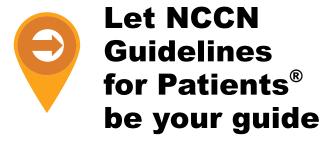








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 - ✓ Based on treatment guidelines used by health care providers worldwide
 - ✓ Designed to help you discuss cancer treatment with your doctors



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NCCN Guidelines for Patients® Follicular Lymphoma, 2022

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1

This chapter answers some common questions about follicular lymphoma. You'll learn what it is, how it's found, and what can be done to treat it.

What is lymphoma?

Lymphoma is a cancer that affects infectionfighting cells called lymphocytes. The lymph system contains many lymphocytes. It is a major part of the immune system—the body's defense against infection and disease.

Like all cancers, lymphoma affects cell growth. Lymphoma cells make many more cells and often build up in tissue, such as lymph nodes. Lymphoma cells can spread throughout the lymph system or in other places like the bone, skin, gut, and lungs.

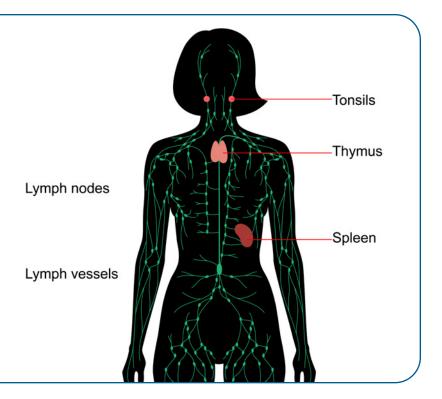
There are many types of lymphomas. They differ by which type of lymphocyte is affected. The three types of lymphocytes are B cells, T cells, and natural killer cells. Lymphoma are categorized into two basic groups:

- Hodgkin lymphoma is a cancer of B cells called Reed-Sternberg cells. These cells are very large. Unlike a normal cell, they may have an "owl-eye" look from having two nuclei.
- Non-Hodgkin lymphoma is the more common type. It is a diverse group of more than 90 cancers. These lymphomas do not have Reed-Sternberg cells. They are cancers of B cells, T cells, or natural killer cells.

Follicular lymphoma is a type of non-Hodgkin lymphoma.

Lymph system

The lymph (or lymphatic) system includes a fluid called lymph.
Lymph travels within a "super highway" of ducts called lymph vessels. As lymph travels, it passes through hundreds of structures called lymph nodes. In addition to nodes, the spleen, tonsils, and thymus contain lymph tissue. There are also small clumps of lymph tissue in your gut, thyroid, lungs, eyes, and skin.



What is follicular lymphoma?

Follicular lymphoma is a cancer of B cells and very often grows slowly. It typically arises in small structures called lymph nodes but is sometimes found in other parts of the body.

Follicular lymphoma is named for where this cancer grows and how it looks. The B cells are from the *follicles* of lymph tissue. Also, follicular lymphoma almost always grows in a *follicular* pattern. This pattern has the shape of a circle.

How is follicular lymphoma found?

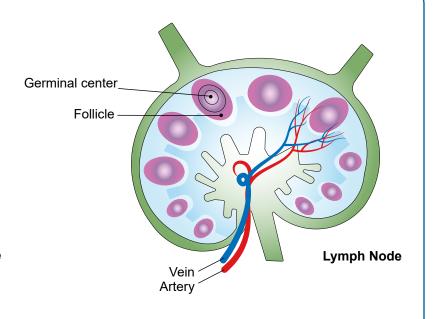
Usually, follicular lymphoma is found because of swollen lymph nodes that can be seen or felt under the skin. Unlike the swelling when you're sick, the swollen lymph nodes caused by lymphoma usually don't decrease within a few days. Swollen nodes can occur anywhere but are most often found in the neck, armpit, and groin area.

Follicular lymphoma is sometimes found in parts of the body that aren't lymph nodes. This is called extranodal disease, which means outside the lymph nodes. Sometimes, follicular lymphoma is found because of an enlarged spleen or liver.

Follicular lymphoma may also be discovered because of "B symptoms." B symptoms include fevers when there's no infection, drenching night sweats, and unexplained weight loss. These symptoms are general, which means many factors can cause them. It may take time to discover that follicular lymphoma is the cause.

Germinal centers

Follicular lymphoma is a cancer of B cells from lymphoid follicles. More specifically, the B cells are from the follicle germinal centers. Germinal centers are short-lived structures that form when an immune response is triggered. They have a dark and light zone. In the dark zone, B cells are called centroblasts. B cells in the light zone are called centrocytes.



Is follicular lymphoma serious?

A prognosis is the likely course and outcome of a disease. It predicts how your illness will turn out. Follicular lymphoma has a better prognosis than some other cancers.

Follicular lymphoma is often a slow-growing cancer. You may have had this lymphoma for many years before symptoms appeared. If it's still slow growing, treatment may not be needed right away.

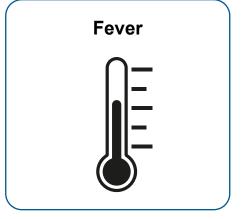
People with follicular lymphoma often live many years with the proper care. But, life won't be the same. You might have to live with symptoms caused by the lymphoma or treatment. You might have to take extra care not to get infections as the lymphoma and treatment increase risk. Ask your care team about ways to improve your quality of life.

Can follicular lymphoma be cured?

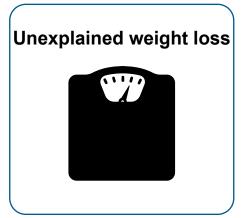
Follicular lymphoma can be treated but only possibly cured in some people. Treatment shrinks the lymphoma reducing its signs and symptoms. For most people, though, the lymphoma eventually grows again and needs to be treated. It may take years before treatment is needed again.

This book explains treatment options for follicular lymphoma. There have been new treatments in recent years. Discuss the options in this book with your care team. Together, you can make a treatment plan that's best for you.

B symptoms







1

Key points

- Lymphomas are cancers of lymphocytes within the lymph system. Follicular lymphoma is a cancer of lymphocytes called B cells. It is so named because the B cells are from the follicles of lymph tissue.
- Follicular lymphoma is commonly discovered when a painless lump is found. Fever, drenching night sweats, and unexplained weight loss may also indicate a lymphoma.
- Follicular lymphomas are usually slowgrowing cancers. Treatment may not be needed right away.
- While follicular lymphoma is sometimes cured, many people need ongoing treatment and follow-up.



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If your doctor thinks that you have lymphoma, you'll need several tests. Cells from lymph nodes are typically tested for markers of lymphoma. Other tests are done to plan what type of treatment is best for you.

This chapter also explains steps to take in case one day you want to have a baby. It's important not to have a baby during cancer treatment no matter your sex. Many people have healthy babies afterward.



Tests you'll take

There are many cancers of B cells. These cancers can be difficult to tell apart. Diagnostic tests can confirm which one you have. Identifying the cancer you have is very important so you get the right treatment. This chapter explains the tests that are needed for diagnosis and treatment planning. See Guide 1 for a list of tests you'll take.

Being diagnosed with NHL is scary, especially during COVID-19. Having a great medical team treating me and never losing faith, has helped me during the journey to believe that I will conquer this.

- Judith

Guide 1 Tests for follicular lymphoma

Tests that are needed

- · Medical history, physical exam, and performance status
- · Lab tests of biopsied lymph or other tissue for cell protein markers
- Lab tests of biopsied bone marrow and bone for some people
- CBC with differential, comprehensive metabolic panel, LDH, and hepatitis B
- Diagnostic CT with contrast, whole-body PET/CT, or both
- Pregnancy test if you can have babies

Tests that may be useful

- Lab tests of changes in chromosomes or genes
- Uric acid, beta-2 microglobulin, and hepatitis C
- SPEP, quantitative immunoglobins, or both
- Neck CT with contrast
- Echocardiogram or MUGA scan if certain chemotherapy is planned

Health history

When lymphoma is suspected, you'll be referred to a cancer doctor called an oncologist. Expect this doctor to review your health in detail. This is known as taking a medical history. Your doctor will want to know a lot about your past and current health. You will likely be asked about:

- Illnesses (especially infections) and injuries
- Prescribed and over-the-counter medicines, herbs and supplements, surgeries, and blood transfusions
- Lifestyle choices, including your diet, how active you are, and whether you smoke or drink alcohol
- Symptoms and complications of lymphoma. Lymphoma can cause "B symptoms." B symptoms include fevers when there's no infection, drenching night sweats, and unexplained weight loss.

