



Newly Diagnosed Navigator

A GUIDE FOR YOUNG ADULTS FACING BREAST CANCER

Acknowledgements

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Introduction

A breast cancer diagnosis, especially at a young age, can bring tremendous challenges and urgent questions. You may feel like you are the only young adult who has ever been diagnosed with breast cancer.

Young Survival Coalition (YSC) created the Newly Diagnosed Navigator to educate and empower newly diagnosed young adults. We want to help you fight the feelings of fear and isolation that can accompany a diagnosis — so that you feel connected, supported and hopeful.

While a diagnosis at any age is life altering, young adults affected by breast cancer have unique issues. Inside this Navigator, you'll find an easy-to-understand breast cancer glossary, questions to ask healthcare teams, information on family planning, a way to track your medical information and helpful tips from young adults who've been down this road.

Take time to look over all the items in this Navigator. When you start to collect cards or notes or any items throughout your treatment, you can store them here, too. If ever you have any questions, comments or want to get involved, contact us at support@youngsurvival.org or call 877.YSC.1011.

Disclaimer

YSC has provided this Navigator for educational, informational and community purposes only as a resource to young adults and other people whose lives are affected by breast cancer. For answers to specific questions or concerns, you should consult your healthcare provider, as treatment for each patient varies with individual circumstances.

The content is not intended in any way to be a substitute for professional counseling or medical advice. You should not rely upon information found in this publication without seeking the advice of a qualified healthcare provider. YSC does not endorse, recommend, or make any warranties or representations regarding any of the materials, products or information provided by organizations referred to in this resource.

Always seek the advice of your physician or other qualified health service provider with any questions you may have regarding a medical condition or treatment. Never delay or disregard medical advice based on information you have read in this resource.

DID YOU KNOW

there are an estimated 250,000 breast cancer survivors living in the U.S. who were diagnosed at age 40 or younger?

YOU ARE NOT ALONE.

Get To Know YSC

In 1998, a group of young adults, all diagnosed with breast cancer before age 40, gathered in New York City and had the first YSC meeting. They had all personally experienced that young adults were missing from the research, community and conversations about breast cancer. More than twenty years later, these needs still define YSC's work.

Unlike their older counterparts - who are overwhelmingly integrated into the design of clinical trials - young adults diagnosed with breast cancer face higher mortality rates, fertility issues and the possibility and ramifications of early menopause.

From our grassroots beginning, YSC has grown into an international movement. Today, YSC has more than 170 Face 2 Face local networking groups, a vibrant online community, and the largest conference program dedicated exclusively to young adults with breast cancer and their caregivers. YSC also produces free educational resources, such as our navigator series, which are comprehensive guidebooks that address every phase of treatment and survivorship.

Visit youngsurvival.org to learn more or order these and other YSC materials.



YSC programs connect, educate and support young adults affected by breast cancer.



Connect To Others

Find young adults who know what it's like to face breast cancer at a young age. There are three easy ways to connect: youngsurvival.org/connect

YSC Virtual Hangouts

YSC Virtual Hangouts allow you to connect with others from the comfort of your own home. Grow relationships with your peers who may share similar diagnoses, life experiences or treatment types.

1:1 Peer Matching

Get matched with another young survivor or thriver who may share a similar diagnosis, treatment or circumstance.

Private Facebook Groups

YSC's Private Facebook Groups offer young adults affected by breast cancer a safe space to build community with those who understand. You can talk to peers, ask questions, share information and build lasting relationships.



Tools You Can Use

YSC offers free resources unique to young adults affected by breast cancer and those who care about them.

Knowledge is Power. Visit youngsurvival.org.

It's the most comprehensive resource for and about young adults with breast cancer. Find information on medical research and updates on clinical trials. Read survivor stories. Download fact sheets, learn about upcoming educational offerings and access videos on hundreds of past topics.

ResourceLink

Includes hundreds of national and local resources in a searchable online database at: youngsurvival.org/directory. Also, you can call 877.972.1011 or e-mail support@youngsurvival.org for assistance.

Summit 360

Whether you're newly diagnosed, living with metastatic disease or several years out YSC has in-person and virtual events just for you. Workshops address the unique issues faced by young adults with breast cancer and their co-survivors. You'll also have the opportunity to connect with a community of other young survivors and co-survivors. Find out more at youngsurvival.org/events. There are even ways to financially support your travel by applying for travel scholarships and fee waivers.

YSC Wellness Weekend Connect and Give Back

If you're looking to connect with other young adults affected by breast cancer, while also taking your body back, join us at the life changing YSC Wellness Summit. Challenge yourself, support YSC and meet others in this incredible community. Learn more at wellness.youngsurvival.org.

What is Breast Cancer?

If you are like most young survivors, the thought of breast cancer never entered your head until you noticed that lump or saw your breast change. Maybe you did not even think about it until after that abnormal test result. So here you are, with breast cancer. How did you get it and why? Unfortunately, we don't know the answers to those questions. No one knows what causes breast cancer. But we do know that you didn't cause it.

Every day, researchers are gaining a better understanding of breast cancer. It is not just one disease. So when someone offers a story about her friend or aunt or grandmother, it does not necessarily apply to you. The term breast cancer applies to a group of diseases that are similar because they involve breast tissue.

Breast cancer starts when normal cells change, grow and reproduce more than they should. The first word you may hear is carcinoma—that is a type of cancer. There are several types of breast cancer. The biggest difference is based on where the tumor started.

DUCTAL BREAST CANCER starts in your breast ducts, the parts of the breast where milk travels.

LOBULAR CANCER begins in the lobes of the breast – the site of milk production.

PAGET'S DISEASE starts in the nipple.

The next category is based on whether the cancer has spread outside its original location.

IN SITU CANCER has not moved beyond the duct or lobe in which it started. You may see it abbreviated as DCIS (ductal carcinoma in situ) and LCIS (lobular carcinoma in situ).

INVASIVE OR INFILTRATING CANCER has begun to grow into nearby tissue. Invasive ductal carcinoma and invasive lobular carcinoma may be abbreviated as IDC and ILC, respectively.

One other type of breast cancer, **INFLAMMATORY**, involves the skin of the breast. Often this type has no lump at all. You may see inflammatory breast cancer abbreviated as IBC.

For information on other, less common forms of breast cancer, please visit the glossary.

After some time, cancer cells can make their way from the breast tissue into other parts of the body. The most common place where breast cancer moves is to the underarm lymph nodes, also called the axillary lymph nodes. These small organs are your body's filtration system. Once in the lymph nodes, cancer cells can move to other parts of the body.

If any of the terms your doctor uses are unclear, be sure to ask questions! A glossary of breast cancer terms is also included in this Navigator.

TIP

Have more questions? Connect with other newly diagnosed young adults at youngsurvival.org/connect

I have Breast Cancer. Now What?

Young adults can and do get breast cancer. So what do you do when you have been diagnosed? How do you navigate the many choices and decisions you have to make? How do you get the best care and the most support? The following suggestions can help you gain control over your own medical care and take an active part in your health.

Understand Your Diagnosis

Breast cancer is not one disease. There are many different factors that can affect your treatment and decisions. Just because a friend of a friend or your aunt had a certain experience, it doesn't mean yours will be the same. Know that it is completely normal to have a head full of questions.

Before you see any practitioner, make a list of any questions you would like answered. Do not leave until your questions have been asked and answered. Remember to ask your doctor for your pathology reports; you will have one from both your biopsy and your surgery. Ask your healthcare team to explain the terms and information on the page. For more information, there is a section on the pathology report in this Navigator.

Know Your Options

Just as there is no one breast cancer, there is no one "right" way to treat it. Feel free to explore all options available to you. Some typical choices involve surgery, chemotherapy, radiation, targeted therapies, and hormonal treatments. Insist that your doctor explain why one treatment is being recommended over another. If you are concerned about your fertility and family planning after your diagnosis, talk to your doctor before treatment if possible and make an appointment with a fertility specialist to discuss ways to preserve your family plans. Speak to your doctor about your family history. Together you may decide to consult with a genetic counselor to assess your risk of hereditary (familial) breast cancer. The results of either of these consults may help determine your treatment choices.

Where Should I Go for My Medical Care?

YSC recommends that all young adults seek treatment at a comprehensive cancer center or large teaching hospital. These centers are most likely to treat many young adults and understand the concerns unique to this population, including fertility.

Advocate for Yourself

In most cases, you have plenty of time to make decisions. Do not let a medical provider rush you into something you are not comfortable with. You have time to ask for a second opinion, gain understanding, research your options or explore other doctors. It is your body; take charge of your health.

Second Opinions

Do not be afraid to get a second opinion on any aspect of your medical care. It is important that you feel comfortable with the surgery and/or treatment you receive. Sometimes, seeking a second opinion to confirm your doctor's recommendations or to provide other options is useful and can make you more comfortable with your decisions. Your doctor should support you getting a second opinion.

Keep Track of Everything

You have the right to your medical records. Ask for copies of everything—from laboratory and radiological scan reports to surgical notes. Use the worksheets in this Navigator to help you organize your medical information. If you need more space, a binder or folders can be helpful. Saving electronic medical records and scanning paper ones can also preserve a digital copy. This is also a great project for someone who would like to help you. This Navigator includes places to keep track of contact numbers, appointments, questions, test and pathology reports and medical bills. The first few appointments will be hard to understand, not to mention remember. Consider bringing someone with you to take notes and/or a recording device like your phone to document what happens at each visit.

You Are Not Alone

Looking for other young adults who have been down this road? Want to ask questions, read stories of other young adults diagnosed with breast cancer and get support? There is no better place than YSC. You do not have to know all the answers right away. You do not have to go through this by yourself. Give yourself time to explore your options, ask questions and connect with other young adults. It can make all the difference in the world.



How to Use This Navigator

Staying organized during this scary time in your life may not be easy. But the more organized you are, the less overwhelming things will seem. As you learn about your diagnosis, meet your healthcare team and discuss treatment options, you will find it helps to have all your notes, records and information in one place.

One of the toughest parts of your breast cancer experience can be the waiting and not knowing about your cancer type, your treatment plan, and the right questions to ask. It can be very frightening. YSC is always here to help.

This Navigator has information to help you ask the right questions during your journey. It also has valuable tools and checklists to help you keep track of your information and stay organized. Take the Navigator with you to appointments, especially at first. Use the space provided to include your test results, doctors' notes and insurance information.

Some Tips:

ASK QUESTIONS!

The more you understand, the easier your decisions will be. Get to know and use the time of your healthcare providers: doctors, nurses, nurse navigators and social workers. You are a team working together to treat your breast cancer. Do not leave the room until all your questions have been answered. Remember, especially at the beginning, to try to have another person with you at your appointments. This person can keep track of the questions, make notes and be an extra set of ears.

GET COPIES OF EVERYTHING!

This Navigator is the perfect place to store copies of your medical records. Some key information to ask for:

- **PATHOLOGY REPORT**
- **BIOPSY REPORT**
- **SCAN REPORTS**
- **DOCTORS' NOTES**

ASK SOMEONE TO HELP!

Family and friends often want to help, yet are not sure what they can do. Keeping track of your records can be a two-person job. If you have someone in your life looking for a way to help, now is a good time to ask for it.

WRITE IT DOWN!

You will come up with questions and concerns at all times of the day and night for a while. Keep a small notebook or this Navigator with you—at home, work, even next to the bed at night. That way, when a question hits you at 3 a.m., you can write it down and remember it later.

TIP

Want to talk to someone who's been there?

Visit youngsurvival.org/connect.

Why Keep Your Records

Keeping track of your personal medical history is a key part of managing your health. Some of the most crucial items are your pathology report and any diagnostic test reports you may have received. Remember to ask for them. Did you know that after every appointment, your doctor makes notes regarding the visit and the recommended next steps? These are also part of your medical file and you have a right to them, too.

If Your Doctor Has Your Medical Record, Why Do You Need to Keep a Copy Yourself?

- Your reports, results and notes help you see and understand the full picture of your diagnosis and care. They also help you to know what questions to ask. You can read them at home and take time to understand and prepare for your next doctor's appointment.
- Each doctor or facility that sees you has a separate medical file. Keeping one yourself combines them into a single, more complete record.
- As your treatment progresses, it becomes increasingly hard to remember when and what procedures, treatments or tests may have been performed. With your own set of records, you don't have to try to remember every detail.
- Keeping your own copy of your medical records makes it easier if you seek a second opinion or go to a new doctor or hospital for treatment. With this information in hand, you can get your new provider your medical information without having to wait for your records to be sent.
- When it comes to filing and managing health insurance, keeping your own records can make all the difference.
- Come tax time, your personal medical file can help identify all the expenses and claim the most deductions possible.

TIP

Take someone with you to all your appointments. There is a lot of information and a lot of decisions to make, and you might be in the "I have cancer?!!" fog. Have that person take notes that you can refer to later.



So What Should You Ask For & Keep?

- Contact information for doctors, nurses or any healthcare provider
- Your personal health history, including previous surgeries, medication allergies, hospitalizations and other health problems
- Your family medical history, especially history of cancer
- Reports from your diagnosis – any diagnostic tests or biopsies
- Copies of pathology and laboratory reports
- Dates of diagnosis and treatments

- Office and doctors' notes from each visit
- Any information on clinical trials in which you enroll
- Treatment information, including drug names and prescribed dosages
- Documented side effects or reactions from treatment
- A schedule for and results of follow-up tests
- Once treatment is complete, a treatment summary and survivorship care plan

How Do I Get My Records?

- When you see your doctor, ask for a copy of anything newly added to your file.
- After any test or procedure, ask that you receive a copy of the report.
- If you are ever hospitalized, ask for a copy of your medical record before you leave.
- Keep copies of medical bills and insurance claims.

If you wait too long before asking for copies, it may be challenging to obtain the information. Ask for copies as you go along; it will make the process much easier. Use this Navigator to keep track of everything. It will be much easier to find important information if it is all in one place.

Once you start collecting your records, you will see how much easier it is to be in control of your own care. Hopefully, this information will empower you to make the healthcare choices that are best for you.

Online Medical Records

It is becoming increasingly common for medical practices and hospitals to store their medical records, test reports, and doctors' notes online instead of on paper. This should make it easier for you to obtain the records you need, and you may be able to download and save them onto your computer. If your doctor or medical facility uses online medical records, be sure to ask for information on how you can access them.

Checklist for Your Appointments

- This Navigator
- Questions for your doctor
- A list of current prescriptions
- Pen
- Someone else to take notes

Your Background

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Your Personal Profile

NAME					
ADDRESS					
CITY		STATE		ZIP	
PHONE		CELL			
EMAIL					

EMERGENCY CONTACT 1					
ADDRESS					
CITY		STATE		ZIP	
PHONE		CELL			
EMAIL					

EMERGENCY CONTACT 2					
ADDRESS					
CITY		STATE		ZIP	
PHONE		CELL			
EMAIL					

Insurance Information and Contacts

INSURANCE COMPANY	
GROUP NAME/NUMBER	
POLICY OR ID NUMBER	
SUBSCRIBER NAME	
SUBSCRIBER DATE OF BIRTH	
SUBSCRIBER EMPLOYER NAME	
CLAIMS PHONE NUMBER	
PHONE/FAX	
ADDRESS	
CASE MANAGER	

SECONDARY INSURANCE COMPANY	
GROUP NAME/NUMBER	
POLICY OR ID NUMBER	
SUBSCRIBER NAME	
SUBSCRIBER DATE OF BIRTH	
SUBSCRIBER EMPLOYER NAME	
CLAIMS LINE	
PHONE/FAX	
ADDRESS	
CASE MANAGER	

Things to Know About Insurance

In order to get the most out of your insurance coverage, you need to understand what services or procedures are covered and the policies you need to follow. You can do this a few ways: visit your insurance provider's website, read your policy or call your health plan's member services department and ask the following questions:

- What is the process and cost for using an out of network doctor?
- Are my intended doctors a part of my insurance plan?
- Do I need pre-approval for a second opinion?
- Can I go out of network or plan to obtain care, and is it covered?
- Do I need pre-approval for any treatment? If so, when and how do I obtain it?

- What services are covered and to what extent?
- Can I switch doctors?
- Can I choose my own specialists?
- What is my deductible? How is it applied? Is there an out-of-pocket maximum?
- Are there co-pays? If so, for which services?
- Is there a required location for me to go for tests, scans, or bloodwork in order for it to be covered?
- Do I need referrals before I can go to a specialist? And from whom do I obtain those referrals?
- Are prescriptions covered? Is there any way to reduce my costs such as through a mail-in option?
- Are clinical trials covered under my insurance plan?

What if I Don't Have Insurance?

Cancer is scary even with the best insurance. If you are currently without coverage, it adds more and complex challenges, but you do have options:

- Ask your oncology social worker for help. Often s/he can point you in the right direction for state and federal government programs.
- Speak to your hospital financial counselor.
- The National Breast and Cervical Cancer Treatment Act provides money to pay for treatment for certain uninsured young adults. Go to their website (cdc.gov/cancer/nbccedp) and click "Contact the program" under the tab on the left.
- If you are enrolled in a clinical trial through the National Institutes of Health, all care and travel is covered.
- Be sure to check YSC's searchable online ResourceLink directory for more financial and insurance resources.

The Affordable Care Act

On March 23, 2010, President Obama signed a law called the "Affordable Care Act," which required health insurance reforms to be put into place. This law should make it easier for young adults diagnosed with breast cancer to get, and keep, health insurance. Key points:

- You cannot be denied health insurance coverage because of a pre-existing condition, including cancer, or be charged more because of your health status.
- Health insurers cannot cancel your coverage if you become sick or are diagnosed with cancer.
- Every state has a high-risk pool to provide coverage for those uninsured for six months or more and who have cancer or other preexisting conditions.

As healthcare policy evolves, we encourage you to access resources at healthcare.gov and materials from the experts at Triage Cancer (trriagecancer.org) to stay abreast of current policy.

