



Low-Grade Lymphoma Cancer Care



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Specialized Doctors and Personalized Care

Learning you have cancer can feel overwhelming. Your life suddenly changes and a cascade of emotions often follows, affecting you and your loved ones. You will likely have many questions as well. Your Kaiser Permanente cancer care team will provide you with the guidance, treatment, and support you need.

This booklet contains information about **low-grade lymphoma**. It explains what to expect and how your care team will work with you to make your treatment as comfortable and successful as possible.

Your care team includes skilled specialists who perform thousands of cancer treatments

every year. Our advanced equipment and techniques ensure that you receive the most current and highest quality care available.

We welcome your questions and encourage you and your family to talk with your care team about any concerns. We're here to help.



Your Kaiser Permanente Cancer Care Team

A team of physicians and other health professionals will provide you with the best care and treatment possible. Our physicians are specialists from different fields, such as radiology, oncology, and surgery. They work together to create a treatment plan specifically for you.

Your care team will meet with you to:

- Explain the details of your diagnosis.
- Discuss your treatment options.
- Help you make decisions and prepare for treatment.

Having a care team is like getting a second, third, and fourth opinion right from the start.

We hope you'll feel comfortable with all members of your care team. Let us know if you have questions or concerns.



Note to loved ones

Having a family member or friend go through this type of care may affect you too. At Kaiser Permanente, we'll provide you with resources to help.



Physicians may include:

- **Medical Oncologist:** A doctor who specializes in treating cancer with drugs, such as chemotherapy, targeted therapy, and immunotherapy.
- **Radiation Oncologist:** A doctor who specializes in the use of radiation to treat cancer.
- **Interventional Radiologist:** A doctor who specializes in image-guided procedures to treat and diagnose diseases, such as CT-guided biopsies of other areas affected by low-grade lymphoma.

Other health care professionals may include:

- **Oncology Nurse:** A nurse who specializes in caring for people who have cancer.
- **Physician's Assistant:** A health professional who practices medicine under the supervision of a physician and is often a member of the low-grade lymphoma care team.
- **Social Worker:** A health professional trained to talk with people and their families about emotional or physical needs, and to find them support services.
- **Registered Dietician:** A health professional with special training in the use of diet and nutrition to keep the body healthy.
- **Patient Care Coordinator or Discharge Planner:** A health professional who coordinates discharge from the hospital and makes sure you have the equipment and care you need at home.

You can use this table to keep track of the names and contact information for your care team so you have it all in one place.

PHYSICIAN	NAME	CONTACT INFORMATION
Primary Care Doctor		
Medical Oncologist		
Radiation Oncologist		
Surgeon		
Medical Center		Daytime: After Hours:
Other		



Your cancer care team may include physicians and other health professionals from different specialties. This team works together to provide the best care for you.

My Doctor Online app

Download our My Doctor Online app for free from the App Store or from Google Play to help you manage your care, including:



- Getting reminders and details of upcoming appointments.
- Emailing your doctor with nonurgent messages.
- Calling our 24/7 Appointment and Advice line.
- Finding maps and directions to Kaiser Permanente medical centers and medical office facilities.

Learning about Low-Grade Lymphoma

Lymphoma is a cancer that forms in the lymph system. It affects white blood cells (lymphocytes) found in your:

- **Lymph nodes**, small bean-like organs that filter impurities.
- **Spleen**, an organ in your abdomen that filters blood and is part of your immune system.
- **Other organs**, which are part of your immune system.

The immune system usually protects your body from infection.

Lymphoma that grows slowly is called low-grade lymphoma. You might also hear it referred to as non-Hodgkin lymphoma or indolent lymphoma. It most often begins in a white blood cell called B lymphocyte (B-cell). B-cells are lymphocytes that mature in the bone marrow.

Low-grade lymphoma can also start in T lymphocytes (T-cells). T-cells mature in the thymus, which is why they are called “T” cells.