Some cancers and other health conditions can run in families. Be prepared to discuss the health problems of your close blood relatives. These include brothers, sisters, parents, and grandparents.

Tips for testing

Results from blood tests, imaging, and biopsies will be used to decide your treatment plan. It's important you understand what these tests mean. Ask questions and keep copies of your test results. Online patient portals are a handy way to access your test results.

Remember these tips for testing:

- Bring someone with you to doctor visits, if possible.
- Write down questions and take notes during appointments. Don't be afraid to ask your care team questions. Get to know your care team and help them get to know you.
- Get copies of blood tests, imaging results, and reports about the specific type of cancer you have.
- Organize your papers. Create files for insurance forms, medical records, and test results. You can do the same on your computer.
- Keep a list of contact information for everyone on your care team. Add it to your phone. Hang the list on your refrigerator or keep it in a place where someone can access it in an emergency. Keep your primary care provider informed of any changes.

Physical exam

Your doctor will also perform a thorough physical exam of your body. This exam may include:

- Checking your vital signs—blood pressure, heart rate, breathing rate, and body temperature—and assessing your overall appearance
- Feeling and listening to organs
- Assessing your level of pain, if any, when you are touched

Checking for swelling

Your doctor will feel parts of your body for swelling. Lymph nodes may be so swollen from lymphoma that they can be easily felt or seen under the skin. Your doctor will gently press on your body to assess their size. Areas that may be touched include your neck, armpit,

belly, and groin. Your doctor will also feel your spleen and liver to assess their size.

Checking your physical ability

Based on your health history and exam, your doctor will rate your performance status. Performance status is your ability to do day-to-day activities. The Eastern Cooperative Oncology Group (ECOG) Performance Status is a common scoring system. It consists of five scores. Lower scores represent a higher ability to take care of yourself.

Lab tests of lymph tissue

The only way to be sure that you have lymphoma is to test body tissue. The tests for diagnosis are done at a lab by a doctor called a hematopathologist. Hematopathologists are experts at diagnosing cancers of blood and immune cells. They spend much of their time

Swollen glands

Swelling of lymph nodes (such as the "glands" in your throat) is often one of the first signs of lymphoma. Lymph nodes may be so swollen that they can be easily felt or seen under the skin. Your doctor will gently press on the areas of your body that have lymph nodes, such as your neck, armpits, and groin.



working with samples of blood, bone marrow, and lymph tissue.

Biopsy

A biopsy is a procedure that removes small samples of tissue or cells from the body. There are several types of biopsies. For B-cell lymphomas like follicular lymphoma, experts from NCCN Cancer Centers advise getting an incisional or excisional biopsy. These biopsies remove lymph nodes through a cut into your skin.

- An incisional biopsy removes only a part of a node that may have cancer.
- An excisional biopsy removes all of the node.

Other types of biopsies are sometimes used. Needle biopsies often don't provide enough tissue for diagnosis but may be used to remove tissue from hard-to-reach areas. Open biopsies involve removing tissue through a large cut into the skin.

Diagnostic tests

The hematopathologist will study the tissue using a microscope to classify the disease. This is called histologic typing. If cancer cells are seen, special tests will be run to assess for certain proteins on the surface and inside of cells. These tests are called immunohistochemistry (IHC) and flow cytometry.

Searching for a signature

Follicular lymphoma has a common pattern or a "signature" of proteins. Finding—or not finding—these proteins can reveal the type of cancer. A common pattern of

proteins on the surface of cells is called the immunophenotype.

For instance, follicular lymphoma cells typically have the proteins CD10, CD20, and BCL62 among others. At the same time, the cells usually don't have proteins CD5 and CD43. So a cell sample with the first group of proteins but without the second group supports a diagnosis of follicular lymphoma.

Looking for additional clues

Follicular lymphoma is often easy to diagnose. When the diagnosis isn't clear cut, the hematopathologist may run other tests that detect tell-tale features of lymphomas. Sometimes, tests that detect features related to prognosis are done, too. (Your diagnosis names the disease you have. Your prognosis predicts how your disease will turn out.)

It is sometimes useful to do more tests of cell proteins but also tests of:

- Abnormal genes, such as EZH2, TNFRSF14, and STAT6 mutations
- Chromosomes that break apart then comes together in a different order, such as immunoglobulin gene rearrangements
- Chromosomes with a part that has moved to another chromosome, such as a translocation between chromosomes 14 and 18 referred to as t(14;18)
- Chromosomes with a missing part, such as 1p36 deletion

Grading the lymphoma

The hematopathologist will assign a grade to your cancer. Cancer grade isn't the same

2

as cancer stage. The cancer stage tells how much cancer is in the body and how far it has spread. Learn more about cancer staging in **Chapter 3**.

Follicular lymphoma is classified into three grades. Each grade is based on the number of centroblasts (large follicle B cells) that can be seen with a microscope.

- Grades 1 and 2 have a lower number of centroblasts.
- Grade 3 has a higher number of centroblasts. It's further divided into Grades 3A and 3B.
 - Grade 3A has a mix of centroblasts and other lymphoma cells called centroblasts.
 - Grade 3B has large sheets of centroblasts.

Grade 3 follicular lymphoma, particularly grade 3B, can grow faster than lower grades.

Your pathology report

Lab results used for diagnosis are put into a pathology report. This report will be sent to your doctor. It's used to plan your treatment.

Ask for a copy of the report. Ask your doctor to review your results with you. Take notes and ask questions.



DO NOT be afraid to ask your medical team ANY questions at any time!!! Your questions will help you and them. No question is stupid.

Managing and or controlling your anxiety when it peaks is one thing you can control.

SteveLiving with follicular lymphoma

Bone marrow tests

Bone marrow is the soft center in the middle of most bones. It is like a sponge holding liquid and cells. Lab tests on bone marrow aren't always needed to diagnose follicular lymphoma but may be used to plan treatment.

- A bone marrow biopsy removes a core sample of the "sponge."
- A bone marrow aspiration removes liquid and cells.

These procedures are often done at the same time. They're performed on the back of the hip bone. You may receive a light sedative to relax you beforehand.

Blood tests

Doctors test blood to check for abnormal blood counts and other signs of disease. Blood tests are also used to learn when treatment should begin. For a blood test, a sample of your blood is removed with a needle inserted into a vein. This is called a blood draw.

Tests that should be done with your blood sample include:

CBC with differential

If not done recently, a complete blood count (CBC) with differential is needed.

- A CBC measures parts of the blood including counts of white blood cells, red blood cells, and platelets.
- A differential measures the counts of the most common types of white blood

cells—basophils, neutrophils, eosinophils, monocytes, and lymphocytes. It also checks if the cell counts are in balance with each other.

Comprehensive metabolic panel

Your liver, bone, and other organs release chemicals into your blood. A comprehensive metabolic panel includes tests for up to 14 of these chemicals. It is a common screening test for many diseases.

LDH

Lactate dehydrogenase (LDH) is a protein that's in almost all cells. It gets into your blood when a cell is damaged. A high level of LDH is a sign of cell damage. High levels can be caused by a fast-growing cancer or other health problems.

Hepatitis B

Some types of cancer treatments can weaken your immune system. This increases your chance of hepatitis infections becoming active again. So it's important to have your blood tested for hepatitis viruses.

Blood tests that may be useful include:

- Beta-2 microglobulin to help predict the results of treatment
- Uric acid to assess your risk for a health problem called tumor lysis syndrome
- Hepatitis C antibodies and antigens since the virus could affect treatment
- Antibody tests called quantitative immunoglobulins and serum protein electrophoresis (SPEP) to see if you have a high risk of infections

Imaging

Imaging makes pictures of the inside of your body. It can show where the cancer has spread—a key factor for planning treatment. There are two types of imaging used to assess follicular lymphoma:

- Computed tomography (CT or CAT scan) uses x-rays to take many images of your body from different angles. You will need to take a contrast agent (also called contrast dye) to get the clearest images. A computer combines the x-rays to make a detailed 3-D image.
- CT can be combined with positron emission tomography (PET) to scan your whole body. This imaging is called a PET/CT scan. The PET scan involves getting a sugar radiotracer that highlights cells that may be cancerous. It can detect even small amounts of cancer.

