

A Program Just for You

Established in 2005, Young and Strong, the Program for Young Adults with Breast Cancer at Dana-Farber Brigham Cancer Center, provides comprehensive care and support to young adults confronting the challenges of living with and beyond breast cancer.

The program, part of the Susan F. Smith Center for Women's Cancers, provides expert medical care as well as social, emotional, and educational support focused on the unique issues young adults and their loved ones face throughout the cancer care journey.

To date, we've helped support more than 7,800 young adults through our program.

For more information, please email us at youngandstrong@partners.org, or visit www.danafarber.org/YoungAndStrong.

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It's POSITIVE:

The News About Pregnancy After Breast Cancer

A cancer diagnosis is life-altering for most people, but young adults with breast cancer often face other unique challenges, including the desire to have a future biological child. In fact, approximately 50% of young breast cancer patients report fertility concerns. Shared decision making between a patient and doctor should, therefore, balance fertility preservation with undergoing the best cancer therapy possible to reduce the risks of breast cancer.

For those with early-stage, hormone-receptor-positive breast cancer, the timing of pregnancy after treatment can be particularly tricky. For many years, patients and doctors have been

concerned about pregnancy-related hormones leading to breast cancer recurrence. Studies have shown that this is not the case.

However, endocrine (hormone) therapies – such as tamoxifen, aromatase inhibitors, and ovarian suppression medications – which are often prescribed for 5-10 years after treatment to prevent recurrence, can make pregnancy impossible or dangerous. Delaying childbearing for 5-10 years to complete endocrine therapy can make it more difficult to conceive because fertility naturally decreases over time.

For this reason, researchers at Dana-Farber Brigham and other institutions studied the safety of temporarily interrupting endocrine

therapy to attempt pregnancy. The POSITIVE (Pregnancy Outcome and Safety of Interrupting Therapy for Women With Endocrine-Responsive Breast Cancer) trial is the first **prospective study** to monitor this. Ann Partridge, MD, MPH, director of Young and Strong, co-led this global study, which was sponsored by the International Breast Cancer Study Group (IBCSG).

From December 2014 to December 2019, more than 500 premenopausal women age 42 or younger who desired to become pregnant enrolled in the POSITIVE trial. The participants had previously completed between 18 and 30 months of endocrine therapy and opted to pause endocrine therapy for approximately two years to try to become pregnant. After years of data collection and analysis, we are excited to finally share the study's preliminary pregnancy and safety outcomes.

The study showed that many women were able to conceive and deliver healthy babies. Of those who attempted to become pregnant:

- 74% had at least one pregnancy
- 70% of those who became pregnant did so within 2 years
- 86% of pregnancies resulted in live births*
- 2% of babies had birth defects**
- 8.9% of study participants had a breast cancer recurrence***

*equal to or higher rate than general population

**not clearly associated with exposure to treatment

***compared to 9.9% among patients who did not pause endocrine therapy

Prospective study:

A study where researchers follow and observe a group of subjects over a period of time to gather information and record outcomes.



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Fortunately, early results have demonstrated that a temporary interruption of endocrine therapy to attempt pregnancy is safe from a disease recurrence perspective. However, it is important to note that further follow-up data is needed to confirm long-term safety. It is also strongly recommended that study participants resume endocrine therapy after pursuing pregnancy, to further decrease recurrence risk.

These preliminary results from the POSITIVE trial demonstrate exciting advances in knowledge for young adults with breast cancer who may hope to have future children. Pursuing pregnancy amidst endocrine therapy is a deeply personal decision and it is encouraging that young adults may be able to optimize breast cancer care and risk reduction while also meeting their family planning goals.

If you are interested in learning more about the possibility of temporarily stopping hormone therapy to attempt pregnancy, speak with your doctor to weigh the benefits and risks for you as an individual before doing so.

Average POSITIVE Participant Profile:

- Median age was **37 years**
- Primarily diagnosed with **stage I or stage II** breast cancer
- 75% had **no prior births**
- More than half had **previously received chemotherapy**
- **Tamoxifen** was the most prescribed endocrine therapy

HER2-Low: High-Priority Update Redefines HER2 Status

While **HER2** status has historically been classified as either positive or negative, many HER2-negative tumors still have a significant amount of the HER2 protein on the tumor cells.