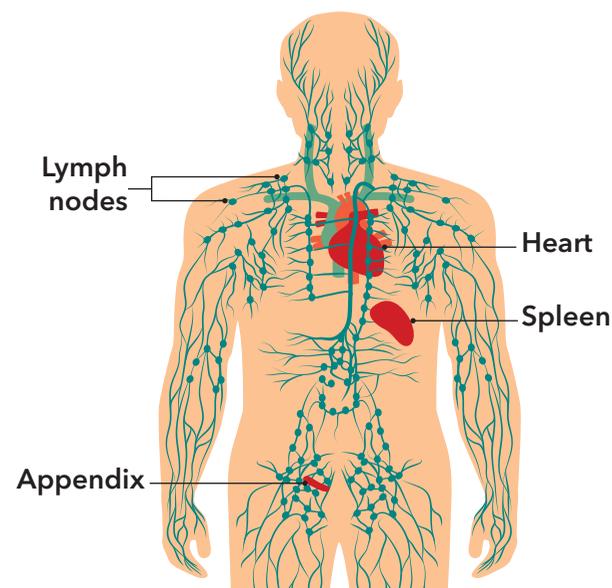
Because low-grade lymphomas grow slowly, some types may not require treatment for years. If you don't need immediate treatment,

we'll regularly monitor you for signs that the disease is progressing. This continued monitoring is called active surveillance or watchful waiting.

Some lymphomas can be cured. Even when not curable, low-grade lymphoma is treatable. You can live for many years with treatment.

When treatment is needed, it may include chemotherapy, radiation therapy, and other methods. Chemotherapy can cure certain types of low-grade lymphoma.

We know being diagnosed with cancer is overwhelming. We're here to provide you with the best treatment and support available.



Types of Low-Grade Lymphoma

There are many types of low-grade lymphoma. The following are a few examples.

Follicular lymphoma is the most common type. It's slow-growing and begins in B lymphocytes. It affects the lymph nodes but might also spread to the spleen or bone marrow. You may not need treatment right away, only monitoring. While it's not curable, you can live for many years with treatment.

Cutaneous T-cell lymphoma (mycosis fungoides) is less common. It's found in the skin and can cause a patchy, scaly, itchy red rash and sometimes solid, raised tumors (plaques).

Anaplastic T-cell lymphoma isn't common. It's aggressive but can be cured. It can appear in the skin, lymph nodes, or organs throughout your body. It may cause skin lesions that might itch.

Mucosa-associated lymphoid tissue (MALT) lymphoma usually develops in the stomach. It can be linked to infection by *H. pylori* bacteria.



Diagnosing Low-Grade Lymphoma

We use information gathered from diagnostic tests to determine the size and spread of your cancer. This information helps us stage the cancer and identify the best treatment plan for you.

We check for swollen lymph nodes and enlarged internal organs, such as the spleen. We may recommend the partial or full removal (biopsy) of a lymph node to check for cancer cells. If cancer is found, additional tests are used to identify the type of low-grade lymphoma.

We also recommend one or more of the following tests:

- **Blood tests**, to see if your blood cells and kidney and liver functions are normal.
- **Imaging tests**, such as chest X-rays, CT scans, or PET scans, to identify enlarged lymph nodes and organs.
- **Bone marrow biopsy**, to see if the cancer has spread to bone marrow. We remove fluid and tissue samples from your hip or pelvic bone.



Staging Low-Grade Lymphoma

Your care team will use staging to determine how far the cancer has spread. Your treatment is based on the stage of the cancer.

The stages of low-grade lymphoma are:

- **Stage I** The cancer affects a specific lymph node area (such as under the arm), or a single area of a tissue or organ (such as the spleen or lung).
- **Stage II** The cancer affects 2 or more lymph node areas on the same side of the muscle used during breathing (diaphragm), or 1 organ and nearby lymph nodes.
- **Stage III** This stage means the lymphoma is found in lymph node areas on both sides of the diaphragm, and possibly the spleen or an organ outside the lymphatic system (such as the liver, lungs, or both).
- **Stage IV** This stage means the lymphoma has spread to other organs or tissues (such as the liver, lungs, or bone marrow).

We also consider the size of the tumor and if you have “B symptoms,” which include:

- Night sweats
- Unexplained weight loss
- Fever
- Fatigue



Choosing Treatment That's Right for You

Treatment of low-grade lymphoma depends on the type. After we learn everything we can about your cancer, we'll talk about the treatment options and develop a plan that's right for you.

