Embrace the noncancer parts of your life. Cancer is not who you are, it's just one part of your life.
When people hear the word cancer, they tend to first think of solid tumors that sometimes spread to other places in the body. But cancers are actually categorized into two main groups: solid cancers and hematologic (blood) cancers. Blood cancers may or may not create an actual tumor and can affect blood, bone marrow, lymph nodes and other organs.

One type of blood cancer is called lymphoma. It arises in the lymphatic system, which is part of the immune system. It is the most common blood cancer in the United States, accounting for approximately 4.3 percent of all cancer diagnoses. The American Cancer Society estimates that nearly 80,500 people will be diagnosed with lymphoma in 2017.

Lymphoma develops when normal lymphocytes (a type of white blood cell) transform into abnormal cancer cells that reproduce uncontrollably. As these cancer cells multiply, they collect in the lymph nodes, bone marrow, spleen, tonsils, adenoids or thymus, where they can form tumors. These cells eventually begin to outnumber normal cells, causing an enlargement of the lymph nodes, spleen or other organs.

ABOUT THE LYMPHATIC SYSTEM
To fully understand lymphoma, it's important to first gain an understanding of the lymphatic system. The lymphatic system is a network of tissues and vessels that carry fluid, called lymph, throughout the body. Lymph contains lymphocytes that attack infectious agents.

The two main types of lymphocytes that can develop into lymphomas are B-lymphocytes (B-cells) and T-lymphocytes (T-cells):  
- **B-cells** produce protein antibodies that attach to infectious organisms, such as bacteria and viruses, marking them for destruction. 
- **T-cells** attack infectious organisms directly and play a part in controlling the immune system.

Both B-cells and T-cells can transform into lymphoma cells. However, in the United States, B-cell lymphomas are much more common.

TYPES OF LYMPHOMA
Lymphoma represents more than 60 different cancer subtypes that involve lymphocytes, and it can occur in adults and children of any age. The two main types of lymphoma are Hodgkin lymphoma and non-Hodgkin lymphoma.

*Hodgkin lymphoma*
With an estimated 8,260 new cases of Hodgkin lymphoma in the United States in 2017, it is not as common as non-Hodgkin lymphoma. Hodgkin lymphoma is characterized by the presence of B-cells (called Reed-Sternberg [R-S] cells), although other cell types also may be present. Hodgkin lymphoma usually starts in the lymph nodes and often spreads from one lymph node to another. It also can spread to other organs.

*Non-Hodgkin lymphoma*
Non-Hodgkin lymphoma (NHL) is the most common cancer of the lymphatic system. An estimated 72,240 new cases of NHL are expected to be diagnosed in the United States in 2017.

NHL is not a single disease but rather a group of several closely-related cancers. The World Health Organization estimates that there are more than 60 types of NHL. Although the various types of NHL share some common features, they differ in their microscopic appearance, molecular features, growth patterns, impact on the body and treatment options.

NHLs are broadly divided into two major groups: B-cell lymphomas and T-cell lymphomas. B-cell lymphomas develop from abnormal B-lymphocytes and account for 85 percent of all NHLs; T-cell lymphomas develop from abnormal T-lymphocytes and account for the remaining 15 percent of all NHLs. NHLs may also be classified as indolent (slow-growing) or aggressive (fast-growing).

*Follicular lymphoma*
Follicular lymphoma is the most common form of low-grade NHL and the second most common type of lymphoma overall diagnosed in the United States. Approximately 25 to 30 percent of people with NHL in the United States have this type. Most follicular lymphoma diagnoses occur in adults over the age of 60, with equal rates of occurrence in male and female individuals; this specific lymphoma is rare in young people.

Follicular lymphoma affects B-cell lymphocytes and is indolent, which means it grows very slowly. Like most lymphomas, follicular lymphoma usually begins in the lymph nodes. The cells can spread into the blood and bone marrow. Other internal organs, including the liver and spleen, may also be affected.

Because follicular lymphoma grows so slowly, doctors may not treat it right away and instead adopt a “watchful waiting” approach. Over time, some follicular lymphomas transform into an aggressive (fast-growing) diffuse B-cell type of lymphoma, so it’s important for people with follicular lymphoma to be monitored closely. Learn more about the several treatment options that are available on page 4.

