New Study Suggests Benefits from More Than Five years of Tamoxifen

Women diagnosed with early stage, hormone receptor positive breast cancer are usually recommended to take five years of an oral hormonal therapy. For young women who are pre-menopausal, the recommended therapy is generally tamoxifen. Tamoxifen blocks the effect of the hormone estrogen, and prevents new and recurring breast cancer from forming. A recently reported clinical trial found that women who took ten years of tamoxifen compared to the standard five years, had lower rates of breast cancer recurrence (breast cancer coming back) and a longer overall survival, suggesting that a greater number of years on tamoxifen should be seriously considered. The benefits were modest in size, but large enough to be potentially beneficial for some women.

When comparing the two groups (5 versus 10 years of tamoxifen) the researchers found a decreased risk of breast cancer recurrence in the group taking tamoxifen for 10 years. The recurrence rate decreased from 25.1% to 21.4%, for an absolute overall benefit of 3.7%. Researchers also looked at differences in mortality (death) due to breast cancer and found a lower percent of deaths in the 10 year group, 12.1%, compared to 15.0% in the 5 year group, a difference of 2.9%. These benefits were not noted until after the 10th year of follow up, suggesting that tamoxifen has a beneficial effect that lasts several years after women stop taking it. All women were followed for 15 years.

The serious risks of taking 5 versus 10 years of tamoxifen were also studied. Serious risks of tamoxifen are relatively rare and include stroke, blood clots, heart disease, and endometrial cancer. The risk of several of these events was slightly elevated in the 10 year group though it was still particularly low for women who are young (under 50). The trial authors noted the importance of continuing to study the long term serious risks of taking tamoxifen.

The decision to take tamoxifen for an additional five years is a personal one. It should involve weighing the expected benefit of extending therapy against the expected risks. Quality of life factors such as side effects and personal preferences (including desire to be off medication or trying to carry a biologic child) should also be seriously considered. Some side effects associated with tamoxifen, for example, hot flashes, affect some women and not others. Women who experience severe side effects might consider including this as a negative factor in their decision to extend or not extend treatment. Another important consideration is the risk associated with the primary breast cancer diagnosis. Women who are at higher risk of recurrence (larger tumors or lymph node involvement) are more likely to benefit from extended tamoxifen than those with lower risk (small, node negative) tumors.

If you would like to learn more about what is the best option for you, we recommend you make an appointment to meet with your oncologist.

To read the full study, see: Davies C, Pan H, Godwin J, et al. Long-term effects of continuing adjuvant tamoxifen to 10 years versus stopping at 5 years after diagnosis of oestrogen receptor-positive breast cancer: ATLAS, a randomised trial. Lancet 2013: 381, pp 805-16.
Young Women Connect Through The Young Adult Program

The Program for Young Women with Breast Cancer is proud to announce the launch of our online interactive community within the Young Adult Program’s website, www.dana-farber-yap.org. This is a space where young women with breast cancer can connect by sharing their thoughts and experiences, asking questions, and supporting each other. The community includes women who are in many different stages of diagnosis, including women currently in treatment and those who are many years out from treatment. If you are interested in joining the online community, please contact Julie at 617-632-3916 or JLonardo@partners.org.

One blogger noted: “It has been great to have people to ask my questions to—people who have been there and get it.”

Another weighed in: “I had a tough couple of years after my diagnosis. Now, years later, I can be encouraging to others who are going through it now.”

Young adults with cancer often face different challenges than those of children and older adults. The mission of the Young Adult Program (YAP) is to provide clinical services and programs that validate and support the needs of young adults with cancer. YAP is committed to easing the emotional burden of living and coping with cancer, empowering young adults to become active participants in their cancer treatment, and providing emotional and social support in the form of educational workshops, conferences, opportunities to network with other young adults with cancer, and clinical mental health services.

For more information about the Young Adult Program, contact Rhian Waterberg at 617-632-6819 or YAP@dfci.harvard.edu.

Many Thanks To Carie and Her Crew!

Carie is a 12 year breast cancer survivor who has become an advocate for young women with breast cancer and was an integral part of the establishment of the Young Women’s Program (YWP). Seven years ago, Carie corralled her friends and relatives to ride the Pan-Mass Challenge with her to celebrate her survivorship and raise money for the cause. To date, Carie’s Crew has raised over $500,000 for the YWP. We are so grateful for this wonderful support! To learn more about Carie’s Crew contact Carie at carielynn@gmail.com.