A slow-growing lymphoma may not require immediate treatment. We'll continue to monitor you for signs that it's growing.

Some types of low-grade lymphoma can be cured. The primary treatment is chemotherapy, radiation therapy, or both. Surgery isn't usually considered.

Treatments

Follicular lymphoma may not need to be treated right away, just monitored. While it's not curable, you can live for many years with treatment. Active treatment may include radiation therapy, chemotherapy, or other treatment options.

Cutaneous T-cell lymphoma (mycosis fungoides) treatment options usually include:

- Topical chemotherapy
- Phototherapy
- Biologic drugs
- Systemic chemotherapy
- Radiation

Anaplastic T-cell lymphoma is aggressive but can be cured with a combination of 4 chemotherapy drugs (called CHOP).

Mucosa-associated lymphoid tissue (MALT) lymphoma can be cured with antibiotics or radiation to the stomach. Treatment depends on where the lymphoma appears.



Questions to ask your care team

What are my treatment options?

What are the risks and possible side effects of each treatment?

What can I do to prepare for treatment?

Will I need to stay in the hospital? If so, how long?

Chemotherapy

Chemotherapy uses drugs to kill cancer cells. It's usually given through intravenous (IV) infusion or sometimes as a pill. You may receive a combination of different types of chemotherapy drugs.

Chemotherapy is treatment that:

- Circulates throughout your entire body (systemic).
- Can destroy cancer cells that travel outside the lymphatic system.

Chemotherapy is given in cycles. The number of cycles you have depends on the type and stage of your low-grade lymphoma. You'll receive treatment and then have a rest period so your body has time to recover.

Low-grade lymphoma usually responds well to chemotherapy.

Chemotherapy side effects

Chemotherapy targets cells that grow and multiply rapidly, such as cancer cells. It can also affect normal cells that happen to quickly grow and divide, which can cause side effects. The severity depends on the type and dose of the drug and the length of time it's given.

You may experience one or more of these common side effects of chemotherapy:

- Hair loss
- Nausea and vomiting
- Loss of appetite
- Mouth sores
- Diarrhea
- Fatigue
- Low blood cell counts

We can help you manage side effects. Most usually go away when treatment ends, although it may take some time.

Radiation Therapy

Radiation therapy uses high-energy radiation, such as X-rays, to kill cancer cells. The most common type delivers radiation from a machine outside the body (external-beam radiation therapy).

We may recommend radiation therapy for certain types and stages of low-grade lymphoma. It might also be used:

- Along with chemotherapy.
- After you have several cycles of chemotherapy.
- To control cancer pain when low-grade lymphoma isn't curable.

Radiation therapy side effects

Radiation side effects depend on the area treated but may include:

- Skin changes, such as redness and dryness
- Fatigue
- Hair loss
- Nausea and vomiting
- Bowel discomfort or diarrhea
- Dry, sore mouth, loss of taste, and difficulty swallowing
- Tooth decay

Side effects are usually worse with high doses of radiation therapy or when it's given at the same time as chemotherapy. They usually go away after treatment ends.

Let us know if you develop side effects. We can help manage them so they don't interfere with your quality of life.



Self-Care for Managing Side Effects

Your cancer care team is with you every step of the way. We'll suggest ways to control any treatment side effects that you may experience. Remember, these usually go away after treatment ends, although it may take a little time.

To reduce fatigue:

- Get plenty of rest.
- Try light exercise every day.
- Use relaxation techniques like deep breathing or a simple meditation before bed to help you sleep better.

To control stomach problems:

- Drink plenty of water.
- Have someone else cook for you if preparing meals makes you feel ill.
- Eat bland foods (bananas, rice, or toast) to control diarrhea.
- Eat high-fiber foods (bran or fruit) to limit constipation.
- Eat small meals or snacks throughout the day, instead of 3 meals a day.
- Take medications for nausea.

