

What is Non-Hodgkin lymphoma?

DIAGNOSIS, TREATMENT AND RECOVERY



What is Non-Hodgkin lymphoma?

Lymphoma refers to a group of cancers that come from a specific group of white blood cells inside your body. These cells are called **lymphocytes**.

Lymphocytes and other white blood cells are part of your lymphatic system (also called "lymph system"). This system helps your body fight off diseases. The lymph system includes the lymph nodes, spleen, and bone marrow where lymphocytes live and often carry out their function. Lymphoma can be located in these areas but can also spread to other areas.

There are **two main types** of lymphoma: **Hodgkin** and **Non-Hodgkin**. You will learn about these two types, as well as how they are diagnosed and treated, and what recovery is like, in this guide. This module

lymphatic Neck (cervical) lymph nodes Spleen Groin (inguinal) lymph nodes

Lymph nodes

Bone marrow

Armpit (axillary) lymph nodes



What is Hodgkin lymphoma?

Hodgkin lymphoma is a cancer that happens in the body's lymph system. Hodgkin lymphoma occurs when lymphocytes (a type of white blood cell) grow out of control.

Common treatments include chemotherapy and/or radiation, and sometimes a stem cell transplant, depending on the stage of disease.

Hodgkin lymphoma is one of the most curable forms of cancer.

What is Non-Hodgkin lymphoma?

Non-Hodgkin lymphoma is a cancer that can also affect the body's lymph system. Non-Hodgkin lymphoma also affects the body's bone marrow and blood.

There are many types of Non-Hodgkin lymphoma. Often, it is classified based on the rate of spread of the cancer:

• Indolent Non-Hodgkin lymphoma grows slower, typically with few symptoms

Hodgkin lymphoma	Non-Hodgkin lymphoma
32 % are 20-34 years old	75% are 55 years and older
Rare	7th MOST diagnosed cancer
86% survive 5 years or more after diagnosis	70% survive 5 years or more after diagnosis
2 subtypes Classical (95%) Nodular lymphocyte-predominant (5%)	61 types & subtypes Most common (85%): B-cell lymphoma



Can I prevent lymphoma?

Unfortunately, there is no sure way to prevent lymphoma. However, there are a few ways to lower your risk:

- Eat a balanced, healthy diet.
 - > Eat lots of fruits, vegetables, and whole grains.
 - > Eat less red meat, processed meat, sugary drinks, and other "junk" foods.
 - > Speak to a UCLA nutritionist if you want help creating a healthy eating plan.
- Maintain a healthy weight.
- Don't use IV drugs since this puts you at greater risk for hepatitis and HIV, which are associated with lymphoma.
- Don't have unprotected sex with many partners since this puts you at greater risk for hepatitis and HIV, that can be associated with lymphoma.

Who is at higher risk of getting lymphoma?

Anyone can get lymphoma. It is one of the more common cancers among kids, teens, and young adults. However, some people are more likely to get it than others.

Some risk factors are:

- Age
 - > Young adults between 15-40 years old
 - Adults 55+ years old
- Males
- A weaker immune system—due to illness or medicines
- Illnesses such as:
 - > Epstein-Barr virus
 - › Helicobacter pylori infection
 - > Hepatitis C
 - > Human T-cell leukemia/lymphoma
 - > HIV/AIDS
 - > Solid organ transplant
- Any blood relative who has had lymphoma
- Being overweight or obese
- Working in a place where there are high levels of chemicals including benzenes or pesticides
- A previous lymphoma diagnosis
- Prior radiation treatment for cancer

Focus on things you can do to lower your risk.

You may not be able to change or eliminate all of your risk factors. And having one or more risk factors does not mean you will get lymphoma.



Keep your immune system as strong as possible



Eat healthy foods



Maintain a healthy weight or lose weight if needed



Get 6-8 hours of sleep each night



drug use and unprotected sex



Exercise regularly



Lymphoma symptoms



What symptoms might mean I have Non-Hodgkin lymphoma?

Non-Hodgkin lymphoma shares the same symptoms as many less-serious illnesses. Not every person with Non-Hodgkin lymphoma experiences signs/symptoms or the same symptoms.

Some common signs of Non-Hodgkin lymphoma are:

- Rashes and itchy skin
- Swollen but painless lymph nodes
- Extreme tiredness
- Coughing and chest pain
- Belly pain
- Bruising easily
- Frequent illness and infections
- Feeling really full even though you didn't eat a lot or feeling full very quickly
- These signs are known as "B symptoms":
 - Severe night sweats
 - > Unexplained fever
 - > Suddenly losing a lot of weight without trying

B symptoms usually mean your lymphoma is in a later stage and is affecting more parts of your body. Your provider considers your B symptoms when making your diagnosis. Speak to your provider if you're concerned about your symptoms.

Do women have different symptoms?

If lymphoma starts in a woman's reproductive organs (pelvic area), they may have other symptoms. These symptoms include:

- A growth or mass in your pelvic area
- Bleeding while not on your period or after menopause
- Pain or pressure in the pelvic area
- Pain during sex

Often, these symptoms are not noticed because they can be caused by other or less-serious illnesses than lymphoma. However, make sure you contact your provider if you have any of these symptoms.



Diagnosis



Diagnosing Non-Hodgkin lymphoma

Diagnosing lymphoma is very important. A diagnosis will help your providers and you understand how fast or slow and where your lymphoma is growing.

There are many different types of Non-Hodgkin lymphoma. Your care team will do several tests to diagnose you correctly. This can take several weeks. These tests may include biopsies and x-rays, which will be explained in this section.

The purpose of these tests is to **identify your lymphoma type, stage, and subtype**. Once these are identified, your care team will discuss the best treatment options with you. Some treatments work better on certain subtypes than others.



5 tests that can show if you have lymphoma







Lymph node biopsy













How will I be diagnosed?

One sign of lymphoma is a swollen lymph node. If your provider suspects lymphoma, they will need to do some tests to diagnose it. There are **5 main tests** that can be used to see if you have lymphoma, as well as what type and stage it is. You may need several of the following tests:

1 Physical exam



Your provider will look at your body to check for swollen lymph nodes. Lymph nodes are in your neck, armpit, and groin. They might also check to see if

your spleen or liver is swollen by pressing on the area gently with their fingertips.