Founded in 1980, the Pan-Mass Challenge (PMC) is an annual bike-a-thon that today raises more money for charity than any other single event in the country. For more information, visit www.pmc.org.
Sex and Intimacy

Sex during treatment
Physically, it’s typically fine to have sex during treatment. The issues that arise may be temporary or lasting, but most are manageable. If sex is an important part of your emotional relationship with your partner, be sure to set time aside for it. Just remember to keep in mind the following:

- Plan sexual activity for times when chemotherapy side effects are minimal. You may want to wait a few days after each treatment.
- If you know your blood counts are low, avoiding sexual activity can reduce your chance of infection. It’s fine to have sex once your blood counts are back to normal.
- If you could get pregnant, use non-hormonal birth control, such as a condom, diaphragm or copper IUD. Remember: If your treatment includes chemotherapy or tamoxifen, you should not get pregnant during treatment. Chemo and hormonal therapies, like tamoxifen, can cause birth defects or miscarriage, especially during the first trimester.

Hormonal changes
It’s common to experience some form of sexual difficulty during or after breast cancer treatment, especially with chemotherapy. Chemo can make the ovaries function irregularly, and lead to changes in hormone levels. These changes can cause symptoms like vaginal thinning or dryness, which may make intercourse uncomfortable or painful. You may also experience changes in libido (desire), arousal, and breast sensitivity.

Libido
Losing the desire for sex is a common experience for women during or after breast cancer treatment. While it can be very distressing, there are ways to get your groove back! A person’s libido doesn’t typically come back on its own; you have to nurture it. Take it slowly, and make time for intimacy. Start by getting to know your new body, and focusing on pleasure rather than sex.

Pain and discomfort
Pain during sex can distract you from enjoying the experience. To reduce pain, try to:

- Plan sexual activity for times when your pain level is lower than other times.
- Take pain medicine an hour before planned sexual activity so it has time to take effect. (If your medicines make you sleepy, work with your doctor to adjust the dosage.)
- Tell your partner what parts of your body are particularly sensitive.
- Find a position that puts as little pressure on sensitive areas as possible.
- Use a vaginal moisturizer regularly or water-based lubricants right before intercourse to make sex more pleasurable and comfortable.

Remember that it is very common for young women to experience challenges with sex and intimacy during and after treatment. Help is available for you and your partner. For more information, contact the Sexual Health Program directly at 617-632-4523 or visit www.dana-farber.org/sexualhealth.

Join us for our next Young Women’s Program Sexual Health Workshop on May 15th!
See back page for details.

Established in 2005, the Program for Young Women with Breast Cancer at Dana-Farber Cancer Institute 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 for younger women through ongoing research focused on young women. Over 1900 young women have been enrolled to date.

For further information about the Program, please contact Julie at: 617-632-3916 or visit our website at: http://www.dana-farber.org keyword: Young Women’s Program.
Additional Resources and Information

Susan G. Komen for the Cure

Susan G. Komen for the Cure is the world’s largest grassroots network of breast cancer survivors and activists working together to save lives, empower people, ensure quality care for all, and energize science to find cures.

www.komen.org

Young Survival Coalition

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

www.youngsurvival.org

Living Beyond Breast Cancer

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

www.lbbc.org

FORCE

Facing Our Risk of Cancer Empowered (FORCE) is the only national nonprofit organization devoted to hereditary breast and ovarian cancer. Their mission includes support, education, advocacy, awareness, and research specific to hereditary breast and ovarian cancer. Programs serve anyone with a BRCA mutation or a family history of cancer.

www.facingourrisk.org

Fertile Hope

Fertile Hope is a national LIVESTRONG initiative dedicated to providing reproductive information, support and hope to cancer patients and survivors whose medical treatments present the risk of infertility.

www.fertilehope.org

Save the Date

Young Women’s Sexual Health Workshop
Sharon Bober, PhD
Wednesday, May 15, 2013, 5:30-7pm
Join Dr. Bober as she discusses common challenges after treatment, including decreased sexual desire, body image concerns, menopausal symptoms and communication difficulties with partners. To register contact Julie at 617-632-3916 or JLonardo@partners.org.

Young Women’s Telephone Support Group
Liz Farrell, LICSW
For young women looking to connect with others who understand the impact of living with and beyond breast cancer. Next session begins in May 2013. For more information or to register, please contact Julie at 617-632-3916 or JLonardo@partners.org.

Facing Forward
Julie Salinger, LICSW
For patients that will complete treatment for breast cancer in 4-6 weeks or those that have completed treatment within the last 3-4 months. Sessions offered year-round. For more information, call Julie S. at 617-632-8081.

Living Proof: Celebrating Survivorship
June 17-20, 2013
This annual week-long event honors the challenge and journey of cancer survivorship. For more information visit www.dana-farber.org/living-proof.

Annual Young Women’s Forum
Friday, October 18th, 2013
Details and formal invitations to follow. For more information contact Julie at 617-632-3916 or JLonardo@partners.org.

Looking for a way to give back to the Program for Young Women with Breast Cancer and help other young women?

VOLUNTEER!

The One-to-One support network matches individuals who are facing a new diagnosis with someone who has been there. We are hoping to expand on this program to create a specialized support system for young women with breast cancer. If you are interested in volunteering, contact Julie at 617-632-3916 or JLonardo@partners.org for more information.