National Comprehensive Cancer Network®

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NCCN Guidelines for Patients®

Version 1.2016

NCCN NON-HODGKIN'S LYMPHOMAS SERIES

Peripheral T-cell Lymphoma

Available online at NCCN.org/patients

Peripheral T-cell Lymphoma (PTCL)

Learning that you have cancer can be overwhelming. The goal of this book is to help you get the best cancer treatment. It explains which cancer tests and treatments are recommended by experts of peripheral T-cell lymphoma.

The National Comprehensive Cancer Network® (NCCN®) is a not-for-profit alliance of 27 of the world's leading cancer centers. Experts from NCCN® have written treatment guidelines for doctors who treat peripheral T-cell lymphoma. These treatment guidelines suggest what the best practice is for cancer care. The information in this patient book is based on the guidelines written for doctors.

This book focuses on the treatment of peripheral T-cell lymphoma. Key points of the book are summarized in the related **NCCN Quick Guide™**. NCCN also offers patient resources on mycosis fungoides, follicular lymphoma, diffuse large B-cell lymphoma, mantle cell lymphoma, and other cancer types. Visit **NCCN.org/patients** for the full library of patient books, summaries, and other resources.

Credits

NCCN aims to improve the care given to patients with cancer. NCCN staff work with experts to create helpful programs and resources for many stakeholders. Stakeholders include health providers, patients, businesses, and others. One resource is the series of books for patients called the NCCN Guidelines for Patients®. Each book presents the best practice for a type of cancer. The patient books are based on clinical practice guidelines written for cancer doctors. These guidelines are called the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®). Clinical practice guidelines list the best health care options for groups of patients. Many doctors use them to help plan cancer treatment for their patients. Panels of experts create the NCCN Guidelines®. Most of the experts are from NCCN Member Institutions. Panelists may include surgeons, radiation oncologists, medical oncologists, and patient advocates. Recommendations in the NCCN Guidelines are based on clinical trials and the experience of the panelists. The NCCN Guidelines are updated at least once a year. When funded, the patient books are updated to reflect the most recent version of the NCCN Guidelines for doctors. For more information about the NCCN Guidelines, visit **NCCN.org/clinical.asp**.

NCCN staff involved in making the guidelines for patients and doctors include:

NCCN Guidelines for Patients

Dorothy A. Shead, MS
Director
Patient and Clinical Information Operations

Laura J. Hanisch, PsyD
Medical Writer/Patient Information Specialist

Lacey Marlow
Associate Medical Writer

NCCN Guidelines

Mary Dwyer, MS
Senior Manager, Guidelines

Hema Sundar, PhD
Oncology Scientist/Senior Medical Writer

Rachael Clarke
Guidelines Data and Layout Coordinator

NCCN Marketing

Susan Kidney
Graphic Design Specialist

Endorsed by

THE LEUKEMIA & LYMPHOMA SOCIETY (LLS)

LLS is dedicated to developing better outcomes for blood cancer patients through research, education and patient services and is happy to have this comprehensive resource available to patients with peripheral t-cell lymphoma.
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Guiding Treatment, Changing Lives.

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National Comprehensive Cancer Network (NCCN)
275 Commerce Drive • Suite 300
Fort Washington, PA 19034
215.690.0300

Contents

Peripheral T-cell Lymphoma (PTCL)

Who should read this book?

Peripheral T-cell lymphoma is the focus of this book. Information on diagnosis, treatment planning, and treatment options are included for the following subtypes: peripheral T-cell lymphoma, NOS; angioimmunoblastic T-cell lymphoma; anaplastic large cell lymphoma; and enteropathy-associated T-cell lymphoma.

People with these subtypes of peripheral T-cell lymphoma and those who support them—caregivers, family, and friends—may find this book helpful. It may help you discuss and decide with doctors what care is best.

Where should I start reading?

Starting with Part 1 may be helpful. It explains what peripheral T-cell lymphoma is and how it is diagnosed. Parts 2 through 5 address issues related to treatment. Part 2 lists which health tests and other types of care are needed before treatment. Part 3 briefly describes all the types of treatments so you can understand your options that are listed in Part 4. Tips for making treatment decisions are presented in Part 5.

Does the whole book apply to me?

This book includes information for many situations. Your treatment team can help. They can point out what information applies to you. They can also give you more information. As you read through this book, you may find it helpful to make a list of questions to ask your doctors.

The recommendations in this book are based on science and the experience of NCCN experts. However, these recommendations may not be right for you. Your doctors may suggest other tests and treatments based on your health and other factors. If other recommendations are given, feel free to ask your treatment team questions.

Making sense of medical terms

In this book, many medical words are included. These are words that you will likely hear from your treatment team. Most of these words may be new to you, and it may be a lot to learn.

Don’t be discouraged as you read. Keep reading and review the information. Don’t be shy to ask your treatment team to explain a word or phrase that you do not understand.

Words that you may not know are defined in the text or in the *Dictionary*. Words in the *Dictionary* are underlined when first used on a page.

Acronyms are also defined when first used and in the *Glossary*. Acronyms are short words formed from the first letters of several words. One example is **DNA** for **d**eoxyribo**n**ucleic **a**cid.

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1 PTCL basics

1 PTCL basics

You've learned that you have or may have peripheral T-cell lymphoma. It's common to feel shocked and confused. Part 1 reviews some basics that may help you learn about this lymphoma and start to cope. These basics may also help you start planning for treatment.

What is the lymphatic system?

The lymphatic system is one of 13 systems of the human body. It transports fluids to the bloodstream and fights germs. As such, it supports your blood-flowing (cardiovascular) and disease-fighting (immune) systems.

Cells are the building blocks of tissue in the body. The spaces between cells are filled with fluid. This fluid is called interstitial or tissue fluid. Most tissue fluid comes from parts of blood plasma that have passed out of blood vessels. Cells also release waste and other products into tissue fluid.

When tissue fluid increases, it drains into vessels. Almost all of tissue fluid drains back into blood vessels. The rest of it drains into lymph vessels. Once inside of lymph vessels, tissue fluid is called lymph. Lymph travels in lymph vessels back to the bloodstream.

The lymphatic system also collects fat and some vitamins from your gut. After you eat, your stomach turns food into a liquid. Then, the liquid drains into

your small intestine. Within your small intestine, fat and some vitamins are absorbed into lymph vessels. This fatty lymph, called chyle, travels in lymph vessels to the bloodstream.

As lymph travels, it will pass through and be filtered by lymph nodes. Lymph nodes are organized masses of lymphoid tissue. There are hundreds of lymph nodes throughout your body. **See Figure 1.1**. High numbers of lymph nodes exist in the middle of your chest, neck, armpit, groin, pelvis, and along your gut.

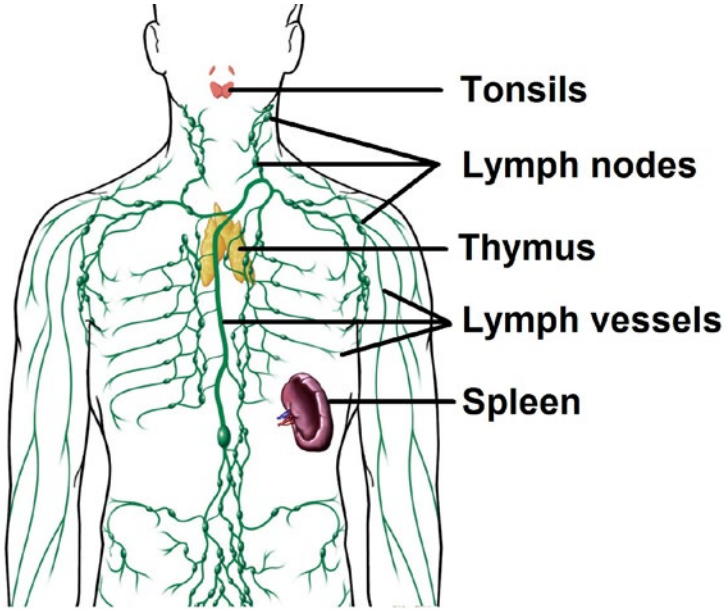
Lymph nodes and other lymphoid tissue are defined by high numbers of white blood cells called lymphocytes. Lymph also has lymphocytes.

Lymphocytes help fight germs. The three types of lymphocytes are NK (natural killer) cells, B-cells, and T-cells. Lymphocytes are made in bone marrow then are moved by blood to the lymphatic system.

Other parts of your body that have many lymphocytes are included in the lymphatic system. In children, the thymus stores T-cells until they are able to fight germs. Germs in blood are filtered and destroyed by lymphocytes within your spleen. Your tonsils kill germs in lymph that enter through your mouth and nose. There are also small clumps of lymphatic tissue in your gut, thyroid, breasts, lungs, eyes, and skin.

Figure 1.1
Lymphatic system

The lymphatic system kills germs in the body and collects and transports lymph to the bloodstream.



What is PTCL?

Cancer is a disease of cells. Lymphomas are cancers that start in lymphocytes within the lymphatic system. There are two main types of lymphomas. Hodgkin lymphoma is defined by the presence of Reed-Sternberg or related cells. Non-Hodgkin's lymphoma includes all the other types of lymphoma. Peripheral T-cell lymphoma is a type of non-Hodgkin's lymphoma.

Peripheral T-cell lymphoma is a cancer of T-cells. There are many types of T-cells and thus, many T-cell cancers. T-cells differ from one another based on the cell's stage of development and what job the T-cells do.

Very early forms (precursors) of T-cells are made in bone marrow. They travel from the marrow to the thymus to become mature T-cells. When T-cells are ready to help fight illness, they leave the thymus and travel to other lymph tissue, such as the lymph nodes. Peripheral T-cell lymphoma starts from T-cells that have left the thymus.

Inside of cells are coded instructions for building new cells and controlling how cells behave. These instructions are called genes. Genes are a part of DNA (**d**eoxyribo**n**ucleic **a**cid), which is grouped together into bundles called chromosomes. **See Figure 1.2.** Abnormal changes (mutations) in genes cause normal B-cells to become cancer cells. Researchers are still trying to learn what causes genes to mutate and cause cancer.

Cancer cells don't behave like normal cells. First, the mutations cause cancer cells to grow more quickly and live longer than normal cells. Normal cells grow and then divide to form new cells when needed. They also die when old or damaged as shown in **Figure 1.3.** In contrast, cancer cells make new cells that aren't needed and don't die quickly when old or damaged. Over time, the lymphoma cells may build up in tissues and may travel in blood or lymph to other sites. Without treatment, the cancer may cause organs not to work.

Figure 1.2
Genetic material in cells

Most human cells contain the "blueprint of life"—the plan by which our bodies are made and work. The plan is found inside of chromosomes, which are long strands of DNA that are tightly wrapped around proteins. Genes are small pieces of DNA that contain instructions for building new cells and controlling how cells behave. Humans have about 24,000 genes.

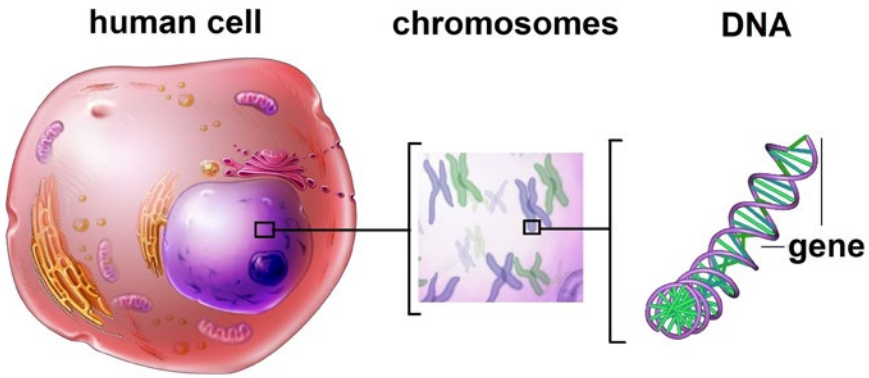
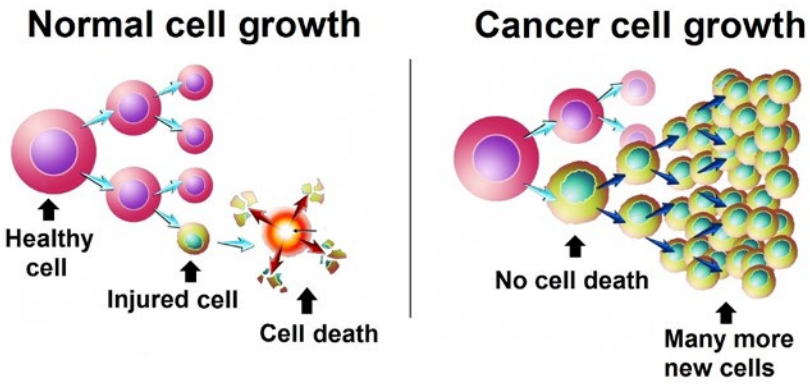


Figure 1.3
Normal cell growth vs. cancer cell growth

Normal cells increase in number when they are needed and die when old or damaged. In contrast, cancer cells quickly make new cells and live longer because of abnormal changes in genes.



