FINDING *your* TRUE NORTH

A Survivor's Guide to Living Well

NORTHSIDE HOSPITAL
CANCER INSTITUTE

life after cancer

This booklet is designed for adults who have finished their cancer treatment(s). You will learn about ways that life and health care might change for you. You will find practical suggestions to help you manage the issues you might be experiencing.

You can share this booklet with your family and friends. It might help them understand what you are dealing with after treatment. Sometimes they struggle with some of the same things that survivors do and need the same kind of help and support.

What is a Cancer Survivor?

An individual is considered a cancer survivor from the time of diagnosis through the balance of life. There are many types of survivors, including those living with cancer and those free of cancer. This term is meant to capture a population of those with a history of cancer rather than to provide a label that may or may not resonate with individuals. (National Cancer Institute, National Coalition for Cancer Survivorship).

The word ***"survivor"*** can describe people who have gone through something difficult. You have just gone through cancer treatment– a real challenge. Whether your treatment is complete, or you are still on some form of treatment, **you are a survivor**. After facing a challenge, you can join other survivors who continue to move forward, to live their lives and even thrive.

What Happens Now?

Having cancer and going through cancer treatment changes your life. Your usual activities are set aside. Your plans focus on doctor visits, tests and treatments. You, your family, friends and your care team work hard to help you complete your treatment. Finally, the last day of treatment comes, and your life will change again. You won't be coming back to your treatment center for months. You might ask, "What happens now?"

First, you need time to recover from cancer treatment.

Some physical side effects will resolve over time and some may not. Emotional well-being, family life, work life and finances also need time to recover. You can help yourself through recovery by:

- Managing your side effects.
- Communicating well with care providers, family and friends.
- Re-connecting with people and activities that you have missed during treatment.
- Making healthy lifestyle choices.
- Re-evaluating where you are in your life.
- Making new decisions when needed.

During your treatment journey, you were empowered by learning about medical terms, treatment options, lab tests, and the roles of your care team. You learned how to take an active part in your care (self-advocacy). You have now moved into a role as "team captain." **Self-advocacy** is more important now than ever. It will be up to you to be aware of what is going on with your body, your emotions, and new steps into home life, work and school. Your care team will still be right beside you, ready when you need them. Continue to contact them to:

- Find information.
- Ask questions.
- Seek support.
- Report symptoms and concerns.


Breast Survivorship Care Plan
Assessment / Testing
Care Provider
Location
Year
Medical History & Physical Exam
Mammography
Gynecologic Exam
Bone Density (DEXA) exam
Cardiovascular Assessment
Breast Self- Awareness
Review of Family History
Breast Cancer Treatment Summary
Additional Treatment Name:
Primary Care Provider:
Phone:
Fax:
Gynecologist:
Phone:
Fax:

PART 1 follow-up care

When your active cancer treatment ends, your follow-up care begins. As you start follow-up care, your care team may give you two forms:

A **Treatment Summary** lists information about your cancer diagnosis and each of the treatments you received. It is a way for you to recall and share the basic outline of your cancer care. It includes:

- Your cancer diagnosis: date, affected area(s), type(s) of surgery, tumor details.
- Treatment therapies you received: surgery, radiation, systemic, endocrine.
- Possible symptoms or side effects you may experience after completion of treatment.

A **Survivorship Care Plan** is the plan for your follow-up care. It includes:

- Your follow-up appointment plan.
- New symptoms to report.
- Information on genetic counseling.
- Common concerns of cancer survivors.
- Routine health care recommendations.
- Healthy lifestyle recommendations.

Keep a copy of your Treatment Summary and Survivorship Care Plan for your personal records. Share them with other doctors you see for routine health care.

Ongoing Follow-Up: Working With Your Care Team

During **the first five years after treatment**, you will continue to have follow-up appointments with a member of your care team. These appointments are usually:

- Scheduled every three (3), six (6) or 12 months.
- Closer together at first and then spread out over time.

IMPORTANT: You are an important part of your care team during cancer follow-up:

- Talk with your care team about your health.
- Ask questions.
- Be honest about your concerns.

During follow-up visits, your care team will:

- Do a physical exam and review test results.
- Monitor side effects.
- Look for any signs of cancer returning.
- Ask questions about:
  - Your health since you were last seen.
  - Existing side effects. Are they getting better, worse or unchanged?
  - Any new problems.
  - Healthy lifestyle choices (tobacco use, diet, exercise and weight control).
- Recommend other specialists or support services when needed.

PART 2 what affects the QUALITY OF YOUR LIFE?

Quality of life is difficult to define. It is related to how satisfied you are with your life. It includes all the different aspects of life, like:

- Health
- Work/School
- Finances
- Home
- Relationships
- Spiritual Life

Your satisfaction changes over time and in response to positive and negative parts of your life.

Survivors usually want to have the same quality of life after treatment that they had before treatment. After treatment, some things will be the same, some things will be worse and some things will be better than they were before. You will sort through the parts of your life, see how you are doing and decide how to get the help you may need.

Practical Matters

Financial Concerns

Medical bills can be stressful, even after treatment is finished. Some survivors may have concerns about the balances they owe. Others may worry about the cost of future services, like follow-up visits, tests or drugs. One of the best ways to manage these concerns is to explore all of the options. **Discuss any cost concerns with your health care team first**, especially if the cost is making you think about:

- Not taking a certain drug.
- Not following through with a test.
- Not going to an appointment.

It is important to keep your follow-up appointments and follow instructions about medications and testing.

What Can I Do?

- **Ask your insurance company** to assign a case manager to you.
- **Use your insurance plan's preferred or in-network doctors**, hospitals or clinics.
- **Compare your health plan options** to see if you can lower future out-of-pocket costs.
- **Ask if financial assistance is available** for the service, drug or outstanding balance.
- **Set up a payment plan** with the hospital and with creditors.
- **See what other options or resources might be available**, such as talking to a financial counselor at the hospital or physicians office or a credit counseling agency.