My Healthcare Team

PRIMARY CARE PHYSICIAN		EMAIL	
PHONE		FAX	
ADDRESS			
NURSE		PHYSICIAN'S ASSISTANT (PA)	
OB/GYN		EMAIL	
PHONE		FAX	
ADDRESS			
NURSE		PA	
BREAST SURGEON		EMAIL	
PHONE		FAX	
ADDRESS			
NURSE		PA	
BREAST SURGEON 2		EMAIL	
PHONE		FAX	
ADDRESS			
NURSE		PA	
PLASTIC SURGEON		EMAIL	
PHONE		FAX	
ADDRESS			
NURSE		PA	

PLASTIC SURGEON 2		EMAIL	
PHONE		FAX	
ADDRESS			
NURSE		PA	
MEDICAL ONCOLOGIST		EMAIL	
PHONE		FAX	
ADDRESS			
NURSE		PA	
MEDICAL ONCOLOGIST 2		EMAIL	
PHONE		FAX	
ADDRESS			
NURSE		PA	
RADIATION ONCOLOGIST		EMAIL	
PHONE		FAX	
ADDRESS			
NURSE		PA	
RADIATION ONCOLOGIST 2		EMAIL	
PHONE		FAX	
ADDRESS			
NURSE		PA	
FERTILITY SPECIALIST		EMAIL	
PHONE		FAX	
ADDRESS			
NURSE		PA	

GENETIC COUNSELOR		EMAIL	
PHONE		FAX	
ADDRESS			
NURSE		PA	
DIETICIAN		EMAIL	
PHONE		FAX	
ADDRESS			
NURSE		PA	
COMPLEMENTARY MEDICINE PROVIDER		EMAIL	
PHONE		FAX	
ADDRESS			
NURSE		PA	
PHYSICAL THERAPIST		EMAIL	
PHONE		FAX	
ADDRESS			
ONCOLOGY NURSE		EMAIL	
PHONE		FAX	
ADDRESS			
NURSE NAVIGATOR		EMAIL	
PHONE		FAX	
ADDRESS			

CASE MANAGER		EMAIL	
PHONE		FAX	
ADDRESS			
SOCIAL WORKER		EMAIL	
PHONE		FAX	
ADDRESS			
PSYCHOTHERAPIST/ COUNSELOR		EMAIL	
PHONE		FAX	
ADDRESS			
PATIENT NAVIGATOR		EMAIL	
PHONE		FAX	
ADDRESS			
YSC CONTACT		EMAIL	
PHONE		FAX	
ADDRESS			
OTHER		EMAIL	
PHONE		FAX	
ADDRESS			

My Personal Health History

NAME					
DATE OF BIRTH		HEIGHT		WEIGHT	

CURRENT PRIMARY CARE PHYSICIAN		CONTACT NUMBER/ FAX NUMBER	
--------------------------------	--	-------------------------------	--

CURRENT OB/GYN		CONTACT NUMBER/ FAX NUMBER	
----------------	--	-------------------------------	--

AGE AT FIRST MENSTRUAL PERIOD		NUMBER OF PREGNANCIES	
NUMBER OF LIVE BIRTHS		AGE AT FIRST LIVE BIRTH	
HORMONAL BIRTH CONTROL	Y/N	WHAT TYPE?	HOW LONG?

CURRENT MEDICATIONS	DOSE	ALLERGIES

PAST HOSPITALIZATIONS	DATES

PAST SURGERIES	DATES

PREVIOUS RADIATION	YES / NO
WHERE AND WHEN?	

ANY HISTORY OF THE FOLLOWING (CIRCLE)?	CANCER	DIABETES	HIGH BLOOD PRESSURE	FATIGUE
	FIBROCYSTIC BREASTS	HYPERTENSION	DEPRESSION	BLOOD CLOTS

DO YOU DRINK ALCOHOL?	Y / N	AMOUNT PER WEEK	
DO YOU SMOKE?	Y / N	HOW OFTEN?	
HISTORY OF DRUG USE/ABUSE?	Y / N		

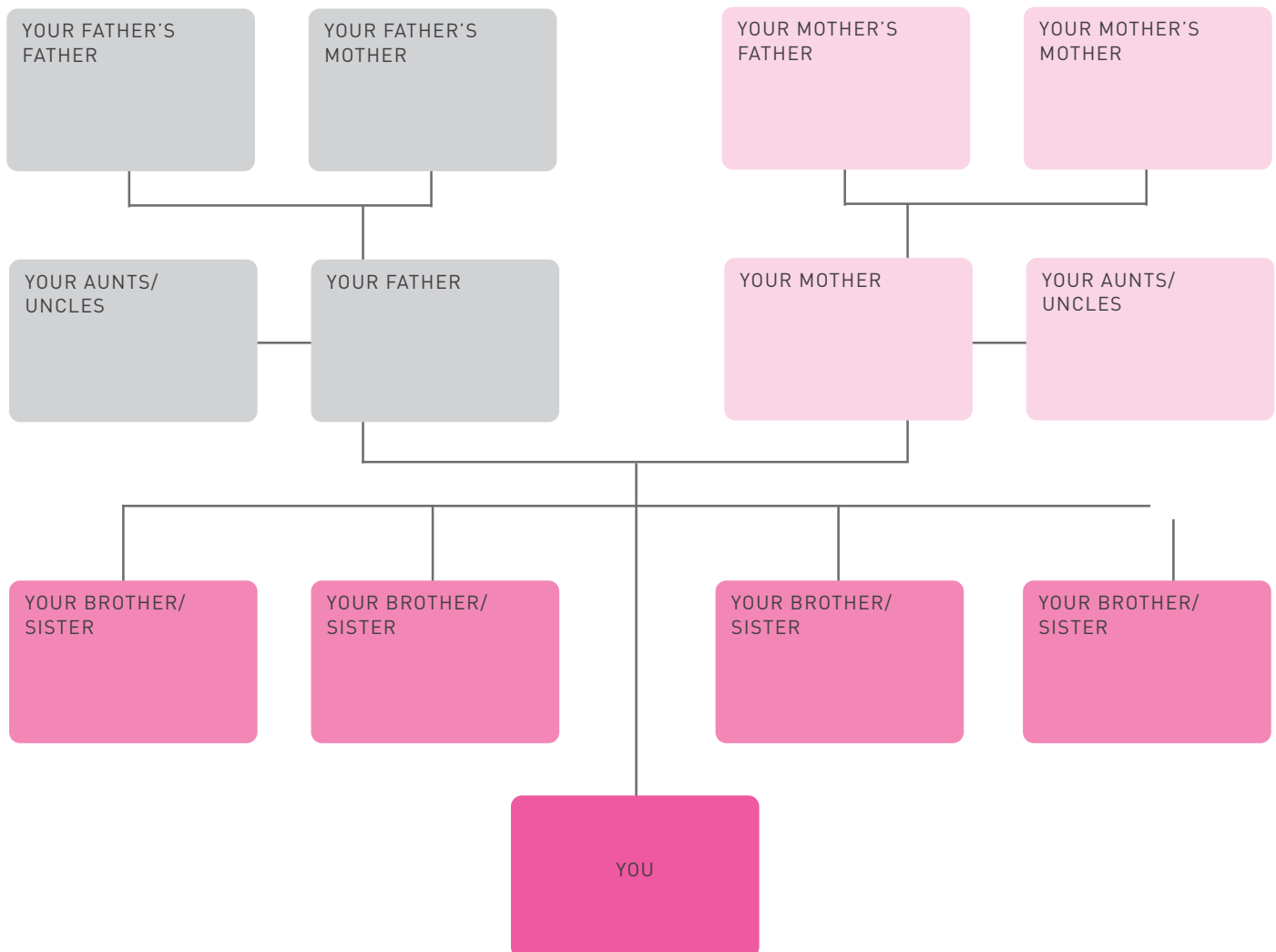
TIP When seeing a new healthcare provider, ask if you can make a copy of these pages to put in your file instead of filling out the same form repeatedly.

Know Your Family History

You may be at greater risk for cancer if you have a personal or family history of cancer or certain other diseases.

To help determine your risk, complete this family medical history chart and share it with your family and your healthcare professional. If you do not know your biological family or do not have access to their medical history, don't worry. Your healthcare team can provide guidance in how to share the information you do have.

- For each blood relation, note in the box any diagnosed cancer (part of body where cancer started) or other chronic diseases the person had and the approximate age at each diagnosis.
- Note any surgeries and the dates of the procedures.
- If you can, note the date of birth and approximate date and cause of death for family members who are deceased.
- This will help you and your healthcare professional better understand which cancer screenings you may need and when to begin screening.



A Complete Family History Includes Information on:

- Parents
- Grandparents
- Great-grandparents
- Great aunts and uncles
- Aunts and uncles
- Siblings
- Cousins
- Nieces and nephews
- Children

When researching your family history, be sure to ask for specifics, if known. Sometimes, family members may not know what type of cancer a relative had, especially if it was a long time ago. Gather any information you can.

What Do You Do with This Information?

Being diagnosed at a young age for any cancer can sometimes be a sign of a possible genetic link. A genetic counselor can give you the most up-to-date information about your genetic history and help you manage your risk or make treatment decisions. It is often a good idea to meet with a genetic counselor soon after diagnosis.

A genetic counselor will:

- Review your family history of cancer
- Describe the risks, benefits and limitations of genetic testing
- Explain the different types of hereditary cancer and explain your possible risk for certain genetic mutations, such as BRCA1 or BRCA2
- Assess whether you are a good candidate for certain genetic tests and whether anyone in your family may need to consider updated testing

MAKE NOTES ABOUT YOUR FAMILY HISTORY HERE:

If you are tested, s/he will:

- Discuss current medical treatment options based on your test results
- Interpret genetic test results and what they mean for you and your family
- Address concerns regarding privacy and discrimination relating to your genetic test results

How Do I Find a Certified Genetic Counselor?

Although there are now at-home genetic testing kits, we do not recommend them in place of meeting with a certified genetic counselor. It is important to see a certified genetic counselor who can discuss whether testing is recommended and explain your results. Many oncologists and cancer centers can direct you to the genetic counselor affiliated with your facility. Additionally, the National Society of Genetic Counselors offers a directory of genetic counselors by state and specialty. Visit nsgc.org for more information. Financial assistance to cover the costs of the testing may also be available. If genetic testing reveals an inherited mutation, FORCE (Facing our Risk of Cancer Empowered) can be a great resource for you: facingourrisk.org.

What Are BRCA1 and BRCA2?

These are two of the most well-known genetic mutations that can predispose a adult to breast cancer. The BRCA 1 and 2 genes are located on chromosomes 17 and 13, respectively, which help to suppress tumor growth under normal circumstances. However, an individual with a BRCA 1 or 2 mutation (altered version of the gene) has a significantly higher risk of developing breast, ovarian and other cancers. Approximately 5-10% of breast cancers are due to BRCA mutations. These mutations can be inherited from either parent.

Are There Others?

With advances in technology, genetic testing can now uncover a wide range of genetic mutations, some of which may increase your risk of breast cancer, such as PALB2, TP53, PTEN, and CHEK2 among others. The problem is that these genetic mutations have not been studied nearly as much and do not increase your risk as significantly as BRCA1 and 2. Little is known about what, if anything, should be done if one of these lesser-studied mutations is present. We recommend relying on the guidance of your genetic counselor in determining what mutations to test for and to understand those results. A more complete listing of mutations and their significance can be found on the website of our partner FORCE: facingourrisk.org/understanding-brca-and-hboc/information/hereditary-cancer/other-genes/.

TIP

NCCN guidelines recommend genetic counseling for anyone diagnosed with breast cancer before age 50.

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Understanding Your Diagnosis

Throughout your treatment, there will be information and terms used that you simply do not understand. IDC, DCIS, HER2, ER Positive... these probably all sound like another language to you. When you are diagnosed with breast cancer, your doctor should be willing to discuss everything, but if you do not understand the lingo, it will be challenging to make good decisions. If you cannot follow the information being presented, ask questions.

After your biopsy, you will have a preliminary pathology report. That, combined with your imaging reports (ultrasound, mammogram or MRI), will determine your preliminary diagnosis. More specific answers, however, are most often available after surgery and will be presented on your pathology report. All of the information presented on your complete pathology report provides specific details on your tumor that will aid in your doctor's recommendations for treatment.

On your pathology report you will see:

THE GROSS DESCRIPTION: This describes what the pathologist sees when looking at the tissue. This may include comments on the color and size of the sample, as well as the part of the breast from which the tissue came.

YOUR PATHOLOGY: This tells you where the cancer began and whether it is contained or has invaded surrounding tissue. Is the cancer ductal or lobular? Is it in situ or invasive? These terms lead to the most common acronyms used in breast cancer. DCIS – ductal carcinoma in situ, IDC – invasive ductal carcinoma, LCIS and ILC, accordingly.

SIZE: How big is the tumor? This is measured in millimeters or centimeters.

LOCATION: Where on your breast the tumor was located.

HISTOLOGIC GRADE: This number is a rating based on how the tumor cells look under a microscope and how fast they are dividing and growing. Tumors are given a grade of 1-3. The higher the number, the faster the cells are dividing. Grade 3s are growing faster than Grade 1s. You may also see the tumor grade described as “differentiation” on your pathology report. A grade 1 tumor may also be called “well differentiated,” because the cancer cells look similar to normal cells. A grade 2 tumor is “moderately differentiated,” and a grade 3 tumor is “poorly differentiated,” because it looks very unlike normal cells.



HORMONE RECEPTOR STATUS:

Hormone receptors are proteins found on some cancer cells that allow a hormone to attach and activate the cell. When a breast cancer is hormone receptor positive, these receptors allow estrogen or progesterone to “feed” the cancer cells. Hormone receptor status is reported as positive or negative and sometimes a percent is also provided (eg, 90% estrogen receptor positive).

PROLIFERATION RATE (CELL DIVISION):

The rate of your cancer’s growth is another measure of how aggressive it may be. Ki-67 is a common way to measure growth. The lower your Ki-67 rate, the slower your cancer divides or grows. This number is reported as a percentage, showing the percent of cancer cells actively dividing. Over 20% is deemed to be a high Ki-67 rate. Do not be alarmed if your pathology report does not contain this information or if your rate is high. There is no conclusive evidence that Ki-67 is associated with survival. For this reason, not all pathology reports will contain this score.

HER2 (OR ERBB2) STATUS:

This is determined by a tumor cell test for a protein called human epidermal growth factor receptor-2 (HER2). If too much of this protein is produced, the tumor is considered HER2 positive. Pathologists test for HER2 status because there are drugs available that target the HER2 receptor. There are two ways to test for HER2 status, which you may see reported. The immunohistochemistry (IHC) test results in a score from 0 to 3. 0 and 1 are a negative result, and 3 is a positive result. A 2 indicates that the result is unclear and further testing may be needed. The FISH (fluorescence in situ hybridization) test gives a positive (HER2 is overexpressed) or negative result.

LYMPHOVASCULAR INVASION:

If your cancer has entered the blood vessels or lymph channels in your breast, the report will say that lymphovascular invasion is present.

SURGICAL MARGINS:

The area around the tumor is checked for any cancer cells. Surgical margin status tells you how close the cancer cells were to the edge of the tissue specimen your surgeon removed. If there are no cancer cells at the edge of the tissue specimen, it is said to be a “clean” or “clear” margin. A “close” margin means that cancer cells were found close to the edge of the tissue. A margin that is close or not clear/clean, may mean that an additional surgery is required.

LYMPH NODES:

This area of the report indicates the number of lymph nodes that were removed, and how many were positive or negative for cancer cells. Because of the sensitivity of today’s testing procedures, the pathologist may also tell you whether any micrometastases, or extremely small pieces of cancer, were found in your lymph nodes.

STAGING

At some point, your doctor may discuss the “staging” of your breast cancer. Staging is a way of classifying the extent of your disease. There are different staging systems. A common one, called the TNM system, assigns a number after each letter to signify the size of the tumor (T), number of lymph nodes involved (N), and whether the cancer has spread or metastasized (M). Once the TNM numbers have been assigned, this information along with the tumor’s ER, PR and HER2 status, as well as its grade is used to determine stage grouping. For more information, please visit <https://www.cancer.org/cancer/breast-cancer/understanding-a-breast-cancer-diagnosis/stages-of-breast-cancer.html>.

STAGE GROUPING:

There are five stages of breast cancer. The higher the number, the more the cancer has spread.

STAGE 0:

Non-invasive or in situ cancer (DCIS, LCIS). In Stage 0 there is no evidence of cancer cells breaking out of the part of the breast in which they started. Paget’s disease is typically stage 0.

STAGE I:

Invasive breast cancer with small tumor size and limited nodal involvement.

STAGE II:

Tumor is between 2 and 5 centimeters with or without nodal involvement.

STAGE III:

Tumor is over 5 centimeters and/or over 4 lymph nodes are involved and/or tumor is in the chest wall or skin.

STAGE IV:

The cancer has spread beyond the breast and lymph nodes to other parts of the body. Common sites of metastasis include the bones, liver, lungs, and brain. If you were diagnosed with stage IV disease, please contact YSC to receive your Metastatic Navigator.

TIP

Do not go onto websites that provide prognosis and survival information based on your stage of breast cancer. Typically, such information is based on data that is 10 years old (or older).

Common Tests Upon Diagnosis

After your initial diagnosis, but before surgery and/or treatment, you may be asked to have additional tests. This testing can help determine the extent of your cancer and what surgery and/or treatments will be best for you.

IMAGING: An ultrasound, mammogram or MRI may be ordered to look for other tumors in the same breast or tumors in the opposite breast. These are routine steps your doctor may take.

SCANS: CT or CAT scans, PET scans, and/or bone scans may be ordered to see if the cancer has spread to another part of your body.

SENTINEL LYMPH NODE BIOPSY (SLNB): The sentinel lymph node biopsy is a relatively new technique that allows a surgeon to “sample” your lymph nodes and determine whether breast cancer may have traveled there. This information aids your doctors in making treatment decisions and lets them know whether additional lymph nodes may need to be removed. Before surgeons used the SLNB technique, they would remove as many lymph nodes as they could during surgery and examine them for the presence of cancer. However, removing a large number of lymph nodes can have long-term consequences including increasing the risk of lymphedema (discussed on page 36). The SLNB technique spares young adults the removal of lymph nodes that may not have been necessary.

In the SLNB procedure, blue dye is injected into the breast. After giving the blue dye time to travel to the lymph nodes, the surgeon removes only the lymph node(s) in which the blue dye is found. These node(s) will be sent to a pathologist for testing to see if cancer is present. If not, additional lymph nodes should not need to be removed. However, the presence of cancer in the sentinel node(s) may require that additional lymph nodes are removed at that time or in a later procedure called an Axillary Lymph Node dissection. SLNB may occur in a separate outpatient procedure before your lumpectomy/mastectomy/treatment or may occur at the same time as your lumpectomy/mastectomy.

In order to treat your breast cancer, your doctors may recommend a variety of actions. This is completely normal. Many young adults choose to get a second opinion. Ask friends or other healthcare providers for recommendations.