Your oncologist will order imaging. The scans are done in the radiology or nuclear medicine department. A radiologist and nuclear medicine specialist are doctors who specialize in imaging. They will review your scans and send the results to your oncologists. Here are some reasons for imaging:

- If you will be treated with systemic therapy—a medical term for cancer drugs—you will need PET/CT, CT, or both. For a CT, your chest, abdomen, and pelvis should be scanned.
- If you will be treated with radiation therapy for early-stage lymphoma, you will need a PET/CT scan that includes your neck.
- It is sometimes useful to have a CT of your neck to look for cancer in lymph nodes.

PET/CT scan

This is a PET/CT scanner. Imaging instruments, like this one, can show what's going on inside your body. During the scan, you lie down on a table that moves into the tunnel of the machine. The scan can detect even small amounts of cancer.



Heart tests

Some cancer treatments can damage your heart. To plan treatment, your doctor may test how well your heart pumps blood. You may get an echocardiogram or multigated acquisition (MUGA) scan. An echocardiogram uses sound waves to make pictures of your heart. A MUGA scan makes pictures using a radiotracer and special camera.

Fertility and pregnancy

Some cancer treatments may affect your ability to have children. However, there are ways to make having a baby in the future possible. Sperm can be frozen and stored in a sperm bank. Similarly, eggs can be removed from ovaries and stored for later use. Talking with a fertility specialist before you begin cancer treatment may help.

Some cancer treatments can harm an unborn baby. If you might be pregnant now, your doctor may give you a pregnancy test. During treatment, don't get pregnant or get someone pregnant. Talk to your doctor about using birth control during treatment.

Testing takes time. It might take days or weeks for all test results to come in.



We want your feedback!

Our goal is to provide helpful and easy-to-understand information on cancer.

Take our survey to let us know what we got right and what we could do better:

NCCN.org/patients/feedback

Key points

- Your doctor will ask you about any health problems and treatments you've had in your lifetime. Tell your doctor if you've recently had fevers, night sweats, or weight loss without dieting. These may be symptoms of follicular lymphoma.
- Your doctor will examine your body to assess your health. Your doctor will check the size of your lymph nodes and organs. You'll also be rated on your ability to do everyday activities.
- Blood tests will be done to look for signs of a fast-growing cancer and other health problems.
- Tests for hepatitis B or hepatitis C may be needed in order to safely receive certain cancer treatments.
- Imaging tests allow your doctors to see inside your body without cutting into it.
 CT, whole-body PET/CT, or both may be needed.
- A biopsy is the only test that can confirm (diagnose) cancer. An incisional or excisional biopsy is often needed to diagnose follicular lymphoma.
- Biopsy samples should be tested by a hematopathologist. The hematopathologist will perform tests for cell type, signature proteins, and genetics.
- A cancer grade is based on how much the cancer cells look like normal cells when seen under a microscope. A cancer grade helps to predict how fast the cancer will grow and how much it could spread.
- Bone tests may be helpful before starting treatment. A bone marrow biopsy is done

- to assess for cancer in the marrow. An aspiration removes liquid marrow.
- You may undergo heart tests to see if you are healthy enough to have certain cancer treatments.
- Cancer treatments can harm unborn babies and affect your ability to have babies. If you may be pregnant, get a pregnancy test before your treatment.
 Eggs and sperm can be frozen and stored until after treatment.

3 Treatment and support

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3

Not everyone with follicular lymphoma receives the same treatment. Discuss the options in this chapter with your care team. Together, you can create a treatment plan that's best for you.

Advances in treatment

Treatment has changed based on a better understanding of lymphoma, such as:

- The grade of the lymphoma—how much the cancer cells look like normal cells.
- The stage of the lymphoma—the extent of cancer in your body
- The ways that lymphoma cells grow, live, and die

Advances in treatment based on lymphoma features have been made possible by clinical trials. Clinical trials are a type of research that studies new ways of stopping cancer growth or improving quality of life. They give people access to health care that otherwise couldn't usually be received.

The best treatments for low-grade lymphoma (grades 1 and 2) and some grade 3 lymphomas are described in this chapter. Grade 3B is commonly treated like a faster-growing lymphoma called diffuse large B-cell lymphoma (DLBCL). Treatment options for this common, treatable lymphoma are discussed in NCCN Guidelines for Patients: Diffuse Large B-Cell Lymphoma, available at NCCN.org/patientguidelines.

Local therapy

A local therapy treats a part of the body, sometimes just one area, with little harm to nearby healthy tissue. Radiation therapy is a local therapy that is often used to treat follicular lymphoma. It uses high-energy x-rays to treat cancer cells.

Systemic therapy

Systemic therapy treats cancer anywhere in the body. The first systemic therapy ever given—chemotherapy—destroys fast-growing cells whether they are cancer or healthy cells. Newer therapies are more specific to how lymphoma cells live, survive, and die. See Guide 2 for descriptions and examples of systemic therapy.

Antibody therapy is often used with another type of treatment. When used with chemotherapy, it is called chemoimmunotherapy.

Supportive care

Supportive care aims to improve your quality of life. It is sometimes called palliative care. It is a key part of cancer care for everyone, not just people at the end of life.

Your palliative care doctor will work with your oncologists to provide you the best care.

Supportive care may start right after diagnosis and continue after treatment ends. It can address many needs. Notably, it can help prevent or treat health issues related to the cancer or treatment.

Guide 2 Systemic therapies used to treat follicular lymphoma

Chemotherapy stops the process by which cells make copies of themselves. Examples:

- · cyclophosphamide
- doxorubicin
- · vincristine

Antibody therapy acts like a beacon guiding your immune system to cancer cells:

- rituximab (Rituxan)
- obinutuzumab (Gazyva)

Immunomodulators boost parts of the immune system so it attacks cancer better:

lenalidomide (Revlimid)

Kinase inhibitors stop signals for cell growth:

Copanlisib (Aliqopa)

Radioimmunotherapy acts like a trojan horse by directly inserting a deadly radioactive agent inside of cancer cells:

ibritumomab tiuxetan (Zevalin)

Histone methyltransferase inhibitors block signals that stop cell death:

tazemetostat (Tazverik)

CAR T-cell therapy reprograms your T cells to attack cancer cells:

- axicabtagene ciloleucel (Yescarta)
- tisagenlecleucel (Kymriah)

Rituximab biosimilars and skin injection

An FDA-approved biosimilar might be used in place of rituximab (Rituxan). A biosimilar is almost an identical drug. It must be used in the exact same way and at the same dose as rituximab. Biosimilars include: Riabni, Ruxience, and Truxima.

Another medication combines rituximab and hyaluronidase human (Rituxan Hycela) and is injected right under the skin. It may be given in place of rituximab but only after the first full dose of rituximab by infusion. It cannot replace rituximab used with ibritumomab tiuxetan.



The good news is that today the medical industry has made great advances in treating cancer. They create a custom designed treatment specifically for you.

SteveLiving with follicular lymphoma

Initial treatment options

Initial treatment of follicular lymphoma is mainly based on the lymphoma stage. The stage describes the extent of lymphoma in the body. Doctors often use the results of blood tests, imaging, and lab tests to stage lymphoma.

Lymphoma stages

The Lugano modification of the Ann Arbor Staging System is used to stage most lymphomas. There are five stages. They are often written with Roman numerals—stages I, II, II bulky, III, and IV. The farther the lymphoma extends within the body, the higher the stage:

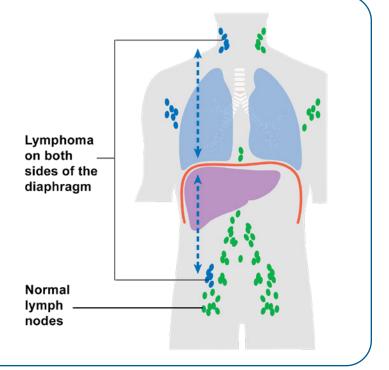
Stage 1 – Lymphoma has been found in one group of lymph nodes or one place outside of the lymph system.