HER2: A protein involved in cell growth and one of the factors that can cause cancer cells to grow more quickly and spread to other parts of the body.

Recently, metastatic breast cancers have been further divided into three categories:

- HER2-positive
- HER2 low positive (or “HER2-low”)
- HER2-negative

HER2-low tumors account for approximately half of all breast cancers. The presence of lower amounts of HER2 protein on tumor cells provided the rationale to test a new type of HER2-targeted antibody-drug conjugate (ADC) called trastuzumab deruxtecan (T-DXd, brand name Enhertu). ADCs are designed to selectively deliver chemotherapy to cancer cells by binding to specific proteins on the cancer cell surface. Trastuzumab deruxtecan has already shown unprecedented activity in patients with HER2-positive breast cancer ([read more about this update in our previous newsletter](#)). When it was initially tested in a small trial of 54 patients with HER2-low metastatic breast cancer, T-DXd demonstrated encouraging activity.

The randomized phase 3 DESTINY-Breast04 trial enrolled patients with HER2-low metastatic breast cancer who had experienced progression on prior endocrine (hormone) treatment and chemotherapy. **T-DXd treatment tripled tumor shrinkage from 16% to 50% and doubled the time without progression from 5 to 10 months.** These impressive results were observed in all subgroups of patients, including patients grouped by age and by estrogen receptor (ER) status. Importantly, patients who received trastuzumab deruxtecan also had **better quality of life**

compared to those who received standard chemotherapy. Based on these data, trastuzumab deruxtecan was granted approval for the treatment of HER2-low breast cancer in August 2022. It is now an available treatment option for not just the 20% of patients with HER2-positive tumors, but also the additional 50% of patients with HER2-low tumors, which includes both patients with hormone-receptor positive and patients with triple-negative tumors.

Many questions remain, particularly regarding the expansion of T-DXd treatment to benefit a larger population of patients. About 30% of patients have HER2-negative tumors and do not currently qualify for treatment with trastuzumab deruxtecan. Could these patients still benefit? Earlier studies have shown that a substantial proportion of patients with HER2-negative metastatic breast cancer still benefit from T-DXd. We hope to receive a clearer answer to this question from the phase 3 DESTINY-Breast06 trial, which is ongoing and includes certain HER2-negative patients, as well as those who have not received prior chemotherapy. Results from this study are expected soon.

The most significant expansion of the benefit of trastuzumab deruxtecan could potentially occur for those with early-stage breast cancer. Currently, many patients with early-stage breast cancer are treated with chemotherapies to reduce the risk of recurrence. Studies are currently ongoing to evaluate whether a targeted delivery of chemotherapy with drugs like trastuzumab deruxtecan may result in better outcomes compared to traditional chemotherapies. The hope is that by refining the way we use T-DXd in patients with tumors traditionally categorized as HER2-negative, we will increase cure rates for this population.

“Start Low, Go Slow”:

Exercise During and After Breast Cancer

When a person receives a breast cancer diagnosis and undergoes treatment, it's common to feel a lack of control over one's own body. From surgery and chemotherapy to radiation and hormone therapy, a person's body undergoes significant changes. Many young adults choose to take back control by focusing on adopting a healthy lifestyle, which often includes exercise. The benefits of exercise are extensive. It can improve heart and bone health, reduce stress, improve sleep, and increase one's endurance and energy to fully participate in normal day-to-day activities, such as completing work demands and/or running after young children. Studies also show that exercise may lower the risk of cancer recurrence.

Because young adults with breast cancer are often unsure about what to do or where to start in terms of exercising, we asked **Exercise Physiologist Nancy Campbell, MS**, to compile some recommendations and strategies. Nancy is a certified exercise trainer who works with patients and survivors through Dana-Farber's Leonard P. Zakim Center for Integrative Therapies and Healthy Living.

SHIFT YOUR MINDSET

When many young adults learn that 150-180 minutes of exercise is recommended per week, it can feel quite daunting, especially for those who do not have an exercise routine in place. At first, many patients claim that they “do nothing” or feel that achieving the “recommended” amount of exercise is impossible. It is therefore important to shift your mindset in two ways:

1. Recognize that all actions add up.

The two main categories of exercise are cardio and strength training. Examples include running, biking, hiking, swimming, dancing, and lifting weights. However, this does not mean that you need to do any of these activities for long periods of time, multiple days a week, for it to count as exercise.