GENETIC TESTING: Tests may be offered or ordered to determine if your cancer is due to an inherited genetic mutation. Please see “Know Your Family History” on page 23.

ONCOTYPE - GENOMIC TESTING: There are several genomic tests currently available. Talk to your doctor about which test might be right for you.

ONCOTYPE/MAMMAPRINT/MAMMOSTRAT: All three of these tests involve examining a piece of the patient’s tumor to estimate the likelihood that the cancer may come back again (called a recurrence) after initial surgery IF no further treatment is given. These tests provide guidance on whether or not chemotherapy should be recommended. For patients with a low risk of recurrence score, chemotherapy may be avoided and for patients with a high risk of recurrence, chemotherapy is likely. Each of these tests is somewhat different in the population that can use them and how the test results will be reported.

ONCOTYPE: For early stage breast cancers (stage I or II) that are node negative, ER+, and invasive. The test will produce a recurrence score between 0 and 100. The higher the score, the greater the risk of recurrence. We know from past studies that young adults with a score of 10 or lower can forgo chemotherapy and take endocrine therapy only. Young adults with a score of 26 or higher benefit from chemo in addition to endocrine therapy. The TAILORx trial results reported at ASCO 2018 provided information on what to do about those women in the “intermediate” range. They provided specific guidance on women under the age of 50. In women under age 50 with stage I or II, hormone receptor positive, HER2-negative, axillary lymph node negative breast cancer and an Oncotype DX Breast Recurrence Score of 11 to 15, there was no survival benefit when chemotherapy was added to endocrine therapy. Therefore, these women can safely forego chemotherapy. However, for young adults under age 50 with a score of 16 to 20 there was a modest benefit by adding chemotherapy and an even bigger benefit was seen in women with a score over 20.

MAMMAPRINT: Can be used in patients with stage I or II, invasive breast cancer with a tumor size under 5 centimeters that is ER+ or ER-. Results will be either low risk or high risk.

MAMMOSTRAT: Estimates the risk of recurrence in early stage, ER+ breast cancer. It produces a risk index score of high, moderate, or low.

What’s Next?

Most young adults will undergo local treatment to remove all evidence of the original tumor. This may include surgery and radiation. Systemic treatment is treatment that treats your entire body with the intention of killing any microscopic cancer cells that may have left the original tumor and traveled elsewhere. Chemotherapy and hormonal therapy are types of systemic treatment. New, targeted therapies like Herceptin, which are directed at specific attributes of the tumor, are also becoming more common. These targeted therapies are aimed only at the cancer cells and not all cells in the body, which may reduce side effects. What your doctor will recommend for you depends greatly on the pathology report results discussed in the prior section and additional testing mentioned above.

Family Planning

Fertility is a major concern for many adults diagnosed with breast cancer. You may have been diagnosed before having any children, or you may not have finished building a family. You may be trying to get pregnant and worry that breast cancer will delay your dreams of motherhood. Or you may be single and wondering if you will be able to have children a number of years from now. These are all valid thoughts and concerns.

Since time is of the essence in fertility preservation, you may have to act quickly if you choose to take steps to preserve your fertility. To avoid delaying breast cancer treatment, speak to your medical team about fertility as soon after diagnosis as possible. To learn more about fertility and breast cancer, use the resources at the end of this section.

How Do Breast Cancer Treatments Affect Fertility?

Breast cancer treatments may include surgery, radiation, chemotherapy, hormonal treatments (such as tamoxifen) and targeted treatments (such as Herceptin). Breast surgery and radiation rarely affect fertility.

Chemotherapy

Chemotherapy can damage or destroy eggs, increasing your risk of infertility immediately or years after treatment has ended. Most, but not all, young adults diagnosed with breast cancer have chemotherapy in their treatment regimen.

Your age and the type and total amount of chemotherapy contribute to the possibility of infertility. The younger you are and the less chemotherapy you have had, the more likely you are to remain fertile. Young adults under age 35 are most likely to have their periods return after treatment. A risk calculator created by Livestrong Fertility can help to estimate your risk of infertility at www.livestrong.org/content/fertility-risk-chart-women.

Tamoxifen

Tamoxifen is a hormonal treatment given to patients with estrogen receptor positive (ER+) breast cancer. Tamoxifen is not known to cause infertility, but it may interfere with childbearing because of the duration of the treatment – usually five to 10 years – during which time patients should not get pregnant. Because taking tamoxifen in early pregnancy may cause birth defects, it will be important not to be on tamoxifen if you are trying to become pregnant. After two years of treatment, some may choose to go off tamoxifen to get pregnant, then resume tamoxifen treatment after giving birth. If you do, consider joining the POSITIVE trial which is following young adults who take a “baby break” from tamoxifen to try to conceive a child: <https://clinicaltrials.gov/ct2/show/NCT02308085>. Talk to your doctor about whether this is a reasonable option for you.

Trastuzumab

Trastuzumab, which you may know by the common brand name Herceptin, is a targeted treatment for HER2+ breast cancer. Herceptin is not known to affect fertility, but young adults should not get pregnant while taking it, and should wait at least six months after completing Herceptin treatments before trying to get pregnant. Herceptin treatments are usually given regularly for one year.

What Are the Options for Preserving Fertility Before Treatment?

Fertility preservation before treatment is an option for young adults who want to protect their ability to have genetically related children in the future. There are a number of options to consider, though each has its pros and cons:

Embryo Freezing

Embryo freezing is an option for young adults who want to use the sperm of a male partner or donor. It involves stimulating the ovaries to produce multiple eggs in a single cycle, and harvesting those eggs through an outpatient surgical procedure. The eggs are fertilized in the lab with sperm (“In Vitro Fertilization” or “IVF”), then frozen and stored. The entire process takes between two and six weeks. Doctors are sometimes concerned that stimulating a adult’s ovaries and the resulting high hormonal levels may adversely affect how she will do in the long run, although evidence for this concern is lacking.

To achieve a pregnancy, frozen embryos are thawed and implanted into the adult’s uterus or that of a gestational carrier (surrogate) who will carry the fetus. To reduce the chance of multiple births, usually no more than two embryos are implanted during any one cycle. There have been thousands of babies born from frozen embryos.

Egg Freezing

Young adults who do not have a male partner or do not want to use donated sperm may choose to freeze eggs over embryos. Like embryo freezing, egg freezing begins by stimulating the ovaries to produce multiple eggs in a single cycle, and harvesting those eggs. The entire process takes between two and six weeks and may start at the beginning of a adult’s period.

To achieve a pregnancy, the eggs are thawed and fertilized with sperm (in vitro) and implanted into the adult’s uterus or that of a gestational carrier. Pregnancy rates from frozen eggs are lower than those for frozen embryos. Eggs are more difficult to freeze and thaw because they have a high water content that can form ice crystals, destroying the egg. However, techniques for freezing and thawing eggs have been improving rapidly. More than 5,000 babies have been born from the use of frozen eggs.



Ovarian Tissue Freezing

Ovarian tissue freezing is an experimental procedure for young adults who feel they do not have the time to go through a cycle of egg or embryo freezing. Ovarian tissue is removed in a simple surgical procedure, then frozen and stored. When a adult is ready to become pregnant, the strips will be re-implanted. The hope is that the tissue will produce hormones and eggs will begin to mature again. Young adults whose treatment includes ovarian suppression will not be able to re-implant the ovarian tissue until after that treatment is completed. Over 100 babies have been born from the use of frozen ovarian tissue.

Ovarian Suppression

Ovarian suppression is an experimental option that may protect your fertility while you undergo treatment. It is possible to shut down your ovaries during treatment with monthly shots (Zoladex or Lupron). Some young adults consider ovarian suppression during chemotherapy in the hope that this will preserve fertility by making the ovaries less susceptible to the harmful effects of chemotherapy. Recent research showed that ovarian suppression during chemotherapy improved fertility preservation and the potential for a full-term pregnancy. Ask your doctor if this is an option for you.

As mentioned earlier, YSC recommends that all young adults seek treatment at a comprehensive cancer center or large teaching hospital. These centers are most likely to treat many young adults and understand the concerns unique to this population—including fertility.

If fertility is a priority for you, be sure to seek care from doctors who understand the importance of integrating fertility preservation into your treatment timelines.

Since egg or embryo freezing may be timed with the start of your period, your cycle may dictate the amount of time needed for these processes. If you are having chemotherapy before surgery (neoadjuvant treatment), talk with your doctor about whether it is possible to delay treatment to preserve fertility.

Making the Decision About Fertility Preservation

The decision to preserve or not to preserve fertility prior to breast cancer treatment is personal. Regardless of their final decisions, young adults who take the time to understand how they feel about parenthood and who understand all their options prior to beginning breast cancer treatment feel better about their decisions. Although many people will encourage you to focus on “saving your life” or “fighting the disease,” the reality is that most young adults survive a breast cancer diagnosis. It is important to prepare for living the rest of your life and making the most of being a survivor, once cancer is behind you.

You will want to preserve your fertility if it is important to you to have children who are genetically related to you and your risk of infertility is high, or if your risk of infertility is low but any degree of risk is unacceptable to you. On the other hand, if your risk of infertility is low, or you are comfortable with your degree of risk and the possibility of having children who are not genetically related to you, you may choose not to preserve your fertility.

Fertility Preservation Costs

Fertility preservation can be expensive and is often not paid for by insurance, but there is hope for financial help. The cost of freezing eggs or embryos can be from \$8,000 to \$15,000 for each cycle, including medication and initial storage costs. Ovarian tissue freezing costs are about the same. Ongoing storage costs can be a few hundred dollars per year.

Financial assistance for fertility preservation is available at participating centers through Livestrong's Sharing Hope program and the Heart Beat Fertility Preservation Program. See resources at the end of this section for details. Other organizations may offer some financial assistance. Be sure to check with your insurance company to see what, if any, fertility treatments will be covered. Ask your reproductive center to see if they offer any discounts or payment plans for cancer patients.

For more information on Family Planning

YOUNG SURVIVAL COALITION

877.YSC.1011

youngsurvival.org

YSC RESOURCELINK

youngsurvival.org/directory

Find resources on family planning through YSC's online ResourceLink directory by choosing "Fertility/Adoption" on the select a category drop-down list.

100 QUESTIONS & ANSWERS ABOUT CANCER AND FERTILITY

by Kutluk H. Oktay, MD; Lindsay Nohr Beck; Joyce Dillon Reinecke, JD (2008, \$15)

HEART BEAT PROGRAM

ferringfertility.com/paying-for-treatment/save-on-your-medication/heart-beat-program/

The Heart Beat program provides select fertility medications at no cost if minimal qualification requirements are met.

ONCOFERTILITY CONSORTIUM

866.708.FERT

oncofertility.northwestern.edu

The Oncofertility Consortium is a national, interdisciplinary initiative designed to explore the reproductive future of cancer survivors. Their website provides patient education and lists of resources, including a list of cancer friendly adoption agencies.

ASCO: FERTILITY CONCERNS AND PRESERVATION FOR YOUNG ADULTS

cancer.net/navigating-cancer-care/dating-sex-and-reproduction/fertility-concerns-and-preservation-women

The American Society of Clinical Oncology (ASCO) is the world's leading professional organization representing physicians who treat people with cancer.

TININA Q. CADE FOUNDATION (CADE FOUNDATION)

cadefoundation.org

The Cade Foundation provides education focused programs to share information about different pathways to parenthood throughout the nation. They also provide grants to help families with the costs of adoption and fertility treatment.

Managing Your Medical Care

Keeping up with treatment and making healthcare decisions is not your only concern during this time of your life. There are also the practical issues of insurance, bills and work. Many young survivors struggle to understand the ins and outs of the medical system. Here are some terms and examples that may help you manage the many facets of your cancer care:

TERM	DEFINITION	EXAMPLE
Copayment	A set amount you pay per visit	<ul style="list-style-type: none">• \$10 per office visit• \$50 per ER visit
Usual and Customary Charges (UCC)	Amount generally charged for a procedure in your area. Note that typically you do NOT owe the amount in excess of your UCC. Check with your insurer to confirm.	<ul style="list-style-type: none">• MD charges \$250 for an office visit• UCC in area \$100• Health Plan reimburses \$100
Deductible	Amount you have to spend before the health plan pays	<ul style="list-style-type: none">• \$500 deductible per inpatient hospital stay. After you have paid \$500, the insurer starts paying the balance.
Coinsurance	Your share of the costs of a healthcare service, usually stated as a percentage of the total charges. Generally used for out of network services	<ul style="list-style-type: none">• Your coinsurance is 20% and your MD charges \$100.• Health plan pays 80%• You pay 20% of the \$100
Yearly or Coverage Maximums	Maximum amount paid for either a benefit or total medical costs annually	<ul style="list-style-type: none">• Benefit example: \$1,500 max paid for durable medical equipment



Some Questions to Ask Your Healthcare Team and Insurance Provider



Financial Aspects of Care

- Who handles questions about health insurance in this office or medical center?
 - Will this person help me work with my health insurance company?
 - Will this person help me figure out my medical bills to make sure they are correct?
 - If an insurance claim is denied, who can help me file an appeal?
 - Do you offer any payment plans?
 - Are there ways to change my treatment schedule, if necessary, to work around my job or child care?
 - Where can I get low-cost or free counseling or support to help me cope with my diagnosis?
-



Medication Costs

- What is my prescription co-pay for this drug?
 - Is this prescription a one-time cost, or will it be an ongoing expense?
 - Is this medication on my health insurance plan's preferred drug list?
 - Can I switch to a less expensive brand-name drug within the same drug class?
 - Is there a generic drug available that will have the same effect? Is it less expensive?
 - Can we regularly go over my list of medications, to see if there are ways to lower my drug costs?
 - For medications for side effects, is there an over-the-counter medicine that has the same effect as the prescribed drug? Is it less expensive?
 - Are there programs that can help cover the costs of my drug(s) for cancer treatment or side effects?
 - NeedyMeds, Inc. ([needymeds.org](https://www.needymeds.org)) and Partnership for Prescription Assistance ([pparx.org](https://www.pparx.org)) can help you apply for prescription medication assistance.
-



Transportation Expenses

- Is there free or low-cost transportation for patients at the medical center where I will have treatment?
- Are there reduced parking rates for patients at the medical center or doctor's office?
- Is there an organization that can help me pay for transportation to and from treatments and medical appointments?
- If I am traveling a long distance, are there free or reduced-cost hotels or lodging near the treatment facility?



Family and Living Expenses

- If I have trouble paying for basic items, like food or heat, due to the cost of my cancer treatment, are there organizations that can help me?
- Where can I get low-cost or free child or elder care during my treatment?
- Where can I get free or low-cost personal items, such as a wig, if needed?
- Is there an organization that can provide low-cost or free counseling or support to my family?



Employment, Legal and Financial Issues

- Who can I talk with if I have lost income because of my cancer?
- If I have on-the-job difficulties related to my cancer, who can help me understand my legal rights?
- If my caregiver has difficulties at his or her job because of my cancer, who can help us understand our legal rights?
- Where can I find out if my medical and related expenses can be deducted from federal income taxes?

Resources for Managing the Practical Concerns of Your Medical Care

CANCER AND CAREERS

cancerandcareers.org

Cancer and Careers offers information and resources for managing your job after a cancer diagnosis.

CANCER LEGAL RESOURCE CENTER

cancerlegalresources.org

The Cancer Legal Resource Center has a telephone assistance line and online tools to help you understand your workplace rights and other legal issues after a diagnosis.

PATIENT ADVOCATE FOUNDATION

patientadvocate.org

The Patient Advocate Foundation provides services to patients, including offering financial aid funds and co-pay relief.

THE PINK FUND

pinkfund.org

The Pink Fund provides financial support for breast cancer patients to help cover their basic needs and living expenses.

TRIAGE CANCER

triagecancer.org

Triage Cancer offers education on the various practical and legal issues that individuals may face following a cancer diagnosis.

Laws That Can Protect You During and After Your Treatment

HIPAA: Health Insurance Portability and Accountability Act. A law that helps protect the privacy of a patient's individual medical information, provides patients with access to their medical records, and helps people maintain their health insurance when they change, leave, or lose a job. Learn more at hhs.gov/ocr/privacy/.

GINA: The Genetic Information Nondiscrimination Act of 2008 is designed to prohibit the improper use of genetic information in health insurance and employment. The Act prohibits group health plans and health insurers from denying coverage to a healthy individual or charging that person higher premiums based solely on a genetic predisposition to develop a disease in the future. The legislation also bars employers from using individuals' genetic information when making hiring, firing and job placement or promotion decisions. This means your genetic test results cannot be used against you. To learn more, go to: www.ginahelp.org/GINAhelp.pdf.

FMLA: The Family and Medical Leave Act requires that covered employers grant an eligible employee up to 12 work weeks of unpaid leave during any 12-month period to take medical leave when the employee is unable to work because of a serious health condition or to care for his/her spouse, child, or parent with a serious health condition. This might allow you to take time off for treatment without worrying about being fired or losing your health insurance coverage. There are some conditions, however, and it is unpaid. For more information, go to www.dol.gov/general/topic/benefits-leave/fmla.

WHCRA: Under Young adults's Health and Cancer Rights Act, "group health plans, insurance companies and health maintenance organizations (HMOs) offering mastectomy coverage also must provide coverage for certain services relating to the mastectomy in a manner determined in consultation with your attending physician and you. This required coverage includes all stages of reconstruction of the breast on which the mastectomy was performed, surgery and reconstruction of the other breast to produce a symmetrical appearance, prostheses and treatment of physical complications of the mastectomy, including lymphedema." This means that you have the right to be symmetrical in your surgery options and that insurance companies must pay for any procedure that is required to do so, even years later. For more information, go to: dol.gov/agencies/ebsa/laws-and-regulations/laws/whcra.

ADA: The Americans with Disabilities Act "requires employers to provide adjustments or modifications to enable people with cancer to enjoy equal employment opportunities unless doing so would be an undue hardship (i.e., a significant difficulty or expense). Not all employees with cancer will need an accommodation or require the same accommodations, and most of the accommodations a person with cancer might need will involve little or no cost. An employer must provide a reasonable accommodation that is needed because of the limitations caused by the cancer itself, the side effects of medication or treatment for the cancer, or both. For example, an employer may have to accommodate an employee who is unable to work while she is undergoing chemotherapy or who has depression as a result of cancer, the treatment for it, or both." See eeoc.gov/laws/types/cancer.cfm for more information.

TIP

Looking for more financial resources?