Do I have PTCL?

One of the most common symptoms of peripheral T-cell lymphoma is a swelling of one or more lymph nodes. Swollen nodes may occur in your neck, armpit, or groin. However, peripheral T-cell lymphoma is often found elsewhere in your body. Other common sites are the skin, GI (**g**astro**i**ntestinal) tract, and bone marrow. The GI tract is a group of organs in which food is broken down, absorbed, and disposed of. When your doctor suspects cancer, testing is needed. The tests that are needed to confirm (diagnose) peripheral T-cell lymphoma are described next.

Biopsy

In general, tissue must be removed from your body and be tested to diagnose cancer. A biopsy removes samples of fluid or tissue. To diagnose peripheral T-cell lymphoma, an incisional or excisional biopsy of the tumor is often done. An incisional biopsy removes only a part of the tumor through a cut made into your body. An excisional biopsy removes the whole tumor and not much else. The methods used to do either biopsy depend on where the tumor is in your body.

FNA (**fi**ne-**n**eedle **a**spiration) removes very small samples with a needle. It should not be used alone to diagnose peripheral T-cell lymphoma. You may have cancer even if no cancer is found in the samples.

Hematopathology review

The biopsy samples will be sent to a special type of pathologist. A pathologist is a doctor who's an expert in testing cells to find disease. For peripheral T-cell lymphoma, the pathologist should be a specialist in hematopathology. Hematopathologists spend all of their time looking at blood and bone marrow and lymph nodes, so they become very good at diagnosing blood cancers. The pathologist will first examine the samples using a microscope.

The hematopathologist will decide if cancer is present. If it is, the type and subtype of cancer will be noted. Furthermore, the pathologist will assess if the cancer will grow slow or fast. Most peripheral T-cell lymphomas grow fast.

The results of these tests and those described next will be recorded in a pathology report. It's a good idea to get a copy of your pathology report. It's used to plan treatment.

Protein tests

For diagnosis, the hematopathologist needs to study the proteins in the cells' surface (membrane). This is called immunophenotyping. The pathologist will study the pattern of surface proteins to decide if the cancer is from B-cells or T-cells and then the cell subtype. An IHC (**i**mmuno**h**isto**c**hemistry) panel is a test for such proteins. It involves applying a chemical marker to cells then looking at them with a microscope.

The IHC panel often tests for ALK, BCL6, CD2, CD3, CD4, CD5, CD7, CD8, CD10, CD20, CD21, CD23, CD30, CD56, CD57, EBER-ISH, and Ki-67. In general, T-cells often express markers such as CD2, CD3, CD4, CD5, CD7, or CD8 while B-cells do not. Otherwise, surface proteins on T-cell lymphomas vary. At times, it may be useful to do an IHC panel of ßF1, TCR-CγM1, PD1/CD279, and CXCL-13 to learn the lymphoma subtype.

Flow cytometry is a newer method that can assess for surface proteins. This method involves first adding a marker—a light-sensitive dye—to cells. Then, your blood will be passed through a flow cytometry machine. The machine measures surface proteins on thousands of cells.

Flow cytometry may be done in addition to an IHC panel. For suspected T-cell lymphoma, it often includes CD2, CD3, CD4, CD5, CD7, CD8, CD10,

CD19, CD20, CD30, CD45, TCRαß, TCRγ, and kappa and lambda light chain proteins. Light chain proteins are part of antibodies.

Genetic tests

A translocation is a switching of parts between two chromosomes. A gene rearrangement is the fusion of one gene with another gene to create a new gene. A translocation can be the cause of a gene arrangement.

There are tests that detect translocations and gene rearrangements. Such tests include karyotype and FISH (**f**luorescence **i**n **s**itu **h**ybridization). One or both tests can aid in diagnosing certain subtypes of T-cell lymphoma.

Often, peripheral T-cell lymphomas have rearrangements in the TCR (**T**-**c**ell **r**eceptor) genes. Also, many anaplastic large cell lymphomas have too many ALK-1 (**a**naplastic **l**ymphoma **k**inase) proteins. There are too many ALK proteins because of a translocation between chromosomes 2 and 5—referred to as t(2;5). In cases of anaplastic large cell lymphoma, it is important to test for ALK1 status. This can be done by IHC for ALK proteins or by genetic tests.

HTLV tests

HTLV (**h**uman **T**-cell **l**ymphotropic **v**irus) is important for diagnosing a subtype of T-cell lymphoma. If you have HTLV, the cancer may be adult T-cell leukemia or lymphoma rather than peripheral T-cell lymphoma. You will need to be tested if your doctor thinks HTLV is important for understanding your diagnosis.

Testing of HTLV is done on a blood sample. Serology is a test that looks for antibodies that target HTLV. If the results from serology are unclear, PCR (**p**olymerase **c**hain **r**eaction) can be done. PCR is a process in which copies of a part of DNA are made, which helps doctors find viruses.

Review

- The lymphatic system consists of lymph and a network of vessels and organs. It helps kill germs in the body and transports fluids to the bloodstream.
- Lymphomas are cancers that start in lymphocytes within the lymphatic system. Peripheral T-cell lymphoma starts in T-cells that have left the thymus (mature T-cells).
- Peripheral T-cell lymphoma is often a fast-growing cancer. Often, it will spread from one group of tissues to the next and so on.
- Incisional or excisional biopsy is needed to diagnose peripheral T-cell lymphoma.
- The biopsy tissue should be tested by a hematopathologist. The hematopathologist will perform a number of tests that assess for cell type, surface proteins, and maybe genetics. You may also be tested for HTLV to know which cancer you have.

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2

Treatment planning

2 Treatment planning

Doctors plan treatment with many sources of information. One of these sources is tests of your health and the cancer. Part 2 describes who should receive which tests before treatment. Some of these tests are repeated during and after treatment. Besides tests, Part 2 describes other types of care that are important to receive before cancer treatment.

Medical history

Your medical history includes any health events and medicines you've taken in your life. You will be asked about illnesses, injuries, health conditions, and more. Some health problems run in families. Thus, your doctor may also ask about the health of your blood relatives.

Some signs and symptoms of peripheral T-cell lymphoma are enlarged lymph nodes, tiredness, and rash. This cancer may also cause "B symptoms." It's important that your doctor knows if you have them. These symptoms include fevers, chills, night sweats, and weight loss without dieting.

A medical history is one of the tests needed for treatment planning. **See Chart 2.1** for a complete list of care that is recommended prior to treatment. Some types of care are for anyone with peripheral T-cell lymphoma while others may be useful for some people.

Physical exam

Doctors often give a physical exam along with taking a medical history. A physical exam is a study of your body for signs of disease. During this exam, your doctor will listen to your lungs, heart, and gut. Parts of your body will likely be felt to see if organs are of normal size, are soft or hard, or cause pain when touched.

For peripheral T-cell lymphoma, there are certain parts of your body that should be checked. You should have a full skin exam. Peripheral T-cell lymphoma is often found in lymph nodes, so areas with lots of lymph nodes should be examined. High numbers of lymph nodes exist in the middle of your chest, neck, throat, armpit, groin, pelvis, and along your gut. The size of your spleen and liver should also be assessed. The upper part of your throat that is behind your nose should also be assessed for signs of cancer.

Results of your medical history and physical exam will be used to rate your performance status. Performance status is your ability to do daily activities. It is used by doctors to assess if you can undergo certain treatments. The ECOG (**E**astern **C**ooperative **O**ncology **G**roup) Performance Scale is a common scoring scale for performance status. This scale consists of scores from 0 to 4. Lower scores mean you can do more activities.

Chart 2.1 Care before treatment

Must haves	Sometimes useful
• Medical history	• HIV testing
• Physical exam	• Neck CT
• Complete blood count with differential	• Head CT or MRI
• Comprehensive metabolic panel	• Skin biopsy
• Lactate dehydrogenase	• Fertility support
• Uric acid	
• Diagnostic CT, PET/CT, or both	
• Bone marrow biopsy	
• International Prognostic Index	
• Echocardiogram or MUGA	
• Pregnancy test if you can have babies	

Blood tests

Blood tests are used to learn if cancer treatment might be needed now. They are also used to find unknown diseases including those related to peripheral T-cell lymphoma. It's important to treat all illnesses. Blood tests for peripheral T-cell lymphoma are:

Complete blood count with differential

A CBC (**c**omplete **b**lood **c**ount) measures the number of blood cells in a blood sample. It includes numbers of white blood cells, red blood cells, and platelets. Your blood counts may be low or high because of cancer or another health problem. It is an essential test that gives a picture of your overall health.

There are several types of white blood cells. A differential counts the number of each type. It also checks if the counts are in balance with each other. Your doctor can learn the cause of an abnormal white blood count from this test.

Comprehensive metabolic panel

Chemicals in your blood come from your liver, bone, and other organs. A comprehensive metabolic panel often includes tests for up to 14 chemicals. The tests show if the level of chemicals is too low or high. Abnormal levels can be caused by cancer or other health problems.

Lactate dehydrogenase

Lactate dehydrogenase is a protein that is in most cells. It gets into your blood when a cell is damaged. Thus, a high level of lactate dehydrogenase is a sign of cell damage. High levels can be caused by cancer or other health problems. If related to cancer, high levels may be a sign that the cancer is widespread.

Uric acid

Some people with peripheral T-cell lymphoma are at risk for **t**umor **l**ysis **s**yndrome (TLS, for short). This syndrome can be life threatening. It occurs when the waste released by dead cells is not quickly cleared out of your body. This results in kidney damage and severe blood electrolyte disturbances.

Tumor lysis syndrome can occur among people with peripheral T-cell lymphoma who are undergoing strong cancer treatments. The cancer treatment kills many cancer cells and results in too much waste too quickly.

Your doctors may want to know your uric acid level before starting treatment. You may be given certain medications that can help prevent tumor lysis syndrome. Also, drinking plenty of water throughout chemotherapy can help. Ask your treatment team for more information.

HIV testing

If you have HIV, treating it is an important part of treating peripheral T-cell lymphoma. HIV treatment will improve how well cancer treatment works. Thus, tell your treatment team if you have HIV and about your treatment. Ask your treatment team if you have not been tested.

Imaging tests

Imaging tests make pictures (images) of the inside of your body. They can show where the cancer is in your body. This information helps your doctors stage the cancer. More information on cancer staging is described later in this chapter.

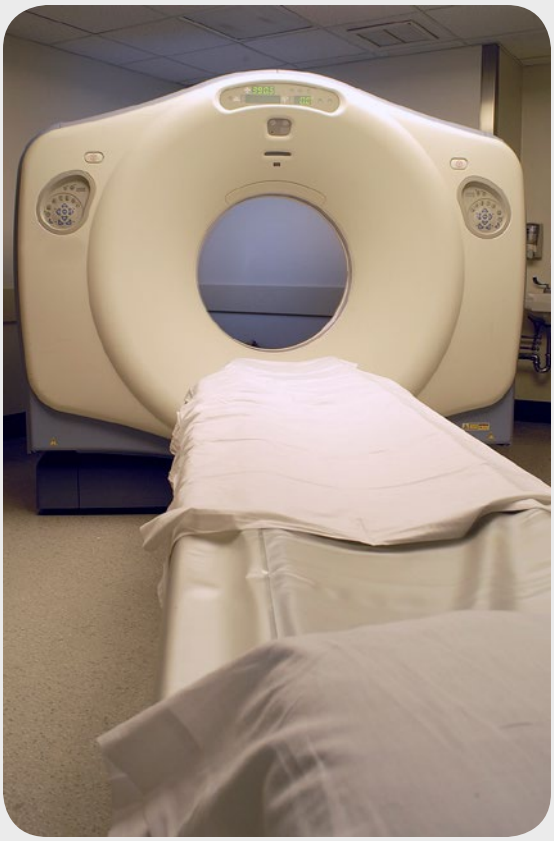
Your treatment team will tell you how to prepare for the test. You may need to stop taking some medicines and stop eating and drinking for a few hours before the scan. Tell your doctors if you get nervous when in small spaces. You may be given a sedative to help you relax.