- Stage 2 Lymphoma has been found in two or more groups of lymph nodes that are on the same side of the diaphragm. It may have grown from lymph nodes into nearby areas.
- Stage 2 bulky Bulky describes stage 2 lymphoma with areas that measure 7.5 centimeters or larger.
- Stage 3 Lymphoma has been found in lymph nodes above and below the diaphragm. Stage 3 also includes lymphoma found in lymph nodes above the diaphragm and in the spleen.
- Stage 4 The lymphoma has widely spread outside of the lymph system. An example is spread to the bone marrow.

Lymphoma stages

Lymphoma stages depend on how much the cancer has spread within and outside of the lymph system. Stage 1 lymphomas have not spread. Stage 2 lymphomas have spread across lymph node groups but it's on one side of the diaphragm. In contrast, stage 3 is on both sides of the diaphragm (shown). Stage 4 lymphoma has widely spread outside the lymph system.

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Stage 1 or 2

Only a small number of people with follicular lymphoma have stage 1 or stage 2 disease. For these people, the cancer may be cured. Treatment is often started right away. See Guide 3 for treatment options.

Radiation therapy works well in treating follicular lymphoma. NCCN experts prefer it for stage 1 and some stage 2 lymphomas. If radiation therapy would likely cause major side effects, a watch-and-wait approach is likely a safe option.

Before having radiation therapy, you may get antibody therapy or chemoimmunotherapy. These medications are sometimes used to shrink larger lymphomas before radiation therapy. Antibody therapy or chemoimmunotherapy is the main treatment for stage 2 nodal groups that are far apart. Even for these lymphomas, radiation therapy may be used to relieve or prevent symptoms. For other early-stage lymphomas, medication by itself is rarely used.

For some people, treatment may not be started right away. Instead, a watch-and-wait approach is used to decide when to start treatment. This approach is also called observation and watchful waiting.

Stage 3 or 4

Treatment for stage 3 or 4 lymphoma greatly varies. Some people can delay treatment while other people start right away. When treatment

Guide 3 Initial treatment of stage 1 and stage 2 follicular lymphoma		
Stage 1	 There are 3 options: Radiation therapy (preferred) Radiation therapy with antibody therapy or with chemoimmunotherapy Antibody therapy or chemoimmunotherapy for select people 	
Stage 2	Options depend on the distance between the groups of nodes with cancer. If the groups of nodes are next to each other, see: • Options for stage 1 If the groups of nodes are far apart, there are 2 options: • Antibody therapy or chemoimmunotherapy; Palliative radiation therapy may also be received • Watch and wait	

3

is needed, you may have more than one option. See Guide 4 for treatment options.

Watch and wait

For a slow-growing lymphoma, you may not have to start treatment right away. Instead, you may start observation. This watch-and-wait approach may be an option if the following statements describe you:

- > The lymphoma is not causing symptoms.
- The lymphoma is not limiting organs from working.
- The lymphoma is not causing low blood cell counts.
- The lymphoma has not grown large or spread far.
- The lymphoma has not increased your spleen size.
- The lymphoma is not growing fast or steadily.
- There are no clinical trials that you can join.

Research has shown that starting treatment now does not treat the cancer any better than treatment after waiting. Your length of life will not be extended. During observation, your doctor will look for signs to start treatment, such as symptoms.

First-line systemic therapy

The first systemic therapy given is referred to as first-line therapy. Your doctor will assess your options based on many factors.

Among treatments that may cause harsh side effects, preferred options include chemoimmunotherapy. The chemotherapy used for first-line therapy is bendamustine, CHOP, or CVP. CHOP is short for cyclophosphamide, doxorubicin, vincristine, and prednisone. CVP stands for cyclophosphamide, vincristine, and prednisone. The other preferred option is lenalidomide with rituximab.

Chemoimmunotherapy may be too intense for some adults. It may do more harm than good. In these cases, the preferred option is rituximab by itself.

Guide 4 Initial treatment of stage 3 and stage 4 follicular lymphoma

There are 4 options:

- · Watch and wait
- First-line therapy

Regimens that may cause harsh side effects

- Bendamustine with obinutuzumab or with rituximab (preferred)
- CHOP with obinutuzumab or with rituximab (preferred)
- CVP with obinutuzumab or with rituximab (preferred)
- Lenalidomide with rituximab (preferred)
- Lenalidomide with obinutuzumab
- Rituximab for very limited lymphoma Regimens that are not likely to cause harsh side effects
- Rituximab (preferred)
- · Chlorambucil with or without rituximab
- Cyclophosphamide with or without rituximab
- Clinical trial
- Palliative radiation therapy

Clinical trial

A clinical trial may be a treatment option. Ask your doctor if there's a clinical trial that is a good fit for you. A clinical trial may test which current treatment is best or may test a new cancer drug. More information on clinical trials is provided later in this chapter.

Radiation therapy

For stage 3 and stage 4, radiation therapy is used to relieve symptoms of cancer. It may be part of your care in addition to systemic therapy. It may also be used alone.

Systemic therapy

Hematologists and medical oncologists are doctors who prescribe systemic therapy. These drugs travel through the bloodstream to treat cancer anywhere. Some are made as pills. Others are liquids that are slowly infused into your blood. Ask your doctor how often and for how long you will be taking systemic therapy. Side effects greatly vary between therapies, so also ask what you should expect.



Radiation therapy

A radiation oncologist is a doctor who is an expert in treating cancer with radiation. This doctor will lead a team that designs your treatment plan and provides treatment. Radiation therapy is typically delivered daily from Monday through Friday. Treatment visits are about 15 minutes. Common side effects are fatigue and feeling like you have a sunburn.



Side effects of treatment

All cancer treatments can cause unwanted health issues. Such health issues are called side effects. Some side effects may be harmful to your health. Others may just be unpleasant.

Side effects depend on many factors. These factors include the treatment type, length or dose of treatment, and the person.

Ask your treatment team for a complete list of side effects of your treatments. Also, tell your treatment team about any new or worse symptoms you get. There may be ways to help you feel better.

Here are some potential side effects and ways they are prevented:

Tumor lysis syndrome

Some cancer treatments kill many cells quickly. Tumor lysis syndrome occurs when the waste released by dead cells is not quickly cleared out of your body. This can result in kidney damage and severe blood electrolyte disturbances. It can be life-threatening.

Tumor lysis syndrome may be prevented with hydration. Drink lots of water. You may get fluid infused into your bloodstream. Medicines that lower uric acid can help, too. Some people are admitted to the hospital before starting cancer treatment.

Reactivation of hepatitis

Hepatitis may be reactivated during antibody therapy. Hepatitis B reactivation may be prevented with antiviral medications. There is a link between hepatitis C and B-cell non-Hodgkin lymphomas. Direct-acting antiviral

agents safely treat hepatitis C and may reduce lymphoma cells.

Cancer-related infections

You are more likely to get infections due to lymphoma or its treatment. Some infections can be prevented by getting a vaccine.

- Pneumocystis jiroveci pneumonia is a fungal infection of the lungs. It can be prevented by taking drugs like sulfamethoxazole and trimethoprim.
- The varicella-zoster virus causes chickenpox. Your risk of chickenpox can be reduced with the vaccine.

Checking treatment results

You will need to have tests to assess treatment results. These tests include positron emission tomography with computed tomography (PET/CT). Contrast should be used with the CT scan. Tests done after treatment will be compared to those done before treatment. There are 4 types of treatment results:

- Complete response is the best result.
 Tests show that the lymphoma is no longer active and suggest a good outlook (prognosis). Organs are a normal size.
 Bone marrow is normal.
- Partial response is a decrease in the amount of lymphoma but some remains.
- No response or stable disease is no clear change in the lymphoma.
- Progressive disease is a worsening of the lymphoma.

Results for stage 1 or 2

People with stage 1 or stage 2 lymphoma that had a complete or partial response may start follow-up care.

When there's no response, the next steps of care depend on your initial treatment. If you had only radiation therapy, you may start initial treatment used for stage 3 or stage 4. If you had systemic therapy, the next treatment options are listed in *When initial treatment doesn't work*.

If the cancer progressed, you may have a biopsy to test to see if follicular lymphoma transformed to DLBCL. If the lymphoma didn't transform, the next treatment options are listed in *When initial treatment doesn't work*. If it did transform, see **Chapter 4** for options.