2 Lymph node biopsy



A biopsy is a test that is done to remove a small tissue sample, in this case from a lymph node, which is an organ of the immune system. A biopsy can be done

a few different ways. Most of the time, a lymph node is safely removed and sent to the lab to check for cancer.

Surgical biopsy

Two kinds are common:

- **Excisional biopsy**: where they take out a whole lymph node
- **Incisional biopsy**: where they take out a small part of the lymph node

Before surgery, you will either be given an injection to numb the area or medicine to make you fall asleep so you don't feel any pain. Then, the surgeon will make a small cut to take out the lymph node(s) they need. The entire surgery usually does not take more than 1 hour, especially if you are not put to sleep.

Needle biopsy

Needle biopsy is where they take out just a small piece of tissue from your lymph node. Surgery is not needed.

• It is not very common to use this method because the needle might not remove enough tissue for an accurate diagnosis.



3 Blood tests



Other signs of lymphoma are low red and white blood cell counts and high levels of different proteins that are produced in response to an infection.

Blood tests can't diagnose lymphoma, but they can show if you have another problem. This is called differential diagnosis, where your provider makes sure you don't have another different disease.

• When you are sick, your immune system reacts by sending out white blood cells to help detect and destroy foreign invaders using antibodies, special chemical signals that attach to cancer cells to mark them for your immune system to destroy.

Bone marrow exam



Bone marrow is inside many bones. It makes red blood cells, white blood cells, and platelets. The bone marrow is also part of the immune system. To

see whether your bone marrow is healthy and working right, your provider may ask for this exam. The exam includes a **bone marrow biopsy** and **aspiration**. The area of your body will be numbed before the needle is put into your bone so you feel less pain.

- Your bone marrow is made up of solid and liquid parts. The biopsy removes a small bit of the solid part; the **aspiration** removes a small bit of the liquid.
- Both of these tests will be done at the same time. This is usually an outpatient procedure, which means you don't need to stay overnight at the hospital.

Sometimes a lumbar puncture, also called a spinal tap, may be done.

5 Imaging tests



Some other tests you might need are CT, MRI, or PET scans. All of these tests take a picture of the inside of your body to see if there is anything

wrong with your lymph nodes or other organs.

Before you get any of these tests, your provider will also need to know about your medical history, your symptoms, possible risk factors, and if you have any other medical conditions. Make sure you have all of this information ready for your appointment.

Where do I go to get tested?

If your provider thinks you might have lymphoma, they will schedule your tests, which are usually done in the hospital. Some tests will need to be sent to a lab before you can get your results.

How long does it take to get my results?

Waiting for your results may take from a few days to a few weeks, depending on the type of test. If your test needs to be sent to an outside lab, such as for a lymph node or bone marrow biopsy, your results may take longer to come back. Your treatment team should be able to tell you when they think your results will come and will keep you updated. Contact your team if your results are taking longer than expected, or if you have a hard time understanding your results.

Your results will be sent to you through MyChart. Your provider will explain what the results mean and any next steps you need to take. Make sure you are signed up for MyChart so that you can receive your results as soon as possible.



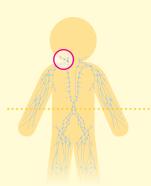
What are the stages of lymphoma and what do they mean?

Once your provider makes a lymphoma diagnosis, the next step is to find out the **stage** of your lymphoma. To do this, your provider will need more tests to see if your lymphoma is small or has begun to spread to other parts of your body. Sometimes lymphoma grows very quickly. Even if you were just diagnosed, you may already be in a later stage.

Lymphomas are grouped based on the "Ann Arbor Staging System." This system determines your stage based on how many organs or lymph nodes are involved (Stage 1–4 or Stage I–IV) and more specific details such as whether you have B symptoms (severe night sweats, unexplained fever, sudden weight loss) and how large your lymphoma has grown.

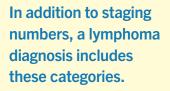
Your Ann Arbor Stage explains where the cancer is inside your body. But the stage **does not predict how effective your treatment will be**, so be sure to discuss this with your provider.

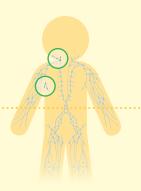
Ann Arbor Staging System



Stage 1 (I)

Your lymphoma is small <u>and</u> only affects one group of lymph nodes <u>or</u> one organ.

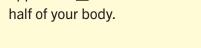




Stage 2 (II)

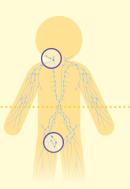
B symptoms

Your lymphoma affects 2 or more groups of lymph nodes and they are located in the upper half or lower half of your body.



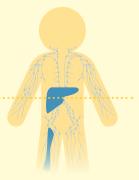
means that you do not show any

- B means you have severe night sweats, unexplained fever, and/or sudden weight loss
- (also called Bulky) means that your lymphoma has grown larger than 10 cm anywhere on your body



Stage 3 (III)

Your lymphoma affects 2 or more groups of lymph nodes and they are located in the both the upper and lower halves of your body.



Stage 4 (IV)

Your lymphoma has spread to areas that aren't part of your lymphatic system, such as your liver or bones.

Understanding your diagnosis can be confusing at first. Ask your care team any questions you have. This can help you feel more in control of your diagnosis and treatment.



What is a lymphoma subtype?

There are many different kinds of Non-Hodgkin lymphoma, which are all called **subtypes**. Subtypes are used to describe more details about your lymphoma. Your care team will help you decide on the **best** treatment for you and your subtype. They can also talk about your subtype with other specialists who may be involved in your care.

One member of your treatment team is a provider called a **hematopathologist** (he-MAT-o-path-ALL-o-jist). This provider can look at your biopsy test results and diagnose your subtype. Once your subtype is known, your care team will decide what treatment is best for you.