Imaging machines are large. You will likely be lying down during testing. At least part of your body will be in the machine. **Figure 2.1** shows one type of imaging machine, which is described next.

After the test, you will likely be able to resume your activities right away. If you took a sedative, you will have a waiting period. You may not learn of the results for a few days since a radiologist needs to see the pictures. A radiologist is a doctor who's an expert in reading the images.

Figure 2.1 Computed tomography machine

A CT machine is large and has a tunnel in the middle. During the test, you will lie on a table that moves slowly through the tunnel.



Diagnostic CT

A CT (**c**omputed **t**omography) of your chest, belly area, and between your hip bones is needed. CT takes many pictures of a body part from different angles using x-rays. A computer combines the x-rays to make detailed pictures.

A contrast dye is used for diagnostic CT. It makes the pictures clearer. The dye will be injected into a vein in your hand or arm. You will also be given a liquid contrast to drink.

The contrast may cause you to feel flushed or get hives. Rarely, serious allergic reactions occur. Tell your doctor and the technicians if you have had bad reactions to contrast.

PET/CT

Another imaging test combines CT with PET (**p**ositron **e**mission **t**omography). PET/CT may be given in addition to or instead of CT. It can show the presence of cancer when other tests do not.

For PET, a sugar radiotracer will be injected into your body. The radiotracer is detected with a special camera. Cancer cells appear brighter than normal

cells because they use sugar more quickly. PET/CT may be done with one or two machines depending on the cancer center.

Neck CT and head CT or MRI

It may be useful to get an imaging test of your neck and head. CT can be used to image your neck. Either CT or MRI (**m**agnetic **r**esonance **i**maging) may be used to image your head. MRI is an imaging test that uses a magnetic field and radio waves to make pictures. A device will be placed around your neck and head that sends and receives radio waves. You may also be given a contrast dye to make the pictures clearer.

Biopsy

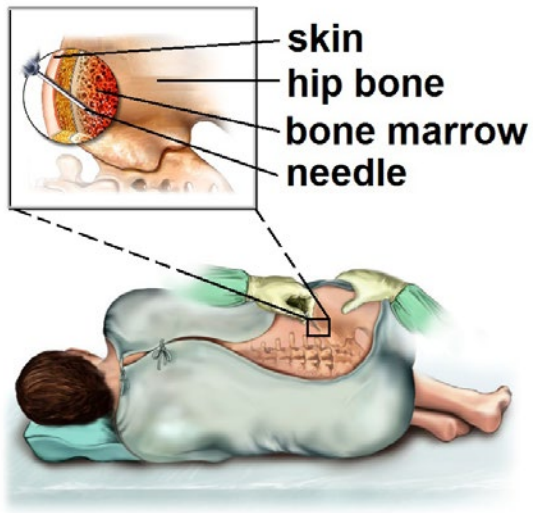
Bone marrow biopsy

At times, peripheral T-cell lymphoma has spread to bone marrow before treatment is started. Thus, a bone marrow biopsy is needed before treatment to confirm if there's cancer. A bone marrow biopsy removes a sample of bone and soft bone marrow.

Often, this test is done at the same time on the back of hip bone. You may receive a light sedative before the test. You will likely lie on your side as shown in **Figure 2.2**. Your doctor will clean your skin and then give local anesthesia to numb the site. Once numb, a wide needle will be inserted into the bone and rotated to remove bone and soft marrow. This biopsy may cause bone pain and can bruise your skin for a few days. The samples will be sent to a lab for testing.

Figure 2.2 Bone marrow biopsy

Doctors use a bone marrow biopsy to remove a sample of bone and marrow for testing.



Skin biopsy

Peripheral T-cell lymphomas and other T-cell lymphomas may involve the skin. Based on your skin exam, your doctor may want you to have a skin biopsy. There are multiple types of skin biopsies. Which one you will have depends on how large and where the abnormal skin is. Skin samples may be removed by excisional, incisional, punch, or shave biopsies. A punch biopsy uses a sharp hollow device—like a cookie cutter—to remove a small but deep sample of both skin layers. A shave biopsy removes the first layer of skin and part of the second layer.

Before the skin biopsy, your skin will be numbed with local anesthesia. You may feel pressure during the biopsy, but no pain. Afterward, you doctor may close the wound and apply a bandage. Often, there are no side effects, but some people do get scars.

Prognostic scores

A prognosis is a prediction of the pattern and outcome of a disease. As part of treatment planning, your doctors will assess the prognosis of the cancer. There are two methods for predicting the prognosis of peripheral T-cell lymphoma, which are described next.

Cancer stage

A cancer stage is a rating by your doctors of how far the cancer has grown and spread. It is used for prognosis, treatment planning, and to check treatment results. The Ann Arbor staging system is used to stage peripheral T-cell lymphoma. In this system, there are four cancer stages.

- **Stage I** is cancer that is in only one cluster of lymph nodes.
- **Stage II** is cancer that is in 2 or more clusters either above or below your diaphragm.
- **Stage III** is cancer that is in lymph tissue on both sides of your diaphragm.
- **Stage IV** is cancer that has widely spread outside the lymphatic system.

When the cancer is staged, other letters are also assigned. The letters “A” and “B” indicate whether B symptoms have been present in the past 6 months. No symptoms is rated A, and if symptoms are present, B. The letter “E” stands for extranodal disease, which is cancer in sites other than the lymph nodes. The letter “X” means the cancer is large (>10 cm).

In general, earlier cancer stages have better outcomes. However, some people with early-stage cancer have poor outcomes. Prognosis depends not just on the cancer stage but other factors. Thus, doctors have created better methods to predict prognosis.

International Prognostic Index

The IPI (**I**nternational **P**rognostic Index) is a scoring system that uses risk factors to assess prognosis. A risk factor is anything that increases your chances of an event. The first IPI was created over 20 years ago.

In the standard version, 1 point is given for every risk factor that describes you. The five risk factors are: 1) older than 60 years of age; 2) lactate dehydrogenase level above normal; 3) performance status score of 2 or greater; 4) stage III or IV; and 5) more than one extranodal site. The total number of points is used to assign you to one of four risk groups, which are:

- **Low risk** includes scores of 0 and 1.
- **Low-intermediate risk** includes a score of 2.
- **High-intermediate risk** includes a score of 3.
- **High risk** includes scores of 4 or more.

There is now more than one version of the IPI. There is an age-adjusted version for people 60 years of age and younger. One point is given for 1) stage III or IV; 2) lactate dehydrogenase level above normal; and 3) performance status score of 2 or greater. A score of 0 is low risk, a score of 1 is low-intermediate risk, a score of 2 is high-intermediate risk, and a score of 3 is high risk.

Prognostic Index for PTCL-Unspecified

The Prognostic Index for PTCL-Unspecified, or PIT, is a newer version for peripheral T-cell lymphomas. One point is given for 1) age greater than 60 years; 2) lactate dehydrogenase level above normal; 3) performance status score of 2 or greater; and 4) cancer in bone marrow. Two points are given for 1) ages 61 to 74; and 2) lactate dehydrogenase level greater than 3. Three points are given for age 75 and older. The total number of points is used to assign you to one of four risk groups, which are:

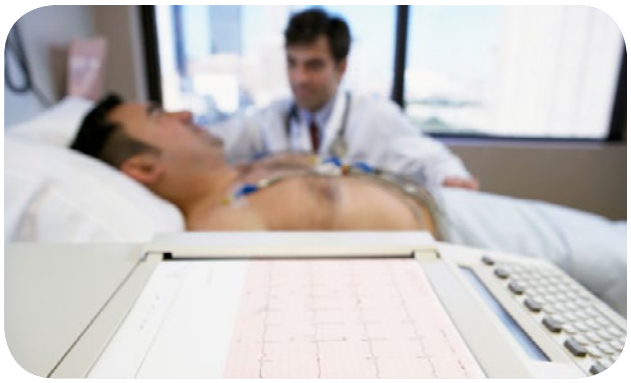
- **Group 1** includes a score of 0.
- **Group 2** includes a score of 1.
- **Group 3** includes a score of 2.
- **Group 4** includes scores of 3 and 4.

Heart tests

Some cancer treatments can damage your heart. Thus, your doctor may test how well your heart works to plan treatment. If it isn't working well, you may receive other treatment.

An echocardiogram is an imaging test of your heart. It uses sound waves (ultrasound) to make pictures. During this test, you will be lying down. Small patches will be placed on your chest to track your heartbeat. Next, a probe with gel on its tip will be slid across part of your bare chest. A picture of your beating heart will be seen at once on a screen. The pictures will be recorded for future viewing.

A MUGA (**mu**lti-**g**ated **a**cquisition) scan measures how well your heart is pumping blood. For this test, patches will be placed on your chest to track your heartbeat. Also, a radiotracer will be injected into your vein. Pictures of your heart will be taken with a special camera that can detect the radiation released by the tracer.



Fertility and pregnancy

Some cancer treatments can limit your ability to have a baby. If you want the choice of having babies after treatment or are unsure, tell your doctors. It may also help to talk with a fertility specialist before you begin cancer treatment. A fertility specialist is an expert in helping people have babies. The fertility specialist can discuss with you how to have a baby after treatment. Some methods of fertility preservation are discussed next. If you are a woman of childbearing age, important information on pregnancy is also addressed.

Sperm banking

Men who want to father children after cancer treatment can use sperm banking. Sperm banking stores semen for later use. This is done by freezing semen with sperm in liquid nitrogen. Talk to your treatment team about the costs of and how well sperm banking works.

Egg freezing and more

Like sperm banking, a woman's eggs can be removed, frozen, and stored for later use. Your frozen eggs can be fertilized with sperm beforehand. Also, a part of your ovary that contains eggs can be frozen and stored.

Pregnancy test

Some cancer treatments can harm an unborn baby. Get a pregnancy test before treatment if you may be pregnant now. Your treatment options will depend on the results. During treatment, take steps to avoid getting pregnant. Your doctors can tell you which birth control methods are best to use while on treatment.

Review

- Tell your doctor if you have recently had fevers, night sweats, and weight loss without dieting. These can be symptoms of peripheral T-cell lymphoma.
- Your doctor will examine your body for signs of disease. He or she will check if your lymph nodes, liver, or spleen are large. You will also have an exam of your skin and upper throat. Your doctor will rate your ability to do everyday activities.
- Blood tests can be done to assess for signs of widespread cancer and for other health conditions.
- Imaging tests allow your doctors to see inside your body without cutting into it. Diagnostic CT, PET/CT, or both is needed to see inside your torso. Imaging of your neck and head may be useful.
- You will need a bone marrow biopsy. This biopsy removes a piece of bone and marrow to test for cancer cells. Sometimes, a skin biopsy is useful.
- Your doctor will assess the outlook (prognosis) of the cancer.
- You may undergo heart tests to see if you are healthy enough to have certain cancer treatments.
- Talk to a fertility specialist to learn about ways to have babies after cancer treatment. If you may be pregnant now, get a pregnancy test since some cancer treatments can harm unborn babies.

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3 Overview of cancer treatments

3 Overview of cancer treatments

In Part 3, the main treatment types for peripheral T-cell lymphoma are briefly described. Knowing what a treatment is will help you understand your treatment options listed in Part 4. There is more than one treatment for peripheral T-cell lymphoma. Not every person will receive every treatment described in this chapter.

Clinical trials

New tests and treatments aren't offered to the public as soon as they're made. They first need to be studied. A clinical trial is a type of research that studies a test or treatment. Clinical trials are the preferred treatment option of NCCN experts for peripheral T-cell lymphoma.

Clinical trials study how safe and helpful tests and treatments are. When found to be safe and helpful, they may become tomorrow's standard of care. Because of clinical trials, the tests and treatments in this book are now widely used to help people with peripheral T-cell lymphoma. Future tests and treatments that may have better results than today's treatments will depend on clinical trials.

New tests and treatments go through a series of clinical trials to make sure they're safe and work. Without clinical trials, there is no way to know if a test or treatment is safe or helpful. Clinical trials have four phases. Some examples of the four phases of treatment are:

- **Phase I trials** – aim to find the best dose of a new drug with the fewest side effects.
- **Phase II trials** – assess how well a drug works to treat a specific type of cancer.
- **Phase III trials** – compare a new drug to the standard treatment.
- **Phase IV trials** – test new drugs approved by the U.S. FDA (**F**ood and **D**rug **A**dministration) in many patients with different types of cancer.

Joining a clinical trial has benefits. First, you'll have access to the most current cancer care. Second, you will receive the best management of care. Third, the results of your treatment—both good and bad—will be carefully tracked. Fourth, you may help other people who will have cancer in the future.