What many people often forget is that walking is usually the most attainable form of exercise – no equipment is needed and walking duration can be gradually increased over time.

Walking as part of your work commute, cleaning your house, caring for pets, or being physically active while playing with children all count. And every little bit helps. Movement that

is already incorporated into your daily life quickly adds up, so you may already be exercising more than you think. By breaking physical activity up into smaller portions, you can get to where you need to be.



2. Let go of rigid time restrictions.

There is no exact formula for how much exercise is needed to be “healthy.” What matters most is that you are simply moving your body in any way that you can. This begins by meeting yourself where you already are. Someone who regularly walks 7 days a week will have different exercise recommendations than someone who is mostly sedentary or has recently undergone surgery. So worry less about how much time you spend doing physical activity and focus more on doing something that you enjoy. If you hate running, don't feel like you have to run. Instead, choose physical activities that you find at least a little bit enjoyable, so that you are more likely to continue them and possibly increase their duration over time. Some movement is better than none at all. By letting go of a time-focused exercise mindset, you are supporting yourself in doing what is right for you.



DON'T SWEAT THE DETAILS

At the beginning or even during a fitness journey, many young adults like to have concrete indicators that they are meeting their exercise goals. Activity trackers are becoming increasingly popular as a way to measure heart rate, steps, and calories burned. However,

exercise physiologists caution that these metrics are not the only indicators of a

worthwhile workout.

It is important to remember that many factors associated with good workouts, such as heart rate



and sweating, are highly individualized. For example, many things can impact your heart rate, including your baseline fitness level, medications, and medical history. **Experts recommend that you focus on the way that you feel during exercise.** There is a false

narrative out there that exercise always needs to be hard work, but exercise physiologists don't recommend becoming completely breathless during a workout, for example. Long story short, the goal is to spend more time being active and less time on the couch or in front of a screen.

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TIPS TO INITIATE AND SUSTAIN A LIFESTYLE CHANGE

Change is not easy – but there are some ways to incorporate exercise into your daily life that make forming and keeping new habits less difficult. Here are our top four strategies.

1 Consistency is key.

Focus less on the intensity or duration of a workout and more on your ability to move your body in some way every day. It is better to walk for 10 minutes each day than to do one hard workout and then not exercise again for a month. Breast cancer treatment and its side effects may make it difficult to exercise some days, so committing to small movements is ideal.



2 Start low, go slow.

Doing too much too soon is a main reason why individuals hurt themselves while exercising. Instead, ease into physical activity. If you are not used to running, don't begin by running a mile on day one. Instead, walk or jog for a few minutes at a time. The same theory applies to strength training. Don't just pick up a 20-pound weight if your body has not been trained to lift weights. It is better to increase weight gradually when beginning your exercise journey. For example, start by lifting 1-pound weights, then increase to 3 pounds, then 5 pounds over time. This allows your muscles to adapt and grow stronger over time.



3 Focus on actions, not outcomes.

Goal setting is an important aspect to initiating and sustaining a lifestyle change. However, it is essential that goals are appropriate and achievable. They shouldn't be so easy that you can accomplish them in a few days, but they should not be so hard that you would not be able to accomplish them for a year. Instead, break down your goals into smaller, specific steps. Goals should also be action-based.

A common downfall is for people to say that their goal is weight focused, such as losing 15 pounds. This is an outcome-oriented goal and does not consider all of the steps and milestones needed in order to get there. It is better to set an action-oriented goal, like walking for 30 minutes, 3 days a week.



4 Treat exercise like a doctor's appointment.

Make time to move your body by adding it to your daily calendar. If another task ends up conflicting, reschedule the exercise time instead of simply skipping it. If you were no longer able to attend an appointment with your doctor, you would not just wait until the next one weeks or months later. Treat exercise the same way – schedule and prioritize it.



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MODIFICATIONS

“Be kind to yourself” is the golden rule when it comes to making modifications to your exercise plan. It is important to acknowledge that your body has undergone a lot since your breast cancer diagnosis. What you are able to do physically today is not necessarily representative of what your body could do last year or even a few years ago. This does not mean that you won’t be able to return to your fittest self. It just means that you should gradually modify your exercise plan over time to get to where you want to be.