OVERVIEW OF LYMPHATIC SYSTEM

<table>
<thead>
<tr>
<th>Thymus</th>
<th>Lymph node</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lymph vessels</td>
<td>Artery</td>
</tr>
<tr>
<td>Tonsils</td>
<td>Vein</td>
</tr>
<tr>
<td>Spleen</td>
<td>Lymph vessel</td>
</tr>
</tbody>
</table>

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ADDITIONAL RESOURCES
- **American Cancer Society**: [www.cancer.org](http://www.cancer.org)  
  Types of Non-Hodgkin Lymphoma
- **American Society of Clinical Oncology**: [www.cancer.net](http://www.cancer.net)  
  Lymphoma — Non-Hodgkin: Subtypes
- **Leukemia & Lymphoma Society**: [www.lls.org](http://www.lls.org)  
  Non-Hodgkin Lymphoma
- **Lymphoma Information Network**: [www.lymphomainfo.net](http://www.lymphomainfo.net)  
  Follicular Lymphoma
- **Lymphoma Research Foundation**: [www.lymphoma.org](http://www.lymphoma.org)  
  Follicular Lymphoma
Several types of tests are used to diagnose follicular lymphoma. These tests provide details that help your doctors make a specific diagnosis and assign a stage to the cancer. (See page 3 for staging information.) Accurately diagnosing and staging your follicular lymphoma is essential for your doctor to determine the best treatment options for you.

**PHYSICAL EXAM**
One of the first steps your doctor will take is to get your complete medical history and perform a thorough physical examination. During the physical exam, the doctor will pay close attention to your lymph nodes, spleen and liver. If lymphoma is suspected, a biopsy of the potentially affected area will likely be recommended.

**BIOPSY PROCEDURES**
A biopsy is the only way to accurately diagnose follicular lymphoma. The type of biopsy your doctor chooses to do is based on your specific situation.

- **Excisional or incisional biopsies** are the most common types of biopsy done if follicular lymphoma is suspected. The doctor removes either an entire lymph node through a cut in the skin (excisional biopsy) or a small section of a suspected tumor (incisional biopsy). For both types, local or general anesthetic is used as necessary.
- **A fine-needle or core-needle biopsy** may be used to diagnose follicular lymphoma. During a fine-needle procedure, computed tomography (CT) or ultrasound is used to guide the insertion of a fine, thin needle into the lymph node or other organ that’s suspected to have follicular lymphoma cells. Fluid or small pieces of tissue are then aspirated. This is rarely a good way to make a diagnosis of lymphoma.

In a core-needle biopsy procedure, the needle is larger and a small cylinder of tissue is removed.

- **Bone marrow biopsy** samples typically are taken from the back of the pelvic bone. During a bone marrow biopsy, a needle is inserted into the bone, and a small piece of bone and marrow is removed. A local anesthetic is used, so only pressure and brief pain are felt during the procedure.

Tissue samples obtained during these procedures are examined by a pathologist to see if follicular lymphoma cancer cells are present. The pathologic evaluation of biopsy samples offers the most valuable information for the diagnosing and staging of follicular lymphoma. In some instances, the pathologist may not be able to identify all the necessary information because the tissue sample is too small. When this happens, another biopsy may be necessary.

**BLOOD TESTS**
Blood tests are frequently ordered to help diagnose follicular lymphoma. A complete blood count (CBC) measures the number of red and white blood cells and platelets in the blood. Low blood cell counts can indicate that the cancer has spread to the bone marrow and is affecting the formation of new blood cells.

Blood chemistry tests to examine kidney and liver function may be ordered, and your doctor might request a lactate dehydrogenase (LDH) blood test as well, as LDH levels can sometimes be high in people with follicular lymphoma. Lastly, your blood might be tested for infections, such as hepatitis or HIV, because these viruses can affect your treatment.

**DIAGNOSTIC IMAGING STUDIES**
Doctors use imaging studies primarily to closely examine the affected area and to see if the cancer has metastasized (spread), which aids in defining the stage of the disease. You may not need every diagnostic imaging study listed here. Your doctors will consider the results of your physical exam, biopsy findings, blood test results and general health status in deciding which tests will provide the most useful information.

- **Chest X-ray** is a photograph of the structures inside your body, particularly your bones. Chest X-rays can help doctors determine whether any lymph nodes in the chest area are enlarged.
- **Computed tomography (CT)** produces three-dimensional, cross-sectional X-ray images, so it can provide more precise details in soft tissues than a standard X-ray. CT scans provide an excellent assessment of the size of the lymph nodes, confirming whether they’re enlarged. In cases of follicular lymphoma, CT images of the abdomen, pelvis, chest, head and neck can be useful.
- **Magnetic resonance imaging (MRI)** uses strong magnets and radiowaves to produce detailed images of lymph nodes. MRI is not used as often as CT for diagnosing follicular lymphoma, but it can help determine whether the cancer has spread to the spinal cord or brain.
- **Positron emission tomography (PET)** images are not as finely detailed as those from CT or MRI, but they can provide useful information, such as whether an enlarged lymph node contains cancer cells and whether an area that looks normal on a CT scan might actually be follicular lymphoma. PET scans are the most sensitive tests for finding follicular lymphoma.

Be sure to talk openly with your health care team to ensure you understand everything involved in the diagnostic phase of your cancer care.

**BY THE NUMBERS**

**DIAGNOSING LYMPHOMA**

Breakdown of estimated lymphoma diagnoses in 2017 in the United States.