Work and School

Returning to Work and/or School

Many people look forward to returning to work or school after treatment has ended. It can help you get back to a regular routine. Returning to work or school can also present challenges, especially if you are still dealing with issues or side effects from treatment. Preparing ahead of time can help ease your anxiety.

What Can I Do?

- **Talk with your care team** about whether you are ready to return to work or school.
- **Find out about your rights and responsibilities** as a cancer survivor (the Americans with Disabilities Act, located on the next page).
- **Ask about flexible work options**, such as part-time or telecommuting, and job or classroom accommodations you might need.
- **Ask about insurance** and benefits coverage.
- **Talk with an oncology social worker** or care team member for helpful resources if you are finding it hard to make the transition back to work or school, or need information on rights and protections.
- **Decide what you want to tell your coworkers** or classmates and how you plan to do it:
  - You may decide to talk privately with a few people.
  - You might find it easier to tell everyone at the same time during a meeting.

New Employment

There can be several reasons that a cancer survivor may look for a new job. Some people might be unable to do the same work they did before or they may prefer to start a new career. Finding a new job could be a good change. For example, the new job may offer a better schedule, lighter workload or more chances to advance.

You do not have to disclose that you have had cancer when you apply for a job. Employers cannot ask you to answer medical questions before making a job offer. They can ask if you are able to perform all of the required duties of the job or how you would perform the job. If you have a disability and cannot do all of the required duties, then you may need to discuss the reason for a change or accommodation. Types of reasonable accommodations may include things like adding a wheelchair ramp, giving more breaks for rest or having items written in large print.

If you are required to pass a medical exam to get the job, then it must be required for all new employees in the same job. An employer cannot take back the job offer if you pass the exam. Ask an oncology social worker or care team member for resources that can help you know your rights and deal with workplace issues.

Protection from Discrimination

Many schools and public and private employers are supportive of students and employees during and after treatment for cancer. It still is important to know the laws and policies that protect you. If you are employed or enrolled in school, review their policy handbook and/or talk with the human resources staff.

The **Americans with Disabilities Act** (**ADA**) does not allow discrimination against people with disabilities in employment, transportation, public accommodations, communications and governmental activities. Most employers, including private employers with 15 or more employees, must comply with Title I of the ADA. Persons eligible for protection under the ADA in the workplace must:

1. **Have a disability under the ADA's definition.** A disability is a physical or mental impairment that substantially limits a **"major life activity."** This can include a current impairment, record of such an impairment or being regarded as having such an impairment.

Major life activities include, but are not limited to:

- Caring for oneself
- Operation of major bodily functions
- Walking, standing, lifting and bending
- Concentrating, thinking, communicating and working
- Performing manual tasks
- Seeing, hearing, eating and sleeping
- Speaking, breathing, learning and reading

2. **Meet the skill, experience, education, and other job-related requirements** of the position held or desired, and be able to perform the essential functions of the job with or without reasonable accommodations. A **"reasonable accommodation"** is a legal term for how an employer makes adjustments to a job that allows an eligible employee to perform the essential functions of that job. Examples may include making a change in the workspace or the work schedule.

Nearly all public and private colleges, universities and vocational schools are subject to the ADA and Section 504 of the **Rehabilitation Act of 1973**. Ask whether your school has an office serving students with disabilities. Ask for guidance on how to request a reasonable accommodation. Accommodations are determined on an individual basis and might include things like allowing additional time to complete a test or record a class.

The **Family and Medical Leave Act** (**FMLA**) allows people dealing with a serious illness, or caring for one of their family members, to take unpaid leave for up to 12 weeks within one calendar year. Employers must continue health benefits during this time.

Some cancer survivors may need to use FMLA leave all at once. Others may take it in blocks of time during post-treatment for things like:

- Attending follow-up medical appointments.
- Completing scans.
- Going to outpatient rehabilitation appointments.
- Having reconstructive surgery.

To be eligible, the employee must have worked with his or her employer at least 1,250 hours over the past 12 months, and work at a location where the company employs 50 or more employees within 75 miles.

An oncology social worker or care team member can provide education on other federal protection laws and agencies that offer advocacy, information regarding your rights and/or legal guidance.

Common Emotional Responses of Cancer Survivors

Many people expect strong emotions while being treated for cancer. But, they can be surprised when they occur after treatment is finished. Often these emotions are positive, but there can be some that are not. It is common to experience joy and gratitude during this period. There also can be feelings of sadness, guilt and worry. Fear or worry may peak when going to follow-up doctor visits or while waiting to receive scan results. There may be times when simply talking with family, friends or co-workers about the cancer journey causes some anxiety.

The end of treatment can also be a time when people have mixed thoughts and feelings. For example, people might feel relieved that treatment is over and are hopeful about the future. Yet they may also feel angry or sad about having gone through such a stressful experience. Some may find that less frequent medical visits help reduce stress, while others might feel a loss of security and support. Going back to work, restoring friendships or needing more time to recover can effect emotions, too. Each person's situation is unique.

What Can I Do?

- **Identify the thoughts and feelings that concern you.**
- **Talk with your care team:**
  - Let them know if you experience anxiety that does not go away, gets worse or is so intense that it interferes with daily life.
  - Ask them for resources in the clinic, hospital or community that can help.
  - Ask your care team for a referral to an oncology social worker or counselor.
- **Talk to those close to you** about your thoughts and feelings.
- **Consider joining a post-treatment support group.**
- **Consider attending a survivorship course.**
- **Tell your care team:**
  - About the support choices you have made.
  - If the support choices are helping or not.

Uncertainty

People do not expect to get cancer. A serious illness can make people more aware of uncertainties, which may lead to questioning what the future holds. Uncertainty may or may not be part of your daily life. There may be times when these feelings are more intense. When searching for a new job, you could have concerns about your ability to work full-time. There could be concerns about future relationships or whether you will be able to have children. You may worry about late effects from the treatment.