There are more than 60 Non-Hodgkin lymphoma subtypes. They are first grouped by what kind of lymphocyte (white blood cell) the lymphoma affects. There are three kinds of lymphocytes and they all play different roles in your immune system:

- **B-cells** (B-lymphocytes): These cells make antibodies when your body detects an infection. Antibodies fight the infection to try to keep you from getting sick.
- **T-cells** (T-lymphocytes): These cells find other cells that have become infected and destroys them. T-cells also send signals to the rest of your immune system to work harder to fight the infection.
- **NK-cells** (Natural killer cells): These cells also destroy infection- and cancer-causing cells.

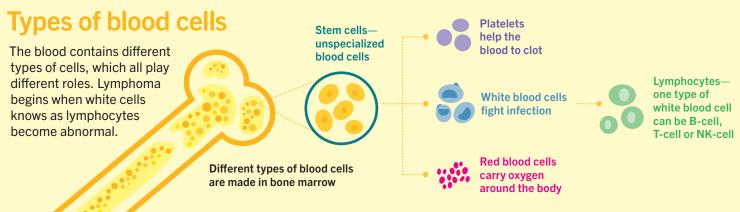
Your lymphoma subtype is then divided into two more categories: aggressive or indolent.

- Aggressive means your lymphoma is growing fast.
- **Indolent** means your lymphoma is growing slower.

What are the most common lymphoma subtypes?

Mature B-cell lymphomas are the most common type of Non-Hodgkin lymphoma; and aggressive (fast-spreading) lymphomas are more common than indolent (slow-spreading) lymphomas. Some common subtypes are:

- **Diffuse large B-cell:** Diffuse large B-cell lymphoma is the most common subtype. It is an aggressive lymphoma and it is more common among older patients (60+).
- Follicular: Follicular lymphoma is an indolent lymphoma. There is no cure for this type of lymphoma. But because it is slow spreading, it is considered a chronic lymphoma. Most patients with follicular lymphoma live for many years after their diagnosis.
- Mantle cell: Mantle cell lymphoma can be aggressive or indolent. This subtype is usually diagnosed at later stages. It is more common among older male patients.





Treatment



Non-Hodgkin lymphoma treatment

After you get your diagnosis, the next step is to discuss your treatment options with your hematologist or oncologist.

This section will go over what to expect when choosing a treatment option, side effects you may experience, how your care team and support system can help you, and how to stay positive during this process.



What are the most common treatments for Non-Hodgkin lymphoma patients?



Chemotherapy

Often called "chemo," this can be either pills taken by mouth or intravenous (IV) medicines or both.



Radiation

Very strong beams of energy used to kill cancer cells



Immunotherapy

Antibodies or other medicines are given through an IV to help the immune system get stronger and fight the lymphoma.

• CAR T-cell therapy is a type of immunotherapy that uses the patients' own T-cells to treat lymphoma. As you learned before, a T-cell is a type of white blood cell that helps your immune system protect you from getting sick. This is done through an IV.

Treatment options continued on page 2

These are not the only treatment options that may be available to you.

Your care team will be able to give you more information on your specific treatment plan: you and your team will decide on it together.





Steroids

Steroids are often added to chemotherapy treatment.



Bone marrow transplant

A procedure to replace damaged or destroyed bone marrow with healthy bone marrow stem cells. Bone marrow is the soft, fatty tissue inside your bones. Stem cells are immature cells in the bone marrow that produce all of your blood cells.

- Allogeneic: This is healthy bone marrow or stem cells from a matched donor that is given to you as a liquid through an IV.
- Autologous: This is your own bone marrow or stem cells, removed, prepared and returned to you as a liquid through an IV.



Stem cell transplant

A similar procedure to replace damaged or destroyed bone marrow with healthy bone marrow stem cells. A stem cell transplant is slightly different from a bone marrow transplant in the way the stem cells are collected. In a stem cell transplant, stem cells from the bone marrow are taken out from the blood through a process called apheresis. The stem cells are then prepared and given as a liquid through an IV.



Watchful waiting

also called "Active surveillance"

For people with very slow-growing lymphomas, their provider may suggest waiting for the lymphoma to grow more before deciding whether or not treatment is needed.

Comparing bone marrow transplants and stem cell transplants

Bone marrow transplant (BMT)	Stem cell transplant (SCT)
Replaces damaged or destroyed stem cells to help you make new blood cells	Replaces damaged or destroyed stem cells to help you make new blood cells
Surgery is needed to take stem cells from the bone marrow and can be painful	Filtering the blood to take out stem cells is not painful
Autologous (self) or allogeneic (donor)	Autologous (self) or allogeneic (donor)
Taken from the bone marrow (aspiration)	Taken from the blood through an IV (apheresis)
	Stem cells can also be taken from a baby's umbilical cord blood, which can be saved after birth



How long will I need treatment?

The length of your treatment depends on your Non-Hodgkin lymphoma subtype, how aggressive your lymphoma is, and how your body responds to treatment.

For example, indolent, slow-growing lymphomas may not need treatment yet. Instead, your provider might recommend "watchful waiting," also known as active surveillance, where you wait for symptoms to occur before beginning treatment.

Each treatment lasts a different amount of time.

On average, this is how long each different treatment option will take:

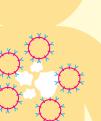
- **Chemotherapy**: Chemo schedules can vary; it can be done daily, weekly or monthly based on your treatment plan.
- **Radiation**: Treatment is about 30 minutes a day, usually 5 days a week for several weeks.
- **Immunotherapy**: The entire therapy may take up to 2 years to keep the cancer from returning.

CAR T-cell therapy: Removing the patient's T-cells from their blood takes 3-4 hours. These T-cells must be changed in a lab so they can kill lymphoma cells, which takes a few weeks. The patient will also get a low dose of chemotherapy. Getting the changed T-cells back takes less than 1 hour. This is a form of immune therapy.