- **Total Lymphoma Diagnoses**
  - 80,500
  - 90% = non-Hodgkin lymphoma

- **Non-Hodgkin Lymphoma Diagnoses**
  - 25-30% are follicular lymphoma

**ADDITIONAL RESOURCES**
- American Cancer Society: www.cancer.org
  - How is Non-Hodgkin Lymphoma Diagnosed?
- American Society of Clinical Oncology: www.cancer.net
  - Lymphoma – Non-Hodgkin. Diagnosis
Once you’ve been diagnosed with follicular lymphoma, the next step for doctors is to determine the stage of the disease and develop an appropriate treatment plan.

To stage follicular lymphoma, doctors will order tests to find out how far the disease has spread and which areas of the body it’s affecting. (See page 2 for more information about diagnostic tests.) Based on the results of these diagnostic tests, the doctor will assign a stage to the disease. The Ann Arbor staging system for follicular lymphoma is the most commonly used system (see Table 1). The higher the stage number, the more advanced the disease.

In addition to the Ann Arbor staging system, oncologists use the Follicular Lymphoma International Prognostic Index (FLIPI) to predict the risk of disease recurrence and overall survival. The FLIPI takes into account the age and general health of the person, the stage of the disease, the hemoglobin level, the number of involved lymph nodes, and the presence or absence of elevated levels of an enzyme called lactate dehydrogenase (LDH) in the blood.

The FLIPI assigns one point for each of the following risk factors:
- Age older than 60 years
- Late-stage disease (Stage III or IV)
- Hemoglobin level less than 12 g/dL
- Four or more involved lymph node areas
- High LDH level

The lower the score, the better the prognosis (predicted outcome from treatment).

The World Health Organization recommends that follicular lymphoma be assigned a histologic grade, which is determined by the number of centroblasts (a special kind of B-lymphocyte) found when examining a sample with a microscope (see Table 2). The grade defines how aggressive the cancer cells are likely to be and helps doctors make various treatment decisions, including when treatment should start. The higher the grade, the more likely the disease is to progress. To determine your prognosis, your doctor may also test how well you are able to function and carry out daily activities by using a functional assessment scale.

- **The Ann Arbor Staging System**

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>The disease is in only one lymph node area or lymphoid organ, such as the thymus.</td>
</tr>
<tr>
<td>IE</td>
<td>The disease is in only one area of a single organ outside the lymph system.</td>
</tr>
<tr>
<td>II</td>
<td>The disease is in two or more lymph node areas on the same side (above or below) of the diaphragm.</td>
</tr>
<tr>
<td>IIE</td>
<td>The disease extends from one lymph node area to a nearby organ, with possible spread to one or more lymph node areas on the same side of the diaphragm.</td>
</tr>
<tr>
<td>III</td>
<td>The disease is in lymph node areas on both sides (above and below) of the diaphragm.</td>
</tr>
<tr>
<td>IIIIE</td>
<td>The disease is in lymph node areas above and below the diaphragm and has spread directly to an adjacent organ.</td>
</tr>
<tr>
<td>IV</td>
<td>The disease has spread outside the lymph system to an organ that is not directly next to the involved lymph node area(s); or it has spread to the bone marrow, lungs, cerebrospinal fluid or liver.</td>
</tr>
</tbody>
</table>

Various letters can be added to the stage to indicate additional factors (all possible combinations not shown above):  
- A: Fever, night sweats and weight loss are not present.  
- B: Fever, night sweats and weight loss are present.  
- E: The cancer affects an organ or tissue outside the lymph system.

- **Histologic Grades of Follicular Lymphoma**

<table>
<thead>
<tr>
<th>Grade</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>0-5 centroblasts per high-power field</td>
</tr>
<tr>
<td>2</td>
<td>6-15 centroblasts per high-power field</td>
</tr>
<tr>
<td>3</td>
<td>More than 15 centroblasts per high-power field</td>
</tr>
<tr>
<td>3A</td>
<td>More than 15 centroblasts, but centrocytes (smaller cells) still present</td>
</tr>
<tr>
<td>3B</td>
<td>Solid sheets of centroblasts with no residual centrocytes</td>
</tr>
</tbody>
</table>

**Additional Resources**
- American Cancer Society: www.cancer.org  
- American Society of Clinical Oncology: www.cancer.net  
- Leukemia & Lymphoma Society: www.lls.org

*This staging system is for Hodgkin lymphoma but it is often applied to non-Hodgkin lymphoma, including follicular lymphoma.*
Multiple options are available to help treat follicular lymphoma. In general, follicular lymphoma responds well to treatment but is difficult to cure. Your doctor will develop a specific treatment plan for you based on several factors, including your overall health and the stage of your disease. Some of the most common options to treat follicular lymphoma are described here (see Common Follicular Lymphoma Drugs, page 5).