Clinical trials have risks, too. Like any test or treatment, there may be side effects. Side effects are unhealthy or unpleasant physical or emotional responses to treatment. Also, new tests or treatments may not help. Another downside may be that paperwork or more trips to the hospital are needed.

To join a clinical trial, you must meet the conditions of the study. Patients in a clinical trial are often alike in terms of their cancer and general health. This is to know that any progress is because of the treatment and not because of differences between patients. Likewise, some clinical trials are only open to people who have not started treatment while other trials include people in treatment.

To join, you'll need to review and sign a paper called an informed consent form. This form describes the study in detail. The study's risks and benefits should be described and may include others than those described above.

Ask your treatment team if there is an open clinical trial that you can join. There may be clinical trials where you're getting treatment or at other treatment centers nearby. You can also find clinical trials through the websites listed in Part 5.

Chemotherapy

Chemotherapy, or "chemo," includes drugs that disrupt the life cycle of cancer cells so they can't increase in number. Some chemotherapy drugs kill cancer cells by damaging their DNA or by disrupting the making of DNA. Other drugs interfere with cell parts that are needed for making new cells. Thus, no new cells are made to replace dying cells. Chemotherapy is often used to treat peripheral T-cell lymphoma.

Many chemotherapy drugs work when cells are in an active growth phase. During the active growth phase, cells grow and divide to form a new cell. Chemotherapy drugs that disrupt the growth phase work well for cancer cells that are growing and dividing quickly. Other chemotherapy drugs work whether cells are in a growth or resting phase. Chemotherapy can kill both cancer and normal cells.

Most chemotherapy drugs for peripheral T-cell lymphoma are liquids that are slowly injected into a vein. A few are made as pills or can be injected under the skin. By any method, the drugs travel in your bloodstream to treat cancer throughout your body. Doctors use the term "systemic" when talking about a cancer treatment for the whole body. Chemotherapy and other drugs used to treat peripheral T-cell lymphoma are listed in **Chart 3.1**.

Chemotherapy is often given in cycles of treatment days followed by days of rest. This allows the body to recover before the next cycle. Cycles vary in length depending on which drugs are used. Often, one total cycle is 2 to 4 weeks long.

Chemotherapy may consist of one or more drugs. When only one drug is used, it is called a single agent. However, not all drugs work the same way, so often more than one drug is used. A combination regimen is the use of two or more chemotherapy drugs.

Part 4 is a guide that explains who should receive which treatments. You will learn which regimens may be part of your treatment. Chemotherapy is sometimes given in high doses and followed by a stem cell transplant. Stem cell transplant is described later in this chapter.

Side effects of chemotherapy

Side effects are unhealthy or unpleasant physical or emotional responses to treatment. Side effects of chemotherapy differ between people. Some people have many side effects. Others have few. Some side effects can be very serious while others can be unpleasant but not serious. Most side effects appear shortly after treatment starts and will stop after treatment. However, other side effects are long-term or may appear years later.

Side effects of chemotherapy depend on many factors. These factors include the drug type, amount taken, length of treatment, and the person. In general, most side effects are caused by the death of fast-growing cells. These cells are found in the blood, gut, hair follicles, and mouth. Thus, common side effects of chemotherapy include low blood cell counts, not feeling hungry, nausea, vomiting, diarrhea, hair loss, and mouth sores. Long-term side effects of chemotherapy for peripheral T-cell lymphoma include increased risk for getting infections.

Not all side effects of chemotherapy are listed here. Please ask your treatment team for a complete list of common and rare side effects. If a side effect bothers you, tell your treatment team. There may be ways to help you feel better. There are also ways to prevent some side effects.

Chart 3.1 Drug treatment for peripheral T-cell lymphoma

Generic name	Brand name (sold as)	Type of treatment
Alemtuzumab	Campath®	Targeted therapy
Belinostat	Beleodaq®	Targeted therapy
Bendamustine hydrochloride	Treanda®	Chemotherapy
Bortezomib	Velcade®	Chemotherapy
Brentuximab vedotin	Adcetris®	Targeted therapy
Carboplatin	–	Chemotherapy
Cisplatin	Platinol®	Chemotherapy
Cyclophosphamide	–	Chemotherapy
Cyclosporine	Neoral®, Sandimmune®	
Cytarabine	Cytosar-U®	Chemotherapy
Dexamethasone, Dexamethasone sodium phosphate	–	Steroid
Doxorubicin hydrochloride	–	Chemotherapy
Doxorubicin hydrochloride, Liposomal injection	Doxil®	Chemotherapy
Epirubicin hydrochloride	Ellence®	Chemotherapy
Etoposide; Etoposide phosphate	Etopophos® Preservative Free	Chemotherapy
Gemcitabine hydrochloride	Gemzar®	Chemotherapy
Ifosfamide	–	Chemotherapy
Lenalidomide	Revlimid®	Immunomodulator
Leucovorin calcium	–	Folic acid analog
Mesna	Mesnex® Injection	Chemoprotectant
Methotrexate; Methotrexate sodium	–	Chemotherapy
Methylprednisolone; Methylprednisolone acetate; Methylprednisolone sodium succinate	A-Methepred®, Depo-Medrol®, Medrol®, Solu-Medrol®	Steroid
Oxaliplatin	Eloxatin®	Chemotherapy
Pralatrexate	Folotyn®	Chemotherapy
Prednisone	–	Steroid
Romidepsin	Istodax®	Chemotherapy
Vincristine sulfate	–	Chemotherapy
Vinorelbine tartrate	Navelbine®	Chemotherapy

Steroids

Corticosteroids are called steroids for short. They are a type of drug that is often used to relieve inflammation. Steroids also are toxic to lymphoma cells and therefore have strong anti-cancer effects. Steroids used to treat peripheral T-cell lymphoma are listed in Chart 3.1.

Steroids are a part of some chemotherapy regimens. They are given on the same days as chemotherapy but only for a few days or a week. Prednisone is made in pill form but dexamethasone and methylprednisolone are made both as a liquid to be injected or a pill to be swallowed.

Most side effects of steroids fade away once the drugs are stopped. Common side effects include feeling hungry, trouble sleeping, mood changes, slow wound healing, upset stomach, and swelling in the ankles, feet, and hands.

Immunomodulators

The immune system is your body's natural defense against illness. Immunomodulators are drugs that modify different parts of the immune system. Lenalidomide is an immunomodulator used to treat peripheral T-cell lymphoma if first-line treatment fails or the cancer returns.

Lenalidomide is made in pill form. It is given in cycles of treatment days followed by days of rest. A cycle may consist of 3 weeks of treatment and 1 week of rest. It may also be given for 4 straight weeks. Cycles may repeat until the cancer grows or side effects become severe.

Lenalidomide treats cancer in more than one way. As an immunomodulator, it boosts the immune system. It also helps stop cancer cells from increasing in number. Third, it also works like a type of targeted therapy called angiogenesis inhibitors. These drugs stop the growth of new blood vessels that would provide food (nutrients) to the cancer.

Common side effects include low blood counts, diarrhea, itching, rash, and severe tiredness despite sleep (fatigue). Serious but less common side effects include blood clots, bleeding disorders, loss of vision, and skin cancer. Ask your treatment team for a full list of side effects.

Targeted therapy

Targeted therapy is a class of drugs that stops the action of molecules that helps cancer cells grow. It is less likely to harm normal cells than chemotherapy. There are 3 targeted therapies that are used to treat peripheral T-cell lymphoma. These treatments are briefly described next. Some side effects are listed. Ask your treatment team for a full list of common and rare side effects. In Part 4, information on who should receive these drugs is provided.

Alemtuzumab

Monoclonal antibodies are man-made antibodies that attach to proteins on cancer cells. The monoclonal antibody used to treat peripheral T-cell lymphoma attach to antigens. When antibodies are attached to antigens on a cell, the cell is marked to be destroyed by your immune system.

Alemtuzumab is a monoclonal antibody that attaches to a molecule called CD52. CD52 is found on peripheral T-cell lymphoma cells, healthy B-cells and T-cells, as well as other cells. Alemtuzumab is rarely used to treat peripheral T-cell lymphoma.

Alemtuzumab is a liquid that will be slowly injected into your vein. It may take up to two hours to get the full dose. Alemtuzuamb can also be given as an injection under the skin. Alemtuzumab is often given three times a week for 12 weeks.

Common side effects include an allergic reaction when receiving the medicine. Also, you may feel nausea, vomit, get diarrhea, and have trouble sleeping. Blood counts are often low when taking this medicine. Taking alemtuzumab will increase your chances of getting a cytomegalovirus or other infection.

Belinostat

DNA is tightly wrapped around proteins called histones to form chromosomes. HDAC (**h**istone **d**e**ac**etylase) removes a chemical group from histones so that DNA can wrap more tightly. HDAC inhibitors enter cells and block the action of HDAC. Blocking can turn on genes that were shut down by cancer and lead to cell death. Belinostat is an HDAC inhibitor. It is used to treat some subtypes of peripheral T-cell lymphoma cells.

Belinostat is a liquid that will be slowly injected into your vein for about 30 minutes. It is given during the first 5 days of a 21-day cycle. Your doctor will discuss with you how many cycles are needed.

Common side effects include nausea, vomiting, fatigue, fever, low numbers of red blood cells. It may also cause liver damage and increase your chance of getting an infection. Belinostat can harm unborn babies.

Brentuximab vedotin

Brentuximab vedotin contains a monoclonal antibody that delivers cell-specific chemotherapy. On the surface of some peripheral T-cell lymphomas are proteins called CD30. Brentuximab attaches to CD30 and enters cancer cells. Once inside, it releases the chemotherapy. By targeting only cells with CD30 proteins, fewer normal cells are harmed.

Brentuximab vedotin is slowly injected into a vein for about 30 minutes. It is often given every 3 weeks. The most common side effects include fatigue, low blood counts, tingling in hands and feet, nausea, diarrhea, fever, rash, and lung infections. Rare but severe side effects include brain infection, serious disorder of skin and mucous membranes, and kidney problems.

Radiation therapy

Radiation therapy consists of high-energy rays that damage DNA. This either kills the cancer cells or stops new cancer cells from being made. Radiation can also harm normal cells. As a result, treatment methods are always being improved to target the tumor more precisely.

Involved-site radiation therapy

ISRT (**i**nvolved-**s**ite **r**adiation **t**herapy) is sometimes used to treat peripheral T-cell lymphoma. It can treat lymph nodes in which the cancer first started and cancer near to these nodes. It is given with a method called EBRT (**e**xternal **b**eam **r**adiation **t**herapy). This method delivers radiation with a machine that is outside your body.

Treatment planning with a simulation session is needed. During simulation, pictures of the tumor will be taken after your body is moved into the position needed for treatment. CT with contrast is used. PET/CT and MRI often enhance treatment planning. For tumors near the breastbone, 4D-CT (**f**our-**d**imensional **c**omputed **t**omography) or fluoroscopy can account for tumor movement from breathing. If your breathing causes large movements, motion control methods during the scans may be used.

Using the scans, your treatment team will plan the best radiation dose, number and shape of radiation beams, and number of treatment sessions. Beams are shaped with computer software and hardware added to the radiation machine. Radiation beams are aimed at the tumor with help from ink marks on your skin.

During treatment, you will lie on a table in the same position as done for simulation. Devices may be used to keep you from moving. These may include a mesh mask and body mold. You will be alone while the therapists operate the machine from the nearby control room.

The therapists will be able to see, hear, and speak with you. As treatment is given, you may hear noises. One session takes less than 10 minutes. The types of EBRT include:

- 3D-CRT (**t**hree-**d**imensional **c**onformal **r**adiation **t**herapy) – Treatment is completed in about 6 weeks and uses photon beams that match the shape of the tumor,
- IMRT (**i**ntensity-**m**odulated **r**adiation **t**herapy) – Treatment is completed in about 6 weeks and uses photon beams of different strengths based on the thickness of the tumor.
- Proton therapy – Treatment is completed in about 6 weeks and uses proton beams that deliver radiation mostly within the tumor.