To care for hair, skin, or mouth problems:

- Brush your teeth with a soft toothbrush after each meal.
- Rinse your mouth with half a teaspoon of salt or baking soda mixed in a glass of water.
- Use mild soaps when bathing.
- Apply thick lotions or creams daily over your entire body to keep the skin moist.
- Avoid using products on the skin, including aloe gel or lotion, that contain alcohol.
- Take short (5 to 10 minute) low-temperature showers.
- Pat your skin dry, instead of rubbing. Avoid using washcloths.
- Protect your scalp by wearing sunscreen or a hat if you're losing hair. Hair usually grows back.

To reduce the risk of infection:

- Wash your hands often.
- Avoid contact with people who are currently sick, such as with a cold or flu.

Your Life, Your Way

We encourage you to live your life as normally as you can during treatment. It can help to stick to regular routines and continue doing things you enjoy as much as possible. After treatment ends and you've had time to recover and get stronger, it will be time to move forward with your life.

Some ways to help maintain control over your life are to:

- Communicate what you feel and ask for what you need.
- Keep a diary of treatments, medications, and side effects.
- Bring family or friends with you to appointments to help keep track of details. This can help them as well.
- Write down questions for your doctor and care team so you won't forget to ask them.
- Let your care team know about symptoms or problems—whether you're feeling better or worse, good or bad. They can respond when they know what's happening in your life.



Our commitment to you continues after treatment.

This includes follow-up, rehabilitation, and survivorship support services.

Support at Every Step

Many aspects of your life may change after your diagnosis. People around you will also be concerned about your well-being. This can trigger a lot of different emotions.

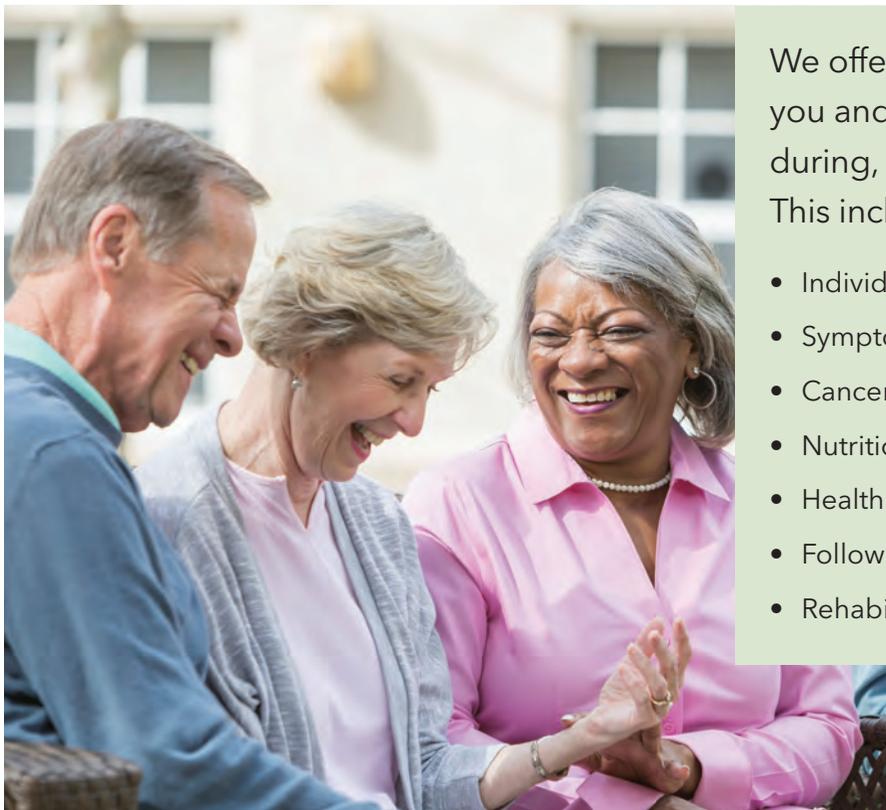
For many people, reaching out to cancer survivors with similar experiences can be helpful. They can offer encouragement and understanding. It may help to know that others get through this even though it can be tough.

Recovering from major surgery and cancer treatment can be both physically and emotionally difficult. It's common to feel anxious or even depressed after your treatment. You may have trouble sleeping and eating. This is normal.

We encourage you to share and discuss your emotions with those around you and with your care team. Kaiser Permanente also offers support services, including counseling, support groups, and psychiatric care.

Let us know how you're feeling. Your care team can respond to any symptoms or problems you may have.