Be aware that as research evolves and new treatments are discovered in studies known as clinical trials, additional treatments may become available (see page 6).

WATCHFUL WAITING
Watchful waiting is an approach your doctor may take to closely monitor your follicular lymphoma. This approach is fairly common because follicular lymphoma develops slowly. Watchful waiting allows you to safely avoid treatment and its side effects until it is absolutely necessary. In some cases, you may never need active treatment; however, if the disease progresses beyond mildly swollen lymph nodes, your doctor may opt to start treatment with chemotherapy, immunotherapy, targeted therapy, radiation therapy or stem cell transplantation.

CHEMOTHERAPY
Chemotherapy is the use of drugs, also called cytotoxic drugs, to stop the growth of cancer cells either by killing them or preventing them from dividing and growing. Chemotherapy, a systemic therapy that travels throughout the body, is sometimes referred to as conventional chemotherapy to distinguish it from immunotherapy and targeted therapy, which also involve the use of drugs that travel throughout the body.

Chemotherapy is a treatment option for all stages of follicular lymphoma and is often the first treatment option used. A single chemotherapy drug may be used, or your doctor may prescribe a combination of chemotherapy drugs or a chemotherapy drug plus a monoclonal antibody.

Some chemotherapy drugs work by damaging the cancer cells’ DNA or by disrupting the making of DNA. Others disrupt the development of new cells. As a result, no new cells are made to replace dying cells. Many chemotherapy drugs are designed to work when cells are in the active growth phase, which includes cells that grow and divide. The drugs disrupt the growth phase. Other chemotherapy drugs work whether the cells are in a growth or resting phase.

Many chemotherapy drugs used to treat follicular lymphoma are liquids that are injected slowly into a vein. Some drugs are a pill that is swallowed. Both types of drugs travel in your bloodstream to treat cancer throughout your body.

Another drug that is sometimes included in many chemotherapy combination regimens is a corticosteroid. This type of drug is not a chemotherapy drug. It is an anti-inflammatory drug that also appears to help cause the death of cancerous white blood cells.

Combination chemotherapy regimens often are used to treat many types of cancer, including follicular lymphoma. The regimens used to treat follicular lymphoma include one or more chemotherapy drugs in combination with a monoclonal antibody or corticosteroid. (See Common Follicular Lymphoma Drugs, page 5).

IMMUNOTHERAPY
Immunotherapy uses the body’s own immune system to slow the growth of and kill cancer cells. To do so, the immune system uses substances made either by the body or in a laboratory to find and destroy cancer cells, much like it fights off foreign bacteria (see Figure 1). The main types of immunotherapies used to treat this particular cancer are monoclonal antibodies, which are laboratory-made versions of immune system proteins designed to attack cancer cells.

One type of monoclonal antibody that is commonly used to treat follicular lymphoma attaches to a specific protein found on B-cells, the cells from which follicular lymphoma arise. It makes the B-cells more visible to the immune system, which helps it attack them more efficiently.

A somewhat similar treatment option involves the use of a radioactive mono-
clonal antibody. An immunotherapy drug combines a radioactive particle with a monoclonal antibody, allowing it to deliver radiation directly to the cancer cells. This approach leaves most of the surrounding healthy cells undamaged.

**TARGETED THERAPY**

Researchers have learned about the cell pathways that can lead to many types of cancers, including follicular lymphoma, and also have learned how to develop drugs that block those pathways. These drugs are known as targeted drugs (or agents), and the treatment is known as targeted therapy. Targeted therapy drugs block the signals that proteins and other molecules send along signaling pathways, which are systems in the body that direct basic cell functions like growth, division and death. Effective targeted therapy depends on two factors: identifying targets that play an important role in the growth and survival of cancer cells, and developing agents that can attack those targets.

One concern associated with both chemotherapy and targeted therapy is that cancer cells can become resistant to the drugs, which may make them less effective over time. Researchers continue to explore ways to overcome resistance and identify new pathways to target and develop agents to disrupt the growth of follicular lymphoma cells.

**RADIATION THERAPY**

Radiation therapy is the use of high-energy X-rays to kill cancer cells or keep them from growing. External-beam radiation therapy is given with the use of a radiation machine and is similar to a conventional X-ray, except the radiation beams are strong enough to kill cancer cells.

Stage I and early Stage II follicular lymphoma may be treated with radiation therapy, which targets the lymph node areas affected by the cancer. In later stage lymphoma, radiation therapy may be used to reduce symptoms or to treat people who cannot tolerate chemotherapy.

If your doctor includes radiation therapy in your treatment plan, a radiation oncologist will carefully plan and oversee your treatment.

**STEM CELL TRANSPLANTATION**

Stem cells are found in the bone marrow, and they have a special feature that enables them to develop into any one of the three types of blood cells — red blood cells, white blood cells (cells that fight infection) and platelets (clotting cells). There are two types of stem cell transplantation: autologous and allogeneic.