- Visit YSC's searchable online ResourceLink directory at youngsurvival.org/directory.
- Contact your local hospital social worker.
- Call our ResourceLink information line at 877.YSC.1011 or email support@youngsurvival.org.

Surgery

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Surgery

You've been diagnosed with breast cancer and have some information about the tumor type, but now what? Once you're diagnosed, things will happen pretty quickly. You will have more tests, discuss treatment and surgery, and be asked to make a lot of decisions that may seem complicated and overwhelming. Everyone's journey is unique and will be based on doctor recommendations, personal preferences and information known about the tumor. The path chosen by someone else may not be right for you and vice versa. The order in which you take steps to treat your cancer may also vary. While some will have surgery first, others may go straight to chemotherapy or other treatment.

The intent of this chapter and the one following is to provide basic information on surgery, treatment, side effects, and related issues so that when you see your doctor, you have some background knowledge and know the questions you may want to ask. It is not intended to replace the advice of your physicians. We recommend you review the list of questions to ask your doctor, located in a separate section of this Navigator, and take this Navigator with you to your appointments. Many survivors have benefitted from taking along a trusted family member or friend with them. That person can take notes while you ask your questions and can listen to your doctors. We have done our best to discuss the major issues and topics you may face, but it is not possible to list every single treatment option or chemotherapy drug. Of course, surgical and treatment advances also occur regularly.

One of the first things your doctor may talk to you about is surgery to remove the tumor. There are two main options: mastectomy and lumpectomy.

MASTECTOMY: A mastectomy is removal of the entire breast, typically including the nipple and areola. While this procedure used to require the removal of skin and muscle, today most mastectomies do not remove either. You may hear the term "skin-sparing" mastectomy, which simply means that the skin of the breast is not removed. The removal of one breast is a unilateral mastectomy, and the removal of both is called a bilateral mastectomy. Nipple-sparing mastectomies, in which the nipple and areola are not removed, may be an option in certain patients.

PROPHYLACTIC MASTECTOMY: A prophylactic mastectomy is the removal of a healthy breast. It may be a recommended surgery if you have a BRCA1 or 2 mutation.

LUMPECTOMY: A lumpectomy, also sometimes called "breast conservation therapy," is where the surgeon removes the tumor and a surrounding area of tissue only. The rest of the breast is left intact. The volume of breast tissue removed will depend upon the size of the tumor and its location. Young adults who choose a lumpectomy will also need to have radiation therapy, which kills any cancer cells that might remain in the breast.

As noted earlier, a sentinel lymph node biopsy or axillary lymph node dissection may also occur at the time of your lumpectomy or mastectomy.

Considerations

Deciding between mastectomy and lumpectomy can be difficult. It is a tough and personal decision. Learn all you can, get multiple opinions, and decide what is best for you. In some cases, you may not have a choice of surgery as the extent or location of your cancer may require a mastectomy. Here are some additional thoughts and considerations. They are provided for your information only and not in an attempt to sway your decision either way.

- There is a risk of recurrence with either surgery.
- For young adults, studies to date have shown no overall survival difference between mastectomy or lumpectomy and radiation. However, there is a higher rate of local recurrence (reappearance of the breast cancer in the area where it was originally found) with a lumpectomy. As new studies are published regularly, ask your doctor to confirm this information.
- You will lose all sensation in your breast after a mastectomy and it does not return.
- Breast reconstruction after mastectomy has advanced, but will not look or feel the same as your “real” breast.
- Radiation treatments occur daily for at least 28 days. However, choosing a mastectomy is not a guarantee of avoiding radiation. Depending on the circumstances, radiation treatments may also be required after a mastectomy.

Possible Risks and Complications

Both surgery options involve some risks and possible complications. They include:

LOSS OF RANGE OF MOTION: Particularly with a mastectomy, you may lose some of your range of motion after surgery and have difficulty reaching or fully extending your arm. This could also occur, although not as frequently, with a lumpectomy. Your surgeon will give you instructions on post-surgical care, including stretching and exercises to be performed after healing. Be sure to follow them. Physical therapy may also be required at a later time to recover your full range of motion.

CORDING: Also called Axillary Web Syndrome, this is a potential side effect from lymph node biopsy or breast surgery. For the patient, it feels like there is a cord or string that stretches from the armpit area down the arm. It may be painful, feel extremely tight and make it difficult to extend or use your arm. Some patients will actually be able to see what looks like a cord in their armpit and running down their arm. It is not known why this side effect may arise, but it can be relieved through stretching, physical therapy and the use of a lymphedema therapist.

LYMPHEDEMA: Lymphedema is a swelling of the arm that can occur after surgery to the lymph node or breast area. It can be temporary or permanent and may occur soon after surgery or at a much later time. Your risk of lymphedema increases as the number of lymph nodes removed increases. Your surgical team should provide you information on how to recognize lymphedema and how to prevent it now and in the future.

Reconstruction

If you have a mastectomy, you may decide to undergo reconstruction of your breast. Reconstruction is not a requirement; it is a personal choice and totally up to you. Learn as much as you can about the process before making a decision. You and those close to you should discuss any questions and concerns about reconstructive surgery with your healthcare team. If you decide to have reconstruction, you may have it at the time of your mastectomy or you may wait and decide to have reconstruction at a later time. The following pages will provide you more information on reconstruction options and considerations to help you make your decision.

Breast reconstruction is a surgical procedure to restore the appearance of a breast for those who have had a breast removed (mastectomy) to treat breast cancer or prophylactically to prevent cancer. The surgery rebuilds the breast shape so that it is about the same size and shape as it was before it was removed or to the desire of the adult facing breast cancer. The nipple and areola may be added as a second stage of reconstruction, usually done three to six months later as an outpatient procedure.

Most young adults who have had a mastectomy can have reconstruction, so long as they are healthy enough to undergo surgery. Young adults who have had a lumpectomy usually do not need reconstruction unless a large amount of tissue has been removed. Breast reconstruction is done by a plastic surgeon; some types of reconstruction may also be done by a surgeon who sub-specializes in microsurgery.

If you are thinking about having reconstructive surgery, it is a good idea to discuss it with your surgeon and a plastic surgeon experienced in breast reconstruction before your mastectomy. This allows the surgical teams to plan the surgery that is best for you, even if you decide to wait and have reconstructive surgery later.

TIP

You should talk about the benefits and risks of reconstruction with your doctors before the surgery is planned. Give yourself plenty of time to make the best decision for you!



Reconstruction Goals

Should you choose reconstruction, the goals of reconstruction are:

- To make your breasts look balanced when you are wearing a bra or swimsuit
- To permanently regain your breast contour
- To help maintain or regain your personal vision of body image and self-esteem, femininity and sexuality
- To alleviate the need for an external prosthesis, if desired.

The difference between the reconstructed breast and the remaining breast may be seen when you are nude. When the breasts are in a bra, though, they should be close enough to one another in size and shape that you will feel comfortable about how you look in most types of clothing. Your body image and self-esteem may improve after your reconstruction surgery, but this is not always the case. Also, you may be disappointed with how your breast looks after surgery. You and those close to you must be realistic about what to expect from reconstruction.

Special Considerations in Breast Reconstruction

You should decide to have breast reconstruction only after you are fully informed about the procedure. There are often many options to think about as you and your doctors discuss what is best for you. The reconstruction process may require one or more operations.

Several types of operations can be done to reconstruct your breast. You can have a newly shaped breast with the use of a breast implant, your own tissue flap (“autologous” reconstruction), or sometimes a combination of the two. All reconstruction is major surgery, and you will need several weeks to recover. The length of your surgery and recovery time will vary depending on the complexity of the surgery chosen.

Many individuals choose not to undergo breast reconstructions and are very happy with their decision. Do not be afraid to ask questions and to consult other individuals who have weighed these options.

You should talk about the benefits and risks of reconstruction with your doctors before the surgery is planned. Give yourself plenty of time to make the best decision for you!

TIP

Check out our list of questions for your plastic surgeon at the end of this Navigator.

Immediate or Delayed Reconstruction

IMMEDIATE RECONSTRUCTION is done at the same time as the mastectomy. There is typically less scarring on the breast with immediate reconstruction. Immediate reconstruction can also mean one less surgery.

DELAYED RECONSTRUCTION is done at a later time. For some young adults, this may be advised if radiation to the chest area is needed after mastectomy. Usually six to 12 months are needed after radiation therapy is over before you are a candidate for delayed breast reconstruction—this allows the radiated tissue to “cool down” and be ready for surgery.

Sometimes thinking about reconstruction is too much while you are coping with a diagnosis of cancer. If this is the case, you may choose to wait until after your breast cancer surgery to decide about reconstruction. Do make sure to ask your surgeon about other factors in delayed reconstruction or “revision” surgery in the future. There is no age or time limit to having your breast reconstructed!

Factors to Consider:

- How much tissue you have available. Very thin young adults may not have enough extra body tissue to make flap grafts possible.
- Scarring is a natural outcome of any surgery, but skin necrosis (tissue death) may occur if your ability to heal is impaired. Your ability to heal may be hindered by previous surgery, chemotherapy, radiation, smoking, alcohol, diabetes, various medicines, and other health factors.
- If you are a smoker, this is a time to stop! Smoking can prevent healing and cause complications with surgery and reconstruction.
- Not all surgery is completely successful, and you may not be completely pleased with your cosmetic result.
- Breast reconstruction restores the shape of the breasts but cannot restore your normal breast sensation. With time, the skin on the reconstructed breast can become more sensitive, but it will not give you the same kind of erotic sensation and related pleasure as before a mastectomy.
- The surgeon may recommend surgery to reshape the remaining breast to match the reconstructed breast. This could include reducing, lifting or enlarging the size of the healthy breast. This decision is up to you and one you should discuss with your breast surgeon. Be sure to ask whether surgery on your unaffected breast will affect sensation.

The **Young adults’s Health and Cancer Rights Act of 1998 (WHCRA)** is a federal law that provides protections to patients who choose to have breast reconstruction in connection with a mastectomy. See page 34.

Breast Implants

Breast implants involve the least amount of surgery of all your reconstruction options. Slim, small-breasted young adults may be good candidates for breast implants because they might not have enough excess belly or inner thigh tissue to form a good autologous transplant (flap). Breast implants come in a wide variety of sizes, projections, widths and shapes.

A surgeon uses implants to form a breast mound. Breast implants are sacs filled with saline (salt water) or silicone gel. The sacs are placed under your skin or sometimes also behind your chest muscle. Breast reconstruction with implants is very different from cosmetic breast augmentation because the skin over the implant is left very thin following mastectomy. To compensate for this, the implants are often placed “under the muscle,” meaning under the pectoralis (chest) muscle and the breast skin.

The implant procedure is either done in a one-stage immediate breast reconstruction at the time of the mastectomy, in which case the surgeon places a breast implant where the breast tissue was removed, or in a two-stage or two-stage delayed reconstruction.

Two Stage Implant Reconstruction

For most young adults, the skin that remains after mastectomy must be stretched or expanded to make room for an implant. To stretch the tissue, the surgeon inserts a balloon-type device called a tissue expander under the chest muscle. The expander has an injection “port” that allows the surgeon to add increasing amounts of liquid over time (about three to six months), without extra surgery. Gradually, your skin and soft tissue are stretched to achieve your desired appearance.

When stretching is done and your other treatments (chemotherapy, radiation or both) are completed, the expander is usually replaced, in another surgery, with a permanent saline or silicone implant.

IMPLANTS ARE NOT CONSIDERED LIFETIME DEVICES. They are subject to wear and tear. Most patients require re-operation at some point to address problems with their implants including leakage, deflation, infection, extrusion through the skin, capsular contracture (becoming hard), pain, and/or desire for size alteration.

Radiation and Implant Reconstruction

If you are likely to have radiation therapy, speak with your doctors about whether the implant form of reconstruction is right for you. Historically, there have been concerns about the radiation hardening the implants or increasing the risk of infection. Recent research suggests that good results can be obtained when expanders are in place at the time of radiation treatment (instead of implants). Ask your doctor what s/he recommends.

Also, if you have an expander and there is any chance you will have radiation therapy, be sure your surgeon uses an expander with a plastic port, not a metal one, to prevent skin damage during radiation.

Scar Tissue

Once a breast implant is in place, scar tissue forms all around it, creating what's called a tissue "capsule." Most of the time these tissue capsules are soft-to-firm and unnoticeable. However, less than 15% of the time, a hard capsule forms that can be painful and distort the breast—this is called "capsular contracture." In these cases, a surgeon can break up the scar tissue with an additional surgery and, if necessary, replace the implant.

If you have radiation therapy to the breast area, the risk of scar tissue and hardening around the breast implant increases to 40–50%. Massage and exercises may reduce the risk of forming a hard capsule (with or without radiation). You can ask your surgeon to show you how to massage the implant and the area around it, firmly but gently.

Your Own Body's Tissue ("Flaps")

Another way to surgically reconstruct a breast is to take your own tissue from an area of your body where you have extra to spare, and move it to your breast area. These are called autogenous or autologous procedures because your own body tissue is used. Skin, fat and sometimes muscle can be taken from the abdomen, back, inner thighs or buttocks. These areas are called "donor sites."

The tissue can be detached as a free piece and moved, called a "free flap." Or, the tissue can remain attached to the veins and arteries as a "flap" and slide under your skin to a new location on the chest. In both cases, the tissue is sewn into place as a new breast.

Some free flaps are also muscle preserving or "perforator flaps." The perforator flaps are referred to as "muscle preserving" because unlike the other autogenous flaps, only fatty tissue is taken without sacrificing muscle. These surgeries are done by specially trained microsurgeons (a subspecialty of plastic surgery). Microvascular surgery is challenging, and there is a risk of blood supply failure to the flap. This means the breast flap could die, and the reconstruction could fail immediately, or that the breast could shrink over time, and the adult would not have a good cosmetic result. This possibility is something to discuss with your doctor.

Breast reconstruction using your own tissue is popular because it is a long-lasting solution (implants usually have to be replaced after about 10 to 15 years) and the consistency of the donated tissue is very similar to natural breast tissue. But the new breast will have little, if any, sensation.

Flaps that Use Muscle

There are currently four types of breast reconstruction that use a muscle from another part of your body in reconstructing a breast:

- Lat (Latissimus) flap
- TRAM (Transverse Rectus Abdominus Myocutaneous) flap
- Gluteal flap
- TUG (Transverse Upper Gracilis) flap

The Lat Flap

The Lat flap cuts away the largest muscle in the back, the latissimus, and uses it to rebuild the breast. This procedure usually requires placement of an implant at the same time to provide adequate volume. The latissimus is a muscle with a very strong blood supply, and this is sometimes a good choice for young adults with healing risks. Sacrifice of the latissimus muscle can produce permanent arm weakness and a scar on the upper back around the bra line. Some plastic surgeons debate the degree of resulting weakness (if any).

PROS AND CONS OF LAT FLAP

PROS:

- Many breast surgeons like this procedure because the flap is easily slipped around front, through a short tunnel in the skin, and put into position. This procedure can produce excellent results with few complications. Nearly any plastic surgeon can perform this procedure.
- The latissimus is a very durable muscle flap that can be used in less than ideal conditions. For this reason, it may be the only breast reconstruction option for some young adults.

CONS:

- The skin on your back has a different color and texture than breast skin.
- May result in some back asymmetry (unevenness in the appearance of your back) and possible weakness if you are a swimmer, rock climber, rower, etc. Back and arm function and strength can be affected, so discuss your lifestyle and types of activities with your surgeon.

TRAM Flap

TRAM stands for the transverse rectus abdominis muscle, which is located in the lower abdomen, between the waist and the pubic bone. The TRAM flap, developed in the late 1970s, allows for use of excess fat in the lower abdomen to reconstruct the breast, creating a tummy-tuck and a hip-to-hip donor site scar. An issue with the TRAM flap is that it removes the muscle of the abdominal wall and almost always requires the use of implanted mesh. The effect of this muscle sacrifice in the abdomen is permanent. The resulting weakness can lead to hernia formation and/or bulging in the abdomen.

The TRAM is not for everyone. It is NOT a good choice for:

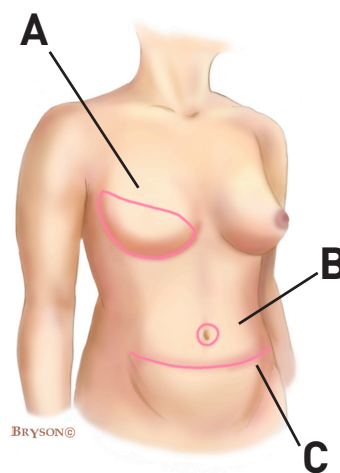
- Thin young adults who do not have enough abdominal tissue;
- Young adults who smoke and therefore have blood vessels that are narrow and less flexible;
- Young adults who have multiple surgical scars on the abdomen (normal Cesarean-section scars are not usually a problem); and
- Bilateral reconstruction.

LINES OF TRAM RECONSTRUCTION INCISIONS

THINGS TO CONSIDER ABOUT TRAM

Here are some things to think about as you consider TRAM:

- **LONG SCAR:** The tummy tuck incision runs across your body from hipbone to hipbone, midway between the top of your pubic hair and your navel.
NOTE: this scar line is higher than the typical DIEP (see page 41) scar.
- **NAVEL DISTORTION:** Your surgeon may need to build you a new belly button because after the abdominal area is reshaped, your natural navel may be stretched, distorted or in the wrong place.
- **LOSS OF FEELING:** Abdominal tissue feels very close to breast tissue. However, because nerves are cut in the course of the surgery, you are not likely to have much feeling or sensitivity in your new breasts.
- **LOSS OF STRENGTH,** risk of lower abdominal bulge or hernia are possible.
- **ONE TIME IS ALL YOU GET:** A surgeon can take tissue from your abdomen only once. If you used the abdominal flap for a single breast mastectomy, and later you need a mastectomy of the second breast, transplant tissue must come from your back, buttocks or thighs, or you will rely on an implant.



A LINES OF RECONSTRUCTED BREAST INCISIONS

B CIRCLE OF RE-POSITIONED "BELLY BUTTON" INCISION

C LINE OF ABDOMINAL SURGERY INCISION

Gluteal Flap

The Gluteal flap uses skin, fatty tissue and muscle from the buttocks to create the breast shape. This flap can be slightly more firm than other donor sites and leaves a scar in the center of bottom of the buttocks. This procedure is rarely done today.