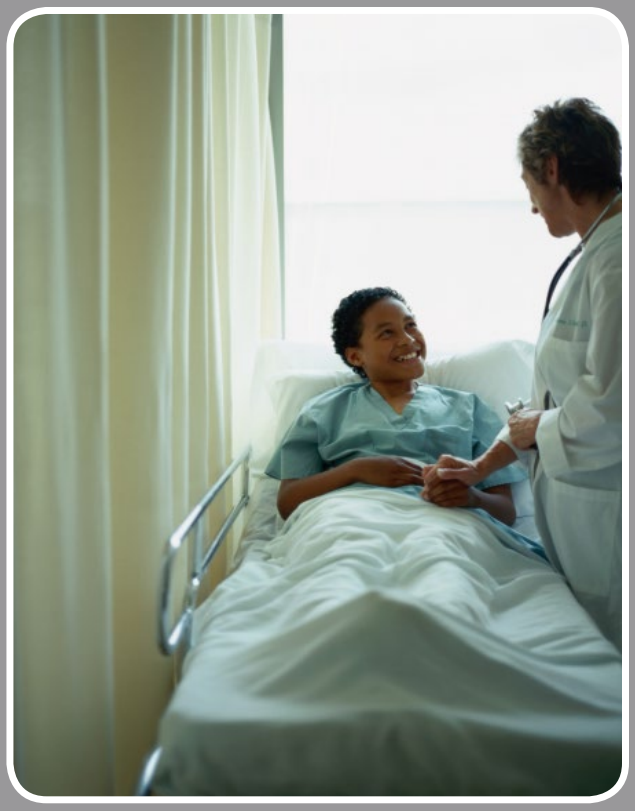
IGRT (**i**mage-**g**uided **r**adiation **t**herapy) can improve how well the radiation beam targets some tumors. IGRT uses the machine that delivers the radiation to also take images of the tumor and normal body structures. This can be done right before or during treatment. These images are compared to the ones taken during simulation. If needed, changes will be made to your body position or the radiation beams.

Side effects of radiation

Most side effects of radiation depend on where the treatment was given. However, many people feel fatigue. Changes in skin are also common right after treatment. Your treated skin may look and feel as if it has a mild sunburn. It may also become dry, sore, and feel painful when touched. You may also have short-term hair loss, but only where treated.

Supportive care

Supportive care doesn't aim to treat cancer but aims to improve quality of life. It is also called palliative care. It can address many needs. One example is treatment for physical and emotional symptoms. Supportive care can also help with treatment decisions as you may have more than one option. It can also help with coordination of care between health providers. Talk with your treatment team to plan the best supportive care for you.



Treatment to the head and neck can cause mouth sores, dry mouth, changes in taste, and a sore throat. Chest radiation can cause a dry cough or a sensation of a lump when you swallow. Radiation near your belly can cause nausea and maybe vomiting, and when given between your hip bones, diarrhea and cramps.

Late side effects of radiation may also occur. Again, the effects depend on the treatment site. Examples include dry mouth, dental cavities, hypothyroidism; lung scarring, heart disease, infertility, and second cancers.

Not all side effects of radiation are listed here. Please ask your treatment team for a complete list of common and rare side effects. If a side effect bothers you, tell your treatment team. There may be ways to help you feel better. There are also ways to prevent some side effects.

Stem cell transplant

Hematopoietic stem cells are cells that develop into mature blood cells. Hematopoietic stem cells and mature blood cells are made in bone marrow. Cancer or its treatment can damage or destroy the cells in bone marrow. A stem cell transplant replaces damaged or destroyed stem cells with healthy stem cells, which form new marrow and blood cells. There are two types of stem cell transplant.

Autologous stem cell transplant uses your healthy stem cells to repair bone marrow. This treatment is also called HDT/ASCR (**h**igh-**d**ose **t**herapy with **a**utologous **s**tem **c**ell **r**escue). Healthy stem cells will be collected from you when imaging tests show that cancer treatment is working. You will then receive intense chemotherapy and maybe radiation to destroy any remaining cancer cells. This intense treatment will also destroy bone marrow, so your healthy stem cells will be put back into your body to "rescue" your marrow.

Allogeneic stem cell transplant uses healthy stem cells that come from a donor. HLA (**h**uman **l**eukocyte **a**ntigens) typing is the test used to check if the donor and your tissue type are a good fit. Chemotherapy will be given to destroy cancer cells and suppress your immune system from attacking the donor cells. The transplanted stem cells will form new marrow and attack remaining cancer cells. This attack is known as the GVT (**g**raft-**v**ersus-**t**umor) effect. On the other hand, there is a serious risk of GVHD (**g**raft-**v**ersus-**h**ost **d**isease). GVHD is when the donated cells see the cells in your body as foreign and attack them.

A stem cell transplant is not an option for every person with peripheral T-cell lymphoma. A stem cell transplant can have severe side effects so it is not given to people who are frail or quite sick. An autologous transplant may be given only when prior drug treatment appears to have worked. An allogeneic transplant may be an option after a second course of drug treatment. Autologous stem cell transplant is more commonly used for peripheral T-cell lymphoma. More details on this transplant are given next.

Collecting your stem cells

The first step of an autologous stem cell transplant is to collect, or harvest, the blood stem cells. Blood stem cells are found in the bone marrow and in the bloodstream. If stem cells are collected from blood, a process called apheresis will be done. First, medicine is sometimes given to increase the number of stem cells in blood. Then, some blood will be removed from a large vein most likely in your arm. The blood will flow through a tube and into a machine that removes stem cells. The rest of the blood will be returned through the other arm.

Apheresis typically takes 4 to 6 hours and does not require anesthesia. It may take two or more sessions to obtain enough stem cells. During the procedure, you may have lightheadedness, chills, numbness around the lips, and cramping in the hands.

Bone marrow aspiration is used to remove bone marrow. For this procedure, either regional anesthesia or general anesthesia will be given. Next, a needle will be inserted through the skin into the hip bone to draw out the bone marrow. The needle must be inserted many times into one or more spots to collect enough marrow. The marrow will then be processed to collect the stem cells.

Collection of the bone marrow takes about 1 hour. The entire hospital stay will likely be 6 to 8 hours, which includes recovery time. The aspiration will likely cause some pain and soreness for a few days. Anesthesia may cause nausea, headache, and tiredness.

After apheresis or aspiration, the harvested cells will be combined with a preservative. Then, they will

be frozen and stored to keep them alive until the transplant. This process is called cryopreservation.

High-dose chemotherapy

Before the autologous transplant, you will receive high doses of chemotherapy. High doses are given to kill any cancer cells that may remain after prior treatment. Chemotherapy is often received for several days. The transplant will occur 1 or 2 days later to allow the chemotherapy to clear from your body. Otherwise, the chemotherapy could damage the healthy stem cells.

Transplanting your stem cells

After chemotherapy, you will receive your healthy stem cells through a transfusion. A transfusion is a slow injection of blood products through a central line into a large vein. A central line (or central venous catheter) is a thin tube. The tube will be inserted into your skin through one cut and into your vein through a second cut. Local anesthesia is used. This process can take several hours to complete.

The transplanted stem cells will travel to your bone marrow and grow. New, healthy blood cells will form. This is called engraftment. It usually takes about 2 to 4 weeks.

Until then, you will have little or no immune defense. You will need to stay in a very clean room at the hospital. You may be given an antibiotic to prevent or treat infection. You may also be given a blood platelet transfusion to prevent bleeding and blood transfusion to treat low red blood counts (anemia). While waiting for the cells to engraft, you will likely feel tired and weak.

Complementary and alternative medicine

CAM (*c*omplementary and *a*lternative *m*edicine) is a group of treatments that aren't often given by doctors. There is much interest today in CAM for cancer. Many CAMs are being studied to see if they are truly helpful.

Complementary medicines are treatments given along with usual medical treatments. While CAMs aren't known to kill cancer cells, they may improve your comfort and well-being. Two examples are acupuncture for pain management and yoga for relaxation.

Alternative medicine is used in place of usual medicine. Some alternative medicines are sold as cures even though they haven't been proven to work in clinical trials. If there was good proof that CAMs or other treatments cured cancer, they would be included in this book.

It is important to tell your treatment team if you are using any CAMs. They can tell you which CAMs may be helpful and which CAMs may limit how well medical treatments work.

My notes

Review

- Clinical trials give people access to new tests and treatments that otherwise can't usually be received. These new tests and treatments may, in time, be approved by the FDA.
- Chemotherapy stops the life cycle of cancer cells so they can't increase in number.
- Some steroids have anti-cancer effects and may be used with chemotherapy.
- Lenalidomide treats peripheral T-cell lymphoma by modifying your immune system and by other means.
- Alemtuzumab marks cancer cells for destruction by your immune system. Brentuximab vedotin attaches to cells with CD30 proteins and then releases chemotherapy into the cells.
- Involved-site radiation therapy kills cancer within lymph nodes and nearby by damaging DNA.
- A stem cell transplant rebuilds bone marrow by giving a person healthy blood stem cells. An autologous transplant uses your healthy stem cells to rebuild marrow damaged by high doses of chemotherapy that was given to kill cancer cells. An allogeneic transplant suppresses your immune system with chemotherapy then transfuses donor stem cells that will attack cancer cells.

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4

Treatment guide

4 Treatment guide

Part 4 is a guide to the treatment options for people with peripheral T-cell lymphoma. Options are listed by the subtype. This information is taken from the treatment guidelines written by NCCN experts of peripheral T-cell lymphoma. These treatment guidelines list options for people with peripheral T-cell lymphoma in general. Thus, your doctors may suggest other treatment for you based on your health and personal wishes. Fully discuss your treatment options with your doctor.

Treatment regimens

Combinations of drugs are almost always used to treat newly diagnosed peripheral T-cell lymphoma. First-line treatment is the first treatment given after diagnosis. It is also called primary treatment. Combinations of drugs are also often used if the disease returns. Second-line treatment is given when first-line treatment didn't work or the cancer came back.

Throughout Part 4, the short names for the regimens are listed. Below, the name of each drug for every regimen is provided.

- CHOEP (cyclophosphamide, doxorubicin, vincristine, etoposide, prednisone)
- CHOP (cyclophosphamide, doxorubicin, vincristine, prednisone)
- CHOP/IVE/MTX (CHOP followed by ifosfamide, etoposide, and epirubicin alternating with intermediate-dose methotrexate)
- DHAP (dexamethasone, cisplatin, cytarabine)
- Dose-adjusted EPOCH (etoposide, prednisone, vincristine, cyclophosphamide, doxorubicin)
- ESHAP (etoposide, methylprednisolone, cytarabine, cisplatin)
- GDP [gemcitabine, dexamethasone, (cisplatin or carboplatin)]
- GemOx (gemcitabine, oxaliplatin)
- GVD (gemcitabine, vinorelbine, liposomal doxorubicin)
- HyperCVAD/R-MTX-Ara-C (cyclophosphamide, vincristine, doxorubicin, and dexamethasone alternating with high-dose methotrexate and cytarabine)
- ICE (ifosfamide, carboplatin, etoposide)

During and after cancer treatment, you may be treated to prevent or control other health conditions. Such actions are a part of supportive care. Health conditions that are a concern for some people include tumor lysis syndrome, reactivated viruses, and other infections. Talk to your doctor about which health conditions you may develop as a result of cancer treatment.

4.1 Peripheral T-cell lymphoma, NOS

Chart 4.1.1 First-line treatment

Treatment options	Test results	Treatment options
• Clinical trial (preferred) • 6 cycles of chemotherapy ± involved-site radiation therapy *Preferred treatments* ◦ CHOEP ◦ CHOP-14 ◦ CHOP-21 ◦ Dose-adjusted EPOCH *Other treatments* ◦ HyperCVAD/R-MTX-Ara-C	No signs of cancer	• Clinical trial • Consider autologous stem cell transplant ± radiation therapy • Observation
	Cancer looks smaller, the same, or larger	• Treatment without stem cell transplant • Treatment with stem cell transplant

Chart 4.1.2 Second-line treatment without stem cell transplant

Treatment options
• Clinical trial
• Drug treatment *Preferred treatments* ◦ Belinostat ◦ Brentuximab vedotin ◦ Pralatrexate ◦ Romidepsin *Other treatments* ◦ Alemtuzumab ◦ Bendamustine ◦ Bortezomib ◦ Gemcitabine ◦ Lenalidomide
• Supportive care, radiation therapy

Chart 4.1.1 lists first-line treatment options for peripheral T-cell lymphoma, NOS. Joining a clinical trial that is right for your disease is the preferred option of the NCCN experts. If a clinical trial isn't an option, a second option is 6 cycles of a standard chemotherapy regimen. Regimens are listed in the chart. You may also receive involved-site radiation therapy to lower your chances of the cancer returning.

After chemotherapy, the results need to be assessed with testing. Any imaging test that showed cancer before treatment should be repeated. If PET/CT still shows signs of cancer, a biopsy may be needed to confirm before receiving more treatment.

There are three options if testing finds no signs of cancer. The first option is to join a clinical trial of additional drug treatment or of a stem cell transplant. You must be fairly healthy to undergo a transplant.