With autologous stem cell transplantation, a person’s own stem cells are removed and preserved so that very high doses of chemotherapy and/or radiation therapy can be given to attack cancer cells. After the conclusion of the intensive chemotherapy or radiation therapy, the person’s stem cells are infused back into the body.

Allogeneic stem cell transplantation is the use of stem cells obtained from a donor with healthy bone marrow whose stem cells are a close match to those of the person being treated. Allogeneic stem cell transplantation is considered to be a form of immunotherapy because it establishes a new immune system.

In cases of follicular lymphoma, stem cell transplantation is most commonly used when the cancer is in remission but likely to come back or when the cancer doesn’t respond to the initial treatment plan.

**COMMON FOLLICULAR LYMPHOMA DRUGS**

**CHEMOTHERAPY**

- bendamustine hydrochloride (Bendeka, Treanda)
- chlorambucil (Leukeran)
- cyclophosphamide
- doxorubicin (Adriamycin)
- lenalidomide (Revlimid)
- vincristine sulfate PFS

**COMBINATION THERAPIES**

- bendamustine (Bendeka, Treanda) combined with lenalidomide (Revlimid)
- BR: bendamustine (Bendeka, Treanda) combined with rituximab (Rituxan)
- R-CVP: rituximab (Rituxan) combined with cyclophosphamide, vincristine sulfate PFS and prednisone
- R-CHOP: rituximab (Rituxan) combined with cyclophosphamide, doxorubicin (Adriamycin), vincristine sulfate PFS and prednisone

**CORTICOSTEROID**

- prednisone

**IMMUNOTHERAPY**

- ibrutinomab tiuxetan (Zevalin)
- obinutuzumab (Gazyva)
- rituximab (Rituxan)

**TARGETED THERAPY**

-idelalisib (Zydelig)

**DEALING WITH RECURRENCE**

Follicular lymphoma is typically a disease that has multiple relapses, which is referred to as recurrences. If your cancer is recurrent, your doctor will begin a new cycle of diagnostic tests to learn about the recurrence. These tests may include another tissue biopsy, laboratory tests and imaging studies. The doctor will confirm if the cancer is recurrent and will determine if it has transformed into a more aggressive subtype, which will affect your new treatment plan.

If your follicular lymphoma has officially returned, your doctor will discuss the best treatment options for you. Many of the options available for your first treatment also are available for treating recurrent follicular lymphoma. In determining your treatment plan options, the following factors will be considered:

- The type of cancer, where in the body it came back, and the size
- Your overall health
- The type of treatment you originally received and how well it worked
- Side effects you experienced with the original treatment
- How long it has been since you finished treatment

When a recurrence happens, it is possible for tumors and cancer cells to be resistant to chemotherapy. Typically, they respond less favorably to treatment than the first tumors did. However, new approaches to treatment may be available to you through clinical trials (see Clinical Trials, page 6).

Whether you choose to receive more cancer treatment or not, consider getting supportive or palliative care, which treats the symptoms of follicular lymphoma. These options are not expected to cure cancer or prolong life, but they focus on making your life the best it can be.

**ADDITIONAL RESOURCES**

- American Cancer Society: www.cancer.org
- Focus on Follicular Lymphoma: www.focusonfl.org
- Lymphoma Research Foundation: www.lymphoma.org
- RT Answers: www.rtanswers.org
Scientists and doctors are always working to find better treatment options for people with follicular lymphoma. Clinical trials, which are volunteer research studies, are currently testing treatments for newly diagnosed follicular lymphoma and/or relapsed disease. These trials assess the effectiveness of new drugs, drug combinations and treatment type combinations that may help produce prolonged remission.

People who choose to participate in a follicular lymphoma cancer clinical trial will receive the standard of care as a foundation and then the experimental treatment may be added to it.

To participate in a clinical trial, you must meet certain eligibility criteria, such as cancer type, overall health, treatment history, etc. Talk to your doctor about whether a clinical trial may be right for you. You can also search online for clinical trials.

You may consider participating in a clinical trial for any of the following reasons.

1. Your current treatment may not be working as well as expected, and a clinical trial may offer a worthwhile alternative.

2. A clinical trial may significantly improve your quality of life. Discuss your personal situation with your health care team, so they are aware of your expectations regarding any side effects.

3. You may have a rare type of cancer that hasn’t been studied as much as other types.

4. By simply participating, you’ll play an integral role in helping refine and improve the way millions of people with all types and stages of cancer are treated. Your participation will help researchers identify those treatments that are effective.

Although all cancer treatments in use today came from clinical trials, patient participation could be improved. Fear of the unknown may prevent people from participating. Consult with your doctor and the health care team that will be conducting the clinical trial to learn what you can expect as a participant. Talk with people who have participated in clinical trials, but remember that not everyone responds to treatments in the same way. You cannot expect an identical experience in terms of response to treatment, side effects, etc.