Living with uncertainty can affect people in different ways. Some may find that this leads to feeling stressed and upset, while others may be motivated to include healthier behaviors in their lifestyle. Understanding the reasons why you might be feeling this way, and knowing where to look for support, can help you feel more in control.

Your Treatment Summary and Survivorship Care Plan can help you know what to expect going forward and what to report to your doctor. Feeling like you are doing something to take charge and promote good health can decrease your uncertainty. Remember, you are your own best advocate. Refer to the "What Can I Do?" section under Fear of Recurrence (at the bottom of this page) for additional suggestions.

Fear of Recurrence

Feeling anxious or frightened that cancer could recur (come back) is one of the most common concerns that cancer survivors have when treatment ends.

It is a real and valid fear. The fear is often more intense during the first year after treatment. Fear or worry usually lessens over time, but can still be triggered by specific events, such as:

- Follow-up tests or appointments
- Your diagnosis anniversary
- Reports in the media
- Certain physical symptoms
- Hearing about others being diagnosed

Developing ways to balance the fear of recurrence with living in the present and enjoying life is very important. If you need some coping strategies, talk to your care team for suggestions.

What Can I Do?

- **Acknowledge your anxiety or fear:**
  - Accept that you sometimes might worry about what the future holds or about cancer coming back.
  - Find healthy ways to cope with the worry or fear.
- **Talk about your concerns.** Many people have found that expressing strong feelings provides a sense of relief.
- **Write your feelings in a journal or notebook.** Some people find that putting their thoughts and feelings on paper helps them let go of worries and fears.
- **Live your life.** Pursue activities that help distract you from your worries.
- **Help yourself relax.** Relaxation can help people reduce stress and worry. Try:
  - Meditation
  - Practicing relaxation techniques
  - Tai Chi or Qi Gong
  - Leisure time with friends or family
  - Listening to music
  - Practicing mindfulness exercises
  - Yoga
  - Guided imagery
  - Spending time with your pet
  - Doing an art activity
- **Focus on what you can control.** Consider the following:
  - Be actively involved in your follow-up appointments.
  - Maintain a healthy diet.
  - Get enough sleep.
  - Practice regular physical activity.

- **Learn the signs of recurrence:** Ask your care team about potential warning signs and what you can do to lessen your chances of recurrence. This knowledge can help ease your concerns.
- **Get help with emotional health:** An oncology social worker or counselor can help you understand how your emotions can change after cancer treatment.
- **Join a support group:** Support groups allow you to share your feelings and learn how others are coping with their fears, which can provide you with a community of strength and understanding.
- **Let your care team know if what you are doing is helping or not.**

Sadness & Depression

Cancer survivors often feel a sense of sadness when treatment ends, partly because it can be a period when there is time to think about all of the changes that have happened. However, sadness is different than depression and it should not last for a long time. Depression is a serious condition. Depression affects your mood, thoughts, eating and sleep. Depression can also change the feelings you have about yourself, how you think about things and your future. It may be harder to concentrate and you may lose interest in doing things you usually enjoy. Depression may make it harder to meet the demands of your home and work duties.

Depression occurs in 15 - 25 percent of people at some time during their cancer experience. The decision to treat depression depends on how long it has lasted and how much it affects your life. If depression continues or becomes worse, your care team can help you find the resources to help manage it.

What Can I Do?

- **Tell your care team:**
  - If you have a history of treatment for depression.
  - How you responded to past treatments.
  - If you have feelings of sadness, hopelessness, loss of interest or pleasure in activities, and changes in appetite or sleep that continue for two weeks or longer.
- **Seek treatment for your depression.** This is often a blend of counseling (individual and group) and medication.
  - **Begin counseling:**
    - Keep your counseling appointments.
    - Participate in the counseling sessions. Talking about your concerns will help your depression.
  - **Take medicine:**
    - Follow the instructions for taking medicine(s) for depression.
    - Tell your care team about any side effects from your medicine(s) for depression.
    - Inform your care team if you want to stop taking medicine for depression. They will help you know how to safely stop taking the medicine(s). It is not safe to stop on your own.
- **Let your care team know if you feel the counseling and medicine(s) are helping or not.**

Relationships and Intimacy

Relationships

Roles and relationships with family, friends and other people can change while you are going through cancer treatment. For example, it may be necessary for your spouse to take on more household chores or assume new parenting roles during treatment. Some friends may become closer, while others might distance themselves. The degree of change can vary based on the nature and closeness of each relationship. Some changes can be temporary, while others may be permanent.

Once you have finished treatment, you may feel like you need to jump back in to all of the roles that you had before. You may even feel as though others around you expect this to happen. This may or may not be realistic. Family members or friends might have difficulty letting go of some of their roles or seem impatient for you to take on other roles. Just as you may need time to adjust to life after cancer, your family, friends and co-workers may need time, too.

What Can I Do?

- **Be patient with yourself.** Move at your own pace.
- **Talk about how you are feeling** with the changes in your lives. Share your thoughts.
- **Be clear about what you can and cannot do;** that way everyone will know what to expect.
- **Tell your family and friends** that you understand it is hard for them, too.
- **Let your family and friends know** if you still need their help.
- **Thank others** for their help.
- **Seek professional support.** Talk to an oncology social worker or counselor about ways to make adjustments following treatment.
- **Talk with other survivors.** Consider joining a support group or attend a survivorship class. (See Resources for Cancer Survivors on page 25)
- **Let your care team know if the things you are doing are helping or not.**

Intimacy

Intimacy means feeling a physical and emotional closeness with someone else. Being intimate is not always about sex. Intimacy is about sharing love, feeling valued and showing mutual care and concern.