Results for stage 3 or 4

People with stage 3 or stage 4 lymphoma that had a complete or partial response may receive additional treatment or start follow-up care. Additional treatment consists of either maintenance or consolidation treatment.

- Maintenance treatment is intended to prolong the amount of time until the cancer comes back. Rituximab maintenance is received every 8 to 12 weeks for 2 years. Obinutuzumab maintenance is received every 8 weeks for 2 years (12 doses).
- Consolidation treatment is given to improve the results of systemic therapy. Rituximab is a consolidation option if initial therapy consisted only of rituximab. It is received every 8 weeks for 8 months (4 doses). Ibritumomab tiuxetan needs further study but may be an option if your bone marrow is healthy enough.

If there was no response or the cancer progressed, you may have a biopsy. The biopsy sample will be tested to see if follicular lymphoma transformed to DLBCL. If the lymphoma didn't transform, the next treatment options are listed in *When initial treatment doesn't work*. If it did transform, see **Chapter 4** for options.

Adults with pediatric-type follicular lymphoma

Pediatric-type follicular lymphoma (PTFL) occurs most often in children, but some adults get it, too. It often occurs in the head and neck region. It is stage 1 or stage 2.

Excision is a type of surgery that removes the tumor and not much else. NCCN experts prefer this option for PTFL. Another option is ISRT. If neither surgery or ISRT is an option, you may receive chemoimmunotherapy. The regimen that is used is called RCHOP, which stands for rituximab, cyclophosphamide, doxorubicin, vincristine, and prednisone.

After radiation or chemotherapy, PET/CT is used to assess the cancer stage again. If there is a complete response, start follow-up care. Follow-up imaging is not needed when the outlook is good. If a complete response wasn't attained, second-line therapy is an option.

Follow-up care

Follow-up care is started after treatment is completed and tests show good results. Your doctor will monitor the status of the lymphoma on a regular basis. See Guide 5 for a schedule of follow-up care.

At office visits, your care providers will ask about your health to update your medical history. Your doctor will examine your body especially looking for enlarged lymph nodes and organs. You will need to get a blood draw, so a complete blood count (CBC) and chemistry panel can be done.

CT is the standard imaging test used during follow-up care. Scans of your chest, abdomen, and pelvis with contrast are advised. PET/CT may clarify if a mass found by CT is cancer or just scar tissue. It is also used if CT can't detect the cancer, such as cancer in bone. If the lymphoma recurs or worsens, see the next section for treatment options.

During follow-up care, you will continue to receive supportive care. Some side effects of

treatment may not quickly resolve and some have a late onset. Long-term and late effects include second cancers, fatigue, poor sleep, and heart disease. Read about common effects in NCCN Guidelines for Patients:

Survivorship Care for Cancer-Related Late and Long-Term Effects, available at NCCN.org/patientguidelines.

The other patient guide in the NCCN two-part book series on survivorship care focuses on healthy living. Read about preventing poor health in NCCN Guidelines for Patients: Survivorship Care for Healthy Living, available at NCCN.org/patientquidelines.





Guide 5 Follow-up care			
Medical history and physical exam at office visits	Every 3 to 6 months for 5 years or when needed • If normal for 5 years, repeat every year or when needed		
CBC, chemistry panel	Every 3 to 6 months for 5 years or when needed • If normal for 5 years, repeat every year or when needed		
CT scan if no symptoms	Not more often than every 6 months for 2 years • If normal for 2 years, repeat no more often than every year		

When initial treatment doesn't work

If initial treatment doesn't work, another treatment might. Likewise, if the lymphoma recurs, you are likely to have a different treatment than before. Options after initial treatment are listed in Guide 6.

Watch and wait

Like initial treatment, you may not have to start another treatment right away. Instead, a watchand-wait approach is used to decide when to start treatment. When treatment is needed, your doctor may want you to get a PET/CT scan to look for areas of transformation.

Systemic therapy

Systemic therapy is the standard treatment for lymphoma recurrences and progression. Most people have systemic therapy as their initial treatment, so now it's called second-line therapy because it's the second therapy to be tried. First-line regimens that were taken before are generally not repeated.

Guide 6 Options when initial treatment doesn't work

There are 4 options:

- · Watch and wait
- Second-line therapy

Regimens for fit adults

- Bendamustine with obinutuzumab or with rituximab (preferred)
- CHOP with obinutuzumab or with rituximab (preferred)
- CVP with obinutuzumab or with rituximab (preferred)
- Lenalidomide and rituximab (preferred)
- · Ibritumomab tiuxetan
- Lenalidomide (if antibody therapy isn't an option)
- · Lenalidomide and obinutuzumab
- Rituximab
- Second-line therapy used for diffuse large B-cell lymphoma

Regimens for frail adults

- Rituximab (preferred)
- Chlorambucil with or without rituximab
- Cyclophosphamide with or without rituximab
- Tazemetostat
- Ibritumomab tiuxetan (needs further study)
- Clinical trial
- Palliative radiation therapy

You may receive additional therapy if there is a complete or partial treatment response after second-line therapy:

Rituximab maintenance every 12 weeks for 2 years is a preferred option. The other preferred option is obinutuzumab maintenance if second-line rituximab didn't work. It is taken every 8 weeks for 2 years (12 doses).

Graft-Versus-Host

Disease

Another option is a hematopoietic stem cell transplant. The two types of transplants are high-dose therapy with autologous stem cell rescue (HDT/ ASCR) and allogeneic

hematopoietic cell transplant. Learn about an important side effect of allogeneic transplants in the NCCN Guidelines for Patients: Graft-Versus-Host Disease, available at

NCCN.org/patientguidelines.

If there was no response or the cancer progressed, you may have a biopsy. The biopsy sample will be tested for transformed follicular lymphoma. If the lymphoma transforms, see **Chapter 4** for options. If it didn't transform, you may take third-line options:

- Therapies listed for second-line may be used for third-line if not taken before
- Copanlisib
- Tazemetostat
- Axicabtagene ciloleucel or tisagenlecleucel

Allogeneic and autologous stem cell transplants

What's the difference?

Hematopoietic stem cell transplants infuse healthy stem cells that form new bone marrow and blood cells in your body.

- Allogeneic transplants use healthy stem cells from a matched donor who may or may not be related to you.
 The healthy cells attack the cancer cells.
- Autologous transplants use your own healthy stem cells that are removed before taking strong cancer drugs that destroy your bone marrow.

Additional treatment after third-line therapy consists of CAR T-cell therapy. It may be an option if you have taken two lines of chemoimmunotherapy. Learn about side effects of CAR T-cell therapy in the



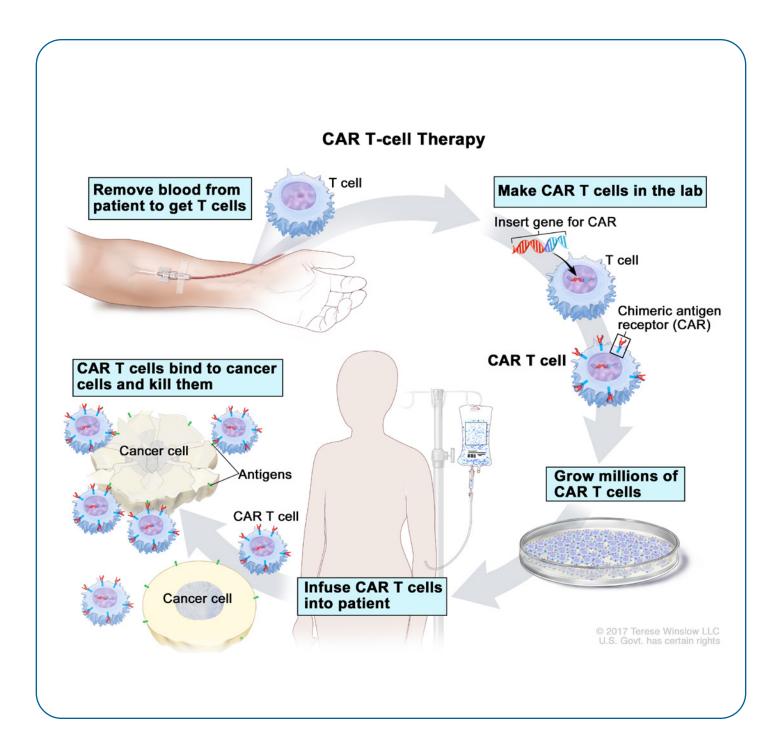
NCCN Guidelines for Patients: Immunotherapy Side Effects – CAR T-Cell Therapy, available at NCCN.org/patientguidelines.