TUG Flap

The TUG or “inner thigh” flap is taken from the upper inner-thigh area in a crescent shape. Only a small amount of the gracilis muscle is taken with the flap to ensure a reliable blood supply. There is no functional consequence to removing the gracilis muscle, which is the same muscle used to reconstruct facial paralysis or forearm injuries. The unique shape of the tissue removed from the inner thigh allows shaping of a breast with an almost ideal contour and projection by “coning” the tissue before transfer to the chest. Immediate nipple and areola reconstruction are also possible with this flap. Often, tattooing is not needed after this procedure.

The TUG flap may be a good option for young adults who lack abdominal fat and desire “A” or “B” cup breasts.

The TUG flap is not performed widely in the United States, but it can provide good aesthetic results. It can be used for immediate or delayed reconstruction.

Muscle-Preserving Options

There are currently three breast reconstruction options that do not require the removal of muscle to create a breast mound:

- DIEP (Deep Inferior Epigastric Artery Perforator) flap
- SIEA (Superficial Inferior Epigastric Artery) flap
- GAP (Gluteal Artery Perforator) flap

DIEP Flap

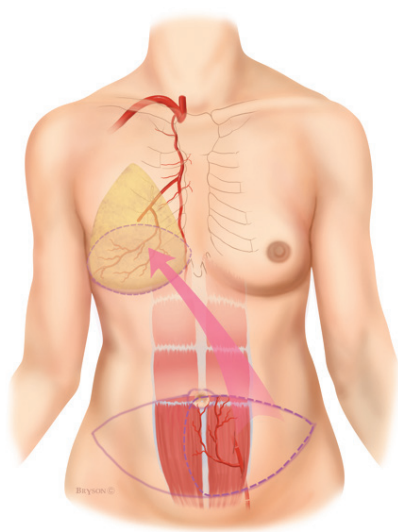
The DIEP flap uses skin and fatty tissue from the lower abdomen to restore the breast without sacrificing the abdominal muscles. The result in the abdomen is much like a tummy tuck. However, there is a significant donor site scar from hip to hip, much like the TRAM procedure. In contrast to the TRAM flap, the DIEP preserves the abdominal strength, avoids hernia and eliminates the need for implanted mesh. DIEP reconstruction can be performed at the same time as a double mastectomy, provided you have enough extra abdominal fat. Because no abdominal muscle is removed, most young adults recover more quickly from DIEP compared to TRAM. Specially trained microsurgeons perform the DIEP.

Another main difference between the DIEP and TRAM procedures is how blood is supplied to the belly tissue once it becomes your new breast. The DIEP is called a “free” flap because the tissue is completely detached from the belly and then reattached to the chest area. Reconnecting the blood vessels from the belly tissue to chest blood vessels is delicate work. Your doctor uses a microscope during surgery to see and disconnect/reconnect the blood vessels, which is why DIEP is known as microsurgery. Because of the extra time required for the blood vessel microsurgery, DIEP flap surgery often takes longer than TRAM flap surgery.

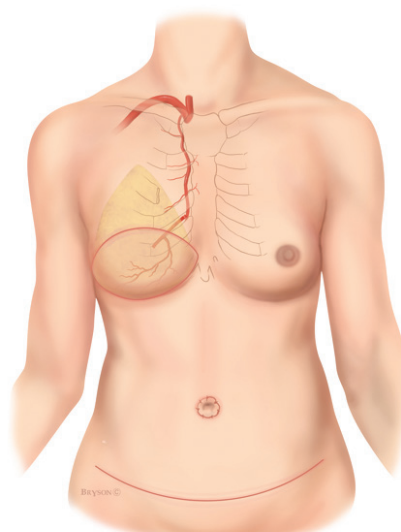
The DIEP flap may be a good choice for young adults who have enough tissue to reconstruct one or both breasts. In general, you can still have DIEP if you've had prior abdominal surgery so long as you have enough abdominal fat, and your scars will not interfere with the blood supply to the tissue. Your surgeon can evaluate whether you are a good candidate for this option.

DIEP may NOT be a good choice for:

- Thin young adults who have very little abdominal fat to spare;
- Young adults who smoke and have blood vessels that are narrow and less flexible;
- Some diabetic young adults who have poor healing ability; and
- Individuals whose weight may put them at higher risk during a long surgery



DIEP PROCEDURE



DIEP SCARS

SIEA Flap

The SIEA flap procedure is otherwise the same as the DIEP procedure and represents a second choice for young adults whose superficial vessels are more dominant than the deep inferior epigastric perforators (DIEPs). In those cases, the SIEA and its accompanying veins may be chosen as the source of blood supply for the borrowed tissue necessary to reconstruct the breast.

It is not known before surgery whether a adult has an adequately sized SIEA blood vessel. These are looked at by the microsurgeon during surgery, and a determination will be made at that time whether they are suitable to supply a flap.

GAP Flap

The GAP Flap procedure allows for reconstruction using your own body's tissue when there is inadequate abdominal fat to restore your breast to its proper size and shape. With GAP flap, the breast is reconstructed with fatty tissue borrowed from the gluteal area without sacrificing underlying muscles. As with the DIEP procedure, the tissue is then sculpted into the new breast mound. There will be a donor site scar on the buttocks. Buttock tissue can be slightly more firm than the belly and less skin may be available. Consequently, the breast reconstructed with this flap may be smaller than with the DIEP or TRAM flap.

The GAP surgery generally takes the same amount of time as a DIEP surgery. However, if GAP is performed at the time of mastectomy, the surgery time for the reconstruction is added to the mastectomy surgery time. This is because unlike the DIEP, where the breast surgeon and plastic surgeon work simultaneously, GAP reconstruction cannot begin until the mastectomy is completed because the patient must be in the face-down position for the GAP surgery to begin.

Nipple and Areola Reconstruction

The decision to have your nipple and areola reconstructed is optional and often considered the final phase of breast reconstruction. This separate surgery is done to make the reconstructed breast more closely resemble the original breast. There are many different techniques for nipple reconstruction. Discuss your options with your plastic surgeon, to see which may be best for you. Reconstructed nipples will not have the physical sensitivity of your original nipple since they will not have the same nerves and blood supply as a real nipple.

The ideal nipple and areola reconstruction requires symmetry in position, size, shape, texture, color and projection. Tissue used to rebuild the nipple and areola is taken from your own body, often from the newly created breast. Nipples can be created with a few strategically placed sutures, and areolas are created with a tattoo.

Skin for creating the new nipple can also come from other locations on your body. Some surgeons will use tissue from the opposite nipple, ear, eyelid, groin, upper inner thigh or buttocks.

Nipple/areola reconstruction is usually performed after the new breast has had time to heal, at least three to six months after surgery. Depending on the type of nipple reconstruction you choose, it can be performed at your doctor's office under local anesthesia or as an outpatient procedure under general anesthesia.

Some young adults choose not to have traditional nipple reconstruction. Instead, some adults have a nipple tattooed onto the breast or get an artistic tattoo such as a full breast design or a small symbol of their breast cancer experience. Self-adhesive nipples are also available, to use during healing, or as a long-term option. You may even find that you enjoy the freedom of not having nipples, which reduces the need for a bra.

What if I Don't Want Reconstruction?

Reconstruction is not a requirement and it is not for everyone. There are plenty of young adults who choose, for various reasons, not to have reconstruction and are happy with their decision. You may not want to have another surgery or are concerned about losing strength or tissue from another area of your body. **Whatever the reason, choosing not to have reconstruction is a perfectly acceptable option and no one should try to tell you otherwise.**

If you want to have the appearance of a breast mound in clothing or swimsuits, without reconstruction, you may wear prostheses that fit into a pocket sewn into your bra or swimsuit. These prostheses are soft and can be made of silicone, foam, or fiberfill. Once you have healed from surgery, it is best to be fitted by a certified fitter who can recommend the best type and size of prostheses for you. Some stores, such as Nordstrom, will also sew pockets into any bra you purchase there at no extra charge. Prostheses may also be covered by your insurance company.

Some individuals choose not to use a prosthesis or padded bra and opt for the look or feel of a flat breast area.

To be connected to a young adult who opted not to have breast reconstruction, contact the YSC Survivorlink program at 877.972.1011 or support@youngsurvival.org.

TIP

No two people are alike and no two cancers are alike. Don't look at statistics. They are numbers and you are not a number!



Treatment

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Treatment

In addition to surgery, your doctor is likely to recommend one or more treatment options, which will help to remove any remaining cancer in your body and hopefully prevent its return. All treatments have risks and benefits. It is important to understand what those are and confirm that the benefit of the treatment outweighs any possible risks. Your doctor should be willing and able to discuss this with you and may be able to provide specific numbers – for example, your risk of recurrence if you have the treatment and the risk of recurrence if you do not.

Any test and pathology results will be utilized by your doctor to determine the best, most appropriate treatment for you. Remember that everyone's situation is unique, so what may be recommended for another patient may not be what is best for you.



Chemotherapy

Chemotherapy is a treatment that kills cancer cells that may have left the original tumor location and be elsewhere in your body. It targets all fast-growing cells in your body, not just cancer cells. For this reason, healthy cells may also be affected by chemotherapy. Hair loss, nausea and neuropathy (numbness and tingling in hands and feet) are common side effects, but they will vary depending on the type of chemotherapy you are offered and your individual reaction to it. More information on side effects is below.

Chemotherapy may be administered adjuvantly, after your initial surgery, or it can be given neoadjuvantly, prior to your surgery. Neoadjuvant chemo may be recommended if your tumor is large and your doctor wants to shrink it before surgery, or if your tumor has aggressive characteristics.

Chemotherapy is typically given intravenously (IV), but some types may be taken in pill form. If you will be given chemo through an IV, your doctor may recommend the placement of a “port” (port-a-cath) before chemo starts. A port is a device surgically implanted into a large vein, usually in the chest wall, through which blood can be withdrawn and chemo delivered. This alleviates the need for repeated needle sticks. Your port will be removed at a later date, after treatment is concluded.

Chemo is given on a regular interval, typically once every three weeks or every two weeks (called “dose dense”). Dose dense is a more aggressive treatment schedule, but it may be recommended for young adults. Depending on the drug and dosage, weekly treatments of some chemos (such as Taxol) may also be recommended. Common chemotherapy drugs for breast cancer include:

- Adriamycin (doxorubicin)
- Taxotere (docetaxel)
- Taxol (paclitaxel)
- Cytoxan (cyclophosphamide)
- Paraplatin (carboplatin)
- Ellence (epirubicin)

Prior to your first treatment, your oncologist will meet with you and give you prescriptions to prepare for treatment. The medications may be steroids or anti-nausea drugs and should be taken exactly as s/he tells you. Sometimes, you will need to take medication before you come to the hospital for chemotherapy. Be sure to write down all the information s/he provides or ask for her to do so. Do not skip taking any of the recommended medication. Trust that the medication is there to support you and follow the instructions in taking it.

If you are interested in preserving your fertility, ask your doctor whether you should receive ovarian suppression during chemotherapy. A recent study suggested that ovarian suppression during chemo may help protect fertility in some patients. Please also refer to the discussion on family planning on page 29.

What Can I Expect at My First Chemo Treatment?

On a typical treatment day, you will go to your hospital or cancer center and have blood drawn. This blood work is checked to ensure that your white blood cell count is sufficient for treatment. After your blood work, you will meet with your care provider so s/he can review your results and check to see how you are doing. Then, s/he will send you to the infusion area for treatment. It is also common practice to return to your cancer center a day or two after treatment to receive an injection of pegfilgrastim (you may know this under the name Neulasta), a drug that helps restore your white blood cell count, which may be knocked down by chemotherapy. Pegfilgrastim is used frequently in combination with dose dense chemotherapy. Sometimes it is possible to have the injection at home, if it is covered by insurance. Neulasta Onpro, a patch that is applied to your skin immediately after chemo, is another option that alleviates a second hospital visit. This patch releases the Neulasta approximately one day after the patch was placed.

It is normal to be anxious before your first chemo treatment, because you don't know what to expect. Find out how long your treatment will last and what they suggest you bring with you (if anything). It's always a good idea to bring someone with you to treatment to keep you company, get you snacks and drinks if you need them, and drive you home. Someone to drive you is especially important, as anti-nausea medications or pre-treatment medications may make you drowsy. If someone is not able to drive you, organizations like the American Cancer Society provide free rides. Call 1-800-227-2345 or ask your hospital for local resources.

Be gentle with yourself during treatment. Drink lots of water to stay hydrated, eat when you can, and get plenty of rest. Once you've had one treatment and see how your body reacts to it, you will have a better idea of how to plan for the treatments ahead. Some young adults are able to work throughout treatment, taking only a day or two off for the treatment itself. Others have a harder time and may need more time to recover after each treatment. If you find that you suffer side effects that significantly impact your wellbeing, be sure to contact your doctor or nurse. There may be medications or other recommended actions you can take to reduce your discomfort.

TIP

Write down your medication schedule and stick with it. Yes, a positive attitude helps, as does humor, but stay ahead of the nausea and pain with medication.

Hormonal Therapy

Hormonal therapies are medications that deprive certain types of cancer cells of the hormones they need to grow. Tamoxifen is hormonal therapy for premenopausal young adults that blocks the estrogen receptor (if a adult has estrogen receptor positive breast cancer). Tamoxifen is taken for a minimum of five years, with 10 years now being recommended by ASCO as an option based on recent study results. Aromatase inhibitors (AIs) are a form of hormonal therapy used in postmenopausal adults, which decrease the body's production of estrogen. Both types of hormonal therapy have been shown to reduce the risk of breast cancer recurrence and are typically started after surgery and chemotherapy have ended. Both tamoxifen and AIs are taken in pill form. For premenopausal young adults, side effects with tamoxifen can include hot flashes and weight gain.

Ovarian Suppression

Ovarian suppression is another form of hormonal treatment, which may be used in premenopausal young adults who are hormone receptor positive. Ovarian suppression may be achieved by oophorectomy, radiation to the ovaries, or an injection given every one to three months that shuts down the ovaries. With ovarian suppression, menstrual periods will cease, and the body will produce less estrogen. Ovarian suppression from radiation or surgery is permanent. However, ovarian suppression by injection is usually temporary, and your menstrual periods may resume when you are no longer receiving injections. Side effects of ovarian suppression are similar to menopause—hot flashes, weight gain, and vaginal dryness, for example.

Ovarian suppression (using injections) may be suggested to try to preserve fertility during treatment, or as a treatment itself to reduce risk of recurrence. Study results released at ASCO 2014 showed that ovarian suppression during chemo may protect fertility in some patients.

Ovarian suppression may also be given with tamoxifen or an aromatase inhibitor (AI) to reduce the risk of recurrence. Two research trials called SOFT and TEXT showed that ovarian function suppression (OFS) in combination with tamoxifen or an AI reduces breast cancer recurrence in young adults, age 35 or younger, who were at high risk of recurrence (high enough risk that chemotherapy was ordered). A combined analysis presented at the San Antonio Breast Cancer Symposium in December, 2017 with over eight years of follow-up, confirmed that an AI with OFS was superior to tamoxifen plus OFS. However, OFS plus tamoxifen is still a reasonable choice given the survival data. Ask your oncologist what is the best path for you.

Targeted Therapy

Targeted therapies are treatments that target the cancer cells, or attributes of the cancer cells, only. They do not target other, healthy cells in the body. For this reason, side effects and toxicities should be less than with chemotherapy. For example, while hair loss is common with many chemotherapy drugs, Herceptin (discussed below) does not cause hair loss. This is because while chemotherapy targets all fast growing cells, even healthy ones like hair, Herceptin targets a part of the cancer cell only.

Targeted therapies are frequently called or described as a form of “chemotherapy” because both are usually given through an IV. However, they are different for the reasons discussed. Targeted therapies are relatively new. We will describe here the most common targeted therapies that exist at this time.

Common Targeted Therapies

TRASTUZUMAB was the first targeted therapy widely used in breast cancer. Commonly known by the brand name, Herceptin, trastuzumab is used in patients with HER2+ breast cancer, and it blocks the HER2 receptor on the cancer cell. This drug has made a dramatic improvement in survival rates for young adults with HER2+ breast cancer. It is typically given along with chemotherapy and will continue for six months or more after chemotherapy ends. Your hair will grow back if you are only taking Herceptin.

KADCYLA (also known as T-DM1) is the first in a new class of drugs called antibody drug conjugates. It delivers chemotherapy through targeted means. Recently FDA approved for use in HER2+ stage IV breast cancer, it has been called a “smart bomb.” The drug is a combination of Herceptin and DM1, a chemotherapy that interferes with cancer cell growth. The chemotherapy is not activated until it reaches the cancer cell, resulting in less toxicity to surrounding cells. T-DM1 is still being studied and is not yet standard as treatment for early stage breast cancer, though recent evidence suggests it may be effective if given after surgery.

PERJETA is the first drug specifically approved for neoadjuvant (before surgery) use in HER2+ early stage breast cancer. Also called pertuzumab, the drug targets the HER2 receptor (like trastuzumab) but at a different location on the cancer cell. In combination with trastuzumab, it therefore appears to result in even greater blocking of the HER2 receptor.

PARP INHIBITOR: PARP (Poly ADP-Ribose Polymerase) inhibitors are a targeted therapy that interfere with a cancer cell’s ability to repair itself. PARP inhibitors attack only cancer cells. Although these drugs showed mixed results in prior studies, it is believed that they hold promise in patients with BRCA1 and 2 mutations.

CDK 4/6 Inhibitors Cyclin Dependent Kinase (CDK) 4/6 inhibitors target enzymes that allow uncontrollable growth in breast cancer cells. Approved for use in metastatic breast cancer that is ER-positive, HER2-negative, these drugs are being studied in early stage breast cancer patients. Current CDK 4/6 inhibitors include palbociclib (Ibrance), ribociclib (Kisqali) and abemaciclib.

Radiation (Local) Therapy

Radiation therapy is standard treatment if you have had a lumpectomy. It may also be recommended in certain circumstances even if you had a mastectomy. You will see a radiation oncologist for radiation therapy. Radiation therapy, which you may also see abbreviated as RT or XRT, uses high energy x-rays directed at the breast, surrounding tissue and lymph nodes to kill any cancer cells that may have remained after surgery. Because RT is directed to the original tumor location, it is considered “local” therapy.

There are different types of radiation therapy treatments. Most commonly, it will involve an external beam that targets the cancer tissue, but radiation can also be delivered from inside your body through use of an implant. Neither type of treatment is painful; you won’t feel the radiation as it passes through.