Cancer can affect your ability to be intimate in physical and emotional ways. It is common for people to feel changes in their body and have a range of thoughts and feelings, both during and after treatment. For some, this can lead to feeling a deeper connection in new ways, while others may feel less close than they did before. It is important to address any problems or changes when they develop.

After treatment ends, some people may be ready to have sex more often, while others may have little interest. Things like fatigue, pain, fear and body changes can affect the desire to have sex. Sexual and sensual desires could continue to vary, just like they did before your cancer diagnosis.

What Can I Do?

- **Talk with your partner.** Tell them how you feel.
- **Listen to your partner.** Don't assume that you know what your partner is thinking or feeling.
- **Make time to do things as a couple** that brought joy or held meaning in the past or try new things together.
- **Even for people who do not have sex, touch is still important.** Offer non-sexual (sensual) touch by giving a tight hug, holding hands, cuddling, caressing or massaging.
- **Tell your care team** about the type of problems that are affecting your sex life.
- **Get treatment for physical problems, like:**
  - Vaginal dryness
  - Vaginal tightness
  - Being able to get and maintain an erection
- **Ask your doctor for a referral to a specialist:**
  - Sex therapist
  - Counselor
  - Physical therapist—that specializes in sexual health issues
- **Let your care team know if the things you are doing are helping or not.**

Spirituality

Survivors may think of themselves as spiritual, religious or both. The way that cancer affects spirituality, faith or religious beliefs varies. Many find that their sense of spiritual or religious beliefs and practices help them cope with illness and recovery.

A health crisis can make some people question their faith and religious convictions. This questioning may lead a person to discover new depths to their spirituality. Or they may have challenges with their beliefs and values. Both reactions are common.

After treatment is finished, people often reflect on their experience of cancer and re-evaluate what brings the most purpose and meaning to life now.

What Can I Do?

- **Join or return** to a community of faith.
- **Work** with a faith-based organization.
- **Visit** spiritual places or peaceful settings.
- **Volunteer** in the community.
- **Speak** with a faith leader.
- **Read** spiritual writings.
- **Pray** or meditate to help gain perspective.

Physical Concerns

Potential Long-Term and Late Effects of Cancer Treatment

Most side effects of cancer treatment go away once the treatment is over. It could take several weeks or several months.

Your risk of experiencing long-term or late side effects depends on the:

- Type of cancer
- Type of treatment(s)
- Treatment dose (strength)
- Length of treatment
- Unique response of each person

Long-Term Effects

The side effects that do not go away are called long-term effects. Survivors are often surprised when side effects do not resolve over time. Your care team will work with you to minimize any side effects. They will address them at each follow-up visit.

Many of the long-term effects are similar to symptoms during treatment. You can manage them like you did before. The book, ***"Taking Control: A Guide for Managing Your Cancer Care,"*** has a library of symptom management ideas. If you do not have a copy of this book, please ask your care provider for one. Your care team can also print Symptom Management Sheets for you.

Oncology rehabilitation can help some long-term effects. A physical therapist, occupational therapist and/or a speech therapist can help. There are also other specialized therapists. Ask your care team if rehabilitation would be helpful for you. You will need a referral to see a rehabilitation therapist.

The table on the next page lists some of the long-term effects that are related to cancer treatments. It does not include all possible long-term effects or all the information about each side effect.

Ask your care team about your particular risks for long term effects.

Potential Long-Term Effects	Description(s) and Effects	Types of Treatment(s)
Cognitive Changes "Chemo Brain"	• Difficulty thinking clearly after cancer treatment • May affect concentration, multitasking, memory and word finding	• Chemotherapy • Head and neck radiation
Emotional Distress	• Common to feel or have symptoms of worry, stress, anxiety, and depression • Contributing factors can be pain, lack of sleep, fatigue, hormone problems, other medical problems, life stress such as return to work or school, financial, etc.	• Surgery • Chemotherapy • Radiation therapy • Immunotherapy
Bowel and Liver	• Diarrhea – colitis • Hepatitis – inflammation of liver	• Immunotherapy
Fatigue	• Persistent feeling of physical, emotional or mental tiredness, or exhaustion • One of more common side effects	• Chemotherapy • Radiation therapy • Hormone therapy • Immunotherapy • Targeted therapies • Cellular therapies
Hormone-Related Symptoms / Disorders	• Changes in hormone levels due to treatment • Premature menopause • May contribute to other symptoms – physical, gynecologic, sexual dysfunction, mood disturbance, cognitive, fatigue • changes to organs or glands that make hormones - thyroid, pituitary, pancreas	• Surgery • Immunotherapy • Chemotherapy • Pelvic radiation • Anti-hormonal therapy
Lung	• Inflammation with associated trouble breathing • May cause a dry cough, fever, chest pain, low oxygen levels	• Immunotherapy
Pain	• A common problem related to cancer and treatments • Often occurs in the treated area • Monitor if the pain is new and increased or if it is chronic • May be related to other side effects or problems like osteoporosis	• Surgery • Radiation therapy

Potential Long-Term Effects	Description(s) and Effects	Types of Treatment(s)
Peripheral Neuropathy	• A type of nerve damage • May cause numbness, tingling, pain, muscle weakness, constipation or dizziness depending on the location of the nerve damage	• Chemotherapy • Radiation therapy
Sexual Health Changes	• Changes in desire for sex • Changes in sexual function • Changes in partner intimacy • Mental health changes such as depression if source could be related to sexual health or intimacy	• Surgery: + Men (prostate, testicles) + Women (ovaries, uterus, vulva, breasts) • Chemotherapy • Hormone Therapy • Pelvic radiation therapy • Head and neck radiation therapy • Presence of a stoma related to colorectal surgery
Skin	• Rash – flat patches and bumps • Location common on torso between hips and shoulders • Blisters – fluid filled sac that forms • Itching – may occur with or without a rash • Psoriasis develops	• Immunotherapy
Sleep Disturbances	• Difficulty falling asleep and/or staying asleep • May be a single symptom or part of a cluster of symptoms like fatigue, depression and pain	• Surgery • Chemotherapy • Radiation therapy • Hormone therapy
Urinary Disturbance	• Difficulty urinating • Problems with leaking or control	• Surgery • Radiation to pelvic region
Weight Changes	• Difficulty maintaining a healthy weight • Weight gain during and after treatment	• Chemotherapy • Hormone treatment • Abdominal radiation therapy • Chest radiation therapy (due to swallowing difficulties or thyroid side effects)

Late Effects

Late effects are symptoms that occur months or years after cancer treatment. Evaluating and treating late effects is part of survivorship care. You and your care team will monitor your progress and look for late effects.

