



Cancer Rehabilitation Program Patient Education Manual



**Go
Beyond.**

Cancer Rehabilitation

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Information in this packet compiled primarily from the following sources:
American Cancer Society (www.cancer.org) and American Society of Clinical Oncology (www.asco.org)

Rehabilitation for Individuals with Cancer

Introduction to Oncology Rehabilitation

Working with you to improve your function with, through, and beyond cancer.

Oncology Rehabilitation is a comprehensive, interdisciplinary treatment team-based approach. The focus of care is on helping people with a cancer diagnosis function at their best physically, socially, and mentally. The goal of rehabilitation is to help you succeed in all aspects of your life and to support you to become as independent and productive as possible. Rehabilitation can be valuable for people and their families who are living or recovering from cancer.

BENEFITS OF REHABILITATION

- ▶ Improve mobility
- ▶ Improve ability to participate in daily living activities (e.g., self-care, household chores, and recreational activities)
- ▶ Decrease pain
- ▶ Increase independence and decrease assistance from caregivers
- ▶ Increase physical strength
- ▶ Provide emotional support
- ▶ Reduce sleep problems
- ▶ Preserve dignity
- ▶ Provide resources
- ▶ Link patients and families to community organizations

Cancer Basics

Cancer is a group of more than 100 different types of diseases. It can develop almost anywhere in the body.

How Cancer Begins

Cells are the basic units that make up the human body. Cells normally grow and divide to make new cells for the body as they are needed. Usually, when a cell gets too old or damaged, it dies so that new cells can take its place. Cancer begins when this process is changed and cells start to grow uncontrollably and crowd out normal cells.

Cancer cells can travel from their original site to other parts of the body and grow there. When cancer cells spread, it is called metastasis. When cancer of the lungs spreads to the bones, it is still called lung cancer. Under a microscope, the cancer cells in the bones look the same as the ones from the lung.

Differences between Cancer Types

Cancers can differ in how they grow and spread. Some grow and spread fast, while others grow more slowly. Cancers can also be different in how they respond to treatment. Some types of cancer are best treated with surgery, while others react better to radiation therapy or drugs called chemotherapy. Often, more than one type of treatment will be used to get the best result.

Tumors and Tumor Grading

When abnormal cells form a lump, it is called a tumor, mass, or a growth. Not all lumps are cancer. Doctors may take a piece of the mass and look at it to find out if it's cancer. Masses that are not cancerous are called benign.

Masses that are cancerous are called malignant. Tumors are also graded or "staged", according to how likely the tumor will spread or grow. Usually, stage 1 and 2 tumors are the least aggressive and grow slowly while stage 3 and 4 tumors grow quicker and spread faster. Some cancers do not form tumors. An example is leukemia (cancer of the blood). In those cases, the abnormal cells are growing in the blood.

Words You May Hear

Benign (be-NINE): A tumor that is not cancer.

Biopsy (BY-op-see): taking out a piece of tissue to see if cancer cells are in it.

Cancer (CAN-sur): A word used to describe more than 100 diseases in which cells grow out of control; or a tumor with cancer in it.

Chemotherapy (key-mo-THER-up-pee): the use of drugs to treat disease. The word most often refers to drugs used to treat cancer. Sometimes it's just called 'chemo.'

Malignant (muh-LIG-nunt): Cancerous (not benign).

Metastasis/metastasized (meh-TAS-tuh-sis/meh-TAS-tuh-sized): the spread of cancer cells to other parts of the body.

Oncologist (on-KAHL-uh-jist): a doctor who treats people who have cancer.

Radiation Therapy (ray-dee-A-shun THER-uh-pee): The use of high-energy rays, like x-rays, to treat cancer.

Remission (re-MISH-un): when signs or symptoms of cancer are all (complete remission) or partly gone (partial remission).

Hematological Malignancies may be referred to as liquid formed cancers.

Stage a word that tells whether a cancer has spread, and if so, how far.

Cancer Treatment

Common Cancer Treatments

The most common treatments for cancer are surgery, chemotherapy, and radiation. Two or more types of treatment may be combined. Complementary therapies may be integrated into traditional treatment.

Surgery: may be used to take out the cancer. Surgery may also remove body parts that the cancer affects. For example, in breast cancer, part or all of the breast might be removed. Surgery is not used for all types of cancer. Blood cancers like leukemia are best treated with medications.

Chemotherapy: also known as ‘chemo,’ chemotherapy is the use of drugs to kill cancer or slow their growth. Chemo may be given by IV (through a needle into a vein) or as a pill. Chemo medications travel to nearly all parts of the body and are useful for cancer that has spread.

