without sexual activity, changes in arousal, or concerns about body image. In fact, we know that most young breast cancer survivors face distressing or bothersome changes in sexual health, either short-term or longer-term, related to their treatment. Some of the most common challenges are associated with the impact of treatment-induced menopause/reduced estrogen levels.

Described as genito-urinary syndrome of menopause, symptoms fall into three categories: **genital** symptoms such as dryness, burning, and irritation, **sexual** symptoms, such as lack of lubrication, discomfort or pain, and impaired sexual function, and **urinary** symptoms, such as urgency, discomfort when urinating, and recurrent urinary tract infections. Although these symptoms can be very bothersome, there are fortunately a variety of very effective treatment strategies that can address these problems. Other common problems are related to changes in body image and feeling comfortable in one's body after undergoing treatments including surgery and/or radiation. It is not always obvious how to feel fully present in one's body after breast cancer without also feeling a little panicky; this can certainly get in the way of intimacy.

Continued on page 2.



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

Questions for Your Oncologist:

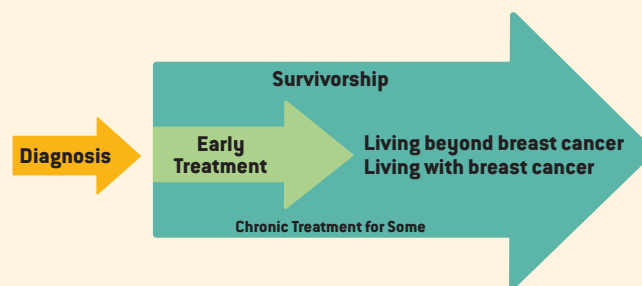
At and After Diagnosis

In last Fall's issue, we shared the Cancer Care Trajectory (as seen to the right) and that Young and Strong, along with the rest of your care team, is here for you every step of the way. Knowing that each phase can bring its own set of challenges and uncertainties, we've compiled a list of questions that you can use as a guide when discussing your care with your oncologist at each stage of the trajectory.

Doctors recommend keeping a running list of these so you can make sure they're covered at subsequent meetings. Nothing should be off-limits; anything that seems relevant or important to you, or anything that you want clarified, can be brought up with your oncologist.

Getting answers is critical because, ultimately, the decision of which treatment to receive is yours to make. Knowing your options, and being clear about your preferences, will help you participate fully in the decision-making process.

Many breast cancers involve treatment not only by a medical oncologist but also a surgical oncologist and radiation oncologist. It's common to have different questions for each of these individuals. Here, we'll focus on questions for your medical oncologist. They can be divided into several categories:



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.

Sexual Health Continued from page 1.

So what can we do about this?

Remember: Every woman has a right to get the support and necessary information she needs to manage sexual side effects of treatment.

The Sexual Health Program at DFCI takes a comprehensive approach to treating sexual problems and thinking about sexual renewal. This means that we look at biological, psychological, interpersonal, and even cultural factors that are often working together. Sexual renewal often means addressing multiple challenges, so we focus on helping women put together an action plan that addresses each of these challenges in tandem. For example, this might mean putting together a treatment plan that aims to not only improve vaginal health in the setting of ovarian suppression treatment, but also focus on helping a woman feel comfortable in her body, enhance personal pleasure, and learn to expand her sexual repertoire and sexual communication with her partner.

Sexual health should be considered like any other aspect of quality of life. But what does this mean if you have concerns and no one is talking about it? First, I encourage you to advocate for yourself by telling your oncologist, nurse, primary care doctor (or anyone else

you feel comfortable with on your treatment team) that you have concerns about how treatment has impacted your sexual function and that you would like to get some help. While your providers value sexual health as an aspect of your quality of life, they may not bring it up unless you indicate that this is important to you. Second, know that there is a deep pool of resources for young woman about sexuality during and after cancer. Your care team can provide you with written patient education materials which are also available online: <https://bit.ly/2kupHNu>. Young and Strong, in conjunction with the Sexual Health Program at DFCI, offers sexual health workshops throughout the year—one just for young women and another for couples. Additionally, in collaboration with the Young Adult Program and the Perini Family Survivors' Center, Young and Strong hosts an annual Sex, Dating, and Relationship Workshop for patients of all disease centers. You are also welcome to make an appointment for an individual and/or couples consultation in the Sexual Health Program. To make a consultation appointment, please call: **617-632-4523**. For more information about sexual health, you may view Young & Strong's website: youngandstrong.dana-farber.org. Other organizations such as the American Cancer Society, Young Survival Coalition, and BreastCancer.org also have various resources on-line that directly address how to improve sexual health during and after cancer.

About the cancer

- What is the stage of my breast cancer?
- How large is it? Are the lymph nodes affected?
- Is it ER (estrogen receptor) positive, meaning its growth is driven by the hormones estrogen or progesterone, and can be targeted by anti-estrogen drugs?
- Is it HER2-positive, meaning the tumor cells express the HER2 protein, which can be targeted by Herceptin and other drugs?
- Should I have genetic testing to understand why I may have been at a higher risk for developing this cancer?

Treatment options

- What diagnostic tests are needed to determine what type of breast cancer I have?
- How does the type of tumor I have affect my treatment options and long-term outcome?
- What are the benefits and risks of each option?
- What treatment do you recommend and why? Should I get a second opinion?
- When should I start treatment?
- How long will treatment last? What will it consist of? Where will it be delivered? How much time will each treatment session take?
- What should I do to get ready for treatment?
- What do you expect the treatment to accomplish? What is my prognosis?
- Am I eligible for a clinical trial of new treatment?