Some of the newer cancer treatments, like targeted therapy and immunotherapy, do not have as much research completed on late effects. Ask your care provider for any new information that becomes available.

The table below lists some of the late effects that are related to cancer treatments. It does not include all possible late effects or all the information about each effect.

Ask your care team about your particular risks for late effects.

Potential Late Effects	Description(s) and Effects	Types of Treatment(s)
Blood Clot/Stroke	• Developing a blood clot in the body (stroke)	• Chemotherapy • Hormone therapy • Immunomodulatory drugs
Bone or Joint Problems	• Thinning of the bones (osteoporosis) • Joint pain • General inflammation of joints, ligaments, tendons, muscles **Higher risk for osteoporosis:** • Physical inactivity • Family history of osteoporosis • Older age • Post-menopausal women (menopause due to treatment) • Being small and thin	• Chemotherapy • Hormone therapy • Radiation therapy • Steroids • Immunotherapy
Dental and Oral Health Problems (mouth, teeth, and salivary glands)	• Tooth enamel changes • Dry mouth, pain, irritated gums or throat, sores, sensitive gums • Changes in taste	• Chemotherapy • High-dose radiation to head and neck
Digestion Problems	• Scarring • Long-term intestinal problems affecting digestion • Chronic diarrhea (affects absorption of nutrients)	• Some abdominal surgeries • Chemotherapy • Radiation therapy • Immunotherapy

Continued

Potential Late Effects	Description(s) and Effects	Types of Treatment(s)
Heart Problems	• Swelling or weakening of the heart muscle • Problems with the heart's ability to pump blood • Coronary artery disease/heart disease (more common with high doses of chest radiation therapy) • Irregular heart beat (arrhythmia) **Higher risk for heart-related side effects** • 65 years old or older • Hypertension • High cholesterol • Obesity • Family history of heart problems • Smoking (in the past or currently)	• Higher doses of chemotherapy • Chemotherapy drugs in the group of drugs called anthracycline • Chest radiation therapy • Immunotherapy
Increased Risk of Developing Secondary Cancers	• Developing a different type of cancer	• Chemotherapy • Radiation therapy • Hormone therapy
Kidney Problems	• Long-term kidney disease • Narrowed blood vessels (arteries) that lead to a decreased blood flow (peripheral arterial disease)	• Abdominal radiation • Chemotherapy drugs • Immunotherapy
Lung Problems	• Changes in how well the lungs work: + Thickening of the lining of the lungs + Inflammation + Difficulty breathing **Higher risk for lung-related side effects:** • History of lung disease • Older age • Smoking (history or currently)	• Chest radiation therapy • Chemotherapy drugs that tend to lead to more lung problems: + Bleomycin (Blenoxane) + Carmustine (BiCNU) + Methotrexate (multiple brand names) • Steroids, such as: + Prednisone + Dexamethasone • Immunotherapy

Continued

Potential Late Effects	Description(s) and Effects	Types of Treatment(s)
Lymphedema	• Build-up of extra fluid caused by a blockage of the lymphatic system: + Most often affects the arms and legs (breast, urinary tract, bladder, kidneys, prostate, testicles and penis cancers) + Can occur in other parts of the body, including below the chin, neck and mouth (cancers of the head or neck) • Symptoms may include heaviness, fatigue, fullness or tightness in the skin or pain	• Surgery • Radiation therapy • Chemoradiation • Treatment to lymphs in axillary, surpraclavicular, neck, or pelvic lymph regions of body • Sentinel node biopsy and/or node dissection
Sexual and Reproductive Problems	• Men: + Unable to father a child + Sexual dysfunction • Women: + Unable to get pregnant + Unable to carry a child to term (stay pregnant) + Menopause + Sexual dysfunction	• Surgery: + Men + Women • Radiation therapy to the pelvis or head and neck • Chemotherapy

What Can I Do?

- **Learn about your side effect(s)**: Read, "*Taking Control*". Ask your care team for a copy if you do not have one.
- **Go to your follow up appointments.**
- **Be aware of persistent (ongoing) or progressive (getting worse) changes to your health:** Report them to your care team.
- **Try the suggestions in**, "What Can I Do?" found throughout this book.
- **Make healthy lifestyle choices.**
- **Ask your care team if:**
  - There are ways to improve your quality of life.
  - There is a Symptom Management Sheet that would be helpful for you.
  - Your symptoms might be helped by oncology rehabilitation or other specialists. If so, ask for a referral.
- **Let your care team know if the things you are doing and the treatments are helping or not.**

Nutrition

Good nutrition is an important part of your recovery from treatment and your efforts to help prevent recurrence.

What Can I Do?