Radiation: may be used to kill or slow the growth of cancer cells. It is like getting an x-ray, or may be given by putting a ‘seed’ inside the cancer to give off radiation.

Immunotherapy: is a type of cancer treatment that helps your immune system fight cancer. The immune system helps your body fight infections and other diseases. As part of its function, the immune system detects and destroys abnormal cells and most likely limits the growth of many cancers. Your oncologist will determine if you can benefit from immunotherapy by reviewing your molecular test results. Several types of immunotherapy are used to treat cancer. These include: immune checkpoint inhibitors, T-cell transfer therapy, monoclonal antibodies, treatment vaccines, and immune system modulators.

Complementary/Alternative Therapies: may include dietary changes, acupuncture, and exercise to help address side effects or improve the response to more traditional treatments.

Goals of Treatment

Treatment may be used to achieve different goals depending on the stage and type of cancer you have. It is important to understand the goal of your treatment:

- ▶ **Cure the cancer:** treatment may be focused on destroying the cancer cells to the point that they can no longer be detected and will not grow back.
- ▶ **Control the cancer:** Keep the cancer from spreading, slow its growth, or destroy cancer cells that have spread.
- ▶ **Improve symptoms:** Ease pain or pressure by shrinking tumors or managing other symptoms that cancer may cause.

Cancer Care does not End with Active Treatment

After cancer treatment has ended, your cancer doctor (oncologist) will continue to monitor your recovery. There may be a need to manage lingering side effects. It will also be important to check to make sure that the cancer has not returned. Follow-up care may include regular physical exams and medical tests in the coming months and years.

Dealing with Side Effects

Common Side Effects

The most common side effects experienced due to cancer and its treatment include: **fatigue, hair loss, pain, higher risk of infection, and emotional distress.** Some patients may also experience the following:

Chemo-Brain - Cancer survivors sometimes use the term “chemo brain” to describe the way that cancer treatment can make it difficult to think clearly. Some survivors who did not even have chemotherapy report feeling these symptoms. Thinking problems can include difficulty concentrating, multitasking, understanding, or remembering things. Treatment may include medication and cognitive training.

Endocrine (Hormone) System Problems – Some types of cancer treatment may affect the endocrine system (the glands and other organs that are responsible for making hormones and producing eggs or sperm). Talk to your doctor if you have concerns about hormonal changes.

Heart Problems - Heart issues may be caused by radiation therapy to the chest and specific types of chemotherapy. Adults 65 and older and people who get higher doses of chemotherapy have a higher risk of developing heart problems which may include swelling of the heart muscle, problems with the heart’s ability to pump blood, or heart disease.

Additional side effects:

- **Radiation:** burns, soft tissue fibrosis (tissue other than bone or cartilage which has decreased movement), delayed wound healing, and swelling.
- **Chemotherapy:** skin rashes, loss of appetite, gastrointestinal problems (including nausea or changes in your bowel habits), numbness or weakness known as neuropathies, bleeding or bruising from minor injuries, ulcers, and anemia.

General Tips to Help Manage Side Effects

- ▶ Maintain good nutrition to support your immune system.
- ▶ Adequate intake of fluids will help avoid dehydration, decrease constipation, and decrease fatigue.
- ▶ Daily physical activity will help to combat fatigue, improve restful sleep, and elevate mood.
- ▶ Go over all medications including vitamins, herbal supplements, and over-the-counter treatments with your oncologist. Some combinations of medications can contribute to side effects or interfere with your treatment.
- ▶ To decrease the risk of infection, practice good hand hygiene and encourage others around you to do the same.
- ▶ Practice relaxation strategies such as yoga, meditation, and deep breathing, which can help you to reduce stress and increase energy.
- ▶ Talk with others openly about your feelings and experiences. This can help you manage your emotions.
- ▶ Tell your treatment team about all side effects you experience. They often have resources, advice, or techniques that may help you manage.

Talk to your doctor if you experience any side effects.

Coping with Fatigue & Getting the Most out of Rehab

Fatigue is the most common complaint of people with cancer

Fatigue is a constant and distressing feeling of tiredness or exhaustion unrelated to recent activity and does not allow for normal activities of daily living.

Physical activity has been shown to help individuals with cancer fight fatigue as well as improve strength, endurance, attitude, and give a feeling of empowerment.

To increase your energy, practice the following energy conserving strategies. These techniques involve small changes to your daily behaviors to be more energy-efficient.