The second option is to receive an autologous stem cell transplant outside of a clinical trial. Before or after the high-dose chemotherapy portion of the transplant, you may receive radiation therapy. A transplant is an option because there is some proof that it may improve results, but more research is still needed.

The third option is observation. Observation or "watch-and-wait" is a period of testing to assess for changes in cancer status. If signs of cancer appear during observation, see Chart 4.1.2 for treatment options that don't include a transplant or Chart 4.1.3 for treatment options that do include a transplant.

If testing finds cancer after 6 cycles of chemotherapy, you have treatment options. Your options partly depend on whether you can and want to undergo a stem cell transplant. If a stem cell transplant will not be part of your treatment, see Chart 4.1.2. Treatment options in Chart 4.1.3 are for people who plan to have a transplant.

Chart 4.1.2 lists second-line options that don't include a stem cell transplant. Second-line treatment is received when first-line treatment didn't work or the cancer came back. Options include joining a clinical trial, drug treatment, and radiation therapy as supportive care. Supportive care aims to reduce symptoms of cancer.

Chart 4.1.3 Second-line treatment with stem cell transplant

Treatment options	Test results	Treatment options
• Clinical trial (preferred) • Drug treatment *Preferred treatments* ◦ Belinostat ◦ Brentuximab vedotin ◦ DHAP ◦ ESHAP ◦ GDP ◦ GemOx ◦ ICE ◦ Pralatrexate ◦ Romidepsin *Other treatments* ◦ Bendamustine ◦ Gemcitabine ◦ GVD ◦ Lenalidomide	No signs of cancer or the cancer looks smaller	• Clinical trial • Consider autologous stem cell transplant ± radiation therapy • Consider allogeneic stem cell transplant ± radiation therapy
	Cancer looks the same or larger	• Clinical trial • *Preferred* or *Other* drug treatment • Supportive care, radiation therapy

Chart 4.1.3 lists second-line options that do include a stem cell transplant. Second-line treatment is received when first-line treatment didn't work or the cancer came back. A clinical trial is the preferred option.

The aim of the second option is to have a good enough response to treatment to be able to undergo a stem cell transplant. The second option starts with treating the cancer with cancer drugs. Regimens are listed in the chart. The results of this treatment will be assessed with tests.

There are three options if testing finds no signs of cancer or the cancer is smaller. The first option is to join a clinical trial of additional drug treatment or of a stem cell transplant. The second and third options are an autologous and allogeneic stem cell transplant outside a clinical trial. Before or after the chemotherapy portion of the transplant, you may receive radiation therapy. More research is needed to learn about the outcomes of these transplants.

If the cancer looks the same or worse after drug treatment, there are 3 treatment options. The first option is to join a clinical trial. The second option is to receive another second-line drug regimen that is listed in the chart. The third option is supportive care, which might include radiation therapy to reduce the symptoms of cancer.

4.2 Anaplastic large cell lymphoma

ALK Positive

Chart 4.2.1 First-line treatment

Cancer stage	Treatment options
Stage I and II	• 6 cycles of CHOP-21 or CHOEP ± involved-site radiation therapy
	• 3 or 4 cycles of CHOP-21 or CHOEP + involved-site radiation therapy
Stage III and IV	• 6 cycles of CHOP-21 or CHOEP

Chart 4.2.2 Second-line treatment without stem cell transplant

Treatment options
• Clinical trial
• Drug treatment *Preferred treatments* ◦ Belinostat ◦ Brentuximab vedotin ◦ Pralatrexate ◦ Romidepsin *Other treatments* ◦ Alemtuzumab ◦ Bendamustine ◦ Bortezomib ◦ Gemcitabine
• Supportive care, radiation therapy

In Part 4.2, treatment options are divided into two sections: ALK positive and ALK negative. The first section is for people who have anaplastic large cell lymphoma that has ALK proteins. The second section is for people who have anaplastic large cell lymphoma without ALK proteins.

Chart 4.2.1 lists first-line treatment options for anaplastic large cell lymphomas with ALK proteins. CHOP and CHOP-like regimens have had good results among this subtype. Two options are listed for stage I and II cancers. Most commonly, 6 cycles of chemotherapy with or without involved-site radiation therapy are given. However, at times, fewer cycles followed by radiation therapy may be advised. Stage III and IV cancers are treated only with chemotherapy since the cancer is too widespread for radiation therapy.

After treatment, the results will be assessed with testing. If first-line treatment didn't work or the cancer returns, you have options. Your options partly depend on whether you can and want to undergo a stem cell transplant. If a stem cell transplant will not be part of your treatment, see Chart 4.2.2. Treatment options in Chart 4.2.3 are for people who plan to have a transplant.

Chart 4.2.2 lists second-line options that don't include a stem cell transplant. Second-line treatment is received when first-line treatment didn't work or the cancer came back. Options include joining a clinical trial, drug treatment, and radiation therapy as supportive care. Supportive care aims to reduce symptoms of cancer.

ALK Positive

Chart 4.2.3 Second-line treatment with stem cell transplant

Treatment options	Test results	Treatment options
• Clinical trial (preferred) • Drug treatment *Preferred treatments* ◦ Belinostat ◦ Brentuximab vedotin ◦ DHAP ◦ ESHAP ◦ GDP ◦ GemOx ◦ ICE ◦ Pralatrexate ◦ Romidepsin *Other treatments* ◦ Bendamustine ◦ Gemcitabine	No signs of cancer or the cancer looks smaller	• Clinical trial • Consider autologous stem cell transplant ± radiation therapy • Consider allogeneic stem cell transplant ± radiation therapy
	Cancer looks the same or larger	• Clinical trial • *Preferred* or *Other* drug treatment • Supportive care, radiation therapy

Chart 4.2.3 lists second-line options that do include a stem cell transplant. Second-line treatment is received when first-line treatment didn't work or the cancer came back. A clinical trial is the preferred option.

The aim of the second option is to undergo a stem cell transplant. The second option starts with treating the cancer with cancer drugs. Regimens are listed in the chart. The results of this treatment will be assessed with tests.

There are three options if testing finds no signs of cancer or the cancer is smaller. The first option is to join a clinical trial of new drugs or of a stem cell transplant. The second and third options are an autologous and allogeneic stem cell transplant outside of a clinical trial. Before or after the chemotherapy portion of the transplant, you may receive radiation therapy. More research is needed to learn about the outcomes of these transplants.

If the cancer looks the same or worse after drug treatment, there are 3 treatment options. The first option is to join a clinical trial. The second option is to receive another second-line drug regimen that is listed in the chart. The third option is supportive care, which might include radiation therapy to reduce the symptoms of cancer.

ALK Negative

Chart 4.2.4 First-line treatment

Treatment options	Test results	Treatment options
• Clinical trial (preferred) • 6 cycles of chemotherapy ± involved-site radiation therapy *Preferred treatments* ◦ CHOEP ◦ CHOP-14 ◦ CHOP-21 ◦ Dose-adjusted EPOCH *Other treatments* ◦ HyperCVAD/R-MTX-Ara-C	No signs of cancer	• Clinical trial • Consider autologous stem cell transplant ± radiation therapy • Observation
	Cancer looks smaller, the same, or larger	• Treatment without stem cell transplant • Treatment with stem cell transplant

Chart 4.2.5 Second-line treatment without stem cell transplant

Treatment options	
• Clinical trial	
• Drug treatment *Preferred treatments* ◦ Belinostat ◦ Brentuximab vedotin ◦ Pralatrexate ◦ Romidepsin	*Other treatments* ◦ Alemtuzumab ◦ Bendamustine ◦ Bortezomib ◦ Gemcitabine
• Supportive care, radiation therapy	

Chart 4.2.4 lists first-line treatment options for anaplastic large cell lymphomas without ALK proteins. Joining a clinical trial that is right for your disease is the preferred option of the NCCN experts. If a clinical trial isn't an option, a second option is 6 cycles of chemotherapy. Regimens are listed in the chart. You may also receive involved-site radiation therapy to lower your chances of the cancer returning.

After chemotherapy, the results need to be assessed with testing. Any imaging test that showed cancer before treatment should be repeated. If PET/CT still shows signs of cancer, a biopsy is needed to confirm before receiving more treatment.

There are three options if testing finds no signs of cancer. The first option is to join a clinical trial of additional drug treatment or of a stem cell transplant. You must be fairly healthy to undergo a transplant.

The second option is to receive an autologous stem cell transplant outside of a clinical trial. Before or after the high-dose chemotherapy portion of the transplant, you may receive radiation therapy. A transplant is an option because there is some proof that it may improve results, but better research is needed.

The third option is observation. Observation or "watch-and-wait" is a period of testing to assess for changes in cancer status. If signs of cancer appear during observation, see Chart 4.2.5 for treatment options that don't include a transplant or Chart 4.2.6 for treatment options that do include a transplant.

If testing finds cancer after 6 cycles of chemotherapy, you have treatment options. Your options partly depend on whether you can and want to undergo a stem cell transplant. If a stem cell transplant will not be part of your treatment, see Chart 4.2.5. Treatment options in Chart 4.2.6 are for people who plan to have a transplant.

Chart 4.2.5 lists second-line options that don't include a stem cell transplant. Second-line treatment is received when first-line treatment didn't work or the cancer came back. Options include joining a clinical trial, drug treatment, and radiation therapy as supportive care. Supportive care aims to reduce symptoms of cancer.

ALK Negative

Chart 4.2.6 Second-line treatment with stem cell transplant

Treatment options	Test results	Treatment options
• Clinical trial (preferred) • Drug treatment *Preferred treatments* ◦ Belinostat ◦ Brentuximab vedotin ◦ DHAP ◦ ESHAP ◦ GDP ◦ GemOx ◦ ICE ◦ Pralatrexate ◦ Romidepsin *Other treatments* ◦ Bendamustine ◦ Gemcitabine	No signs of cancer or the cancer looks smaller	• Clinical trial • Consider autologous stem cell transplant ± radiation therapy • Consider allogeneic stem cell transplant ± radiation therapy
	Cancer looks the same or larger	• Clinical trial • *Preferred* or *Other* drug treatment • Supportive care, radiation therapy

Chart 4.2.6 lists second-line options that do include a stem cell transplant. Second-line treatment is received when first-line treatment didn't work or the cancer came back. A clinical trial is the preferred option.

The second option is to plan to undergo a stem cell transplant. The second option starts with treating the cancer with cancer drugs. Regimens are listed in the chart. The results of this treatment will be assessed with tests.

There are three options if testing finds no signs of cancer or the cancer is smaller. The first option is to join a clinical trial of additional drug treatment or of a stem cell transplant. The second and third options are an autologous and allogeneic stem cell transplant outside a clinical trial. Before or after the chemotherapy portion of the transplant, you may receive radiation therapy. More research is needed to learn about the outcomes of these transplants.

If the cancer looks the same or worse after drug treatment, there are 3 treatment options. The first option is to join a clinical trial. The second option is to receive another second-line drug regimen that is listed in the chart. The third option is supportive care, which might include radiation therapy to reduce the symptoms of cancer.

4.3 Angioimmunoblastic T-cell lymphoma

Chart 4.3.1 First-line treatment

Treatment options	Test results	Treatment options
• Clinical trial (preferred) • 6 cycles of chemotherapy ± involved-site radiation therapy *Preferred treatments* ◦ CHOEP ◦ CHOP-14 ◦ CHOP-21 ◦ Dose-adjusted EPOCH *Other treatments* ◦ HyperCVAD/R-MTX-Ara-C	No signs of cancer	• Clinical trial • Consider autologous stem cell transplant ± radiation therapy • Observation
	Cancer looks smaller, the same, or larger	• Treatment without stem cell transplant • Treatment with stem cell transplant

Chart 4.3.2 Second-line treatment without stem cell transplant

Treatment options	
• Clinical trial	
• Drug treatment *Preferred treatments* ◦ Belinostat ◦ Romidepsin	*Other treatments* ◦ Alemtuzumab ◦ Bendamustine ◦ Bortezomib ◦ Cyclosporine ◦ Gemcitabine ◦ Lenalidomide ◦ Pralatrexate
• Supportive care, radiation therapy	

Chart 4.3.1 lists first-line treatment options for angioimmunoblastic T-cell lymphoma. Joining a clinical trial that is right for your disease is the preferred option of the NCCN experts. If a clinical trial isn't an option, a second option is 6 cycles of a standard chemotherapy regimen. Regimens are listed in the chart. You may also receive involved-site radiation therapy to lower your chances of the cancer returning.