- **Steroids**: Patients may take a dose of steroids for 1 week of their 3-week chemo. They will take steroids 6 to 8 times over the course of their chemo.
- Bone marrow transplant: If either the patient is their own donor, or has a matched donor, the transplant takes about 2-3 hours. The time to recover and for the bone marrow to make healthy cells again takes around 2 weeks, with more complete immune recovery taking about 3 months.
- Stem cell transplant: Stem cell transplants take several hours each day for 3 weeks for allogeneic transplants and around a month for autologous transplants. For autologous (using your own blood) transplants, collecting the stem cells from your blood is done four hours at a time. This can be done every day until enough cells are gathered. It can take up to a year to fully recover from allogenic transplants and around 3 months for autologous transplants.
- **Watchful waiting**: Time depends on the speed of the lymphoma's growth. Some patients wait 3-10 years before needing treatment. Some patients do not need treatment at all.

As you discuss your options with your care team, they will be able to tell you how long they think your treatment will take.

CAR T-cells attack the lymphoma cells



- cancer.gov/publications/dictionaries/ cancer-terms/def/car-t-cell-therapy
- lymphoma.org/aboutlymphoma/ treatments/cartcell/



Common side effects of treatments

What are some side effects I might experience during treatment?

You may experience side effects depending on the kind of treatment you have decided on. Side effects are also different from person to person. Some people may have stronger side effects and others may not have any at all.

See chart for common side effects for each treatment.

Watchful waiting has no side effects. However, it is critical to keep your care team updated with your current health and keep all appointments. You also must let them know as soon as possible if you experience new or worsening symptoms.

Many of these treatments can also have some possible long-term side effects such as:

- Organ damage
- Infertility
- Other cancers
- Weakened immune system
- Depression

Before you start your treatment, your care team will talk with you about the short- and long-term side effects and risks for you. It's also important to remember that even though these side effects sound scary and difficult, your treatment team will help you feel as comfortable as possible during treatment. Whichever treatment you decide on, it is aimed to help you get better. Treatment can be a long and tiring journey, so do not be afraid to reach out for help and support from your care team, family, or friends!

Treatment	Side effects
Chemotherapy	Feeling tiredHair lossEasy bruising or bleedingNauseaInfections
Radiation	 Skin redness and blisters Feeling tired Nausea Diarrhea Hair loss in the treated area
Immunotherapy	 Low white blood cell counts Infections Nausea Feeling tired Constipation
CAR T-cell therapy	 Feeling like you have the flu Shortness of breath Low blood pressure Fast heart rate Shakiness Trouble finding words Infections
Steroid therapy	 Muscle pain Wanting to eat a lot Difficulty sleeping Infections Mood changes
Bone marrow transplant	 Nausea Infections Bleeding Bone marrow rejection Graft-versus-host disease
Watchful waiting	No side effects



How can I manage the side effects from treatment?

The treatment will help you by destroying the lymphoma cancer inside you. Unfortunately, many patients feel ill during the time of treatment. Here are some ways to help with the side effects you may experience:

Nausea and vomiting: Your provider can give you anti-nausea medicines to help with these symptoms. Aromatherapy and/or meditation may also help reduce nausea. Make sure you keep hydrated: call your provider if your mouth feels dry or your urine is dark.

Feeling really tired: Make sure you are getting enough sleep (7-8 hours a night) and rest throughout the day. If needed, your provider can check a blood test and see what you might need. Daily easy exercise, such as walking, may help you feel less tired and can improve sleep at night.

Hair loss: Not everyone loses hair during chemo. But, if you begin to notice your hair falling out, be gentle when washing and brushing your hair. You may want to buy a head covering or wig, especially if your head feels cold. The body can lose a lot of heat from the head. This may matter more in winter months. Some people decide to shave their head, especially in the summer months.

If you are worried or bothered by any of your side effects, let your care team know and they will do everything they can to help you to feel more comfortable.

Keep yourself as healthy as possible.

Infections: During treatment your immune system will be very weak: it will be harder for your body to fight any infection. It is important for you to protect yourself.



Exercise when you can.



Wash your hands often.



Stay away from sick people and crowds. Wear a face mask if you can't physically distance.



Eat a balanced diet of whole (unprocessed) foods.



If you get symptoms of an infection sore throat, diarrhea, muscle aches, fever or chills—call your provider <u>right away</u>.



Treatment Side Effects

Side effects	Why it's happening	What you can do	What your provider can do
Feeling really tired	 Side effects of medications or chemo Chemo can decrease red blood cells, which makes you feel tired. Malnutrition 	 Get enough sleep (7-8 hours a night). Take rests throughout the day. Easy daily exercises may help you feel more energized and can improve sleep at night. 	May order a blood test.
Hair loss	 Cancer treatment targets cancer cells and the normal cells that divide rapidly, like hair cells. New hair will grow after completion of treatment. 	 Be gentle when washing and brushing your hair. Buy a head covering or wig, especially if your head feels cold. Protect scalp from sun/wind, wear sunscreen. 	 Connect you to resources for caps, wigs, scarves. Connect you to support groups or a social worker.
Infections	Your immune system will be weak during treatment, which makes it harder for your body to fight off infections.	 Eat a balanced diet of whole (unprocessed) foods and follow safe food preparation. Exercise when you can. Practice good personal hygiene (bathe 2 times daily, brush your teeth 2 times daily, use mouth wash, wash your hands). Stay away from sick people and crowds. Wear a face mask if you can't physically distance. 	 Treat you for infection. Order blood work and imaging tests to find out the source and type of infection. May prescribe medications to treat the infection. Call immediately if you have a sore throat, diarrhea, muscle aches, fever, or chills.



Side effects	Why it's happening	What you can do	What your provider can do
Trouble swallowing	 Chemo Radiation Lymphoma growth near your throat 	 Eat soft foods and drink liquid supplements. Eat smaller meals more often if you can't eat big meals. Take liquid medicines instead of pills. Use liquid thickeners to prevent choking 	 May schedule a swallow study if you find that you have severe trouble swallowing or feel like you're choking. May switch prescriptions from pills to liquid for easier swallowing.
Sores in mouth	 Chemo Radiation BMT Lymphoma growth near your throat 	 Avoid any alcohol-containing mouthwash. Diet: avoid citrus (acidic) and spicy foods. Rinse your mouth often during the day.with dry mouth oral rinses Try cold therapy: ice chips, frozen foods (popsicles, yogurt, etc.). May need to take medicines to heal mouth sores. Brush your teeth twice a day: soft bristle toothbrush with mild toothpaste or dry mouth toothpaste Floss gently between teeth. Keep lips moist with lip balm. 	 Can prescribe pain medications or special mouth wash that works to heal and prevent sores. If sores are infection, may need a special medicine.
Sore throat	ChemoRadiationBMTLymphoma growth near your throat	 Stay hydrated. Suck on throat lozenges. Gargle with warm salt water (1 tsp salt in 1 cup warm water). 	 Can prescribe pain medications if needed. May order antibiotics if it is an infection.