- ▶ Get enough sleep each night so that you feel rested.
- ▶ Eat smaller, frequent meals and snacks throughout the day, rather than three large meals, to increase your overall intake.
- ▶ Pace yourself - avoid rushing, and work slowly. Working too fast can make you feel exhausted. Take breaks *before* you feel fatigued!
- ▶ Reduce distractions when trying to concentrate on a task or conversation.
- ▶ Sit to work when possible instead of standing.
- ▶ Avoid sitting in low chairs, it requires more energy to get out of them.
- ▶ Plan ahead and be organized - space your activities out, and alternate light and heavy activities. Gather all the materials you need prior to starting an activity.
- ▶ Make a list of daily and weekly necessary tasks and stick to it. Prioritize, and focus on tasks that cannot be put off.
- ▶ Plan a routine with specific times for chores, rest, exercise, and recreation. Keep a regular sleep schedule.
- ▶ Choose the best time of day for each activity – consider your personal pattern of fatigue, and plan your activities accordingly.
- ▶ Avoid unnecessary movements. Take time to develop efficient ways to complete tasks, or ask for help when needed.
- ▶ Avoid extreme temperatures (e.g., hot bath or cold shower).
- ▶ Consider adaptive equipment such as a shower/bath chair, or long-handled sponge.

Work with your rehabilitation doctor and therapists to help tailor an exercise program that is right for you!

Managing Pain During Cancer Rehabilitation

Tracking Your Pain

Pain may occur for various reasons including direct impact from the cancer or treatment. You are the expert on your experience, so be sure to communicate with your team about it. Consider the following:

Severity - Rate your pain on a scale of 0-10. Try to think of the time in your life when you experienced the worst pain you can remember, that is a pain level of 10. A 0 is “no pain.”

Location - Where do you feel the pain?

Frequency and Duration - When do you have pain? Does it come and go, or is it constant? How long does it last? Is it new?

Quality - Describe the pain. Is it burning or stabbing? Sharp or dull? Cramping?

Change - What makes the pain better (e.g., medication, a heating pad) or worse (e.g., moving, coughing)?

Managing Your Pain

While in rehab, you may have pain medication prescribed by your physician. This order will be PRN (“as needed”). This means that you will need to ask for your pain medication when you need it, and the nurse will then provide it to you. It will not be given automatically with the rest of your medications.

General tips with pain medication:

- ▶ Do NOT wait until your pain is out of control to take your medication. It is easier to stop pain before it starts or to prevent it from getting worse.
- ▶ Plan to take your pain medication prior to therapies. We recommend 30-60 minutes prior to your treatment session.
- ▶ Medication side effects frequently include drowsiness, nausea, and constipation. Speak with your team about any concerning symptoms.

Complementary Pain Management

- ▶ Hot or cold compresses
- ▶ Relaxation techniques, including guided- imagery and deep breathing
- ▶ Mindfulness
- ▶ Meditation
- ▶ Distraction
- ▶ Repositioning for comfort
- ▶ Exercise and stretching
- ▶ Aromatherapy
- ▶ Tai Chi or yoga

Coping with a Cancer Diagnosis

It is normal to experience a wide range of emotions when you are first diagnosed including fear, disbelief, shock, anger, worry, sadness, grief, or even a sense of numbness.

Sadness and periods of depressed mood are a normal reaction to a cancer diagnosis. This may be experienced in the initial stage, or later on in the treatment process. Signs and symptoms include low energy, trouble making decisions, and feelings of uselessness or hopelessness. This change in mood may be brought on by life changes associated with survivorship, and made worse by the physical effects of cancer or its treatment.

These symptoms can interfere with your participation in rehabilitation and recovery. *One in four people with cancer experience clinical depression, meaning that they have symptoms that do not go away, and interfere with their ability to function in their daily life. It is not a sign of weakness or anyone's fault.* Speak with your treatment team if you are experiencing symptoms of depression.



Coping Strategies

Cancer affects each person's body and mind differently. As you look for ways to cope that work for you, consider some of these techniques:

- ▶ Learn as much as you can about cancer and the various treatment options
- ▶ Express your feelings by talking with friends, keeping a journal, or engaging in art
- ▶ Take time to do things you enjoy every day
- ▶ Exercise
- ▶ Reach out to others – Take time to reach out to friends, family, or support groups to share your fears, hopes, and triumphs every step of the way

The Value of Support

As you are going through this process, it is important to know that you do not have to suffer silently, be positive all the time, or pretend everything is ok. Finding support from those around you can help you cope with a cancer diagnosis. Knowing that you are not alone may be meaningful and powerful. There are many different ways to reach out to individuals in your support network including: talking with a friend or family member, working with a psychologist or therapist individually, or engaging with others in a support group. While it may initially be uncomfortable, expressing emotions with others can:

