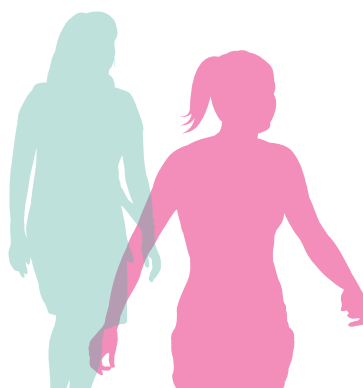


Young and strong®

A PROGRAM FOR YOUNG WOMEN
WITH BREAST CANCER

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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 4,500 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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International Consensus Guidelines Support Care for Young Women

As a young woman with breast cancer, you've probably wondered at one point or another: what makes treatment for young women different, and who defined those guidelines? The first official guidelines for the treatment of young women with breast cancer were laid out at the 1st International Consensus Conference for Breast Cancer in Young Women (BCY1) held in Dublin, Ireland, in November 2012. The guidelines are prepared by a panel that includes Dana-Farber's Ann Partridge, MD, MPH, founder and Director of Young and Strong – the Program for Young Women with Breast Cancer at Dana-Farber. They are published in a medical journal so that they can be accessed widely to improve the quality of care for young women with breast cancer worldwide. They are updated regularly to incorporate new clinical studies and data as they pertain to young women.



In most ways, breast cancer treatment doesn't vary significantly with age except that young women are more likely to be premenopausal (having menstrual periods) – and to stay that way throughout chemotherapy treatment – which has implications for hormonal therapy options. Other key differences pertain primarily to concerns specific to younger women. Thus, the guidelines cover considerations spanning from hormonal therapy to fertility to psychosocial needs and are divided into the following categories:

- General recommendations: screening, diagnosis, and imaging for staging
- Genetic counseling and testing
- Early local treatment
- Neoadjuvant/adjuvant systemic treatment
- Advanced breast cancer
- Special issues for BRCA mutation carriers
- Supportive and follow-up care

The guidelines specify that genetic testing should be offered to all younger patients but only be performed after consultation with a genetic counselor, given the results' implications on decision-making and family members. The guidelines generally recommend that treatment decisions be made after multi-disciplinary consultations (i.e. with surgical, medical, and radiation oncologists), and that being of younger-than-average age does not necessarily warrant more aggressive treatment. On side effects, particularly those affecting sexual health and fertility, younger patients are to be well-advised by a team of appropriate professionals. Throughout the breast cancer care trajectory, resources should be provided to optimize care – such as navigators to guide the patient through what may be for some a new cultural setting, and counseling surrounding the psychosocial impacts of diagnosis and treatment.

Continued on page 2.



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

Survivor Perspective: Breast Cancer and Quality of Life – How I Chose Not to Suffer in Silence

My experiences as a 29 year old, about to get married, and diagnosed with breast cancer

By Amanda DeGiorgi, a member of the Young & Strong Community since early 2017

Menopause, arthritis, wigs, astronomical medical bills, less sex, no sex... sounds more like a retiree's worst nightmare than my reality as a 29-year-old about to be married. But life rarely goes as planned and can take you on a wild ride when you're least expecting it. I think everyone reading this newsletter has a Netflix binge-worthy story about life's cruel unpredictability.

Now that surgery, chemotherapy, radiation, and two of five years of medically induced menopause are in my rearview mirror (can't hit that gas pedal hard enough!), I've been thinking a lot about what has helped me to get through the most challenging period of my life so far, what sustains me, and what helps me thrive. Because I am thriving. Thriving and enjoying a place I hope all breast cancer survivors can get to. Despite a very rocky road and more obstacles than Brookline Avenue after winter, I finally found myself and a sense of peace in the world, neither of which I had before cancer.

While I keep working on myself and my joy, I want to share what's helped me along the way. I have met so many incredible women on my cancer journey who, like me, are lucky enough to be "out of the woods" or who have been given a little extra time on this planet, but who also suffer in silence over things that may not qualify as life-threatening yet have a huge impact on their quality of life.

So here are some thoughts from one special-breasted woman to another on those day-to-day things that don't always come up with the oncologist (note: if they don't, bring them up!).

Sexual health

I'll start with the good stuff: sex. More broadly, I mean sexual health; it's about you first, then it's about you and your partner (or partners). My world of sex changed when I started injecting myself



Amanda DeGiorgi

with hormones to create what felt like grapefruit-sized ovaries and harvest some healthy, 29-year-old eggs before chemo. If that wasn't excitement enough, having a total stranger probe me every couple of days sure made me rethink getting naked. I also struggled with my new breast, body image (what woman doesn't?), and trust in my own body (stop trying to kill me!). Physical and libido changes from the endocrine medications didn't help either. I'm like Samantha on Sex

International Consensus Guidelines Continued from page 1.

It is important to note that guidelines exist to provide a general framework. While this set informs best practices for younger women with breast cancer, each patient is unique and individual needs and preferences still factor into care. Given the continuous advancements in research and subsequent expansion of treatment options, the guidelines are reviewed every two years. The most recent conference (BCY4) was held in October 2018 in Lugano, Switzerland. More than 300 healthcare professionals and patient advocates convened to discuss updates and other relevant topics. When the most recent update of the guidelines

are published, we will alert program members via our monthly email and post a copy on our website. If you have any questions or concerns specific to you, please consult your oncologist and/or other providers.