The cost of clinical trials is another reason people hesitate to volunteer, but patient-care costs (such as going to the doctor, hospital stays or certain testing procedures) may be covered by insurance. It’s common, but not guaranteed, for the trial sponsor to cover research costs directly related to the study, and insurance does not typically cover research costs. Ask your insurance provider about coverage before entering into a clinical trial.

People may hesitate to volunteer because of the many misconceptions about clinical trials. Be your own best advocate, and learn more about clinical trials so you can make an educated decision. People often find they have more positive treatment experiences when they are educated about and actively involved in decisions about their care.

Following are a few resources where you can search for clinical trials in your area and learn more about how clinical trials work:

- Centerwatch: www.centerwatch.org
- ClinicalTrials.gov: www.clinicaltrials.gov
- The Leukemia & Lymphoma Society: www.lls.org
- Lymphoma Information Network: www.lymphoma.org
- Lymphoma Research Foundation: www.lymphoma.org; 800-500-9976; helpline@lymphoma.org
- TrialCheck: www.trialcheck.org

The Informed Consent process should give potential participants a reasonable amount of time to review the trial’s information and ask questions before volunteering. They should use this time to check with any insurance providers to determine what procedures are covered and what they are expected or required to pay out of pocket. Although many trials cover the costs of certain treatments, other expenses may be the responsibility of the participants, which would best be discovered before starting a trial.

Potential participants need to understand their role as “subjects of research” and not as patients. Although they may receive personal treatment, they are not guaranteed to benefit from the study. They may be exposed to unknown risks, and they are entering a study that may be very different from current standard medical practices.

Before volunteering for a clinical trial, potential participants receive detailed information about the clinical trial in an Informed Consent form. This form details the purpose of the research, including what the participant’s role will be in the trial and how the trial will work. It also includes risks, benefits and other pertinent information to answer a potential participant’s questions. To ensure they fully understand what they are agreeing to, potential participants are required to review the form during the Informed Consent process.

The Informed Consent information should be explained in easy-to-understand language and will describe the study’s purpose, the length of time of the study, predictable risks, possible benefits, expectations, protocols, alternative beneficial procedures or treatments, the research subject’s rights, where more information can be found and answers to additional questions about the research. The document will include some of the following information:

- The trial and its goals.
- How the participant will be monitored and what side effects to expect.
- The best standard regimen of care for that stage of disease, regardless of the doctor or institution.
- The safeguards in place. All clinical trial participants are protected by rules that apply nationwide to all facilities.
- How to withdraw from the trial at any time.

The Leukemia & Lymphoma Society: www.lymphoma.org; 800-500-9976; helpline@lymphoma.org

Clinical Trials.gov: https://clinicaltrials.gov/ct2/about-studies/learn
U.S. Food and Drug Administration: www.fda.gov
Informed Consent for Clinical Trials
Throughout my initial chemo, I didn’t think I needed any support when I was just caring for our children and dealing with the short-term discomforts while helping me hold on to my identity as a physician. More important, writing distracted me from my pain and other challenges forced me to stop practicing medicine. The doctors felt an urgent need to begin treatment right away. My oncologist consulted with lymphoma specialists around the country to determine the best course of treatment for me: a cocktail of seven chemotherapy drugs.

After chemotherapy, I achieved remission, but the lymphoma recurred less than a year later. For the next 15 years, I went in and out of remission, my lymphoma responding to each of eight more courses of various cancer therapies, including immunotherapies received in three different clinical trials. My last treatment was in 2007, and my lymphoma has stayed in complete remission since.

The first time I was treated was before the availability of effective antiemetics (anti-nausea medications), growth stimulating factors and ports. I was ill with nausea, vomiting, leg pain, fatigue, insomnia and gastrointestinal issues, such as esophagitis (inflammation of the esophagus) and colitis (inflammation of the colon). The ongoing illness and side effect challenges forced me to stop practicing medicine. My primary focus became my family and helping my three children deal with the changes. They were not quite 2, 4 and 6 years old when I was first diagnosed. Unexpectedly, I began writing articles and books for patients, using my perspective as physician survivor to help others. My husband and I joke that I wrote my first book while I was awake at night because of the steroids I was taking. More important, writing distracted me from my pain and other discomforts while helping me hold on to my identity as a physician.

The support of family and friends was so important, especially during the first few years when I needed help caring for our children. Throughout my initial chemo, I didn’t think I needed any support groups or counseling. Even though I had referred many of my patients to social workers and counselors, I now know that I didn’t fully understand how valuable they can be when dealing with a serious illness.