After chemotherapy, the results need to be assessed with testing. Any imaging test that showed cancer before treatment should be repeated. If PET/CT still shows signs of cancer, a biopsy is needed to confirm before receiving more treatment.

There are three options if testing finds no signs of cancer. The first option is to join a clinical trial of additional drug treatment or of a stem cell transplant. You must be fairly healthy to undergo a transplant.

The second option is to receive an autologous stem cell transplant outside of a clinical trial. Before or after the high-dose chemotherapy portion of the transplant, you may receive radiation therapy. A transplant is an option because there is some proof that it may improve results, but better research is needed.

The third option is observation. Observation or "watch-and-wait" is a period of testing to assess for changes in cancer status. If signs of cancer appear during observation, see Chart 4.3.2 for treatment options that don't include a transplant or Chart 4.3.3 for treatment options that do include a transplant.

If testing finds cancer after 6 cycles of chemotherapy, you have treatment options. Your options depend on whether you can and want to undergo a stem cell transplant. If a stem cell transplant will not be part of your treatment, see Chart 4.3.2. Treatment options in Chart 4.3.3 are for people who plan to have a transplant.

Chart 4.3.2 lists second-line options that don't include a stem cell transplant. Second-line treatment is received when first-line treatment didn't work or the cancer came back. Options include joining a clinical trial, drug treatment, and radiation therapy as supportive care. Supportive care aims to reduce symptoms of cancer.

Chart 4.3.3 Second-line treatment with stem cell transplant

Treatment options	Test results	Treatment options
• Clinical trial (preferred) • Drug treatment *Preferred treatments* ◦ Belinostat ◦ DHAP ◦ ESHAP ◦ GDP ◦ GemOx ◦ ICE ◦ Romidepsin *Other treatments* ◦ Bendamustine ◦ Gemcitabine ◦ Lenalidomide ◦ Pralatrexate	No signs of cancer or the cancer looks smaller	• Clinical trial • Consider autologous stem cell transplant ± radiation therapy • Consider allogeneic stem cell transplant ± radiation therapy
	Cancer looks the same or larger	• Clinical trial • *Preferred* or *Other* drug treatment • Supportive care, radiation therapy

Chart 4.3.3 lists second-line options that do include a stem cell transplant. Second-line treatment is received when first-line treatment didn't work or the cancer came back. A clinical trial is the preferred option.

The aim of the second option is to undergo a stem cell transplant. The second option starts with treating the cancer with cancer drugs. Regimens are listed in the chart. The results of this treatment will be assessed with tests.

There are three options if testing finds no signs of cancer or the cancer is smaller. The first option is to join a clinical trial of additional drug treatment or of a stem cell transplant. The second and third options are an autologous and allogeneic stem cell transplant outside a clinical trial. Before or after the chemotherapy portion of the transplant, you may receive radiation therapy. More research is needed to learn about the outcomes of these transplants.

If the cancer looks the same or worse after drug treatment, there are 3 treatment options. The first option is to join a clinical trial. The second option is to receive another second-line drug regimen that is listed in the chart. The third option is supportive care, which might include radiation therapy to reduce the symptoms of cancer.

4.4 Enteropathy-associated T-cell lymphoma

Chart 4.4.1 First-line treatment

Treatment options	Test results	Treatment options
• Clinical trial (preferred) • 6 cycles of chemotherapy ± involved-site radiation therapy *Preferred treatments* ◦ CHOEP ◦ CHOP-14 ◦ CHOP-21 ◦ Dose-adjusted EPOCH *Other treatments* ◦ CHOP/IVE/MTX ◦ HyperCVAD/R-MTX-Ara-C	No signs of cancer	• Clinical trial • Consider autologous stem cell transplant ± radiation therapy • Observation
	Cancer looks smaller, the same, or larger	• Treatment without stem cell transplant • Treatment with stem cell transplant

Chart 4.4.2 Second-line treatment without stem cell transplant

Treatment options
• Clinical trial
• Drug treatment *Preferred treatments* ◦ Belinostat ◦ Brentuximab vedotin ◦ Pralatrexate ◦ Romidepsin *Other treatments* ◦ Alemtuzumab ◦ Bendamustine ◦ Bortezomib ◦ Gemcitabine ◦ Lenalidomide
• Supportive care, radiation therapy

Chart 4.4.1 lists first-line treatment options for enteropathy-associated T-cell lymphoma. Joining a clinical trial that is right for your disease is the preferred option of the NCCN experts. If a clinical trial isn't an option, a second option is 6 cycles of a standard chemotherapy regimen. Regimens are listed in the chart. You may also receive involved-site radiation therapy to lower your chances of the cancer returning.

After chemotherapy, the results need to be assessed with testing. Any imaging test that showed cancer before treatment should be repeated. If PET/CT still shows signs of cancer, a biopsy is needed to confirm before receiving more treatment.

There are three options if testing finds no signs of cancer. The first option is to join a clinical trial of additional drug treatment or of a stem cell transplant. You must be fairly healthy to undergo a transplant.

The second option is to receive an autologous stem cell transplant outside of a clinical trial. Before or after the high-dose chemotherapy portion of the transplant, you may receive radiation therapy. A transplant is an option because there is some proof that it may improve results, but better research is needed.

The third option is observation. Observation or "watch-and-wait" is a period of testing to assess for changes in cancer status. If signs of cancer appear during observation, see Chart 4.4.2 for treatment options that don't include a transplant or Chart 4.4.3 for treatment options that do include transplant.

If testing finds cancer after 6 cycles of chemotherapy, you have treatment options. Your options depend on whether you can and want to undergo a stem cell transplant. If a stem cell transplant will not be part of your treatment, see Chart 4.4.2. Treatment options in Chart 4.4.3 are for people who plan to have a transplant.

Chart 4.4.2 lists second-line options that don't include a stem cell transplant. Second-line treatment is received when first-line treatment didn't work or the cancer came back. Options include joining a clinical trial, drug treatment, and radiation therapy as supportive care. Supportive care aims to reduce symptoms of cancer.

Chart 4.4.3 Second-line treatment with stem cell transplant

Treatment options	Test results	Treatment options
• Clinical trial (preferred) • Drug treatment *Preferred treatments* ◦ Belinostat ◦ Brentuximab vedotin ◦ DHAP ◦ ESHAP ◦ GDP ◦ GemOx ◦ ICE ◦ Pralatrexate ◦ Romidepsin *Other treatments* ◦ Bendamustine ◦ Gemcitabine ◦ GVD ◦ Lenalidomide	No signs of cancer or the cancer looks smaller	• Clinical trial • Consider autologous stem cell transplant ± radiation therapy • Consider allogeneic stem cell transplant ± radiation therapy
	Cancer looks the same or larger	• Clinical trial • *Preferred* or *Other* drug treatment • Supportive care, radiation therapy

Chart 4.4.3 lists second-line options that do include a stem cell transplant. Second-line treatment is received when first-line treatment didn't work or the cancer came back. A clinical trial is the preferred option.

The aim of the second option is to undergo a stem cell transplant. The second option starts with treating the cancer with cancer drugs. Regimens are listed in the chart. The results of this treatment will be assessed with tests.

There are three options if testing finds no signs of cancer or the cancer is smaller. The first option is to join a clinical trial of additional drug treatment or of a stem cell transplant. The second and third options are an autologous and allogeneic stem cell transplant outside a clinical trial. Before or after the chemotherapy portion of the transplant, you may receive radiation therapy. More research is needed to learn about the outcomes of these transplants.

If the cancer looks the same or worse after drug treatment, there are 3 treatment options. The first option is to join a clinical trial. The second option is to receive another second-line drug regimen that is listed in the chart. The third option is supportive care, which might include radiation therapy to reduce the symptoms of cancer.

Review

- Treatment options for peripheral T-cell lymphoma are grouped by subtype.
- In general, first-line treatment begins with chemotherapy and may be followed by involved-site radiation therapy. For most subtypes, joining a clinical trial or having autologous stem cell transplant is an option if first-line treatment works.
- If first-line treatment fails or the cancer returns, there are multiple options for drug treatments. Some people who aren't too sick may undergo a stem cell transplant after drug treatment.

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5

Making treatment decisions

5 Making treatment decisions

Having cancer is very stressful. While absorbing the fact that you have cancer, you have to learn about tests and treatments. In addition, the time you have to accept a treatment plan feels short. Parts 1 through 4 described the cancer and the test and treatment options recommended by NCCN experts. These options are based on science and agreement among NCCN experts. Part 5 aims to help you make decisions that are in line with your beliefs, wishes, and values.

It's your choice

The role patients want in choosing their treatment differs. You may feel uneasy about making treatment decisions. This may be due to a high level of stress. It may be hard to hear or know what others are saying. Stress, pain, and drugs can limit your ability to make good decisions. You may feel uneasy because you don't know much about cancer. You've never heard the words used to describe cancer, tests, or treatments. Likewise, you may think that your judgment isn't any better than your doctors'.

Letting others decide which option is best may make you feel more at ease. But, whom do you want to make the decisions? You may rely on your doctors alone to make the right decisions. However, your doctors may not tell you which to choose if you have multiple good options. You can also have loved ones help. They can gather information, speak on your behalf, and share in decision-making with your doctors. Even if others decide which treatment you will receive, you still have to agree by signing a consent form.

On the other hand, you may want to take the lead or share in decision-making. Most patients do. In shared decision-making, you and your doctors share information, weigh the options, and agree on a treatment plan. Your doctors know the science behind your plan but you know your concerns and goals. By working together, you are likely to get a higher quality of care and be more satisfied. You'll likely get the treatment you want, at the place you want, and by the doctors you want.

Questions to ask your doctors

You will likely meet with experts from different fields of medicine. Strive to have helpful talks with each person. Prepare questions before your visit and ask questions if the person isn't clear. You can also record your talks and get copies of your medical records. It may be helpful to have your spouse, partner, or a friend with you at these visits. A patient advocate or navigator might also be able to come. They can help to ask questions and remember what was said. Suggested questions to ask include:

What's my diagnosis and prognosis?

It's important to know that there are different types of cancer. Cancer can greatly differ even when people have a tumor in the same organ. Based on your test results, your doctors can tell you which type of cancer you have. He or she can also give a prognosis. A prognosis is a prediction of the pattern and outcome of a disease. Knowing the prognosis may affect what you decide about treatment.

1. Where did the cancer start? In what type of cell?
2. Is this cancer common?
3. What is the cancer stage? Does this stage mean the cancer has spread far?
4. Is this a fast- or slow-growing lymphoma?
5. What other test results are important to know?
6. How often are these tests wrong?
7. Would you give me a copy of the pathology report and other test results?
8. Can the cancer be cured? If not, how well can treatment stop the cancer from growing?

What are my options?

There is no single treatment practice that is best for all patients. There is often more than one treatment option along with clinical trial options. Your doctor will review your test results and recommend treatment options.

1. What will happen if I do nothing?
2. Can I just carefully monitor the cancer?
3. Do you consult NCCN recommendations when considering options?
4. Are you suggesting options other than what NCCN recommends? If yes, why?
5. Do your suggested options include clinical trials? Please explain why.
6. How do my age, health, and other factors affect my options?
7. Which option is proven to work best?
8. Which options lack scientific proof?
9. What are the benefits of each option? Does any option offer a cure? Are my chances any better for one option than another? Less time-consuming? Less expensive?
10. What are the risks of each option? What are possible complications? What are the rare and common side effects? Short-lived and long-lasting side effects? Serious or mild side effects? Other risks?
11. What can be done to prevent or relieve the side effects of treatment?

What does each option require of me?

Many patients consider how each option will practically affect their lives. This information may be important because you have family, jobs, and other duties to take care of. You also may be concerned about getting the help you need. If you have more than one option, choosing the option that is the least taxing may be important to you:

1. Will I have to go to the hospital or elsewhere? How often? How long is each visit?
2. Do I have a choice of when to begin treatment? Can I choose the days and times of treatment?
3. How do I prepare for treatment? Do I have to stop taking any of my medicines? Are there foods I will have to avoid?
4. Should I bring someone with me when I get treated?
5. Will the treatment hurt?
6. How much will the treatment cost me? What does my insurance cover?
7. Will I miss work or school? Will I be able to drive?
8. Is home care after treatment needed? If yes, what type?
9. How soon will I be able to manage my own health?
10. When will I be able to return to my normal activities?

What is your experience?

More and more research is finding that patients treated by more experienced doctors have better results. It is important to learn if a doctor is an expert in the cancer treatment he or she is offering.