Side effects	Why it's happening	What you can do	What your provider can do
Losing voice	ChemoRadiationBMTLymphoma growth near your throat	Rest your voice as much as possible.Stay hydrated.Use a humidifier.Do not whisper	 Let your doctor know: if swelling is causing it, they may prescribe steroids or other medicines.
Nausea and vomiting	 Chemo can affect your GI tract. Nausea can also be associated with memories/smells. 	 Stay hydrated during the day. Eat small, frequent meals. Avoid food that is fried, spicy, fatty, or has strong odor. Take anti-nausea meds as prescribed. Aromatherapy and or meditation may also help reduce nausea. 	 Your provider can give you anti-nausea medicines to help with these symptoms. Call your provider if your vomiting does not stop or you become dehydrated (dark-colored pee, dry mouth, dry eyes, headache). Your provider may review/adjust your current medications in case any are causing these symptoms. Your provider may order tests to find out the cause if the vomiting persists.
	Some treatments can slow down the GI tract which can cause constipation.	 Stay hydrated. Add more fiber to your diet (whole grains, fruit, vegetables, beans, etc.). Keep doing light activity/ exercise. 	 Consult with your provider before taking any laxatives or stool softeners if the diet changes do not help. Your provider may review/adjust your current meds in case any are causing these symptoms



Side effects	Why it's happening	What you can do	What your provider can do
Headaches	 Immunotherapy Chemo Lumbar puncture (when a needle is put into your spine to take out fluid for tests) 	 Keep hydrated. Take mild over-the-counter pain relievers approved by your doctor. Rest in a darkened room. Play soothing music. Place a cool, wet washcloth on your forehead. 	 Ask your provider before taking any over-the-counter medicines. Call your provider if your headache gets worse or doesn't stop with rest/prescribed medicines—they may be able to prescribe other treatments and referrals (acupuncture, reflexology).
	 Some cancer treatments can harm nerves. Tumors can press on nerves. 	 Report any new numbness/ tingling, loss of sensation, changes in motor function. Be careful when walking; wear proper shoes. 	 For new or worsening symptoms: may prescribe medication. Cancer treatment may need to be adjusted to lessen symptoms (depends on chemo used). Occupational or physical therapy may be ordered.
*Tingling, pain, burning, numbness, cramps—often in hands/arms and/or feet/legs		This is not a comprehensive list of all side Ask your provider for additional informati any other side effects unique to you.	

Reference for added information:

Olsen, M.M., LeFebrve, K.B., & Brassil, K.J. (2019). Chemo and Immunotherapy Guidelines & Recommendations for Practice. Oncology Nursing Society



What are the pros and cons of each treatment type?

There are different pros and cons to think about when deciding on your treatment options based on your current age, health status, lymphoma type, and lymphoma stage. Your treatment team will talk about these pros and cons with you as you all talk about which treatment will be the best for you.

Pros and cons of each treatment type

Treatment	Pros	Cons
Chemotherapy	 Destroys cancer cells Helps stop the spread of cancer Potentially slows growth of cancer Can be taken as pills or IV 	 Destroys healthy cells too Weakens the immune system Does not guarantee that the cancer is gone forever Sometimes requires hospitalization Higher risk for infection
Radiation	 Destroys cancer cells Slows the growth of cancer Quick and painless treatment 	 Must go to treatment every day for period of time Destroys healthy cells too Does not guarantee that cancer is gone forever Exposure to radiation Can cause other cancers Higher risk for infections May feel sick from side effects
Immunotherapy	 Makes body's immune system stronger to fight cancer Can help prevent getting cancer again Increases body's white blood cells to fight cancer 	 Stronger immune system may also destroy healthy cells Sometimes requires hospitalization May cause severe side effects



Treatment	Pros	Cons
CAR T-cell therapy	 Higher success rates than other treatments for disease resistant to chemotherapy Makes body's immune system directed to fight cancer Do not have to be in remission to receive therapy May be more successful in treating relapsed patients 	 More expensive Stronger immune system may also destroy health cells Must stay in the hospital afterwards for side effect monitoring Side effects are numerous and different from the therapies listed above
Steroid therapy	 Destroys lymphoma cells Slows the growth of cancer Increases effectiveness of chemotherapy while decreasing side effects Increases appetite, may help the body stay energized and get stronger 	 Higher risk of infections and other health issues like high blood pressure, high blood sugar, muscle and bone weakness, mood swings Certain vaccines may be less effective while on steroids
Bone marrow or stem cell transplant	 Healthy bone marrow or stem cells are given through an IV Helps body's immune system fight cancer Helps with high-dose chemotherapy Works well with physically fit patients and patients with relapsed lymphoma 	 Must be in the hospital for treatment Patients with other major health problems may not be eligible Can cause severe side effects Risk of rejection of transplant, if from a donor
Active surveillance ("watchful waiting")	 Must check in with provider often Determines the stage of lymphoma Helps to plan for treatment 	 Does not stop the spread of cancer cells Can take away time from daily routine



Getting to know your care team & support system

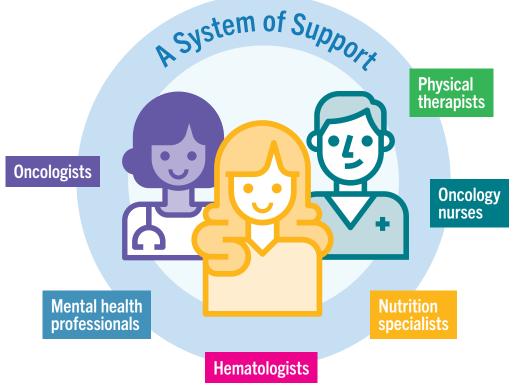
Who is part of my treatment team?