During my first remission, without access to the survivorship resources that are available today, my post-treatment anxiety and sadness blindsided me. Fortunately, I met a social worker during an overnight hospital stay for a post-treatment complication. She told me about her support group, which I joined. Soon, I began seeing her privately on a regular basis. One-on-one counseling proved to be incredibly helpful for dealing with my uncertainty and stress. She helped me face my fears and learn to manage them. Having a professional to talk to helped me put my emotional life back together after cancer had fractured it. Those sessions helped me embrace life between sessions, whatever was happening medically. I cannot stress enough how valuable oncology social workers can be when you are dealing with cancer.

All these years, I’ve done a lot of advocacy work. I’m a founding member of the Dallas chapter of the Lymphoma Research Foundation and have been team captain of Wendy’s Eagles in the Dallas Lymphoma Walk since 2004, raising more than $100,000. I’ve been involved in patient advisory boards and cancer survivorship workgroups on local, state and national levels. I don’t fear recurrence anymore. I tamed that fear by accepting the uncertainty and focusing on all the things I can do to stay healthy (follow-up appointments; healthy diet; regular exercise; sleep; fulfilling relationships and work). I maintain hope that effective treatments will be available if I need them — a realistic hope, given the advances in lymphoma treatments. I nourish confidence that I’ll deal with whatever happens.

There is no single “right” way to do survivorship. Everyone forges and follows his or her own personal journey. To others going through cancer, I recommend you obtain sound knowledge, find and nourish realistic hope, and take effective action. Learn from others how you do — and don’t — want to handle things. Ask for and accept help when needed. When you’re not making treatment decisions or dealing with a medical problem, embrace the noncancer parts of your life. Cancer is not who you are; it is just one part of your life. There is life after cancer. Make it a good life.
**INDICATION**

What is ZYDELIG?

ZYDELIG is a prescription medicine used to treat adults with:

- **Follicular B-cell non-Hodgkin Lymphoma (FL)** when the disease worsens after treatment with at least 2 prior medicines. ZYDELIG was approved based on response rates. Data are not yet available to show if ZYDELIG improves symptoms or survival.

ZYDELIG should not be used as the first medicine to treat people who have been diagnosed with FL.

**IMPORTANT SAFETY INFORMATION**

What is the most important information I should know about ZYDELIG?

ZYDELIG can cause serious side effects that can lead to death, including:

- **Liver problems.** Abnormal liver blood test results are common during treatment with ZYDELIG. ZYDELIG can cause severe liver problems. Your doctor will do blood tests before and during your treatment with ZYDELIG to check for liver problems. Tell your doctor right away if you get yellowing of your skin or the white part of your eyes (jaundice), dark or brown (tea-colored) urine, pain in the upper right side of your stomach area (abdomen), or bleeding or bruising more easily than normal.

- **Severe diarrhea.** Diarrhea is common during treatment with ZYDELIG and can sometimes be severe. Tell your doctor right away if the number of bowel movements you have in a day increases by 6 or more. Ask your doctor about medicines you can take to treat your diarrhea.

- **Lung or breathing problems.** Your doctor may do tests to check your lungs if you have breathing problems during treatment with ZYDELIG. Tell your doctor right away if you get new or worsening cough, shortness of breath, difficulty breathing, or wheezing.

- **Infections.** Tell your doctor right away if you have a fever or any signs of an infection while taking ZYDELIG.

- **Tear in intestinal wall (perforation).** Tell your doctor or get medical help right away if you get new or worsening stomach area (abdomen) pain, chills, fever, nausea, or vomiting.

- **Severe skin reactions.** Tell your doctor right away if you get painful sores or ulcers on your skin, lips, or in your mouth; a severe rash with blisters or peeling skin, or a rash with itching.

If you have any of the above serious side effects during treatment with ZYDELIG, your doctor may completely stop your treatment, stop your treatment for a period of time, or change your dose of ZYDELIG.
**INDICATION**

What is ZYDELIG?

ZYDELIG is a prescription medicine used to treat adults with:

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- **Infections.** Tell your doctor right away if you have a fever or any signs of an infection while taking ZYDELIG.

- **Tear in intestinal wall (perforation).** Tell your doctor or get medical help right away if you get new or worsening stomach area (abdomen) pain, chills, fever, nausea, or vomiting.

- **Severe skin reactions.** Tell your doctor right away if you get painful sores or ulcers on your skin, lips, or in your mouth; a severe rash with blisters or peeling skin, or a rash with itching.

If you have any of the above serious side effects during treatment with ZYDELIG, your doctor may completely stop your treatment, stop your treatment for a period of time, or change your dose of ZYDELIG.

Who should not take ZYDELIG?

- Those with a history of serious allergic or skin reactions, as determined by a doctor.

What are the other possible side effects of ZYDELIG?

ZYDELIG can cause serious side effects, including:

- **Serious allergic reaction.** Tell your doctor or get medical help right away.

- **Low white blood cell count (neutropenia).** Neutropenia is common during treatment with ZYDELIG and can sometimes be severe. Your doctor will check your blood counts regularly during treatment with ZYDELIG. Tell your doctor right away if you have a fever or any signs of an infection.