Clinical trial

A clinical trial may be an option if the cancer worsens after initial treatment. Ask your doctor if there's a clinical trial that is a good fit for you. More information on clinical trials is provided in the next section.

Radiation therapy

Radiation therapy may be used to relieve symptoms of lymphoma. It may be part of your treatment plan in addition to systemic therapy. It may also be used alone.



Clinical trials

Despite advances in treatment, more research is needed to develop even better treatments.

A clinical trial is a type of medical research study. After being developed and tested in a laboratory, potential new ways of fighting cancer need to be studied in people. If found to be safe and effective in a clinical trial, a drug, device, or treatment approach may be approved by the U.S. Food and Drug Administration (FDA).

Everyone with cancer should carefully consider all of the treatment options available for their cancer type, including standard treatments and clinical trials. Talk to your doctor about whether a clinical trial may make sense for you.

Phases

Most cancer clinical trials focus on treatment. Treatment trials are done in phases.

- Phase I trials study the dose and safety of an investigational drug or treatment approach.
- Phase II trials study how well the drug or approach works against a specific type of cancer.
- Phase III trials test the drug or approach against a standard treatment. If the results are good, it may be approved by the FDA.
- Phase IV trials study the long-term safety and benefit of an FDA-approved treatment.



Finding a clinical trial

In the United States
NCCN Cancer Centers
NCCN.org/cancercenters

The National Cancer Institute (NCI) cancer.gov/about-cancer/treatment/clini-cal-trials/search

Worldwide

The U.S. National Library of Medicine (NLM)

clinicaltrials.gov/

Need help finding a clinical trial?

NCI's Cancer Information Service (CIS)

1.800.4.CANCER (1.800.422.6237)

cancer.gov/contact

Who can enroll?

Every clinical trial has rules for joining, called eligibility criteria. The rules may be about age, cancer type and stage, treatment history, or general health. These requirements ensure that participants are alike in specific ways and that the trial is as safe as possible for the participants.

Informed consent

Clinical trials are managed by a group of experts called a research team. The research team will review the study with you in detail, including its purpose and the risks and benefits of joining. All of this information is also provided in an informed consent form. Read the form carefully and ask questions before signing it. Take time to discuss with family, friends, or others you trust. Keep in mind that you can leave and seek treatment outside of the clinical trial at any time.

Start the conversation

Don't wait for your doctor to bring up clinical trials. Start the conversation and learn about all of your treatment options. If you find a study that you may be eligible for, ask your treatment team if you meet the requirements. Try not to be discouraged if you cannot join. New clinical trials are always becoming available.

Frequently asked questions

There are many myths and misconceptions surrounding clinical trials. The possible benefits and risks are not well understood by many with cancer.

Will I get a placebo?

Placebos (inactive versions of real medicines) are almost never used alone in cancer clinical trials. It is common to receive either a placebo with a standard treatment or a new drug with a standard treatment. You will be informed, verbally and in writing, if a placebo is part of a clinical trial before you enroll.

Are clinical trials free?

There is no fee to enroll in a clinical trial. The study sponsor pays for research-related costs, including the study drug. You may, however, have costs indirectly related to the trial, such as the cost of transportation or child care due to extra appointments. During the trial, you will continue to receive standard cancer care. This care is billed to—and often covered by—insurance. You are responsible for copays and any costs for this care that are not covered by your insurance.

Key points

Key points

- Treatment for follicular lymphoma has improved. Researchers have identified better treatment methods with fewer side effects. They have also identified new systemic therapies that address specific ways that lymphoma grows.
- Supportive care is an important part of your cancer care before, during, and after cancer treatment. It can help prevent or reduce side effects.
- The stage of lymphoma describes the extent of the cancer in the body. Stages 1 and 2 are lymphomas with limited growth. Stages 3 and 4 are advanced lymphomas that involve multiple parts of the body.
- Initial treatment for follicular lymphoma is mainly based on its cancer stage. For small stage 1 and stage 2 lymphomas, the main treatment is often radiation therapy. Antibody therapy or chemoimmunotherapy may be used before radiation therapy to shrink the cancer. For other stage 2, stage 3, and stage 4 lymphomas, the main treatment is a systemic therapy. Some people initially do watch-and-wait delaying active treatment until it's needed.
- Ask your treatment team for a complete list of side effects of your treatments.
 Also, tell your treatment team about any new or worse symptoms you get.
- Testing is needed to assess the results of treatment. There are four types of treatment responses. A complete or partial response means the lymphoma has shrunk. No response means the lymphoma is about the same. Progression means the lymphoma has worsened.

- After systemic therapy, some people receive additional therapy to prolong or improve the good results of the main treatment. Your oncologist will assess whether additional therapy may help you.
- Follow-up care involves monitoring the status of the lymphoma after treatment and supportive care for symptoms.
- If initial treatment doesn't work or the lymphoma recurs, a standard treatment is a systemic therapy. Before starting active treatment, you may undergo a period of watchful waiting.
- Clinical trials are needed to improve treatment of follicular lymphoma. They are a type of research that studies new ways of curing and controlling cancer compared to standard treatment. Ask your treatment team if a clinical trial is an option for you.



A common myth is that palliative care is only for terminally ill patients. It is so much more!

Reach out to palliative care in your hospital or clinic. They treat the whole patient, not just cancer.

RobertDiagnosed with lymphoma

4 Transformed lymphoma

- 38 Testing
- 38 Treatment options
- 39 Key points



This chapter presents the tests and treatment options for when follicular lymphoma changes into a fastergrowing lymphoma. Discuss with your doctor which options are right for you.

Testing

Follicular lymphoma sometimes changes into diffuse large B-cell lymphoma (DLBCL). Doctors call this transformed lymphoma. When it does transform, it most often does so after cancer treatment though treatment is not the cause. Only a few people have transformed follicular lymphoma when first diagnosed.

If the lymphoma worsens, your doctor may suspect the cancer has transformed. Signs of a transformation include:

- A lymphoma is growing fast in one area
- A lymphoma has spread outside the lymph system
- Rising lactate dehydrogenase (LDH) level
- New B symptoms

Positron emission tomography (PET) may help detect transformed cancer. Fluorodeoxyglucose (FDG) should be used for the radiotracer. But, only lab tests on biopsy samples can confirm if the cancer has transformed.

Lab tests of translocations related to highgrade B-cell lymphomas will be done. A translocation is a chromosome with a part that has moved to another chromosome.

High-grade B-cell lymphomas with MYC and BCL2 and/or BCL6 translocations include:

- "Double-hit" high-grade B-cell lymphoma has an MYC translocation and either a BCL2 or BCL6 translocation.
- "Triple-hit" high-grade B-cell lymphoma has all three translocations.

Treatment options

The treatment options that are best for you depend on many factors, such as your age, health, and prior treatment.

You've had little or no prior systemic therapy

Doctors consider one course of single-agent therapy, such as rituximab by itself, as little therapy. Treatment options are based on whether or not the transformed lymphoma is a double- or triple-hit high-grade B-cell lymphoma.

High-grade B-cell lymphoma is a very aggressive, fast-growing cancer. Treatment options for double- and triple-hit lymphomas include:

- Clinical trial (recommended)
- Radiation therapy (preferred for limited) lymphoma), typically received after chemoimmunotherapy
- RCHOP regimen consisting of rituximab, cyclophosphamide, doxorubicin, vincristine, and prednisone
- > DA-EPOCH-R, which stands for doseadjusted etoposide, prednisone,

- 4
- vincristine, cyclophosphamide, and doxorubicin with rituximab
- R-HyperCVAD is rituximab, cyclophosphamide, vincristine, doxorubicin, and dexamethasone alternating with high-dose methotrexate and cytarabine
- R-CODOX-M/R-IVAC combines rituximab, cyclophosphamide, vincristine, doxorubicin, and methotrexate alternating with rituximab, ifosfamide, etoposide, and cytarabine

When the transformed lymphoma isn't a highgrade B-cell lymphoma, treatment options for DLBCL are used:

 Chemoimmunotherapy with anthracyclinebased regimens like RCHOP (preferred), which may be followed by radiation therapy

These treatment options are discussed in NCCN Guidelines for Patients: Diffuse Large B-Cell Lymphoma, available at NCCN.org/patientguidelines.