Your UCLA treatment team is a group of **lymphoma specialists**, **oncologists** and **hematologists** who treat cancers of the blood and lymphatic system (lymph).

The team will coordinate your treatment and follow-up care with you. Depending on your treatment, your team may also include:

Your primary care provider (PCP) may not be a cancer specialist so they will work with a **hematologist-oncologist specialist** to care for you and treat your cancer.

- · Oncology nurse
- Oncologist
- Specialty care providers
- Mental health providers
- · Physical therapist
- Nutritionist/dietician





What does each team member do?

Oncologists

Oncologists are providers who specialize in treating solid tumors and cancer.



Medical oncologists

Medical oncologists specialize in treating cancers using drugs, especially chemotherapy.

A medical specialist (**oncologist or hematologist**) usually leads the treatment team.

Neuro-oncologists specialize in cancers of the nervous system (nerves, brain, and spinal cord).



Radiation oncologists

Radiation oncologists treat cancers with radiation.



Surgical oncologists

Surgical oncologists are on your treatment team if you need surgery or a biopsy (removal of a small tissue sample to test your cancer type).



Hematologists

Hematologists are providers who specialize in treating blood diseases. They are in charge of finding what type of lymphoma you have and deciding on the best treatment for you.



Oncology nurses

Oncology nurses are registered nurses (RNs) who are trained to care for people with cancer. The RN will help you learn about the treatment process, side effects, and medicines you may need to take. Some work in the clinic with your provider. Some work mainly in the hospital.



Mental health professionals

Mental health professionals can help you stay positive, keep calm, and stay motivated during treatment.



Physical therapists

Physical therapists can help you restore strength after treatments that make you feel tired and weak.



Nutrition specialists

Nutrition specialists (dieticians or nutritionists) will work with you to help you maintain a healthy weight, keep your body strong with nutritious foods, and make sure you get enough of the right vitamins and minerals during treatment.

Other specialized providers

Since lymphoma can affect other parts of your body, other **specialized providers** may be on your team. Common ones are:

- Dermatologists: who care for skin problems
- Neurologists: who focus on the nervous system



How can I communicate effectively with my team?

Communication with your team is crucial. You need to know your care plan and understand your treatment. You also need to let your team know how you feel about the care you are getting or if you are having a difficult time with your treatment. Your team can support you and adjust to make sure you get the right care for yourself.

Here are some tips to help you communicate the best with your team:

- **Use a health calendar** to help you stay organized. It can help you track upcoming appointments, exams, and anything else to keep you on top of your treatment plan.
- Make a list of questions before your visit(s) about your lab results, diagnosis, treatment, or anything else. Your team is here to help you throughout your journey. It's okay to ask your team to slow down while explaining things or try to explain things differently.
- If you are having trouble asking your care team questions or understanding their answers, ask your caregiver, a friend or family member to come with you to your appointments.
 They can help you ask the questions and write down the answers if that helps.
- It's okay to take notes and ask questions during your visits with members of your care team. You can even ask if you can record your visit to listen again later.
- Keep your team updated with your personal information and let them know if your insurance, medical, or contact information changes.

How do I stay positive during treatment?

Lymphoma treatment can be a long, difficult process that may make you feel sad and frustrated at times. It is normal to feel this way, but it is important to remember that you are not alone. There are people and resources that are here to support you in this journey.

Here are a few tips to help you stay positive:

- Surround yourself with positivity. Your family and select friends are here to support you every step of the way. Look to them for encouragement!
- Empower yourself by being informed. Ask your treatment team questions and research things on your own to learn about lymphoma. Being informed can help you feel more in control of your diagnosis.
- Keep doing what you love. At times, you may feel too tired or sick to do your regular hobbies. Modify your activities to meet your limits or find new hobbies that you can do without wearing yourself out. Hobbies are also a great way to relax and calm your mind.
- Find a support group: At UCLA, the Simms
 Manns Center offers group activities and
 therapy for patients and their loved ones to help
 cope with anxiety and with the challenges that
 come with cancer care.
- **Help someone else**. Your participation in a support group can also help other people and this can be very rewarding.
- verywellhealth.com/how-to-keep-a-positiveattitude-with-cancer-2248819
- simmsmanncenter.ucla.edu



My health calendar	Month:	Year:
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Sun	Mon	Tues	Wed	Thurs	Fri	Sat

Questions & notes:	



Recovery



Non-Hodgkin lymphoma recovery & remission

Most patients diagnosed with classical Hodgkin lymphoma are cured in one treatment. However, some people, especially with advanced-stage lymphoma, may see their lymphoma come back. This section explains what to do if your lymphoma does come back, and also gives helpful tips on how to stay healthy and gain energy back after treatment.

Caregiving

What is a caregiver and what do they do?

A caregiver is someone who can support you during your treatment and recovery. A caregiver can make things easier for you so you can focus on your health. A caregiver can help in a lot of ways such as:

- Encourage and support you on this journey to recovery.
- Drive you or go with you to your medical appointments.
- Monitor you while you exercise.
- Help you with shopping, cooking, cleaning, and other household chores.
- Remind you to take your medicines.
- Help you bathe, dress, and eat if you need it.
- Monitor you day-to-day for any changes, signs, or symptoms that need to be reported to your provider.

Caregiver services



Medication reminder



Escort services







House keeping





Check-in and visit



Meal prep and groceries



Night surveillance



How do I choose a caregiver?

Many people find a family member or very close friend to be their caregiver. Your caregiver should be someone you like being around, trustworthy, attentive, and organized.

Your caregiver must be able to take care of themselves as well. If they work outside the home, they must make plans with their work so they can have flexible work hours to care for you.

They should also find out their options regarding:

- Family and Medical Leave Act (FMLA)
- Sick time
- Vacation time
- Paid Family Leave

What if my caregiver changes?