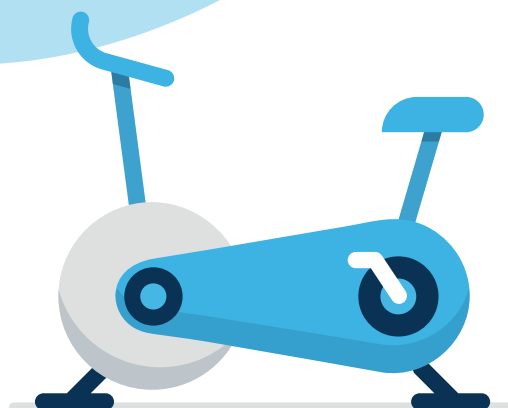
Young adults often follow workout plans that they find online which frequently include movements like burpees, crunches, sit ups, and sprints. When following workout plans or

participating in a general exercise class, you

should listen to your body. It will tell you when something you are doing is not a good idea. For example, if you are attempting three sets of 10 burpees and your body is telling you to stop after two

sets, there is no reason to push yourself to complete the last set. Or, for those experiencing joint issues or who have bone density conditions such as osteopenia or osteoporosis, high-impact exercises may not be best for you. Burpees, running, jumping rope, and box jumps are examples of high-impact exercises where you are working against gravity. Switching burpees with a lower-impact cardio exercise, such as biking or swimming, or a strength-training exercise would be better for your joints.

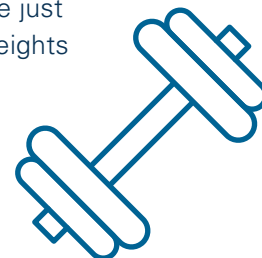
Overall, it is better to make small modifications to your exercise plan to ensure that you are able to *consistently* move your body rather than to overdo it and have a setback. When you are done with your workout, it is better to feel like you could have done a little bit more than be so exhausted that you need a nap or are sore for days, especially in the first year after breast cancer treatment. By adapting your workout as needed, you will be more likely to stick with it and see improvement over the long term.



MUSCLE, MUSCLE, MUSCLE!

Chemotherapy and early menopause induced by cancer treatment can cause breast cancer patients to lose muscle mass. Therefore, one focus of exercising should be to regain some of that muscle back and to keep your muscles and bones as strong as possible. Strength training is the best way to accomplish this.

There is a common misconception that lifting weights can lead to lymphedema (swelling). However, with the right approach – starting slow and building strength gradually – the risk of developing lymphedema is very low. If you haven’t lifted weights in a long time or if you have just had surgery, immediately lifting heavy weights could increase your lymphedema risk. It is essential to instead re-train your muscles to this type of movement by gradually increasing weight over time. **Remember to start low and go slow!**



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CONNECTING WITH AN EXERCISE PHYSIOLOGIST

There is no one-size-fits-all approach to exercise. For those seeking specific and individualized guidance, consider consulting with an exercise physiologist. At Dana-Farber and other cancer care centers, utilizing in-house specialists can be beneficial. Not only will the exercise physiologist have access to your medical records and therefore make accurate recommendations based on your health history, but they will also be more knowledgeable about the various types of breast cancer treatment than a personal trainer outside of a health care facility. For example, they understand what different surgery and reconstructive procedures entail, and stay up-to-date with related cancer research. Exercise physiologists also tailor any exercise plans to your personal fitness and health goals.

Dana-Farber patients can schedule a no-cost virtual exercise consult with an exercise physiologist who can answer your fitness-related questions and provide personalized exercise tips. To schedule an appointment, call the Zakim Center at 617-632-3322 or email Zakim_Center@dfci.harvard.edu. We encourage patients who do not receive ongoing care at Dana-Farber to talk with their local care team about similar offerings.

If you look for an exercise professional in your community, be sure to first learn about their background, experience, and expertise. The American College of Sports Medicine's Cancer Exercise Trainer certification is considered the gold standard for those in the field, but many trainers do not have this certification. Take time to make sure that the exercise professional is a good fit for you and your needs by asking a few questions.