Remember, we are here to support you in every way we can for as long as you need us.



We offer complete care for you and your family before, during, and after treatment. This includes:

- Individual counseling
- Symptom management
- Cancer support groups
- Nutrition counseling
- Health education classes
- Follow-up services
- Rehabilitation

Clinical Trials

Clinical trials are research studies that involve cancer patients. They discover new ways to prevent, detect, diagnose, or treat cancer. Those who take part in clinical trials have an opportunity to contribute to our greater knowledge about cancer, and to help in the development of improved cancer prevention and treatments.

Kaiser Permanente is nationally recognized as a leading research organization. We are part of the **National Cancer Institute (NCI) Community Oncology Research Program**.

We participate in more than 70 clinical trials available to patients at any given time. Because of this, our patients have access to cutting edge treatment options and research.

We believe it's important for you to understand all of your treatment options, including being part of a clinical trial. If you're interested, talk with your cancer care team.



Kaiser Permanente Resources

Member Services Department

Member Services will help answer your questions and obtain the services or assistance you may need related to:

- Health plan benefits, premiums, and copay explanations
- Your enrollment status
- Registration on kp.org (so you can email your doctor or view visit summaries)
- Getting or replacing a member ID card
- Advance Health Care Directives and Durable Powers of Attorney
- Health plan coverage while traveling
- Information about health plan documents

You can offer suggestions or convey concerns to Member Services in person at your medical center, online, or by phone:

- Member Services Call Center: (800) 464-4000
- Senior Advantage and Medicare: (800) 443-0815

Insurance and Employment

You may be concerned about how your treatments may affect your job and insurance status. Your care team will work with you to manage any side effects and minimize their impact on your normal schedule.

You may still need to change your regular work hours or take time off work to recover from treatments. If this happens, your care team social worker can connect you to insurance and employment resources to help manage changes. Ask your social worker for further information about California and federal regulations and programs, such as:

- State Disability Insurance (SDI)
- California Paid Family Leave Program
- Federal Family and Medical Leave Act (FMLA)

Release of Medical Information (ROMI) Department

You may need to send part of your Kaiser Permanente (KP) medical record to another organization. For example, Kaiser Permanente members applying for disability insurance through the California Employment Development Department (EDD) may request copies of medical records to support their application. We only release medical information by request of the patient. Only members or their legal agent may authorize release of medical information.

To obtain information from your Kaiser Permanente medical record, your care team can direct you to the Release of Medical Information Department (ROMI), which will help you complete the necessary documentation.

If you need to forward medical information from a non-Kaiser Permanente physician to KP, you can ask your non-Kaiser Permanente provider to send the information directly to your Kaiser Permanente primary doctor (not to ROMI). Your Kaiser Permanente primary doctor will review outside medical records before including the information to your file.

If you are seeking medically related time off from work or applying for Family Medical Leave (FMLA), you do not need to request a form from ROMI. Instead, ask for “Work Status Activity Forms” from your doctor.



Financial Services Department

If you have concerns or questions about medical bills, payments, refunds, or need financial assistance during or after a hospital stay, you can contact a Patient Financial Advisor in the Financial Services Department.

Financial Services is also responsible for billing all non-Kaiser Permanente plans on a patient’s behalf, including Medicare, Medi-Cal, Third Party Liability (TPL), Coordination of Benefits (COB), Health Maintenance Organization (HMO), and secondary insurance companies.

Patient Financial Advisors are available to answer questions about alternative payment needs or to help locate resources and assist during and after a hospital stay. You can ask your care team or social worker about the best way to contact an Advisor at your facility.

Additional Resources

- **Kaiser Permanente Cancer Care**
kp.org/mydoctor/cancer
- **American Cancer Society**
cancer.org
- **National Cancer Institute**
cancer.gov
- **Cancer Care**
cancercares.org



This information is not intended to diagnose health problems or to take the place of medical advice or care you receive from your physician or other medical professional. If you have persistent health problems, or if you have additional questions, please consult with your doctor. If you have questions or need more information about your medication, please speak to your pharmacist.

Some photos may include models and not actual patients.

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195013-007 (Revised 9/17) RL 8.7