Here are a few tips from the American Institute for Cancer Research (AICR) and the American Cancer Society to get you started:

- **Maintain a healthy weight** to help decrease the risk of cancer recurrence and other chronic diseases, like diabetes and heart disease. Carrying extra body fat, especially around the belly, raises hormone levels that can increase the risk of colon, uterine, breast (after menopause), and pancreatic cancers.
  - Ask your care team what a healthy weight is for you. Let them know if you have recently gained unwanted weight.
- **Follow a plant-based diet using vegetables, fruits, whole grains and legumes (such as beans) to fill up at least 2/3 of your plate.** Vary the colors of your fruits and vegetables to get a good variety of vitamins and minerals.
- **Choose foods that are high in protein for the other 1/3 of your plate:**
  - Lean meats, fish, chicken, turkey and eggs
  - Beans, peas, nuts, seeds and soy products
  - Low-fat dairy products, like milk and cheeses

- **Limit:**
  - **Processed foods** that are high in added sugar, low in fiber or high in fat: soda, cookies, cakes and chips.
  - **Red meat:** beef, pork and lamb. Eat no more than 18 ounces of red meat per week.
  - **Alcohol intake:** Despite some evidence linking moderate alcohol intake to lower risk for heart disease, this does not apply to cancer. The American Institute for Cancer Research recommends avoiding even small amounts of alcohol. If you choose to drink alcohol, limit it to one (1) drink for women and two (2) drinks for men in a 24-hour period.
  - **Salty foods** and foods processed with salt (sodium). Try not to use the salt shaker. Most people get far more sodium than they need from processed foods. Read food labels. Choose low-sodium foods with no more than 300 milligrams of sodium per serving.
- **Avoid:**
  - **Processed meats** (smoked, salted and cured): cold cuts, bacon, sausage and ham.
  - **Sugary drinks:** colas, juice and sweet tea.
- **Use of dietary supplements**:
  - **Talk with your care team before taking any supplements.**
  - **Do not rely on supplements to protect against cancer.** Dietary supplements do not replace the cancer prevention power and nutrients from fresh foods. Incorrect use of dietary supplements can increase the risk of certain cancers and other health conditions. A dietitian can do an assessment and create an individual supplement plan for you.
- **Ask your care team for a survivorship visit with a dietitian.**

Exercise

Choosing to exercise regularly is a healthy lifestyle choice you can make.

Exercise helps to:

- Maintain how the body functions and moves.
- Keep or improve muscle and bone strength and balance.
- Improve the ability of your body to do activities important to you.
- Increase blood flow through your body.
- Improve constipation, tiredness, depression and sleep problems.
- Decrease your dependence on other people for your normal activities.
- Improve how you feel about yourself.
- Be able to join in social activities.
- Improve the quality of your life during and after cancer treatment.

A healthy goal is to exercise for at least 30 minutes, five (5) days a week. The type of exercise you do is your choice:

- Aerobic exercise strengthens your heart muscle.
- Strength training tones and builds muscles.
- Stretching exercise keeps muscles and joints flexible.

Balance your activity with a mix of aerobic exercise, like walking 3 to 5 times per week and strength training 2 times per week.

If you currently do not exercise regularly, you may not be able to exercise for 30 minutes at the beginning. You may need to break the 30 minutes into smaller blocks of time. Start slow and gradually increase the amount of time that you exercise until you reach your 30-minute goal.

If you currently do exercise regularly, keep it up. Most exercises are safe to do during and after cancer treatment.

What Can I Do?

- **Choose an exercise that you can enjoy.** If you are not sure what to do, ask to see a physical therapist to help you plan an exercise program. You can also attend exercise classes in person and virtually at the Cancer Support Community Atlanta (See Resources for Cancer Survivors on page 25).
- **Ask a friend to be your exercise buddy.**
- **Walk: anytime and anywhere.** Walking does not require any special exercise equipment.
- **Wear comfortable clothes** and appropriate shoes.
- **Drink water** when you exercise.
- **Take time to warm up** before you exercise.
- **Cool down** after you exercise.
- **Listen to your body:**
  - If you hurt or are very tired after you exercise, you may be trying to do too much or exercising incorrectly. Ask your care team or physical therapist for advice.
  - If on some days you do not have as much energy, change what you do. Do stretching rather than aerobic exercise. Exercise in five- or 10-minute blocks rather than 30 minutes at the same time.
- **Ask your care team for a referral to a rehabilitation therapist.**
- **Ask your care team for a referral to a registered dietitian.**

PART 3

defining your needs
AND FINDING HELP

As you continue to take control of your follow-up care and advocate for yourself, communicate with your care team and seek information and support.

What Can I Do?

- **Ask for a Survivorship Care Plan:**
  - Keep these documents with your other health records.
  - Share them with all of your current and future doctors.
- **Monitor your own health** and report your symptoms and concerns.
- **Use the distress form** (see example on next page) to help you discover your needs and talk with your care team.
- **Go to regular follow-up appointments.** Ask questions.
- **Ask your health care team** how cancer rehabilitation services could help in your recovery:
  - These services may improve your strength and the ability to care for yourself.
  - They can also help you either adjust to or overcome physical problems that cancer or treatment may have caused.
- **Explore cancer support services:** counseling, support groups or mind-body wellness classes.
- **Look into other resources** for insurance, legal or financial needs.
- **Stay informed** about new research in the treatment of late and long-term effects for your type of cancer.
- **Let your care team know** how things are going.

How Am I Doing?

During follow-up care you spend more time at home and less time in a clinic. You are an important member of your care team. You know best how you are feeling. You can define your problem areas. You can ask for the help you need.

As a cancer survivor, you will continue to experience changes that affect different parts of your life. Some of these changes may lead to feeling distressed. Distress is an unpleasant emotional state that can affect how you feel, think and act. It can include feelings of unease, sadness, worry, anger, helplessness and guilt.