With every type of radiation treatment, it is important to ensure the right area is targeted, while avoiding vital organs as much as possible. To help with this, there are several different methods your medical team might use.

These include:

- Surface Guided Radiation Therapy (SGRT) to help precisely target your cancer with sub-millimeter (the width of piece of paper) accuracy and can eliminate the need for permanent tattoos and marks.
- Immobilization devices to keep you from moving during treatment.
- The use of tattoos and marks to help align your body.
- The use of additional X-Ray imaging.

You will be given a CAT or CT scan to find the right places on your body to radiate. This will allow your doctor to see the inside of your body from many different angles. This will be key to your treatment plan.

Your radiation oncologist then uses those CT images to set up your treatment each day. Some centers may choose to use small permanent tattoos, dots of permanent ink about the size of a small freckle, to mark the spot to be radiated. Many women say that getting the tattoos feels similar to a pin prick. Other centers may use Surface Guided Radiation Therapy (SGRT) to set up, monitor, and track your positioning during treatment – this often means you won’t need tattoos or other marks.

One potential concern is the impact this radiation could have on your heart. One way to reduce the risk of this type of risk is to use a technique called Deep Inspiration Breath Hold (DIBH). With DIBH, you will be guided to hold your breath during treatment. When taking this breath in, your lungs will fill with air and your heart will move away from your chest wall. This separation will help keep the beam away from your heart and help prevent short and long-term side effects.

Parts of this section come from contributions by [SaferRadiationTherapy.com](https://www.saferadiationtherapy.com).

Other potential side effect or concerns

Your skin may become red or look sunburned during RT. Be sure to speak with your doctor or nurse about creams you can use to protect your skin, as well as other recommendations to avoid irritating your skin (such as use of certain types of deodorant.)

If you are in the process of undergoing reconstruction with implants or plan to do so in the future, be sure that your radiation oncologist is aware of this and has communicated with your surgeon and plastic surgeon. RT can sometimes cause complications with implants and there may be steps that can be taken prior to RT to try to minimize or avoid those complications.

How long you will be treated for depends on the kind of treatment you receive. Because there are different types of radiation for breast cancer, ask your doctors to let you know what to expect and take the opportunity to ask them to explain why they have recommended a certain kind of treatment for you.

TIP

- Ask your doctor about using complementary and alternative medicine (CAM) such as acupuncture and meditation to combat side effects. For more information: nccam.nih.gov/health/whatiscam.
- Don't be afraid to ask friends or family for help. There are online tools that can be used to help friends organize assistance such as LotsaHelpingHands.com.
- Easily keep family and friends updated using websites such as CaringBridge that allow you to post regular updates, which people (whom you've invited) can see.

Clinical Trials

Clinical trials are crucial to breast cancer research and advances. It is through clinical trials that doctors can identify new surgeries, medicines, treatments, relief of side effects, and breast cancer prevention. These studies are the final steps in developing new treatments or methodologies. As such, it is often the most cutting edge treatment offered. By examining the results of clinical trials, doctors can find better ways to treat cancer and take care of their patients. The more people who participate in clinical trials, the faster we can learn what does and does not work.

Most trials you may hear about are for the treatment of breast cancer. In most treatment trials, patients receive either the standard treatment (what is currently being used) or a new treatment that looks promising.

All clinical trials must be run pursuant to regulations of the US Food and Drug Administration, and the hospitals or cancer centers where the clinical trials take place must also approve the trial.

The possible benefits of participating in a clinical trial are helping to advance the state of knowledge and treatment of breast cancer, as well as having access to a new treatment or advance before it is otherwise available. Possible risks include side effects and that the new treatment may not work. Before you participate in any clinical trial, the possible risks and benefits of that trial should be discussed with you in detail.

Clinical trials are for patients with all stages of cancer. Ask your doctor if there are any trials that may be right for you. You can also search on clinicaltrials.gov or breastcancertrials.org for trials that fit your type of breast cancer. For more information on clinical trials, please visit: cancer.gov/about-cancer/treatment/clinical-trials.

Side Effects

Each treatment carries a risk of possible side effects, and these side effects vary widely from person to person and treatment to treatment. It is important to always ask your doctors what possible side effects you may encounter at each step and what you can do to prevent or lessen them. All patients have access to palliative care services, which may help alleviate some treatment side effects. Ask your doctor about what is available to you. A discussion of every possible side effect you may encounter is beyond the scope of this Navigator. However, here are some of the more common ones:

FATIGUE: The stress of diagnosis as well as the surgery and treatments themselves can leave you feeling very rundown and tired. This is normal. Get as much rest as you can, eat well, and stay hydrated. Light exercise, like walking, can also help.

HAIR LOSS: A side effect of many chemotherapy drugs is hair loss, and this can be especially devastating for a young adult. Preparation is key in dealing with this issue. Speak with your nurse or doctor about whether you will lose your hair, and when you can expect it to occur. Preparations such as getting wigs, scarves, hats, or having a shaving party before any hair loss occurs can help you regain a sense of control. Speaking with other young adults who have gone through this or are currently going through this can also be helpful. Note that many insurance companies will cover some or all wig expenses, but you may need a prescription from your doctor to get coverage. Recent innovations in hair loss prevention include “cold caps,” which patients wear on their heads during chemotherapy. The Paxman and DigniCap systems have been approved for use by the FDA. Speak with your doctor about whether this may be an option for you. Cold caps may not work with all chemotherapies, especially anthracyclines such as adriamycin. Also check to see whether this will be covered by your insurer.

NEUROPATHY: Some chemotherapy drugs (typically taxanes) can cause pain, numbness and tingling, especially in your hands and feet. Be sure to report any such symptoms to your doctors. S/he may have suggestions on how to ease the symptom, or if the neuropathy is especially bad, s/he may even lower your chemo dosage.

EARLY MENOPAUSE/AMENORRHEA: Chemotherapy and other breast cancer treatments can cause your menstrual periods to stop (amenorrhea). In some cases, this will be temporary and your periods will return after treatment has concluded. In other cases, it can be permanent and may put a young adult into early menopause. There is no way of knowing for certain before treatment who will be put into menopause and who will not. But generally, the younger you are, the greater the chance of your periods returning. A tool by Livestrong Fertility can help estimate this risk (teamlivestrong.org/we-can-help/fertility-services/risks/), but not all chemotherapy drugs are listed. Recent studies have shown that use of paclitaxel (Taxol) and trastuzumab (Herceptin) in HER2+ patients appears to cause lower rates of amenorrhea (which is associated with infertility and menopausal symptoms) than other standard chemotherapies.

HOT FLASHES: Hormonal therapy, chemotherapy and early menopause/amenorrhea can cause you to experience hot flashes – sudden bursts of body heat during which you may become overheated, flushed and sweaty. Hot flashes often occur at night and can interfere with your sleep. They are a normal and common side effect. If they become particularly bothersome, speak with your doctor about possible options to help reduce them. If it is your hormonal therapy causing the hot flashes, taking it at a different time of day could help reduce them. If you are suffering hot flashes at night, sleep in cotton layers, and keep the temperature in your room cooler if possible.

NAUSEA AND VOMITING: Nausea and vomiting can be side effects of chemotherapy, some medications and anesthesia. If you will be receiving a chemotherapy drug that is likely to cause nausea or vomiting, your doctor will prescribe anti-nausea medications prior to the start of treatment. Be sure to take the medications as recommended. Do not wait until you become nauseated because at that point it is difficult to control it. Staying hydrated by drinking lots of water during treatment can also help reduce symptoms. Keep your doctor informed of the extent to which you experience nausea and/or vomiting. S/he may be able to switch your medications or make other recommendations on how to reduce your symptoms. You may also ask for a recommendation or referral to an oncology dietitian who can help you make food choices that may alleviate symptoms.

Emotional Effects

A cancer diagnosis is devastating for the patient, as well as family members and friends. It is normal to feel sad, angry and overwhelmed. The medications and/or chemotherapies that you may take can increase these depressed and anxious feelings.

It can be helpful to connect with other young breast cancer patients and survivors who understand what you're feeling. To connect online, visit the the discussion boards at community.youngsurvival.org or request a connection through SurvivorLink, support@youngsurvival.org or 877.972.1011. To connect in person, find a Face 2 Face group located near you: youngsurvival.org/meet-in-person. Our searchable online ResourceLink directory also includes other places to find emotional support.

If you feel sad for a long period of time or it is interfering with your daily living, contact your doctor or nurse as soon as possible. They can discuss the situation with you and make recommendations, which may include meeting with a counselor or taking medication. If, at any time, you should have thoughts of suicide, call the National Suicide Prevention Lifeline at 1-800-273-TALK.

A Counselor Can Help

Being diagnosed with cancer brings an understandable wealth of emotions to the surface. Some of them, like depression, can be a brand new and confusing experience. An oncology social worker or licensed therapist may be able to help. Ask if you have an oncology social worker available to you, as counseling services are often provided at no cost to you. Therapists may provide a sliding fee scale.



Some topics you may discuss with your counselor:

1. How can you help me cope with my fear?
2. I'm not able to take care of all of my responsibilities. How do I deal with that?
3. I think I may be anxious or depressed.
4. Roles at home and work have shifted.
5. I can't sleep.

Helping Kids Cope with Breast Cancer

Trying to raise your children while dealing with a cancer diagnosis is challenging. Your children may have many questions and concerns, and they may feel scared.

Every family situation and every child is different. Generally, it is best to tell your children about your cancer and what you may be going through in a straightforward, age-appropriate manner. Kids are very intuitive and will know that something is going on, even if you don't say anything. YSC's searchable online ResourceLink directory includes resources that can assist you in talking to your children and organizations that may offer them support.

15 Tips To Help Children Cope with Breast Cancer

1. Plan the conversation in advance.

Plan what you are going to say and how you are going to say it. Consider practicing in the mirror. Know your child's prior knowledge and experiences with cancer (e.g., grandparent who passed away due to cancer) and be prepared for tough questions that may arise.

2. Provide age-appropriate information.

Younger children will not understand cancer-related terms like chemotherapy and radiation, while older children may need and want these details. Don't be surprised if teenagers talk to their friends rather than you.

3. Give "headlines."

Let children's questions guide the rest of the conversation to help prevent them being overwhelmed with information.

4. Keep communication lines open.

After you tell your children about your diagnosis and treatment, check in and keep lines of communication open. Tell them it's okay if they don't have anything to say, but let them know that you will check in with them on a regular basis.

5. Be honest.

Naming the illness is important. Say cancer; it should be out in the open. This helps prevent children from creating ideas of something much worse than reality or magical thinking (e.g., "If I am good, Mommy will get better").

6. Explain how cancer treatment will affect you.

Tell children how treatment for cancer will affect you. Prepare them for potential side effects of treatment, such as hair loss due to chemotherapy and feeling sick or tired at times. Use of the term “treatment” may be preferable to “medicine.” It will be less likely to confuse children, who also take medicine and may fear that they will experience the same side effects as mom.

7. Use an optimistic approach, while not making promises.

Use a calm, reassuring voice, even while you may show emotion or become sad.

8. Reassure children that their needs will be met.

Since you may not always be able to care for them during treatment, tell them about the trusted friends, relatives, or others who will help out until you feel strong again.

9. Make it clear it's not their fault.

Make sure children know that the cancer is not their fault.

10. Tell them cancer is not contagious.

Children may be worried that they can catch cancer and should be reassured that cancer does not spread from person to person like a cold.

11. Keep usual routines in place.

Maintain normal schedules and structure where possible. This will create a sense of safety and reassurance for your children better than giving them special privileges or treats.

12. Enjoy time when cancer isn't the main focus.

Restrict phone calls and visits during meals or around bed time, so that you can focus on the children instead.

13. Inform others.

Let teachers, school counselors, coaches and other caregivers know what is going on. They can help you know how your child is doing and can become a source of support.

14. Be prepared for regression.

Regression or backsliding to an earlier development phase is common for kids under stress. Teenagers may “act out.” If you notice that your child still isn't him or herself after two to three weeks, then it may be time to talk with a counselor or pediatrician.

15. Encourage other forms of expression.

Provide opportunities for children to express their feelings such as talking, art, dance, music, journaling, or playing. Many local communities have programs for children whose parents are undergoing cancer treatment.

Pregnancy

A breast cancer diagnosis during pregnancy can make one of the happiest times of your life feel scary. Did you know that breast cancer is the most common form of cancer in young adults who are pregnant or have recently given birth, occurring once in every 3,000 pregnancies?



While a diagnosis during pregnancy requires special considerations, in most cases, the pregnancy can continue and you can receive some form of surgery or treatment before the baby is born and more afterward.

Connect to another young adult who knows what it's like to face breast cancer during pregnancy. YSC has trained SurvivorLink volunteers who were diagnosed with breast cancer while pregnant, and they are available to talk and provide hope. Contact support@youngsurvival.org or 877.972.1011 to connect with another young survivor.

One of YSC's partner organizations, Hope for Two, also offers several services including peer support, an international registry and connection to a Maternal Fetal Medicine physician who offers guidance to young adults and/or their physicians. Learn more at hopefortwo.org.

TIP

Take it one day at a time! Only think about getting through the day, not the rest of the journey.

Glossary



Glossary

A

ADJUVANT THERAPY

Additional treatment such as radiation or chemotherapy given after surgery to lower the chance of cancer coming back. Adjuvant chemotherapy is given after surgery in breast cancer.

AMENORRHEA

The absence or halting of the menstrual cycle in premenopausal young adults.

AMERICAN SOCIETY OF CLINICAL ONCOLOGY (ASCO)

A professional organization that represents doctors who treat cancer patients. ASCO has an annual conference in June at which new research results are shared.

ANGIOGENESIS

The formation of new blood vessels that cancer cells need to grow.

ANTHRACYCLINES

A type of antibiotic that comes from certain types of *Streptomyces* bacteria. Anthracyclines are used as chemotherapy to treat many types of cancer. Anthracyclines damage the DNA in cancer cells, causing them to die. Doxorubicin (trade name Adriamycin) and epirubicin are both anthracyclines.

ANTIBODY DRUG CONJUGATE (ADC)

A new class of targeted therapy drugs, where a very strong chemo drug is attached to an antibody that targets and binds to a specific cancer cell protein or receptor. The chemo is delivered directly to the cancer cell and is not activated until it reaches it.

ANTIEMETICS

Medications that reduce nausea and vomiting.

AREOLA

The ring of pigmented skin surrounding a nipple.

AROMATASE INHIBITOR (AI)

A drug that stops the production of estrogen, a female hormone, by interfering with an aromatase enzyme. Aromatase inhibitors are used as a type of hormone therapy for postmenopausal adults who have hormone-dependent breast cancer.

ATYPICAL CELLS

Cells that are not typical, are abnormal. Atypical is often used to refer to the appearance of precancerous or cancerous cells.

AUTOLOGOUS OR AUTOGENOUS

Coming from one's own tissue/body. Autologous breast reconstruction uses the patient's own tissue to rebuild a breast.

AXILLA

The armpit area.

AXILLARY LYMPH NODE DISSECTION

The surgical removal of most or all of the lymph nodes in the axilla for the purpose of examining the lymph nodes to determine if cancer is present, and/or to remove cancer that may have traveled there from the original breast tumor. See Sentinel Lymph Node Biopsy.

AXILLARY LYMPH NODE INVOLVEMENT

The spread of cancer from the primary tumor to the axillary lymph nodes, which are located in the armpit area. The axilla is typically the first site of spread of breast cancer.

AXILLARY WEB SYNDROME

Also called cording, this is a potential side effect from lymph node biopsy or breast surgery. A weblike structure develops in the armpit area and may extend down the arm. The patient may be able to see what looks like a cord underneath the skin. It may be painful, feel extremely tight, and make it difficult to extend or use your arm. It is not known why this side effect may arise, but its effects can be lessened with stretching, physical therapy or the use of a lymphedema therapist.

B

BENIGN

Not cancerous.

BILATERAL

Affecting both sides of the body.

BIOLOGICAL THERAPY

Also known as immunotherapy or biotherapy, this term refers to treatments designed to use the body's immune system (either directly or indirectly) to fight cancer or reduce side effects of cancer treatment. Cancer vaccines, now in development, are a type of biological therapy as is Herceptin, a common treatment for those with HER2+ breast cancer.

BIOPSY

The removal of a sample of tissue or even the whole tumor for examination under a microscope to check for cancer cells. Physical exam and imaging can show that something abnormal is present in the breast, but a biopsy is the only sure way to know whether the problem is cancer.

BISPHOSPHONATES

A group of drugs routinely used in the treatment of osteoporosis. In cancer, bisphosphonates may reduce the incidence of metastasis to the bones and, when cancer has spread to the bones, they have been shown to prevent fractures, promote healing and reduce pain.

BONE SCAN

A nuclear imaging test that may be performed to look for the spread of cancer to the bones. Sometimes performed as part of the initial cancer staging.

BOOST DOSE

An extra dose of radiation administered in addition to the regular dose.

BRCA1 AND BRCA2

Abbreviations for Breast Cancer Genes 1 and 2. These genes located on chromosome 17 and 13, respectively, help to suppress tumor growth under normal circumstances. However, an individual with a BRCA 1 or 2 mutation (altered version of the gene) has a significantly higher risk of developing

breast, ovarian, and other cancers. Approximately 5-10% of breast cancers are due to BRCA mutations. These mutations can be inherited from either parent.

BREAST-CONSERVATION THERAPY (BCT)

Treatment for early-stage breast cancer involving surgery, in which the tumor and a portion of the surrounding breast tissue are removed, followed later by radiation therapy. Lumpectomy is a type of breast-conserving surgery. For many young adults with small tumors, BCT represents an effective and appealing alternative to mastectomy (surgical removal of the entire breast), allowing good disease control and improved cosmetic results.

BREAST IMPLANT

A sac used to increase breast size or restore the contour of a breast after mastectomy. The implant shell is made of silicone and the sac is filled with either sterile saltwater (saline) or silicone gel.

C

CAPSULAR CONTRACTURE

Scar tissue formation around the implant that tightens and squeezes the implant. It can be painful. Possible side effect from the implant form of breast reconstruction.

CHEMOTHERAPY

Often referred to simply as chemo. The use of drugs to kill cancer cells. Chemotherapy can be taken orally or by needle into a vein or muscle. Chemotherapy is called a systemic therapy because the drugs enter the blood stream and travel throughout the body. Chemotherapy can therefore kill cancer cells outside of the breast.