If you need to find a new caregiver, do not take shortcuts and do not decide until you are ready. Carefully think about who can take over the role and choose someone you trust to be a good caregiver. It's also a good idea to have a backup caregiver, so you don't have to worry about needing to find a replacement at a moment's notice.

What support services are there for caregivers?

Caregiving is a big responsibility and it can be overwhelming for some people. Finding a caregiver support group can help both you and your caregiver manage their feelings during this time. It's a good idea for a caregiver to get involved in a support group right from the start, so they don't feel so overwhelmed. Groups like Simms/Mann UCLA Center for Integrative Oncology offers meaningful support for caregivers through both individual supportive counseling and support groups.

Examples of services for caregivers support groups:

- Caregiver support websites
- Caregiving guides
- Cardiopulmonary resuscitation (CPR) and basic life support training
- Please provide links

These resources can help your caregiver feel more confident about their role, which will not only help them, but you as well.





Nutrition

What is malnutrition and why is it a problem for lymphoma patients?

Malnutrition happens when your body isn't getting the right amount of energy from food. It happens when you are not eating enough, are unable to eat, or you are not eating the right things in the right amounts. Malnutrition can affect how your body reacts to certain medicines, and this can make you feel even worse.

Some lymphoma patients experience malnutrition because of their illness or their cancer treatments. Side effects can cause you to:

- Have trouble keeping food down
- Feel sick to your stomach
- Feel too tired to eat
- Have diarrhea
- Have mouth pain

If you are struggling with eating, let your care team know so they can help.

Healthy eating plate vegetables whole grains healthy oils healthy proteins

How can I prevent malnutrition?

Members of your care team or your caregiver can help you prevent malnutrition by doing a few things.

- Eat healthy foods you enjoy.
- Eat foods high in iron—your dietitian can help you find these foods. Examples include: dark leafy greens like spinach, kale, chard.
- Eat foods high in protein—like lean meats, fish, eggs, yogurt, cheese, milk, beans, nut butters.
- Add unflavored protein powder to hot cereals, yogurt, soups, pancakes, or other foods for extra protein in your diet.
- Eat healthy fats (olive oil, avocados, nuts). Avoid lard, butter, and hydrogenated fats (shortening).
- Limit the amount of sugar in your diet. Avoid candy and sugary drinks.
- If it's hard to eat a big meal, eat small healthy snacks throughout the day. Try 6-7 small meals/ snacks a day instead of 3 big meals.
- Ask your provider if they are able to provide you antiemetics to prevent vomiting and nausea.
- Drink enough water and other drinks without caffeine. Try an electrolyte replacement like Pedialyte, Gatorade, or hydration mixes such as Liquid IV once a day.
- Work with your dietitian to create healthy and enjoyable meal plans.
- If possible, have your caregiver make your meals or snacks and encourage you to eat. If you feel sick to your stomach, try to stay away from the kitchen while food is prepared.
- Sometimes, it is easier to drink your nutrition.

 Try a protein smoothie that you can make at home with Greek yogurt, banana or other fruit, any kind of milk, nut butter and protein powder. Frozen fruits are great in smoothies. You can also buy premade protein shakes like Orgain® to drink as a snack anytime.



What food safety steps do I need to be mindful of?

During your treatment for lymphoma, you are at higher risk of getting sick from food poisoning. Some foods can easily go bad or are more likely to cause food poisoning, which can make you very sick. For this reason, you should **avoid**:

- Raw and rare meat and fish
- Raw eggs
- Raw or unpasteurized juice, milk or cheese
- "Moldy" cheeses like gorgonzola or blue cheese
- Raw sprouts and unwashed fruits and vegetables
- Water that is not from a filtered tap or bottled water
- Buffets, potlucks, food stands, picnics, and other high-risk places

When preparing food, to avoid food poisoning, follow these general safety tips:

- Wash your hands with soap and water for 20 seconds before making food and again before eating.
- Store your groceries and leftovers at the correct temperature.
- Do not thaw frozen meat at room temperature.

 Thaw meats in the microwave or in the refrigerator.
- Wash all fruits and vegetables before eating them.
- Throw away any food that has gone moldy or has a bad smell.
- Be careful of "cross-contamination." Keep a separate cutting board for raw meats vs. vegetables or fruits. Clean and disinfect them after each use; and rinse.
- Clean and disinfect cooking areas and cutting boards before and after use.
- Disinfect hard surfaces using 1 tsp liquid bleach in 1 cup of water.
- Do not eat with the same utensils you cooked with.

 Wash your kitchen tools with warm water and soap, especially after cooking raw meat.

Ask your dietitian, nutritionist, or care team for more food safety tips and a list of foods and drinks to avoid.

If you think you might have food poisoning, call your care team right away.

Most food poisoning is not very serious and symptoms go away after a few days. However, because cancer makes your immune system weaker, food poisoning can become very serious or even life-threatening for you. Early treatment is vital.

For more information on food safety and nutrition tips:

cancer.net/survivorship/healthy-living/foodsafety-during-and-after-cancer-treatment

cancer.org/treatment/survivorship-during-andafter-treatment/staying-active/nutrition/ weak-immune-system.html

Can I take supplements and vitamins?

Talk to your provider <u>before</u> taking <u>any</u> vitamins or supplements. Some supplements may not mix well with the medicines you are taking, and they can interfere with your treatment.

For example, during treatment, it is best to avoid high doses of antioxidants in amounts above what a multivitamin contains. Common antioxidants are vitamins A, C, and E.

And even if you have been taking vitamins and supplements before your diagnosis, let your care team know everything you are taking. You may be asked to bring your supplements to a visit. Always let them know before you make any changes to your health routine.



Relapse & remission

What does it mean to have refractory lymphoma?

Refractory lymphoma means your lymphoma is still growing or did not go away after treatment. Refractory and relapsed lymphoma are called **resistant** lymphoma. However, just because your cancer did not respond to one treatment does not mean other treatments may also not work. Refractory lymphoma is different from relapsed lymphoma, but are often considered together as resistant lymphoma.

What does it mean to have relapsed lymphoma?