Stay abreast of events and other news by visiting www.youngandstrong.dana-farber.org! If you'd like to receive our monthly e-newsletter, please email youngandstrong@partners.org.

and the City waiting for her boyfriend's flowers to bloom after chemo, but still waiting.

So I got help. First, I put aside my embarrassment and was honest with my social worker. Then I found out about an incredible woman named Dr. Sharon Bober, a psychologist specializing in sexual health at Dana-Farber. Dr. Bober, through workshops, one-on-one meetings, and clinical studies, taught me more than I've ever known about the vagina (it folds?!) and, more importantly, how to take care of those special parts during and after cancer treatment. She also referred me to a pelvic floor physical therapist. Dr. Bober gave me a copy of *Sexuality for the Woman with Cancer*, a booklet published by the American Cancer Society, and I recommend it to every woman who has gone through cancer treatment. For me, sexual health is my biggest challenge, but I've at least made progress with help.

Coping with physical changes

Far more visible markers of the cancer experience are physical changes like hair loss, surgical scars and reconstruction, weight gain or loss, aches and pains, neuropathy, or even lymphedema. For some reason, the number one response from concerned friends when you mention chemo is, "But you have such beautiful hair!" instead of the fact that you're about to willingly subject your body to poison. But many women do lose hair (as I did), which, although temporary, can exacerbate feelings of vulnerability and unfamiliarity. The bottom line is that during and after treatment, you often look and feel different.

I was very active before cancer; after chemo, I spent days on the couch during radiation and celebrated a simple walk around the block. Luckily, resources abound for these exact issues – your oncologist or

My words of wisdom here are to be honest with where you're at physically, give yourself compassion, and start small.

social worker can help you find occupational and physical therapists, nutritionists, self-care and beauty programs, exercise classes, and wig and clothing stores for breast cancer patients. My words of wisdom here are to be honest with where you're at physically, give yourself compassion, and start small. I was so hard on myself for not doing more and progressing faster, like those ultramarathon-runner/CEO/supermodel cancer survivors. Of course, those people don't exist and that kind of thinking only made things worse. I eventually found what worked for me, and two years after diagnosis am proud of where I am today, which is almost free of arthritis (take that, Lupron!).

Mental health

Now, mental health. Woof. I fancied myself a mentally strong person. Then I met cancer, who introduced me to PTSD, depression, anxiety,

and sleep deprivation. I could write a book on this topic alone, but for purposes of brevity, the key takeaways are that you're not alone and to not give up. My mental health journey since diagnosis has included three social workers, a psychiatrist, a few months on anti-depressants, a therapist, a SoulMates mentor, Patty Arcari's Mind Body Resilience class at the Leonard P. Zakim Center for Integrative Therapies and Healthy Living, many books, and continued mindfulness work of my own. I felt, and continue to feel, so much pressure as a cancer patient and survivor to project the image of a strong, positive, happy person when life is flinging mud at me. I have learned that it's completely healthy to need or want a space (or many spaces!) to be with all that is in my mind and body, positive and negative, and to be guided through to a better me.

If any of this sounds familiar and you're struggling with something, don't stay silent. Whatever it is, talk to your oncologist and social worker about what options are available and what will work for you, your needs, and your budget or insurance plan. If you don't have a social worker, ask for one! Keep in mind that it may not be a perfect fit on the first try. The third time was the charm for me and she's helped me through many challenges. The Young and Strong Program or the Adult Survivorship Program can help you find a social worker or therapist.

Please know that, even on the loneliest of days, you're never alone—there is an entire community of us young women and support is always available. To connect with any of the resources I've mentioned or to talk with someone else who has been there, call the Young & Strong Team at 617-632-3916 or email youngandstrong@partners.org.



A Dana-Farber social worker meets with a young adult patient.

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/2qxcgceS>

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**.

Facing Forward

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, email youngandstrong@partners.org.

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

Webcast: Breast Cancer Treatment: How Do I Know It's Working?

September 12, 2019, 12 – 1 p.m.

Led by Philip D. Poorvu, MD

Look for sign up information in the monthly e-mail.

Dating, Sex, and Cancer Workshop

September 17, 2019 6 - 8 p.m. | 450 Brookline Ave., Yawkey Center, Boston, MA 02215

Led by Sharon Bober, PhD, and Christopher John Recklitis, PhD, MPH

In collaboration with the Young Adult Program and the Perini Family and Survivors' Center, join us for a workshop for young adult cancer survivors who are single, and interested in dating. This event includes dinner and a social hour. To register or learn more, email youngandstrong@partners.org.

Jimmy Fund Walk

September 22, 2019

Join Team Young & Strong for a day of celebrating each other. To register, visit tinyurl.com/JFWalk-youngandstrong. For any questions email youngandstrong@partners.org.

Metastatic Breast Cancer Forum

October 5, 2019, 9:00 a.m. – 3:15 p.m. | 450 Brookline Ave., Yawkey Center, Boston, MA 02215

To register, please visit www.mbcforum2019.eventbrite.com.

Forum for Young Women with Breast Cancer

October 4, 2019, 7:30 a.m. – 5:30 p.m. | Boston Marriott Long Wharf, 296 State St., Boston, MA 02109

This annual event for patients of all stages and their loved ones includes a patient/survivor panel, a panel of breast cancer experts, group sessions with social workers, and an evening social. For information or to register, email youngandstrong@partners.org.