1. Are you board certified? If yes, in what area?
2. How many patients like me have you treated?
3. How many procedures like the one you're suggesting have you done?
4. Is this treatment a major part of your practice?
5. How many of your patients have had complications?

Weighing your options

Deciding which option is best can be hard. Doctors from different fields of medicine may have different opinions on which option is best for you. This can be very confusing. Your spouse or partner may disagree with which option you want. This can be stressful. In some cases, one option hasn't been shown to work better than another, so science isn't helpful. Some ways to decide on treatment are discussed next.

2nd opinion

The time around a cancer diagnosis is very stressful. People with cancer often want to get treated as soon as possible. They want to make their cancer go away before it spreads farther. While cancer can't be ignored, there is time to think about and choose which option is best for you.

You may wish to have another doctor review your test results and suggest a treatment plan. This is called getting a 2nd opinion. You may completely trust your doctor, but a 2nd opinion on which option is best can help.

Copies of the pathology report, a DVD of the imaging tests, and other test results need to be sent to the doctor giving the 2nd opinion. Some people feel uneasy asking for copies from their doctors. However, a 2nd opinion is a normal part of cancer care.

When doctors have cancer, most will talk with more than one doctor before choosing their treatment. What's more, some health plans require a 2nd opinion. If your health plan doesn't cover the cost of a 2nd opinion, you have the choice of paying for it yourself.

If the two opinions are the same, you may feel more at peace about the treatment you accept to have. If the two opinions differ, think about getting a 3rd opinion. A 3rd opinion may help you decide between your options. Choosing your cancer treatment is a very important decision. It can affect your length and quality of life.

Support groups

Besides talking to health experts, it may help to talk to patients who have walked in your shoes. Support groups often consist of people at different stages of treatment. Some may be in the process of deciding while others may be finished with treatment. At support groups, you can ask questions and hear about the experiences of other people with peripheral T-cell lymphoma.

Compare benefits and downsides

Every option has benefits and downsides. Consider these when deciding which option is best for you. Talking to others can help identify benefits and downsides you haven't thought of. Scoring each factor from 0 to 10 can also help since some factors may be more important to you than others.

My notes

Websites

American Cancer Society
cancer.org/cancer/non-hodgkinlymphoma/detailedguide/index

National Coalition for Cancer Survivorship
www.canceradvocacy.org/toolbox

National Cancer Institute
cancer.gov/types/lymphoma

NCCN
nccn.org/patients

The Leukemia & Lymphoma Society (LLS)
LLS.org/informationspecialists

Review

- Shared decision-making is a process in which you and your doctors plan treatment together.
- Asking your doctors questions is vital to getting the information you need to make informed decisions.
- Getting a 2nd opinion, attending support groups, and comparing benefits and downsides may help you decide which treatment is best for you.

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Glossary

Dictionary
Acronyms

Dictionary

allogeneic stem cell transplant
A cancer treatment that replaces blood stem cells with donor stem cells which in turn make a new immune system and attack the lymphoma.

anesthesia
Loss of feeling with or without loss of wakefulness that is caused by drugs.

antigen
Any substance that activates the immune system.

autologous stem cell transplant
A cancer treatment that destroys cancer cells with high doses of chemotherapy then rebuilds destroyed bone marrow with your own healthy blood stem cells. Also called an HDT/ASCR (high-dose therapy with autologous stem cell rescue).

B symptoms
Fevers, heavy night sweats, and weight loss without dieting caused by B-cell cancers.

B-cell
One of three types of a white blood cell called a lymphocyte.

biopsy
Removal of small amounts of tissue or fluid to be tested for disease.

bone marrow
Soft, sponge-like tissue in the center of most bones where blood cells are made.

bone marrow biopsy
Removal of a small amount of solid bone and bone marrow to test for disease.

cancer stage
Ratings of tumors that suggest the outlook of the disease.

chemotherapy
Drugs that stop the life cycle of cells so they don't increase in number.

chromosome
Strands of genetic material inside of cells.

chyle
A fatty liquid absorbed from the gut into the lymphatic system.

clinical trial
Research on a test or treatment to assess its safety or how well it works.

complete blood count (CBC)
A test of the number of blood cells in a sample.

comprehensive metabolic panel
Tests of up to 14 chemicals in your blood.

computed tomography (CT)
A test that uses x-rays to view body parts.

contrast
A dye put into your body to make clearer pictures during imaging tests.

deoxyribonucleic acid (DNA)
A chain of chemicals inside cells that contains coded instructions for making and controlling cells.

diagnose
To identify a disease.

diaphragm
A sheet of muscles below the ribs that helps a person to breathe.

differential
Measurement of the different types of white blood cells present in a blood sample.

echocardiogram
A test that uses sound waves to make pictures of the heart.

external beam radiation therapy (EBRT)
Treatment with radiation that is delivered by a machine into the body.

fatigue
Severe tiredness despite getting enough sleep that limits one's ability to function.

fertility specialist
An expert who helps men and women have babies.

flow cytometry
A test that looks at certain substances on the surface of cells to identify the type of cells present.

fluorescence in situ hybridization (FISH)
A lab test that uses special dyes to look for abnormal chromosomes.

four-dimensional computed tomography (4D-CT)
A CT scan that can show the movement of organs.

gastrointestinal (GI) tract
The group of organs through which food passes after being eaten.

gene
Instructions in cells for making and controlling cells.

gene rearrangment
The fusion of parts from two genes that creates a new gene.

general anesthesia
A controlled loss of wakefulness from drugs.

human leukocyte antigen (HLA) typing
A blood test that finds a person's unique set of proteins on cells.

image-guided radiation therapy (IGRT)
Radiation therapy that uses imaging tests during treatment to better target the tumor.

imaging test
A test that makes pictures (images) of the inside of the body.

immune system
The body's natural defense against infection.

immunohistochemistry (IHC)
A test of cancer cells to find specific cell traits involved in abnormal cell growth.

immunomodulator
A type of drug that modifies some parts of the body's disease-fighting system.

intensity-modulated radiation therapy (IMRT)
Radiation therapy that uses small beams of different strengths based on the thickness of the tissue.

involved-site radiation therapy (ISRT)
Treatment with high-energy rays (radiation) that is delivered to lymph nodes and nearby sites with cancer.

karyotype
A test that uses a microscope to examine a cell's chromosomes.

lactate dehydrogenase
A protein that helps to make energy in cells.

liver
Organ that removes waste from the blood and helps to digest food.

local anesthesia
A controlled loss of feeling in a small area of the body caused by drugs.

lymph
A clear fluid containing white blood cells.

lymph node
Small groups of special disease-fighting cells located throughout the body.

lymph vessel
Tube-shaped ducts that carry lymph throughout the body.

lymphatic system
Network in the body that collects and transports a fluid (lymph) and fights germs.

lymphocyte
A type of white blood cell that helps protect the body from illness.

lymphoma
Cancer that begins in white blood cells called lymphocytes that are within the lymphatic system.

magnetic resonance imaging (MRI)
A test that uses a magnetic field and radio waves to make pictures of the insides of the body.

medical history
All health events and medications taken to date.

monoclonal antibody
Man-made antibodies that attach proteins on cancer cells.

multi-gated acquisition (MUGA) scan
A test of the heart that uses radiation to make pictures.

natural killer (NK) cell
One of three types of a white blood cell called a lymphocyte.

observation
A period of testing for changes in cancer status while not receiving a specific treatment.

pathologist
A doctor who's an expert in testing cells to find disease.

performance status
A rating of one's ability to do daily activities.

physical exam
A review of the body by a health expert for signs of disease.

positron emission tomography (PET)
A test that uses radioactive material to see the shape and function of body parts.

positron emission tomography/computed tomography (PET/CT)
A test that uses radioactive material and x-rays to view the shape and function of organs and tissues.

proton therapy
Radiation therapy that uses protons to treat a disease. Also called hadron therapy.

punch biopsy
Removal of a skin sample using a sharp hollow device.

radiation therapy
The use of radiation to treat cancer.

regional anesthesia
A type of drug used for short-term loss of feeling or awareness in a part of the body without loss of wakefulness.

sedative
A drug that helps a person to relax or go to sleep.

shave biopsy
Removal of a skin sample from the first skin and part of the second layers.

side effect
An unplanned physical or emotional response to treatment.

spleen
An organ to the left of the stomach that helps protect the body from disease.

stem cell transplant
A cancer treatment that destroys bone marrow then replaces it by adding healthy blood stem cells.

steroid
A drug used to reduce redness, swelling, and pain, but also to kill cancer cells.

supportive care
Treatment for the symptoms or health conditions caused by cancer or cancer treatment.

targeted therapy
Drugs that stop the growth process that is specific to cancer cells.

T-cell
One of three types of a white blood cell called a lymphocyte.

three-dimensional conformal radiation therapy (3D-CRT)
Radiation therapy that uses beams that match the shape of the tumor.

thymus
A gland located behind the breastbone.

tonsil
A group of tissue within the throat that contains many white blood cells called lymphocytes and fights germs that enter the mouth and nose.

translocation
The switching of parts between two chromosomes.

tumor lysis syndrome
A condition that occurs when many cancer cells die very quickly and release their contents into the blood, which can damage the kidneys and other organs.

ultrasound
A test that uses sound waves to take pictures of the inside of the body.

uric acid
A chemical that is made and released into the blood when cells and other substances in the body break down.

Acronyms

3D-CRT
three-dimensional conformal radiation therapy

4D-CRT
four-dimensional conformal radiation therapy

ALK
anaplastic lymphoma kinase

CAM
complementary and alternative medicine

CBC
complete blood count

CT
computed tomography

DNA
deoxyribonucleic acid

EBRT
external beam radiation therapy

ECOG
Eastern Cooperative Oncology Group

FDA
Food and Drug Administration

FISH
fluorescence in situ hybridization

FNA
fine-needle aspiration

GI
gastrointestinal

GVHD
graft-versus-host disease

GVT
graft-versus-tumor

HDAC
histone deacetylase

HDT/ASCR
high-dose therapy with autologous stem cell rescue

HLA
human leukocyte antigen

HTLV
human T-cell lymphotropic virus

IGRT
image-guided radiation therapy

IHC
immunohistochemistry

IMRT
intensity-modulated radiation therapy

IPI
International Prognostic Index

ISRT
involved-site radiation therapy

MRI
magnetic resonance imaging

MUGA
multi-gated acquisition

NK cells
natural killer cells

PCR
polymerase chain reaction

PET
positron emission tomography

PIT
Prognostic Index for PTCL-Unspecified

TCR
T-cell receptor

TLS
tumor lysis syndrome

NCCN Abbreviations and Acronyms

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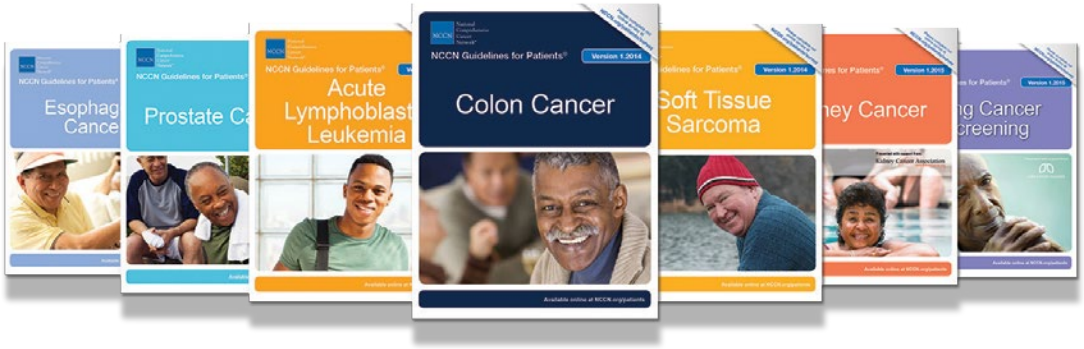

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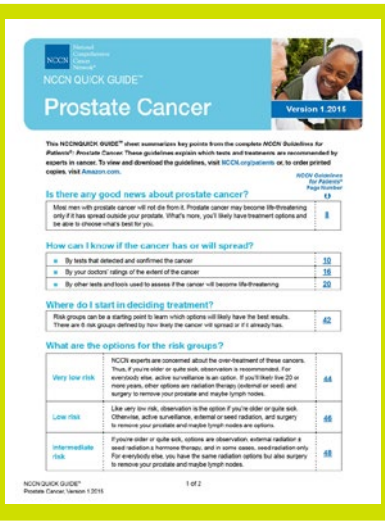

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C. Babis Andreadis, MD, MSCE
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Nancy Bartlett, MD
Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine

John C. Byrd, MD
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Luis E. Fayad, MD
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