- ▶ Decrease feelings of anger or despair
- ▶ Improve self-confidence and sense of purpose
- ▶ Improve an individual's expression of support, empathy, interest, and humor
- ▶ Decrease feelings of isolation
- ▶ Improve physical functioning
- ▶ Improve overall quality of life

Talking with Friends and Family

Talking about cancer can be difficult, even with those who are closest to you. Sometimes it is hard to know how you feel, much less talk with others about it. Your loved ones may have a hard time discussing cancer, too. Here are a few tips to help you and your loved ones deal with cancer and to help you build your support system:

- ▶ Tell those closest to you about your cancer as soon as you feel up to discussing it. Eventually, they will learn you have cancer and hearing from someone else may make it difficult to maintain open communication.
- ▶ Explain to others what kind of cancer you have, and how it will be treated.
- ▶ Allow friends and family to help you and tell them clearly what kind of help you need. If you need a ride, childcare, or help around the house, let them know that, too.
- ▶ Tell those closest to you how you feel. This may be very difficult but can help both you and those you love to process those emotions.

Talking with Children about Cancer

Children often sense and know more than we think. It is natural to want to protect children through silence, but this can backfire. When children pick up on anxiety and hear parts of conversations but are not provided with information about what is happening, they may be blaming themselves or filling in the blanks with fears of the worst.

- ▶ Coordinate with other adults who care for the children, to be on the same page about how you will discuss matters with them.
- ▶ Provide simple and concrete information in language that your child understands.
- ▶ Encourage questions and provide honest answers.
- ▶ Ask what they already know and address any misunderstandings.
- ▶ Children under the age of 8 will not need a great deal of detail, while older children and adolescents will require more.
- ▶ Be prepared for age-appropriate reactions to stress (e.g., reverting to younger behaviors in young children, acting out in older children).

Wellness Through Nutrition and Physical Activity

Exercise regularly – Exercise improves quality of life, reduces anxiety, depression, and fatigue, improves self-esteem and heart health, increases feelings of optimism, boosts muscle strength and diabetes, and reduces risk of high blood pressure, heart disease, stroke, and diabetes.

Remember, start slow and build up. Speak to your physician before you start an exercise program.
 Physical fitness comprises three areas:

Aerobic Exercise
Strength
Flexibility

150 minutes of moderate exercise (i.e., walking) is recommended every week.
The smallest amount of physical activity is beneficial.

Eat healthier – Nutritious foods help survivors regain strength. Your doctor or dietician can help.

The National Cancer Institute recommends the following tips
<p>Stay away from foods that cause gas:</p> <p>Soda, Peas, Broccoli, Radishes, Cucumbers, Brussels sprouts, and Green Peppers</p>
<p>If constipated, try:</p> <p>Whole-grained cereals (i.e., Beans, Vegetables oatmeal, bran) and breads</p>
<p>If nausea is a problem, try:</p> <p>Small, frequent meals</p> <p>Sips of cool beverages between meals</p> <p>Cold or chilled foods</p> <p>Dry, starchy, and salty foods throughout the day</p>
<p>Eat foods that have high-protein and high-calorie to increase energy and help heal wounds.</p> <p>Eggs, Ice Cream, Meat, Cheese, Nuts, Poultry, Whole Milk, Peanut Butter, and Fish</p>
<p>Additional Recommendations:</p> <p>Take nutritional supplemental drinks between meals.</p> <p>Make changes in your diet, such as eating small meals throughout the day.</p>

SURVIVORSHIP

Living with, Through, and Beyond Cancer

Defining Survivorship:

Survivorship in cancer patient care is **the process of living with, through, and beyond cancer**. Survivorship is something that begins at diagnosis. Survivorship includes people who continue to receive treatment, and those who are managing chronic disease related to cancer.

Some people don't feel comfortable calling themselves a "survivor" if they live with cancer every day. No matter how you define survivorship, it is unique for every person. The most important thing to know about survivorship is that it is a way of navigating the changes and challenges that occur as a result of living with cancer.

Survivorship Care Planning

A survivorship care plan summarizes important information about your cancer and treatment. This information can help you and your healthcare providers understand each other. Talk with your oncologist about your survivorship care plan, and share it with other healthcare professionals you see (e.g., your primary care doctor, surgeon, physiatrist, psychologists, therapists, etc.)

Questions to consider during your journey:

- Will I need to have any more treatment after the active treatment phase has ended?
- Who will be part of my healthcare team after active treatment ends, and what will each member do?
- Are there groups or online resources that would help me learn more about survivorship after my diagnosis?
- Whom should I contact if I have any questions or concerns?

<https://www.nccn.org/patients/guidelines>