Relapsed lymphoma is a lymphoma that comes back after successful treatment and a period of remission. You might have relapsed lymphoma following complete or partial remission. This can happen if a small amount of lymphoma remains in your body after treatment and then gradually regrows. This small number of lymphoma cells may not be detected on tests.

What is the possibility of relapsing?

Following treatment, you may be in remission, which means that all signs of lymphoma are gone. It's important to know that remission doesn't mean that you are cured.

- **Partial remission**—your lymphoma responded to treatment but didn't completely go away.
- **Complete remission**—there's no evidence of lymphoma in blood tests or scans after treatment. If you are in complete remission for more than 5 years, then your provider may say you are "cured."

We understand that you may worry about your cancer coming back.

Even after treatment, it's important to go for all regular follow-ups with your provider and continue to take care of yourself. Your provider will help monitor you and your health to determine whether more treatment is needed and keep track of long-term effects from treatment.

Most lymphoma patients who go into remission will not have lymphoma relapse.

However, some types of lymphoma are more likely to relapse, such as **mantle cell lymphoma** and **many types of T-cell lymphoma**. It's more likely for relapse to occur the first two years after remission. The more time that passes after treatment, the more likely the lymphoma will stay in remission.

During remission, it is important to contact your medical team if you have any of the following symptoms:

- Enlarged lymph nodes for more than a week
- Unexplained pain that doesn't go away for a long time
- Unexplained and fast weight loss
- Feeling very tired
- Night sweats for more than a few weeks
- Itching
- Diarrhea

They will run tests on you again to check if your lymphoma has come back.



What treatment or lifestyle choices are available to help prevent relapse?

No lifestyle choice can prevent cancer from relapsing, but good decisions can help keep your immune system strong.

Eat a healthy diet of nutritious foods such as vegetables, fruits, and whole grains. Limit your intake of red meat, processed meats, refined grains, sugars, and sugary beverages. Talk to a UCLA dietician if you would like more information on how to stick to a healthy diet.

Some vitamins or other dietary supplements may be needed if your vitamin levels are low on blood tests, but make sure you talk to your provider before starting to take any of them, especially if you are taking medicines during remission. Some ingredients in supplements may react badly with your medicines.

It's also important to take part in regular physical activity. Regular physical activity reduces depression, symptoms of fatigue, pain, and nausea. It also improves mood and self-esteem.

What happens if the cancer comes back?

If the cancer relapses, more blood tests and scans will be needed for providers to determine the right treatment for you. Your medical team will work hard to provide you with the best treatment.

This might include drugs, radiotherapy, a different chemotherapy regimen, or a stem cell transplant. Even if you experience more than one relapse, there are treatment options available. Your hematologist or oncologist can answer any questions you may have.

What does it mean to be in remission?

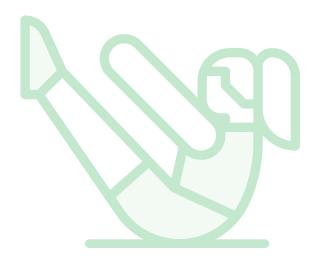
Remission is the time after treatment when your lymphoma is either completely gone and is no longer detected on tests (complete remission) or mostly gone (partial remission).

During remission, keep all regular visits with your provider(s). They may do blood tests and scans to make sure your lymphoma hasn't come back or gotten worse.

If your lymphoma relapses or comes back, you will receive the treatment you need. You may enter remission more than once.

It is important to stay positive and take care of your health through exercise and good nutrition. Talk to your care provider right away if you think you have a symptom that might mean return of your lymphoma.

For more information on relapse see the "Can lymphoma relapse?" section in the module.





How can I be empowered during remission?

Empowerment is having the knowledge, confidence, means, or ability to do things or make decisions for yourself. You can be empowered by taking control of your recovery and learning all you can about your lymphoma and how to fight it.



Talk with your provider about your fears and concerns. Your care team is working with you and for you.



Take notes during appointments and keep track of your care plan.



Make sure to schedule and attend all follow-up visits and routine screening.



Continue to go to all of your medical appointments.



Ask your team questions. Speak up when you have a question or feel unsure about something.



Sign up for MyChart so you can message your providers and see your test results online.

What medical visits will I have during remission?

You'll continue to meet with your oncologist, but you may need to meet with them less often as time goes on. Your appointment schedule will be unique to you, but you can expect an average appointment routine like the following:

- Meet with your oncologist every 2 to 6 months starting 1 to 2 years after achieving remission.
- Meet with your oncologist every 6 to 12 months starting 3 to 5 years after achieving remission.
- Meet with your oncologist annually starting
 5 years after achieving remission.

During medical visits, your care provider may run more lab tests and scans. This is done to check your health and to make sure your lymphoma hasn't returned.

What warning signs should I continue to watch for?

It's important to talk with your care provider if you feel unwell, if you feel something may be wrong, or if you are experiencing any symptoms. Let your provider know if you have:

- An enlarged lymph node for more than a week
- Unexplained and fast weight loss
- Night sweats for over a few weeks
- Diarrhea
- Worsening tiredness
- Constant and unexplained pain
- Trouble keeping food down
- Low energy
- Possible feelings of depression or low motivation



Where do I find psychosocial support?

Your mental health is just as important as your physical health. Being diagnosed with cancer and going through the treatment can be very difficult and scary.

To help deal with any negative emotions, here are a few ways to feel empowered and supported:



Take control of your treatment

There are many uncertainties with lymphoma that may make you feel anxious, scared, and powerless. Before your appointments, do your own research at home and bring a list of questions that your provider can answer. Learning more about your diagnosis can feel empowering. In addition, your road to recovery is a team effort! Your voice matters when deciding on your treatment plan.



Talk to your friends and family

Cancer is the major life-changing experience. But you do not have to go through it alone. By talking with your family and select friends, you create a support system you can rely on as you get treatment.



Seek support services

Asking for help is a sign of strength, not a sign of weakness. You can find support by talking to your loved ones or joining an online or in-person support group. You can also consider individual counseling where you meet with a counselor one-on-one. Or join group counseling where you participate in a counseling session with people also battling lymphoma.