You've had multiple systemic therapies

Options after having multiple lines of systemic therapy for follicular or transformed lymphoma are:

- Clinical trial
- Systemic therapy with or without radiation therapy
- CAR T-cell therapy
- Radiation therapy
- Best supportive care

There are many options for systemic therapy. RCHOP is preferred if you haven't had it before. Options for CAR T-cell therapy are lisocabtagene maraleucel, axicabtagene ciloleucel, and tisagenlecleucel.

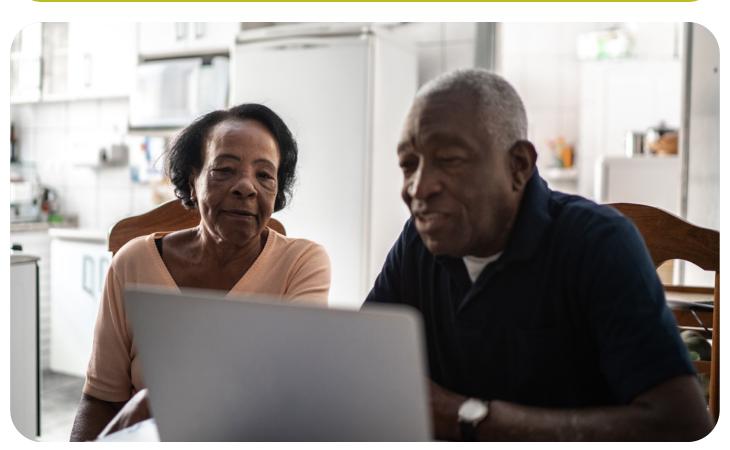
If the lymphoma shrinks, a hematopoietic stem cell transplant may be used for consolidation treatment. Consolidation is given to improve the results of a drug regimen. Radiation therapy may be used to treat a certain area.

Key points

- Sometimes, follicular lymphoma transforms into a faster-growing lymphoma. These lymphomas may be diffuse large B-cell lymphoma or highgrade B-cell lymphoma.
- A biopsy is needed to confirm the presence of transformed lymphoma.
- For most people with transformed lymphoma, NCCN experts advise a clinical trial. Other options include chemoimmunotherapy, which is sometimes followed by radiation therapy. Supportive care may be received to relieve symptoms.

5 Making treatment decisions

- 41 It's your choice
- 41 Questions to ask
- 48 Resources



5

It is important to be comfortable with the lymphoma treatment you choose. This choice starts with having an open and honest conversation with your care team.

It's your choice

In shared decision-making, you and your care team share information, discuss the options, and agree on a treatment plan. It starts with an open and honest conversation with them.

Treatment decisions are very personal. What is important to you may not be important to someone else.

Some things that may play a role in your decision-making:

- What you want and how that might differ from what others want
- Your religious and spiritual beliefs
- Your feelings about certain treatments like chemotherapy or transplants
- Your feelings about having side effects, such as pain or nausea
- Cost of treatment, travel to treatment centers, and time away from work
- Quality of life and length of life
- How active you are and the activities that are important to you

Think about what you want from treatment. Discuss openly the risks and benefits of specific treatments and procedures. Weigh options and share your concerns. If you take the time to build a relationship with your care

team, it will help you feel supported when making treatment decisions.

Second opinion

It is normal to want to start treatment as soon as possible. While cancer should not be ignored, there is time to have another doctor review your test results and suggest a treatment plan. This is called getting a second opinion, and it's a normal part of cancer care. Even doctors get second opinions!

Things you can do to prepare:

- Check with your insurance company about its rules on second opinions. There may be out-of-pocket costs to see doctors who are not part of your insurance plan.
- Make plans to have copies of all your records sent to the doctor you will see for your second opinion.

Support groups

Many people diagnosed with cancer find support groups to be helpful. Support groups often include people at different stages of treatment. Some people may be newly diagnosed, while others may be finished with treatment. If your hospital or community doesn't have support groups for people with cancer, check out the websites listed in this book.

Questions to ask

Possible questions to ask your care team are listed on the following pages. Feel free to use these or come up with your own. Be clear about your goals for treatment and find out what to expect from treatment. Keep a notebook handy to record answers to your questions.

Questions about cancer testing

- 1. What tests do I need? Where will the tests take place? How long will the tests take and will any test hurt?
- 2. What if I am pregnant?
- 3. How do I prepare for testing? Should I bring a list of my medications? Should I bring someone with me?
- 4. How long does it take to get the test results? How often are these tests wrong?
- 5. What type of lymphoma do I have? What is the cancer grade and stage and what do they mean?
- 6. Would you give me a copy of my test results, including the pathology report, and explain the results?

7. Who will talk with me about the next steps? When?					

Questions about treatment options

- 1. What are my treatment options?
- 2. Is a clinical trial or a stem cell transplant an option for me?
- 3. What will happen if I do nothing?
- 4. Are you suggesting options other than what NCCN recommends? If yes, why?
- 5. How do my age, sex, overall health, and other factors affect my options?
- 6. What if I am pregnant, or planning to become pregnant?
- 7. Does any option offer a cure or long-term cancer control? If the cancer can't be cured, how well can its growth be controlled?
- 8. What are the side effects of the treatments?
- 9. How do I get a second opinion?
- 10. How long do I have to decide about treatment, and is there a social worker or someone who can help me decide?

Questions about what to expect

- Does this hospital or cancer center offer the best treatment for me?
 Do I have a choice of when to begin treatment?
- 3. How long will treatment last?
- 4. Will my insurance cover the treatment you're recommending?
- 5. Are there any programs to help pay for treatment?
- 6. What supportive care services are available to me and my caregivers?
- 7. Who should I contact with questions or concerns if the office is closed?
- 8. How will you know if treatment is working?
- 9. What are the chances of the cancer worsening or returning?
- 10. What follow-up care is needed after treatment?

Questions about side effects

- 1. What are the possible complications and side effects of treatment?
- 2. Does the cancer itself cause any side effects?
- 3. Which side effects are most common and how long do they usually last?
- 4. Which side effects are serious or life-threatening?
- 5. Are there any long-term or permanent side effects?
- 6. What symptoms should I report right away, and who do I contact?
- 7. What can I do to prevent or relieve the side effects of treatment?
- 8. Do any medications worsen side effects?
- 9. Do any side effects lessen or worsen in severity over time?
- 10. Will you stop or change treatment if there are serious side effects?

Questions about clinical trials

- 1. Do you recommend that I consider a clinical trial for treatment?
- 2. How do I find clinical trials that I can participate in?
- 3. Where will the clinical take place? If not at your office, will you still provide care for me?
- 4. What are the treatments used in the clinical trial?
- 5. Has the treatment been used for other types of cancer?
- 6. What are the risks and benefits of this treatment?
- 7. What side effects should I expect and how will they be managed?
- 8. How long will I be in the clinical trial?
- 9. Will I be able to get other treatment if this doesn't work?
- 10. How will you know if the treatment is working?
- 11. Will the clinical trial cost me anything?

Questions about your care team's experience

- 1. What is your experience treating follicular lymphoma? What is the experience of those on your team?
- 2. Do you only treat lymphoma? What else do you treat?
- 3. How many people of the same age, gender, and race have you treated?
- 4. Will you be consulting with experts to discuss my care? With whom will you consult?
- 5. How many procedures like the one you're suggesting have you done?
- 6. Is this treatment a major part of your practice?
- 7. How often is a complication expected? What are the complications?
- 8. Who will manage my day-to-day care??