Effects of treatment

- What are the most common side effects of the treatment I'll be receiving?
- Will I lose my hair from chemotherapy? Is there anything I can do to reduce my hair loss?
- Will I experience peripheral neuropathy (a loss of feeling in the hands and feet)?
- Am I likely to experience cognitive problems as a result of therapy? How long do they usually last?
- Will treatment be painful or fatiguing? Will I experience nausea?
- How will treatment affect my ability to perform daily activities? Can I still work full-time or part-time? Will I be able to take care of my family? What changes may I need to make in my daily routine?
- Do I need to limit my sun exposure?
- What are the possible long-term effects of my treatment?
- How will treatment affect my sex life? Can I become pregnant while undergoing treatment?
- Will I go through menopause as a result of the treatment? Will I be able to have children after treatment? Would I be able to breastfeed?
- What will I need to consider if I'm pregnant when diagnosed?

Self-care options

- Are there certain foods I should eat or avoid eating?
- Am I likely to lose weight as a result of treatment? Should I increase my calorie intake?
- Is exercise helpful or harmful?
- What kinds of integrative therapies - such as acupuncture, massage, and Reiki - might be helpful, and are there any I should avoid?

Genetic testing

- Should I be tested for genetic mutations that may have increased my risk of developing breast cancer, and may raise my risk of developing it again?
- If I test positive for such a mutation, what steps can I take to reduce the chance of developing breast or other cancer again?
- If I test positive, should other family members be tested as well?

During treatment

- How will we know if the treatment is working?
- What symptoms or side effects should I tell you about right away?
- Will I need special tests, such as imaging scans or blood tests? How often?
- What is the best way to reach you with questions? Who else on the care team may be able to provide answers?
- What can I do to manage side effects?

Following treatment

- Are there limits on what I can do?
- Do I need to follow a special diet? For how long?
- Am I at risk for lymphedema (swelling caused by a backup of lymph)? How can I reduce my risk of developing it?
- What other symptoms should I watch for?
- What kind of exercise do you recommend?
- When will the side effects of therapy subside? How long will it take my hair to grow back?
- How often will I have to come in for follow-up exams, including blood tests and imaging scans?
- What is my long-term outlook? What are the chances the cancer will come back? How long until I'll be considered in the clear?
- How will I know if the cancer comes back? What signs should I watch for?
- If it does come back, what are my treatment options?

A variety of non-medical questions — such as the availability of support groups, psychological counseling, relaxation support, spiritual guidance, transportation to and from the treatment center, financial concerns, etc. — can often be answered by other members of your care team, including the Young and Strong team, social workers, and patient navigators.

To stay updated on events and other news, please visit <http://youngandstrong.dana-farber.org/>

If you'd like to receive our monthly e-newsletter, please email youngandstrong@partners.org.

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 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**.

Metastatic Breast Cancer Support Group

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, please email youngandstrong@partners.org.

Young Women's Telephone Support Group

Angelee Russ-Carbin, MSW, LICSW | Fall 2019

These weekly group calls, facilitated by a breast oncology social worker, give young patients and survivors an opportunity to discuss topics relevant to young women with breast cancer. 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. If you're interested in registering for the Fall cohort, please e-mail youngandstrong@partners.org or call **617-632-3916** for more information.

Save the Date

Facing Forward

Facilitated by Ashley Boyd, MSW, LCSW

A six-session series held twice yearly for patients who have recently completed early-stage (0-III) breast cancer treatment. For more information or to register, please call **617-632-6859** or email ashley_boyd@dfci.harvard.edu.

All sessions will be held at **450 Brookline Ave., Yawkey Center, Boston, MA 02215**

October 23, 2019, 6 - 7:30 p.m.

Welcome & Introduction to Facing Forward

October 30, 2019, 6 - 7:30 p.m.

Physical Recovery: Ask the Oncologist

November 6, 2019, 6 - 7:30 p.m.

Coping & Mindfulness

November 13, 2019, 6 - 7:30 p.m.

Maintaining Your Health: Eating Well & Exercise

November 20, 2019, 6 - 7:30 p.m.

Emotional Recovery: Ask the Psychiatrist

December 18, 2019, 6 - 7:30 p.m.

Sexual Health & Intimacy

Sexual Health Workshop for Couples

Tuesday, October 29, 6 - 7:30 p.m. | 450 Brookline Ave., Yawkey Center, Boston, MA 02215

Facilitated by Sharon Bober, PhD

Sharon Bober, Ph.D., Director of Dana-Farber's Sexual Health Program, will address common challenges faced by patients and their partners during and after breast cancer treatment. You and your partner, married and otherwise, are invited to gather and learn useful strategies for improving sex and intimacy.

Light dinner and complementary parking will be provided.

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

Galentine's Day Celebration

Thursday, February 13, 2020 | Harpoon Brewery, 306 Northern Ave., Boston, MA 02210

Save the date for this special evening of celebrating the women in our lives who bring us joy, love, and support. More information will be included in the monthly email. If you do not receive our monthly e-newsletter and would like to be added to our distribution list, please email youngandstrong@partners.org.