CLINICAL TRIALS

Studies of new treatments, methodologies, side effect relief or prevention of cancer in patients. Clinical trials are only done when there is a reason to believe that the treatment being studied may be of value to patients.

CLINICALLY SIGNIFICANT FINDINGS

Findings considered important on clinical evaluation.

COINSURANCE

The share of the costs of a healthcare service paid by the insured, usually stated as a percentage.

COLLOID BREAST CANCER

Also called mucinous breast cancer, this is a form of invasive ductal carcinoma that makes mucus. It is typically less aggressive than other forms of breast cancer.

COMORBID

The presence of additional or coexisting disease. Comorbidity may be considered a factor in prognosis. For example, if you have diabetes in addition to breast cancer, diabetes is a comorbid condition that must be taken into consideration when making treatment decisions for your breast cancer.

CONTRALATERAL

Affecting or located on the opposite side of the body. The opposite of ipsilateral (same side).

COPAYMENT (COPAY)

A set out-of-pocket amount paid for a covered healthcare service.

CORDING

See Axillary Web Syndrome.

CT SCAN

A series of detailed pictures of areas inside the body taken from different angles. The resulting 3D images are created by a computer linked to an x-ray machine. Also called CAT scan, computed tomography scan, and computerized axial tomography scan. CT scans are generally used to determine if cancer has spread.

CYST

A closed sac or capsule, usually filled with fluid or semisolid material. Breast cysts are benign (not cancer).

D

DCIS

Ductal carcinoma in situ. Often referred to as pre-cancer, DCIS is the term for a type of breast cancer still contained in the ducts of the breast. DCIS is Stage 0 breast cancer.

DEDUCTIBLE

The amount paid by the insured for healthcare services before the insurance plan starts to pay.

DIEP (DEEP INFERIOR EPIGASTRIC ARTERY PERFORATOR) FLAP

A type of breast reconstruction in which blood vessels called deep inferior epigastric perforators (DIEP), and the skin and fat connected to them are removed from the lower abdomen and used to recreate the breast. Muscle is left in place.

DONOR SITES

In reconstruction, this term means the place on your body from which tissue and/or muscle is removed to reconstruct a breast mound. The abdomen, back, buttocks and thighs are common donor sites for breast reconstruction.

DOSE DENSE CHEMOTHERAPY

An aggressive treatment plan in which chemotherapy is given every two weeks (instead of every three weeks). Dose dense is more commonly used in younger adults.

DYSPLASIA

Cells that look abnormal under a microscope but are not yet cancer.

E

ENDOCRINE THERAPY

Treatment that adds, blocks or removes hormones. To slow or stop the growth of certain cancers (such as prostate and breast cancer), synthetic hormones or other drugs may be given to block the body's natural hormones. Sometimes surgery is needed to remove the gland that makes a certain hormone. Also called hormonal or hormone therapy.

ERBB2

See HER2/neu.

ESTROGEN-RECEPTOR STATUS

This refers to whether the tumor is ER-positive or ER-negative. Estrogen receptors allow the hormone estrogen to attach and activate the cell.

ESTROGEN RECEPTOR-POSITIVE (ER+)

This is an indication of whether the individual cancer cells in the tumor express an estrogen receptor, which means that they are receptive and sensitive to estrogen. Many breast cancer treatments include the use of drugs such as tamoxifen that block the receptors in the cancer cells and prevent estrogen from getting to them.

EXCISION

The act of cutting out; the surgical removal of part or all of a structure, such as a breast mass.

EXPANDER

See Tissue Expander.

EXTENSIVE INTRADUCTAL COMPONENT (EIC)

Extensive intraductal component. The term used to describe situations in which 25% or more of the primary tumor consists of DCIS, and in which DCIS is seen in ducts extending beyond the primary mass. EIC is more common in young patients and is associated with a higher risk of local recurrence.

F

FIBROADENOMA

Benign (not cancerous) solid tumor in the breast. More common in young adults.

FINE-NEEDLE ASPIRATION (FNA)

A type of biopsy to determine if cancer is present. A thin needle is inserted into the suspicious area and a sample of the cells removed.

FISH (FLUORESCENCE IN SITU HYBRIDIZATION)

A type of lab test to detect a protein called human epidermal growth factor receptor-2 (HER2). If too much of this protein is produced, the tumor is considered HER2 positive. The FISH test will give a result of positive (HER2 is over-expressed) or negative.

FLAP

A segment of tissue that contains skin, fat and occasionally muscle that is surgically removed from another part of the body. It can be a pedicle (remains attached and then tunneled under the skin to the new position) or free flap (unattached and moved to another location).

G

GENES

Basic unit of heredity, genes are made up of DNA. Everyone has two copies of each gene, one inherited from each parent.

GENETIC TESTING

A form of medical testing that looks for changes or alterations in a person's genes that may make them more susceptible to certain diseases such as cancer.

GAP (GLUTEAL ARTERY PERFORATOR) FLAP

A muscle-preserving form of breast reconstruction in which fatty tissue is taken from the gluteal (buttocks) area to create a new breast mound.

GLUTEAL FLAP

A newer type of flap reconstruction procedure that uses tissue and gluteal muscle from the buttocks to create the breast shape.

H

HER2/NEU (HUMAN EPIDERMAL GROWTH FACTOR RECEPTOR 2)

A protein involved in normal cell growth. It is found on some types of cancer cells, including breast and ovarian. Cancer cells removed from the body will be tested for the presence of HER2/neu to help decide the best type of treatment. If too much of the HER2 protein is produced, the tumor is considered HER2 positive, also called ERBB2.

HORMONE RECEPTOR

A protein on the surface of a cell to which a specific hormone binds. The hormone causes many changes to take place in the cell. When a breast cancer is hormone receptor positive, these receptors allow estrogen or progesterone to "feed" the cancer cells.

HORMONE (HORMONAL) THERAPY

See Endocrine Therapy.

I

IMAGING

Any one of a variety of radiologic techniques, including x-ray, mammography and MRI, used to visualize the breast tissue in order to detect or evaluate any visible, suspicious masses.

IMMUNOHISTORY (IHC)

A type of laboratory test used by pathologists to examine a tissue specimen and determine if cancer is present and if so, what type of cancer. For example, IHC can be used to determine if a breast cancer is HER2 positive (HER2+).

INCIDENTAL FINDINGS

Findings made while looking for something else; findings that occur by accident.

INFLAMMATORY BREAST CANCER (IBC)

An aggressive form of breast cancer that occurs when cancer cells block the lymphatic vessels in the skin of the breast. The breast may swell, redden or look like it has an infection. There may not be a lump.

IN SITU

A latin phrase that means "in position." Breast cancer that is in situ remains in the location it started and has not spread into surrounding tissue.

INVASIVE

A term used in breast cancer to describe cancer cells which have spread beyond the duct or lobule where they started and into surrounding tissue.

INVASIVE/INFILTRATING DUCTAL CARCINOMA (IDC)

One of several specific patterns of breast cancer. It begins in the cells of the breast ducts and spreads into the surrounding breast tissue. An estimated 65% to 85% of all breast cancers are of this type.

INVASIVE/INFILTRATING LOBULAR CARCINOMA (ILC)

One of several specific patterns of breast cancer.

It begins in the cells of the breast lobules and spreads into surrounding breast tissue.

IPSILATERAL

Affecting or located on the same side of the body. The opposite of contralateral (the other or opposite side).

K

KADCYLA

See T-DM1.

L

LAT (LATISSIMUS) FLAP

A form of breast reconstruction that tunnels the latissimus dorsi muscle, fat and skin from the upper back to the chest to create a breast mound. An implant is still usually required for reconstruction to add volume to the breast mound.

LCIS (LOBULAR CARCINOMA IN SITU)

A type of breast cancer that starts in the lobules of the breast and is still contained there. It has not spread into surrounding tissue.

LOBULES

The glands in the breast that make milk.

LOCAL-REGIONAL RECURRENCE RATE

The rate at which cancer cells from the primary tumor occur again, at a later time, in the same area as the original tumor. See Recurrence.

LUMPECTOMY

A type of breast-conservation therapy in which the tumor is removed, along with some surrounding tissue. Lumpectomy is typically followed with radiation to the breast area. See Breast-Conservation Therapy.

LYMPH NODES

Part of the body's lymphatic and immune system, they filter out harmful substances (including cancer cells) from lymphatic fluid. We have hundreds of lymph nodes throughout our body.

LYMPHATIC INVASION

Sometimes called lymphovascular invasion, it is one of the many factors that the pathologist

looks for when evaluating tissue from the primary tumor obtained by biopsy. If cancer cells are seen (under the microscope) in the middle of a blood vessel or a lymphatic vessel, this is called vascular invasion or lymphatic invasion. Such invasion in the primary tumor suggests that the cancer is potentially more dangerous than if there is no such invasion, as there is a greater likelihood of the cancer moving, via the lymphatics, to the lymph nodes in the axilla.

LYMPHEDEMA

A condition involving swelling of the arm that can follow surgery to the axillary lymph nodes or radiation. It can be temporary or permanent and may occur soon after surgery or at a much later date.



MAGNETIC RESONANCE IMAGING (MRI)

A test performed by radiologists to look for injuries or diseases such as cancer. MRI uses magnetic field and radio waves to create a detailed picture of the organs and tissue in your body. A breast MRI may be used to look for tumors. MRI of other parts of your body can be used to look for injuries or metastases.

MAMMAPRINT

Similar to Oncotype DX, this diagnostic test estimates the risk of a distant recurrence and provides guidance on whether or not chemotherapy could benefit the patient. MammaPrint can be used in adults with stage I or II, invasive breast cancer under 5 cm in size, that is ER+ or ER-. The test will state whether there is a low or high risk of recurrence if no additional treatment is given beyond surgery. This information is used to make an informed decision about whether or not chemotherapy should be given.

MAMMOGRAM

A low-dose x-ray of the breast used to look for presence of disease.

MAMMOSTRAT

A diagnostic test similar to Oncotype DX and MammaPrint. It estimates the risk of recurrence

of early stage ER+ breast cancer, providing a risk index score of high, moderate, or low. This information can be used to make decisions regarding chemotherapy.

MARGINS

This term refers to the area of normal, noncancerous breast tissue between the tumor and the surgeon's knife. Tumor margins are examined following removal of the tumor to see whether they are free of cancer cells. The role of margins as a predictor of local recurrence is an important and controversial issue.

MASTECTOMY

Surgery in which the entire breast, nipple and areola are removed for the purpose of removing breast cancer.

MEDULLARY BREAST CANCER

A rare form of invasive ductal breast cancer that resembles the color of brain tissue (the medulla) under the microscope. It is usually triple negative, more common in adults with a BRCA mutation and less likely to have lymph node involvement.

METASTASIS

The spread of cancer from one part of the body to another. Plural is metastases.

METASTATIC BREAST CANCER

Breast cancer that has spread from its original location, beyond the axillary lymph nodes, to other places in the body. Also called stage IV breast cancer.

MUCINOUS BREAST CANCER

See Colloid Breast Cancer.

MICROMETASTASIS (MICROMET)

An extremely small number of cancer cells that have moved from the original tumor location. With advanced technology, it is now possible to pick up a micrometastasis in lymph nodes, for example.

MUGA (MULTIGATED ACQUISITION) SCAN

This is a test to determine the health of your heart. It may be ordered before chemotherapy to ensure there are no preexisting heart problems or after chemotherapy to check for heart damage.

MULTICENTRIC DISEASE

The meaning of this term, along with that of multifocal disease, is subject to variation. In general terms, multicentric disease involves two or more distinct primary tumors found within the breast, usually in different quadrants of the breast.

MULTIFOCAL DISEASE

The meaning of this term, along with that of multicentric disease, is subject to variation. In general terms, multifocal disease refers to multiple breast tumors, all of which arose from one original tumor, typically in the same quadrant of the breast.

N

NECROSIS

Dead tissue.

NEOADJUVANT CHEMOTHERAPY

Chemotherapy taken before surgery.

NEUROPATHY

A nerve problem that causes pain, numbness, tingling, swelling, or muscle weakness in different parts of the body. It usually begins in the hands or feet and gets worse over time. Neuropathy may be caused by some cancer treatments such as chemotherapy. Also called peripheral neuropathy.

NEUTROPENIA

A condition in which there is a lower-than-normal number of neutrophils (a type of white blood cell). It may occur as a result of chemotherapy.

NIPPLE SPARING MASTECTOMY

A mastectomy in which the nipple and areola are not removed.

NODE POSITIVITY

A finding of cancer cells in the lymph nodes indicating that the cancer has a higher risk of spreading to other parts of your body.

O

ONCOLOGIST

A doctor who specializes in treating cancer. Some oncologists specialize in a particular type of cancer treatment. For example, a radiation oncologist specializes in treating cancer with radiation.

ONCOTYPE DX TESTING

For early stage breast cancers (stage I or II) that are node negative, ER+, and invasive. The test will produce a recurrence score between 0 and 100. The higher the score, the greater the risk of recurrence. See page 28 for more information.

OOPHORECTOMY

Removal of the ovaries.

OVARIAN SUPPRESSION

The use of chemicals, radiation or surgery on the ovaries to halt their functioning and thereby “shut off” the menstrual cycle.

OVEREXPRESSION

The excess of a particular protein on the surface of a cell. Overexpression of certain proteins is associated with the growth of cancer cells.

P

PAGET'S DISEASE

A form of breast cancer in which the tumor grows from ducts beneath the nipple onto the surface of the nipple and/or skin of the areola. Symptoms commonly include itching and burning and an eczema-like condition around the nipple, sometimes accompanied by oozing or bleeding.

PALLIATIVE THERAPY

Treatment given to relieve the symptoms and reduce the suffering caused by cancer and other diseases. Palliative cancer therapies are given together with other cancer treatments, from the time of diagnosis through treatment, and beyond.

PATHOLOGIST

A physician who examines tissue and performs laboratory tests to diagnose disease and extent of disease.

PATHOLOGY

A field of medicine which examines body tissues, fluids, and organs to look for the presence of disease and to provide additional information about that disease.

PEGFILGRASTIM

A drug given by injection that helps to maintain or restore your white blood cell count, which may lower as a result of chemotherapy.

PERJETA

A new drug specifically approved for neoadjuvant use (before surgery) in HER2+ early stage breast cancer. This drug is a type of targeted therapy that targets the HER2 receptor (like Herceptin) but at a different location on the cancer cell.

PERTUZUMAB

See Perjeta.

PET (POSITRON EMISSION TOMOGRAPHY) SCAN

A procedure in which a small amount of radioactive glucose (sugar) is injected into a vein, and a scanner is used to make detailed, computerized pictures of areas inside the body where the glucose is used. Because cancer cells often use more glucose than normal cells, the pictures can be used to find cancer cells in the body.

PHYLLODES TUMOR

A rare form of breast cancer that begins in the connective tissue of the breast, not in a duct or lobule. Phyllodes tumors are typically fast-growing. They may be benign (not cancer) or cancerous.

POLY ADP-RIBOSE POLYMERASE (PARP) INHIBITOR

A type of targeted therapy that interferes with a cancer cell's ability to repair itself. PARP inhibitors are used in patients with BRCA1 and BRCA2 mutations.

PORT

An implanted device through which blood may be withdrawn and drugs may be infused without repeated needle sticks. Also called port-a-cath.

PROGESTERONE-RECEPTOR STATUS

This refers to whether the tumor is PR-positive or PR-negative. Progesterone receptors allow the hormone progesterone to attach and activate the cell.

PROGESTERONE RECEPTOR-POSITIVE (PR+)

An indication of whether the cancer cells in the tumor express a progesterone receptor, which means they are receptive and sensitive to progesterone, a hormone that regulates important functions in a female.

PROGNOSIS

A forecast of the likely course of a disease. The prospect of recovery from a disease as indicated by the nature and symptoms of the case.

PROPHYLACTIC MASTECTOMY

Surgery to reduce the risk of developing breast cancer by removing one or both breasts before disease develops.

PROSTHESIS

A device that replaces a missing body part or makes a body part work better. In the context of breast cancer, a breast prosthesis usually refers to a soft form that can be placed in a bra or bathing suit to replace a breast. It can be made of silicone, fiberfill, or foam. Also called a breast form.

**QUADRANT**

The breast is spoken of in clinical terms as having four quarters, known as quadrants: the upper-outer, the upper-inner, the lower-outer and the lower-inner quadrants.

R

RADIATION ONCOLOGIST

A medical doctor who treats cancer using radiation.

RADIATION THERAPY (RT)

Treatment with high-energy rays (e.g., x-rays) to the breast to kill any remaining cancer cells and decrease the risk of cancer recurrence. Also called radiotherapy. Radiation therapy to the breast area is given after lumpectomy and sometimes after mastectomy. Radiation therapy can also be used on metastases.

RECONSTRUCTION

Rebuilding of the breast mound after mastectomy. Reconstruction can be immediate, at time of mastectomy, or delayed and done at a later time.

RECURRENCE

Cancer that has recurred (come back), usually after a period of time during which the cancer could not be detected. The cancer may come back to the same place as the original (primary) tumor or to another place in the body.

RE-EXCISION

A follow-up surgical procedure at the original tumor removal location site for the purpose of removing any residual tumor cells left behind during the initial surgery. A re-excision commonly occurs if your pathology report shows you had positive, close or unclear surgical margins, that is, there were tumor cells on the very edge of the tissue they removed in the first surgery. The tissue removed during the re-excision will be examined to ensure that all tumor cells have been removed.

REPRODUCTIVE ENDOCRINOLOGIST

A physician who specializes in reproductive medicine. This will be the specialist you consult with about preserving your fertility, if you desire to do so.

RESIDUAL TUMOR

Tumor cells that remain behind, after an initial attempt has been made to remove the cancer.

S

SENTINEL LYMPH NODE BIOPSY

A technique used in breast cancer to determine the presence and extent of cancer in the axilla. Prior to the procedure, dye is injected into the breast and the lymph nodes examined to determine which node(s) the dye travels to first. These are the sentinel lymph nodes that are removed and examined for the presence of cancer cells. It is based on the basic concept that the first lymph node in the axilla to receive drainage of lymph from the primary tumor will be the first node to harbor cancer cells. If no cancer cells are found in this "sentinel" node(s), the axilla is considered to be free of cancer and no further lymph nodes are removed. This technique is most successful for staging of early-stage breast cancers and for suitable candidates, it offers a less invasive alternative to axillary lymph node dissection.