Resources

American Cancer Society

cancer.org/cancer/non-hodgkin-lymphoma.html

Be the Match

bethematch.org

BMT InfoNet

bmtinfonet.org

Lymphoma Research Foundation

lymphoma.org

The Leukemia & Lymphoma Society (LLS)

LLS.org/PatientSupport

National Bone Marrow Transplant Link (nbmtLINK)

nbmtlink.ora

National Cancer Institute

www.cancer.gov/types/lymphoma

National Coalition for Cancer Survivorship

canceradvocacy.org/toolbox

NCCN for Patients

NCCN.org/patients

U.S. National Library of Medicine Clinical Trials Database

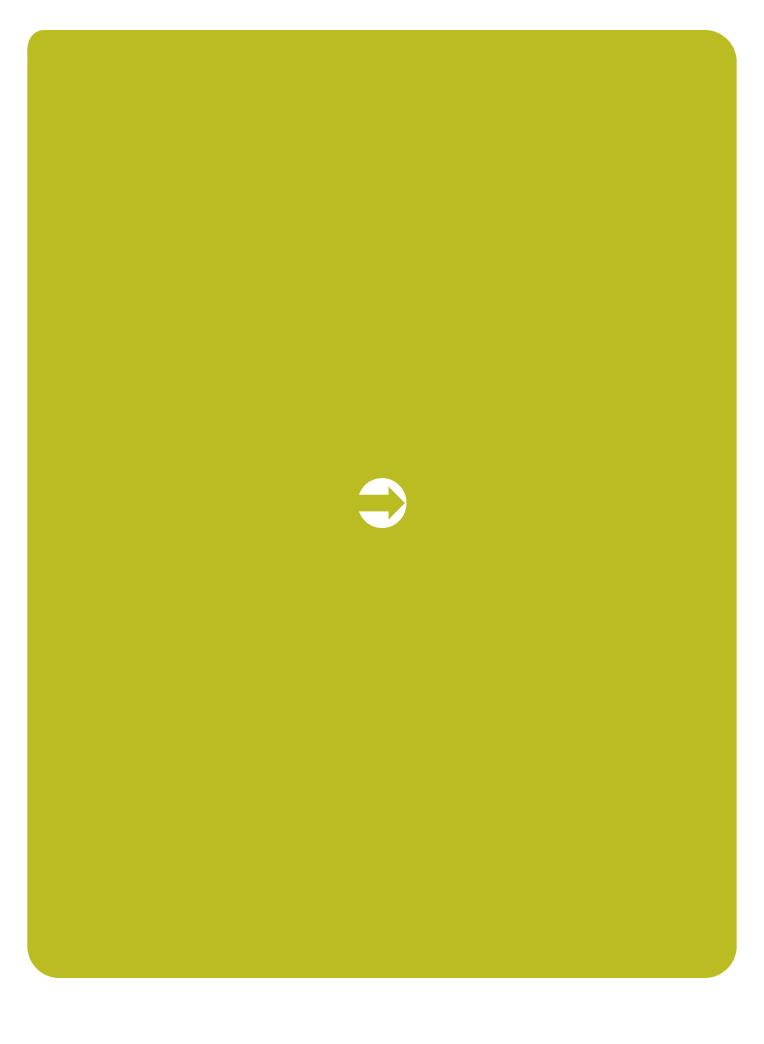
clinicaltrials.gov/



Let us know what you think!

Please take a moment to complete an online survey about the NCCN Guidelines for Patients.

NCCN.org/patients/response



Words to know

allogeneic hematopoietic stem cell transplant

A cancer treatment that replaces abnormal blood stem cells with healthy donor cells.

antibody therapy

A type of cancer drug that stops growth signals.

B cell

A type of a white blood cell called a lymphocyte. Also called B-lymphocyte.

B symptoms

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

beta-2 microglobulin

A small protein made by many types of cells.

biopsy

A procedure that removes fluid or tissue samples to be tested for a disease.

bone marrow

The sponge-like tissue in the center of most bones.

bone marrow aspiration

A procedure that removes a liquid bone marrow sample to test for a disease.

bone marrow biopsy

A procedure that removes bone and solid bone marrow samples to test for a disease.

cancer grade

A rating of cancer cells based on cell features.

cancer stage

A rating of the outlook of a cancer based on its growth and spread.

CAR

chimeric antigen receptor

centroblast

A type of fast-growing B cell within lymph structures.

centrocyte

A type of B cell that is found within lymph structures and has a dent in its edge.

chemotherapy

Drugs that stop the process of cancer cells making copies of themselves.

chromosome

The structures within cells that contain coded instructions for cell behavior (genes).

clinical trial

A type of research that assesses how well health tests or treatments work in people.

complete blood count (CBC)

A lab test that measures the number of red blood cells, white blood cells, and platelets.

complete response

Lymphoma that is no longer active after treatment.

computed tomography (CT)

A test that uses x-rays from many angles to make a picture of the insides of the body.

consolidation

A treatment phase to further reduce the number of cancer cells.

contrast

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

deletion

A chromosome with a missing part.

diagnosis

An identification of an illness based on tests.

diaphragm

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

differential

A lab test of the number of white blood cells for each type.

DLBCL

diffuse large B-cell lymphoma

echocardiogram

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

ECOG

Eastern Cooperative Oncology Group

FDA

Food and Drug Administration

fertility specialist

An expert who helps people to have babies.

flow cytometry

A lab test of substances on the surface of cells to identify the type of cells present.

gene

Coded instructions in cells for making new cells and controlling how cells behave.

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

A cancer treatment that destroys cancer cells with intense treatment then rebuilds destroyed bone marrow with your own healthy blood stem cells.

imaging

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

immune system

The body's natural defense against infection and disease.

immunohistochemistry (IHC)

A lab test of cancer cells to find specific cell traits involved in abnormal cell growth.

immunomodulator

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

immunotherapy

A treatment with drugs that may help the body find and destroy cancer cells.

kinase inhibitor

A drug that blocks the transfer of phosphate.

lactate dehydrogenase (LDH)

A protein that helps to make energy in cells.

lymph

A clear fluid containing white blood cells.

lymph node

A small, bean-shaped, disease-fighting structure.

lymph system

A network of organs and vessels that collects and transports a fluid called lymph.

lymphocyte

One of three main types of white blood cells that help protect the body from illness.

lymphoma

A cancer of white blood cells called lymphocytes that are within the lymph system.

maintenance

A treatment phase that is given to prolong good treatment results.

medical history

A report of all your health events and medications.

multigated acquisition (MUGA) scan

A test that uses radiation to make pictures of the heart.

mutation

An abnormal change in a gene.

physical exam

A study 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.

prognosis

The likely course and outcome of a disease based on tests.

PTFL

pediatric-type follicular lymphoma

quantitative immunoglobulin

A test that measures the amount of different types of antibodies in the blood.

radiation therapy

A treatment that uses intense energy to kill cancer cells.

radioimmunotherapy

A treatment that attaches to cancer cells then releases radiation.

rearrangement

A chromosome that breaks apart then comes together in a different order.

relapse

The return of cancer after a period of improvement.

serum protein electrophoresis (SPEP)

A test that measures how many types of antibodies are present.

side effect

An unhealthy or unpleasant physical or emotional response to treatment.

spleen

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

supportive care

Health care that includes symptom relief but not cancer treatment. Also called palliative care.

T cell

A type of a white blood cell called a lymphocyte.

translocation

A chromosome with a part that has moved to another chromosome.

white blood cell

A type of blood cell that fights disease and infection

NCCN Contributors

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617.726.5130
massgeneral.org/cancer-center

Duke Cancer Institute

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888.275.3853 • dukecancerinstitute.org

Fox Chase Cancer Center *Philadelphia, Pennsylvania* 888.369.2427 • foxchase.org

Fred & Pamela Buffett Cancer Center Omaha, Nebraska 402.559.5600 • unmc.edu/cancercenter

Fred Hutchinson Cancer Center/ Seattle Cancer Care Alliance Seattle, Washington 206.606.7222 • seattlecca.org 206.667.5000 • fredhutch.org

Huntsman Cancer Institute at the University of Utah Salt Lake City, Utah 800.824.2073 • huntsmancancer.org

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Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine St. Louis, Missouri 800.600.3606 • siteman.wustl.edu

St. Jude Children's Research Hospital/ The University of Tennessee Health Science Center Memphis, Tennessee 866.278.5833 • stjude.org 901.448.5500 • uthsc.edu

Stanford Cancer Institute Stanford, California 877.668.7535 • cancer.stanford.edu

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800.293.5066 • cancer.osu.edu

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Vanderbilt-Ingram Cancer Center Nashville, Tennessee 877.936.8422 • vicc.org

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