Suggested questions to ask a potential trainer:

- Have you had any specific training in exercise after cancer?
- Have you worked with other breast cancer patients before?
- How often and how much do you personalize their exercise plans?
- How many years of experience do you have?
- Do you have experience working with someone with bone loss and/or other orthopedic issues?
- Do you have experience working with someone who has undergone breast surgery and/or reconstruction?
- Do you have experience working with someone who is undergoing long-term hormonal therapy?

FINDING COMMUNITY IN EXERCISE

Many people find motivation to exercise by doing it surrounded by other people. One avenue to explore is asking your friends and family for help. These are the same people who may have asked what they could do to help you through your breast cancer treatment. Ask them to schedule time to take a walk with you. This can be a good time not just to socialize with your friend or loved one, but also improve your physical and mental health.

If you want more structured opportunities, consider the Zakim Center's **Zoom-based fitness classes**. They can be a great way to interact with other patients, while also connecting with trained professionals. Class recordings are also available. Offerings include:



- | | |
|--------------------------------|---------------------|
| • Aerobics and Cardio Workouts | • Qigong |
| • Chair Stretch and Strength | • Strength Training |
| • Chair Yoga Flow | • Tai Chi |
| • Core Strength | • Yoga Flow |
| • Dance and Movement | • Yogalates |

Please visit [MyZakim](#) to learn more.

We also suggest exploring other options in your community. Some local YMCAs offer the **Livestrong Program** for cancer patients. If you live in Massachusetts, consider **Wellness Warriors**, which invites cancer survivors of all skill levels to participate in dragon boat teams.

You can also [learn more about exercise](#) on our Young and Strong website.

Community and Support

Young and Strong offers many opportunities to connect with other young adults living with or beyond breast cancer. For more information about any of these supports, please email youngandstrong@partners.org

VIRTUAL SUPPORT GROUP

Megan DelSesto, MSW, LICSW

This six-week group, held twice yearly and facilitated by a breast oncology social worker, gives Young and Strong patients and survivors an opportunity to discuss topics relevant to young adults with breast cancer. This group is best suited to those diagnosed with stage 0-IIIc breast cancer before age 45 and who are within 12 months of the diagnosis.

FACING FORWARD

Jessica Mosey, MSW, LICSW

This six-session educational series is held twice yearly for patients of all ages who have recently completed early-stage (0-IIIc) breast cancer treatment. Each session focuses on a survivorship topic such as physical recovery, psychosocial counseling, sexuality and intimacy, nutrition and exercise, and mindfulness.

VIRTUAL LUNCHTIME SOCIALS

Offered every other month, these social events provide an opportunity for Young and Strong patients and survivors to discuss what's on their mind and engage with peers. There are two sections:

- 1: Patients who are newly diagnosed or undergoing active treatment for stage 0 to stage IIIc breast cancer
- 2: Patients who have completed active treatment for stage 0 to stage IIIc breast cancer within the last five years

EMBRACING YOUNG AND STRONG

This community is specifically designed for young adults with stage IV, metastatic breast cancer. Virtual social events are held twice monthly for young adults with MBC to meet and connect with each other.



Join Team Young and Strong for The Jimmy Fund Walk on October 1, 2023

The Jimmy Fund Walk is a great opportunity to engage with the Young and Strong community and raise money to support the Program. We'll be back on the iconic Boston Marathon route, walking to defy cancer at Dana-Farber Cancer Institute and around the world. Join us on the course or walk "your way" virtually. Donations are also greatly appreciated.

Please visit [our team page](#) to sign up.

ADDITIONAL RESOURCES AND INFORMATION



Susan G. Komen
www.komen.org

Susan G. Komen is the only organization that addresses breast cancer on multiple fronts such as research, community health, global outreach, and public policy initiatives in order to make the biggest impact against this disease.



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 adults 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 people in their recovery or management of the disease.



LIVESTRONG Fertility
<https://rb.gy/hwawut>

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.



Ellie Fund
www.elliefund.org

The **Ellie Fund** is a nonprofit organization that provides non-medical services to patients with breast cancer who live or receive treatment in Massachusetts. Support services include transportation to medical appointments, childcare, housekeeping, grocery assistance, and meal delivery.



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.