SIEA (SUPERFICIAL INFERIOR EPIGASTRIC ARTERY) FLAP

A type of reconstruction very similar to the DIEP, in which skin and fatty tissue are removed from the lower abdomen to create a new breast mound. No muscle is taken from the donor site. The main difference between the SIEA and the DIEP is the artery used as the source of blood supply for the borrowed tissue. In the DIEP, the deep inferior epigastric artery is used and in SIEA, a superficial inferior epigastric artery is used. It is typically not known prior to surgery which artery will be used.

SKIN-SPARING MASTECTOMY

A mastectomy surgery that saves the skin envelope, typically resulting in minimal scarring and a better cosmetic outcome.

SUPRACLAVICULAR LYMPH NODES

Lymph nodes located above the clavicle (collarbone).

T

TAMOXIFEN

An anticancer drug that works by blocking the effect of the body's natural estrogen. In breast cancer treatment, tamoxifen can be used as a preventive agent to prevent the onset of breast cancer, or as adjuvant therapy to control the spread of breast cancer or delay/prevent its return. Tamoxifen is typically prescribed to premenopausal young adults who are ER-positive.

TARGETED THERAPY

A cancer treatment that acts on the cancer cells only and not all cells in the body. Herceptin is an example of a targeted therapy. Because these therapies work on the cancer cells only, they tend to have fewer side effects.

TAXANES

A type of chemotherapy drug that blocks cell growth by stopping mitosis (cell division). Taxol and Taxotere are two taxanes commonly used in breast cancer chemotherapy.

TISSUE EXPANDER

A balloon-type device used in the implant form of reconstruction by a plastic surgeon. During surgery, the tissue expander is inserted under the chest muscle. Over a period of three to six months, the plastic surgeon adds liquid to gradually increase the size of the expander. The skin and soft tissue is stretched to achieve your desired size and appearance. In a later surgery, the expander will be removed and replaced by a silicone or saline implant.

TRASTUZUMAB

A treatment that is used for HER2 receptor positive breast cancer. It is an antibody that attaches to HER2 cancer cells and blocks them from growing and dividing.

TRIPLE NEGATIVE BREAST CANCER

A type of breast cancer where the cancer cells tested negative for estrogen receptors (ER-), progesterone receptors (PR-) and HER2 (HER2-).

TUBULAR BREAST CANCER

A form of invasive ductal carcinoma made up of tube-like structures. This type of breast cancer tends to be small and slow-growing.

TUG (TRANSVERSE UPPER GRACILIS) FLAP

The transverse upper gracilis flap, or inner thigh flap. Skin, fat and a small amount of muscle is taken from the upper inner thigh, coned to create a projecting breast shape and transplanted to the chest to create a breast mound.

TRAM (TRANSVERSE RECTUS ABDOMINUS MYOCUTANEOUS) FLAP

A procedure that uses tissue and muscle from the lower tummy wall to reconstruct a breast mound. It can be a pedicle (attached and then tunneled) or free flap (unattached).

U

ULTRASOUND

Also called a sonogram, this medical test uses high-frequency sound waves to create a picture of some part of the inside of the body. In the context of breast cancer, an ultrasound may help determine whether a lump is benign or cancerous.

UNILATERAL

Having to do with one side of the body.

V

VASCULAR INVASION

See Lymphatic Invasion.



Questions For Your Doctors

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Your Breast Surgeon

Questions About Surgery

Where is my cancer located? _____

What kinds of surgery can I consider? _____

What type of surgery do you specialize in? _____

Which operation do you recommend for me? _____

How many operations of this type of surgery have you performed? _____

What are the potential risks and side effects of this operation? _____

Should I have any other tests before this surgery? _____

How long will the surgery take? _____

Will I need to be admitted into a hospital for this operation?
If so, how long will I need to stay in the hospital? _____

Will my health insurance cover the surgery? _____

What type of anesthesia will I need for this surgery? _____

What are the advantages and disadvantages of a lumpectomy or a mastectomy? _____

Do I need a mastectomy?
If so, would you recommend breast reconstruction immediately following the mastectomy? _____

Do you work with specific plastic surgeons, and can you recommend them? _____

Will I have any lymph nodes in my underarms removed? If so, how many? _____

What is a sentinel lymph node biopsy? Do you recommend this for me?_____

Should I consider chemotherapy before surgery?_____

What should I do to get prepared for the surgery?_____

Are there any medications and supplements I should stop taking before the operation? _____

How much time can I take before making a decision about surgery?_____

Questions About Recovery

How long is the recovery time, and when can I resume work and regular activities?_____

Will I need someone to help care for me after the surgery?_____

Is there anything I should be watching for (infection, redness, oozing) and when should I call you?_____

What will my chest look like immediately following surgery? Long term?_____

Will I have stitches, and how will I care for my surgical site?_____

Will I have surgical drains? How do I care for them?_____

When can I know the pathology test results from the surgery?_____

When will I need to return for a follow-up appointment with you?_____

Questions About Surgical Side Effects

Is there anything I can do to alleviate the side effects?_____

Will there be any permanent effects from the surgery?_____

What are the short- and long-term effects of having lymph nodes removed?_____

What is lymphedema and its long-term effects?_____

Based on the surgery to be performed, what is my level of risk for eventually having lymphedema?_____

Your Pathology Report

What kind of breast cancer do I have? Is it invasive?_____

What is the tumor size?_____

What is the stage of the disease, and what does this mean?_____

What is the grade of the disease, and what does this mean?_____

Is the breast cancer estrogen receptor-positive (ER+) or progesterone receptor-positive (PR+)?
What does this mean?_____

Is the cancer HER2 positive and what does this mean?_____

Were you able to remove all of the cancer from my breast?_____

What is the status of my lymph nodes? How many nodes are affected?_____

Has the cancer spread elsewhere in my body? _____

Are there areas of concern in my healthy breast? _____



TIP

DON'T FORGET! Ask for a copy of your pathology report.

Following Surgery

Will I need any additional surgery?_____

Will I need chemotherapy or radiation therapy?_____

How soon will I need to make a decision about additional treatment?_____

Should I see other doctors such as an oncologist and radiation oncologist?_____

Can you recommend an oncologist and radiation oncologist (if needed)? _____

Do you have a social worker and/or nurse navigator available to assist me with coordinating my care and recommending resources to help me?_____

Your Medical Oncologist

What tests or scans do I need to have? _____

Do I need more tests to find out if there is cancer anywhere else in my body? _____

Should I have genetic testing? _____

Should I consider my family's history of breast cancer in my treatment decision? _____

Has my ER/PR or HER2 status changed since diagnosis? (especially important to ask if your cancer is a recurrence)

Am I a candidate for a gene assay test (Oncotype DX, MammaPrint, Mammostrat or others)? _____

What are my treatment options, and which do you recommend? _____

Will my health insurance cover these treatments? _____

What is the expected timeline for each treatment option?_____

Are there any risks that I should know about?_____

Are there any experimental treatments I might consider?_____

If applicable, when should I see a fertility specialist?_____

If you have ER or PR-positive breast cancer, ask:

Will I need hormonal therapy such as tamoxifen? Why will I need this treatment?_____

What medicine will I be taking? How often and for how long?_____

What are the side effects of these medications?_____

What can I do to relieve side effects?_____

Do you recommend ovarian suppression? Why? _____

What type of chemotherapy will I receive and for how long? _____

How will the chemotherapy be given (IV, orally, or both)? _____

What are the short- and long-term side effects of chemotherapy? _____

How can I manage the side effects of treatment? _____

Will there be any restrictions on my daily life? _____

Will I be able to exercise? _____

Can I work while I am getting chemotherapy? _____

Will I lose my hair? If so, for how long?_____

Can I have sex? How will treatment affect my sex drive?_____

How will each treatment affect my daily life?_____

Could this treatment affect my fertility (ability to have children in the future)?_____

What are the success rates with these forms of treatment?_____

What are the chances of the cancer coming back again?_____

By how much will each of the treatments you are recommending reduce the chances of the cancer coming back again? (ask for percentages if possible)_____

What about my diet or nutrition during treatment? Should I see a nutritionist?

Do you have a social worker and/or nurse navigator available to assist me with coordinating my care and recommending resources to help me?_____

Can I try complementary treatments such as acupuncture or massage therapy?_____

How much time can I take before making any decisions?_____

After treatment, what type of follow-up care will be needed?_____

How often will I need to see a doctor? What tests, and how often will I need these?_____

Do you have any materials or suggested reading on my type of cancer?_____



TIP

Educate yourself! Always ask questions and demand an answer.

Clinical Trials

Is there a clinical trial right for me?_____

If I were a part of this trial, how would that impact your other treatment recommendations?_____

Why do you think I am a good candidate for this study?_____

What are the eligibility requirements?_____

What are the potential benefits and risks associated with the trial? Possible side effects?_____

What are the procedures, tests and treatments involved?_____

Who oversees my care, safety and review of the trial?_____

Will my insurance cover the costs and what costs am I responsible for?

How do I learn more about clinical trials?_____

Your Radiation Oncologist

What is radiation therapy? _____

What are the chances that this treatment will prevent the cancer from coming back?
(request percentages) _____

What is my chance of the cancer coming back if I do not have radiation therapy? _____

How many weeks will I receive radiation therapy? _____

How long will each visit take? _____

When will the treatment begin? When will it end? _____

Can I schedule treatments at a certain time of day? _____

What will happen during each visit? _____

Will you describe what I will experience when I receive radiation therapy? Will it hurt? _____

How will my normal tissue (heart and lung) be avoided by the radiation beam?_____

In which position will I be treated? On my back or on my stomach?_____

Why not on my stomach to best avoid lung and heart?_____

How will I know if the radiation is working?_____

Will there be any restrictions on my daily life?_____

Will I be able to work during radiation treatment?_____

Will I be able to exercise?_____

What are the short- and long-term side effects of radiation?_____

What can I do to minimize the side effects?_____

How do I get ready for this treatment?_____

How will my skin be affected during radiation therapy? How do I care for my skin during treatment?_____

Can I use my usual cosmetics (skin products, deodorant, soap, perfume) during treatment?_____

Do I need to be concerned about sun exposure?_____

Should I avoid certain foods, vitamins or supplements?_____

If I decide to have reconstructive surgery, how would that affect my treatment plan?_____

Will my health insurance cover these treatments?_____

Are there special services for patients receiving radiation therapy, such as certain parking spaces?_____

Your Plastic Surgeon

Are you board-certified?_____

Is breast reconstruction your specialty?_____

What are all of my options for breast reconstruction?_____

What type of surgery are you recommending and why?_____

What are the advantages and disadvantages of each type?_____

When can I have reconstruction?_____

How long will it take to complete my reconstruction surgery?_____

How much experience do you have with the reconstruction you are recommending?_____

Will I need surgery to the non-reconstructed breast to make my breasts symmetrical? _____

Can you show me photos of others who have had the type of reconstruction that you recommend?

If I have radiation therapy, does that change my options for reconstruction?_____

Is this surgery performed on an outpatient basis, or will I need to stay overnight in the hospital?_____

What are the possible complications for this type of reconstruction surgery?_____

How long will it take me to recover from the surgery?_____

What type of anesthesia will I need for this surgery?_____

TIP Don't forget to ask about post-surgical breast garments.
Often they will be covered by insurance.

Implant Reconstruction

What are tissue expanders and will I need them?_____

Will I need to have surgery again in the future to replace the implants? When?_____

What type of implants do you use? Saline or silicone?_____

How long does a saline/silicone implant last?_____

What are the advantages/disadvantages of each?_____

Which type of implants do you recommend and why? What size implants?_____

Will I have surgical drains, and what kind of post-operative care will be needed?

How long will I have the drains?_____

What will my reconstructed breast look and feel like after surgery?_____

Will there be a scar or other permanent effects from the reconstruction surgery?_____

What type of results can I expect? What changes can I expect over time?_____

When will I need to return for a follow-up appointment following surgery?_____

What can I expect if my weight changes or I become pregnant in the future?_____

What other physical limitations will I have post-surgery? _____

When can I resume my daily activities? Exercise?_____

What about my nipple? How will a nipple be created? When could I have a nipple reconstruction?_____

Will I have any feeling in the reconstructed breast and nipple?_____

How much will the surgery cost, and will it be covered by my insurance carrier?_____

A Second Opinion

Do you agree with the first diagnosis? _____

If not, what is your diagnosis and why? _____

What kind of treatment do you recommend and why? _____

Additional notes: _____

About Your Fertility

Discussions about your fertility concerns should occur as early in the process as possible. If your doctor does not mention fertility, and it is of concern to you, don't be afraid to speak up. Below are suggested questions for your surgeon, medical oncologist, and fertility specialist (reproductive endocrinologist).

Will my cancer treatments affect my fertility?_____

Is my cancer estrogen sensitive? If so, how does that affect my reproductive options - now and later?

Are there alternative ways to treat my cancer without compromising my fertility?_____

What are my fertility preservation options?_____

How much time do I have to preserve my fertility before I need to start my cancer treatments?_____

Can you refer me to a reproductive endocrinologist?_____

Does the reproductive endocrinologist offer discounts to cancer patients? _____

What are the risks and benefits of each fertility preservation option? _____

What is the probability of success of each option? _____

Which option would you recommend for me? _____

Is fertility preservation safe for me? Will it increase the risk of my cancer spreading? _____

What are the costs of each fertility preservation option? _____

Is fertility preservation covered by my insurance? _____

Are there resources or organizations that can assist me in paying for fertility preservation? _____

How will I know if I am fertile after treatment? Are there tests that I can take?_____

Are premature ovarian failure or hormone deficiencies possible side effects of my treatment?

If so, how do I treat them?_____

After my treatments are over, how long will it take for my periods to begin again?

If I am not having periods, should I still use contraceptives?_____

If I do not preserve my fertility, what are my parenthood options after treatment?_____

Is pregnancy safe for me after treatment?

If so, how long should I wait after treatment to become pregnant?_____

What are the risks to my future children based on my cancer and the treatment I receive?_____

How do I know if I am infertile or in menopause and whether it is permanent?_____

TIP Give yourself a break. Don't worry about trying to make it easy for everyone else around you. Sometimes you will feel sad and it is natural to grieve.

Your Genetic Counselor

Should I undergo genetic testing?_____

What are the risks and benefits of genetic testing?_____

Will my insurer cover the costs of genetic testing?_____

How is genetic testing done?_____

When can I expect my results?_____

What do my results mean?_____

How do these results impact my treatment plan?_____

Based on these results, are there any steps I should take to reduce my risk of another cancer diagnosis?_____

Based on these results, what kind of cancer screening and tests should I have and how often?_____

Will you share these results with my oncologist?_____

Does anyone else in my family need to be tested?_____

What resources can I provide them?_____

Should I share my test results with my family?_____

Do you have any recommendations on how to share my results with my family?_____

What is the possibility that my children could carry the same genetic mutation I have?_____

Are my genetic test results private? Can anyone use them against me (insurer, employer)?_____

Keeping Track

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My Pathology and Diagnosis

Cancer in left right both breasts

Number _____ and _____ location _____ of _____ tumors:

Type of Breast Cancer: DCIS IDC LCIS
 ILC Paget's Medullary
 Tubular Mucinous (Colloid) IBC
 Papillary Other

Tumor(s) size _____

Sentinal node biopsy: positive negative

Positive Nodes	_____ of _____
Tumor Stage	
Grade	
ER Status	
PR Status	
HER2 Status (IHC or FISH)	

MRI	
Bone	
PET	
CT	
Genetic Testing	
Other Testing	

My Treatment Plan

CANCER TYPE	
PRE-TREATMENT TESTS	
TEST	
DATE	
OUTCOME	
TEST	
DATE	
OUTCOME	
TEST	
DATE	
OUTCOME	
TEST	
DATE	
OUTCOME	

SURGERY	
SURGEON	
DATE	
TYPE	
OUTCOME	

CHEMO	
TYPE	
# OF CYCLES	
SPACING	
DOSAGE	
START	
FINISH	

CHEMO	
TYPE	
# OF CYCLES	
SPACING	
DOSAGE	
START	
FINISH	

TARGETED THERAPY	
TYPE	
# OF CYCLES	
SPACING	
DOSAGE	
START	
FINISH	

RADIATION	
TYPE	
NUMBER	
TOTAL DOSAGE	
BOOSTS	
START	
FINISH	

HORMONAL TREATMENT	
TYPE	
DOSE	
FREQUENCY	
START	
FINISH	

OTHER	
TYPE	
NUMBER OF CYCLES	
SPACING	
DOSAGE	
START	
FINISH	

CLINICAL TRIAL	
NAME OF TRIAL	
RESEARCH NURSE AND PRINCIPAL INVESTIGATOR	
INTERVENTION	
START	
FINISH	

Appointment Log and Notes

Doctor/procedure: _____

Date/time: _____

Purpose: _____

Questions: _____

Symptoms/concerns: _____

Medication changes/new prescriptions: _____

Test results: _____

Notes: _____

Decisions: _____

Follow up: _____

Medication Log

MEDICATION	DOSAGE	PRESCRIBED BY	START DATE	END DATE	PURPOSE

Health and Side Effects Diary

Use these pages to note how you are feeling on specific days during your treatment. This may help you see patterns in side effects and make you better able to explain issues to your healthcare provider.

MY PAIN SCALE: Grade your pain using the scale below. A value of 1 is minimal pain. A value of 10 is the most pain you have ever experienced.

NO PAIN 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 MOST PAIN YOU HAVE EVER EXPERIENCED

DATE	DAYS SINCE LAST TREATMENT	WHAT TREATMENT?	PAIN SCALE	SIDE EFFECTS

DATE	DAYS SINCE LAST TREATMENT	WHAT TREATMENT?	PAIN SCALE	SIDE EFFECTS

Health Provider Contact Log

DATE	PROVIDER	REASON	OUTCOME	FOLLOW UP

TIP Use this log any time you call or email to ask a question or speak to a nurse, doctor, etc.

Insurance Contact Log

Use this table to track issues with insurance claims and relevant communication with your carrier.

DATE	NAME	INVOICE #	DATE OF SERVICE	ISSUE	OUTCOME	NOTES

Insurance and Payment Log

USE THIS TABLE TO TRACK INSURANCE INVOICES, CLAIMS AND DETAILS OF YOUR VISIT.

DATE	PROCEDURE/ APPOINTMENT	PROVIDER	DATE OF INVOICE	INVOICE #	INVOICE FROM	INSURANCE BILLED	INSURANCE PAID DATE	BALANCE DUE	DATE PAYMENT MAILED/SUBMITTED	DATE PAYMENT RECORDED



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