At Northside Hospital Cancer Institute, we use a distress screening form to help people with cancer and survivors:

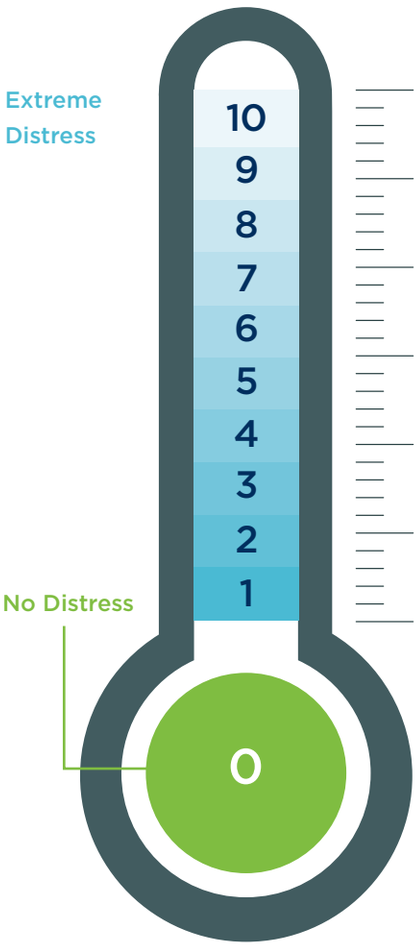
- Rate their distress level.
- Identify the parts of their life that are related to their distress.
- Choose the kind(s) of help they want.

You may be familiar with this form if you filled it out while you were in treatment.

Now you can use this form at home. It can help you tell your care team what is happening and what you need. By using this tool, you can help your care team understand which aspects of your life are impacting your distress level and the severity of the problem. They will be able to help you connect with services to meet your specific needs.

INSTRUCTIONS: Please **circle** the number (0-10) that best describes how much distress you have been experiencing within the **past week** including today.

Distress Rating



Psychological Problem / Concern List

Please indicate if any of the following has been a problem or concern within the **past week** including today, by placing a ☑ next to any that applies to you.

PRACTICAL PROBLEMS

- ☐ Child care
- ☐ Transportation
- ☐ Insurance/financial
- ☐ Housing
- ☐ Work/school
- ☐ Treatment decisions

EMOTIONAL PROBLEMS

- ☐ Feeling depressed
- ☐ Feeling sad and/or loss of interest in usual activities
- ☐ Difficulty sleeping
- ☐ Nervous and/or worried
- ☐ Body image or intimacy

FAMILY/SOCIAL PROBLEMS

- ☐ Family health issues
- ☐ Dealing with children
- ☐ Ability to have children
- ☐ Dealing with partner
- ☐ Dealing with support system/friends

SPIRITUAL/RELIGIOUS CONCERNS

- ☐ Question faith/belief
- ☐ Loss of meaning/ purpose

PHYSICAL CONCERNS

- ☐ Having a physical symptom that is new or getting worse
- ☐ Having pain and/or sever fatigue
- ☐ Loss of balance
- ☐ Having trouble with completing daily activities
- ☐ Having incontinence, pelvic pain or sexual dysfunction

NUTRITION CONCERNS

- ☐ Difficulty eating or swallowing
- ☐ Gained or lost +/- 5 lbs.
- ☐ Experiencing nausea, diarrhea or constipation
- ☐ Other problems

Service Information

Are you interested in any of the following? **Please mark ☑ all that apply.**

- ☐ Advanced directives
- ☐ Clinical trials
- ☐ Smoking cessation
- ☐ Insurance counseling
- ☐ Financial assistance
- ☐ Legal assistance
- ☐ Fertility preservation
- ☐ Community resources
- ☐ Emotional support/ counseling
- ☐ Support groups
- ☐ Mind-body and education programs
- ☐ Spiritual support
- ☐ Dietary/nutritional services
- ☐ Genetic counseling
- ☐ Physical therapy
- ☐ Speech language pathology
- ☐ Audiology
- ☐ Occupational therapy

Using the Distress Form

STEP 1: Start on the left side of the table in the column titled Distress Rating.

- Think about your last week.
- Rate your level of distress on the thermometer. (0 is no distress. 10 is extreme distress.)

STEP 2: Move to the center column marked Psychosocial Problem/Concern List.
Look at each choice carefully. Be honest with yourself. Mark the ones that apply to you.

STEP 3: The third column, Service Information, is a list of support services that might help.
Choose the services that you think will be helpful. Here are a few examples:

- If you marked the box "insurance/financial," then you might find help from financial assistance.
- If you marked "feeling depressed," then you might choose emotional support/counseling or a support group.
- If you marked "having pain and/or severe fatigue," then you might choose to call your care team for help, mark physical therapy or see a specialist.

What Do My Answers Mean?

Distress Score is 0-3: Your distress is low.

At this level, your distress is well managed, but you might want to learn more about resources that can help keep your distress in check. Review the Patient and Family Support Services brochure to see if there is anything that interests you. If you are not sure about what might help, ask your care team. They can help you decide.

Distress Score is 4-7: Your distress is moderate.

Distress at this level might be impacting your quality of life and your ability to manage your day-to-day tasks. Contact your care team at the clinic. Tell them your distress number and what is distressing you. They can help you contact resources or make referrals.

Distress Score is 8-10: Your distress is high.

You need to report your distress level to your care team as soon as possible. We want to work with you to bring it down. This level of distress is likely to have negative consequences for you.

- **If you need help right away, contact the Georgia Crisis and Access Line at 800.715.4225**: This is a behavioral health crisis and suicide hotline that is available 24 hours/day.
- **Contact your primary physician's office and ask for a care team member - physician, nurse, or social worker.** Tell them about your distress and ask them for the kinds of help you want.
- If you're in the Atlanta area, **contact Northside Hospital Behavioral Health Outpatient Services** at **404.851.8960**: Monday - Friday 8:00 a.m. - 5:00 p.m.

In addition to the support that your care team provides, there are local and national resources available.

What Can I Do?

- **Ask your care team for suggestions** to reduce your distress.
- **Review the choices** listed on the distress tool.
- **Let your care team know if the things you are doing are helping or not.**
- **Follow your care team's suggestions.**
- **Look through** "Resources for Cancer Survivors" on page 27.

PART 4

resources
FOR CANCER SURVIVORS

As a cancer survivor, you will likely want to look for more information or help for some of your concerns or needs. The internet and apps are great tools, but be aware that not all websites you find have correct information. Wrong information could lead you to make poor choices or even be harmful.

Here is a list of websites and apps you can trust from local and national organizations. These sites have information on programs and services, such as education, counseling, support groups, legal aid, wellness and more. Remember, these sites are tools and **do not replace expert medical advice and care**. Your care team is here to support you. Please ask them for suggestions or help finding information.

Local Resources

NORTHSIDE HOSPITAL CANCER INSTITUTE
BUILT TO BEAT CANCER

Call Center
web: *builttobeatcancer.com*
404.531.4444
Information and referral center for oncology and support services at Northside Hospital Cancer Institute.

Behavioral Health and Psych-Oncology Services
web: *northside.com/behavioralhealth*
email: *behavioral.healthservices@northside.com*
404.851.8960
Our team of psychiatrists, licensed therapists, oncology social workers and psychiatric nurses are available to provide you with coping strategies, support and education groups, medicine management and counseling services.

BUILT TO QUIT
Resources to help you stop smoking and using tobacco

web:
northside.com/community-wellness/built-to-quit
email: *behavioral.healthservices@northside.com*
404.851.8960
Smoking and tobacco cessation resources to provide education and help individuals quit smoking cigarettes, e-cigarettes, cigars, pipes, water pipes and using other forms of smokeless tobacco including chewing tobacco and dissolvable tobacco.medicine management and counseling services.

CANCER SUPPORT COMMUNITY ATLANTA
AFFILIATED WITH NORTHSIDE HOSPITAL CANCER INSTITUTE

web: *cscatlanta.org*
404.843.1880
Provides free education and support services to those affected by cancer through support groups, educational programs, nutrition seminars, cooking demonstrations and exercise and stress reduction classes. Services are provided at multiple locations and on-line. Please visit cscatlanta.org for the current event listing.

GEORGIA core
CENTER *for* ONCOLOGY RESEARCH & EDUCATION

web: *georgiacancerinfo.org/survivorship/*
404.523.8735
A comprehensive resource that provides evidence-based information for survivors, caregivers and healthcare professionals, highlighting the resources and services available across Georgia.

YSC youngsurvival.org

web: *youngsurvival.org*
877.972.1011
Provides resource kits, support programs, educational events and caregiver networking opportunities for breast cancer survivors.

SURVIVOR MENTORING

network of hope
Giving back. Moving forward.

email: *Networkofhope@northside.com*
404.303.3676
Volunteer cancer survivors and caregivers are available to mentor you during treatment. After you complete your treatment, you can join this group as a mentor and wellness advocate in your community.

National Resources

American Cancer Society

web: *cancer.org/cancer/survivorship*
Provides information and tips on staying active and healthy during and after cancer treatment. You can also get information on managing your health care as a cancer survivor.

CANCERcare

web: *cancercare.org/tagged/post-treatment_survivorship*
800.813.4673
Provides free cancer-related education, counseling, support groups and resource information.

CANCER+ CAREERS

web: *cancerandcareers.org*
email: *cancerandcareers@cew.org*
646.929.8032
Empowers and educates people with cancer to thrive in their workplace by providing expert advice, interactive tools and practical and legal information.

CANCER SUPPORT COMMUNITY ATLANTA

web: *cancersupportcommunity.org/mylifeline*
email: *help@cancersupportcommunity.org*
888.793.9355
MyLifeLine easily connects cancer patients and caregivers with friends and family in order to reduce stress, anxiety and isolation. You can create your own private website and participate in discussion boards.

LIVESTRONG

web: *livestrong.org/how-we-help*
877.236.8820
Offers free personalized information, resources, tools and services for patients, caregivers and survivors.

NIH NATIONAL CANCER INSTITUTE

National Cancer Institute: Office of Cancer Survivorship
web: *dccps.nci.nih.gov/ocs*
Post-treatment resources and information for survivors and caregivers, researchers, health care professionals and advocates.

TRIAGE CANCER

TriageCancer
web: *triagecancer.org*
424.258.4628
Provides free education on the practical and legal issues that arise after a cancer diagnosis.

Cancer Survivor Apps

IMPORTANT: Northside Hospital Cancer Institute does not endorse the use of any specific app on this list.

An app can run on the internet, on your computer or on your phone or other electronic devices. Before agreeing to accept any charges for downloading or using an app, and before providing the app any personal or private information, it is important to read the privacy policies and terms of use of the application.

Many of these apps are available both on the iTunes store and Google Play.

Download on the App Store | GET IT ON Google Play

GENERAL

ACS Cares
web: *cancer.org/support-programs-and-services/acs-cares*
Mobile app that provides you, your family, and your caregivers with the resources to navigate your cancer journey with confidence.

EXERCISE & NUTRITION APPS

My Fitness Pal
Food tracker and health app.

Fooducate: Nutrition Coach
Provides a nutrition and health tracker to assess the quality of calories and help you stay on track with your dietary goals.

Yummly Recipes and Cooking Tools
Offers personalized guidance from recipe recommendations to handy tools and helpful videos.

MINDFULNESS & MEDITATION APPS

Calm
Guided meditations, sleep stories, music, soundscapes, breathing exercises and more, to help you tackle everyday stresses. Subscription required.

Headspace
Your guide to practicing mindfulness in your everyday life with daily meditations, sleep meditations, stress relief and coping mechanisms. Subscription required.

Insight Timer
Guided meditations, music, ambient sounds to calm the mind, focus, sleep better and relax.

QUITTING SMOKING APPS

EasyQuit
Stop smoking app that helps you quit your smoking habit for good.

QuitGuide
A free app that helps you understand your smoking patterns and build the skills needed to become and stay smokefree.

quitSTART
The quitSTART app takes the information you provide about your smoking history and gives you tailored tips, inspiration, and challenges to help you become smokefree.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