The most common side effects of ZYDELIG when used alone include feeling tired, nausea, cough, fever, stomach area (abdomen) pain, pneumonia and rash.

What should I tell my doctor before taking ZYDELIG?

- **All of your medical conditions,** including if you have liver, lung, or breathing problems or an infection.

- **If you are pregnant or plan to become pregnant.** ZYDELIG may harm your unborn baby. Women who are able to become pregnant should use effective birth control (contraception) during treatment with ZYDELIG and for at least 1 month after the last dose of ZYDELIG. Talk to your doctor about birth control methods. Tell your doctor right away if you become pregnant or think you are pregnant during treatment with ZYDELIG.

- **If you are breastfeeding or plan to breastfeed.** You and your doctor should decide if you will take ZYDELIG or breastfeed. You should not do both.

- **All the medicines you take,** including prescription and over-the-counter medicines, vitamins, and herbal supplements. ZYDELIG and certain other medicines may affect each other.

Please see Important Facts about ZYDELIG, including important warnings, on the following page.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.
**IMPORTANT FACTS**

This is only a brief summary of important information about ZYDELIG and does not replace talking to your healthcare provider about your condition and your treatment.

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**MOST IMPORTANT INFORMATION ABOUT ZYDELIG**

ZYDELIG can cause serious side effects that can lead to death, including:

- **Liver problems**, which can be severe. Tell your doctor right away if you get any of these symptoms: yellowing of your skin or the white part of your eyes, dark or “tea-colored” urine, pain in the upper right side of your stomach area, or bleeding or bruising more easily than normal.

- **Severe diarrhea.** Tell your doctor right away if the number of bowel movements you have in a day increases by 6 or more. Ask your doctor about medicines you can take to treat your diarrhea.

- **Lung or breathing problems.** Tell your doctor right away if you get new or worsening cough, shortness of breath, difficulty breathing, or wheezing.

- **Infections.** Tell your doctor right away if you have a fever or any signs of an infection while taking ZYDELIG.

- **Tear in intestinal wall (perforation).** Tell your doctor or get medical help right away if you get new or worsening stomach area pain, chills, fever, nausea, or vomiting.

- **Severe skin reactions.** Tell your doctor if you develop painful sores or ulcers on your skin, lips, or in your mouth, or if you develop a severe rash with blisters, peeling skin, or itching.

Your healthcare provider will need to do tests to monitor your health before and during treatment with ZYDELIG. This can include testing your liver, lungs, and white blood cell counts. If you have any of the above serious side effects during treatment with ZYDELIG, your doctor may completely stop your treatment, stop your treatment for a period of time, or change your dose of ZYDELIG.

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**ABOUT ZYDELIG**

ZYDELIG is a prescription medicine used to treat adults with:

- Chronic Lymphocytic Leukemia (CLL) when the disease comes back after prior cancer treatment. It is used in patients who may otherwise be treated with Rituxan alone due to other health concerns.

- Follicular B-cell non-Hodgkin Lymphoma (FL) and Small Lymphocytic Lymphoma (SLL) when the disease has come back after treatment with at least 2 prior medicines.

ZYDELIG should not be used as the first medicine to treat people who have been diagnosed with CLL, FL, or SLL.

**Do not take ZYDELIG if you** have a history of serious allergic reactions or severe skin reactions.

Take ZYDELIG exactly as your healthcare provider tells you to take it.

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**POSSIBLE SIDE EFFECTS OF ZYDELIG**

ZYDELIG can cause serious side effects including:

- Those in the “Most Important Information about ZYDELIG” section

- Serious allergic reactions

- Low white blood cell count

Tell your doctor or get medical help right away if you have a serious allergic reaction or if you have a fever or signs of infection.

The most common side effects of ZYDELIG when used with Rituxan include pneumonia, fever, feeling tired, rash, cough, and nausea.

The most common side effects of ZYDELIG when used alone include feeling tired, nausea, cough, fever, stomach area pain, pneumonia and rash.

These are not all the possible side effects of ZYDELIG. Tell your healthcare provider if you have any new symptoms while taking ZYDELIG.

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**BEFORE TAKING ZYDELIG**

Tell your healthcare provider if you:

- Have liver, lung, or breathing problems or an infection

- Have any other medical condition

- Are pregnant or plan to become pregnant. ZYDELIG may harm your unborn baby. Females who are able to become pregnant should use effective birth control during treatment with ZYDELIG and for at least 1 month after stopping treatment. Tell your doctor right away if you become pregnant or think you are pregnant during treatment with ZYDELIG.

- Are breastfeeding or plan to breastfeed. You should not take ZYDELIG if you are breastfeeding or plan to breastfeed.

ZYDELIG and other medicines may affect each other. Tell your healthcare provider about all the medicines you take:

- Keep a list of all your medicines, including prescription and over-the-counter medicines, vitamins, and herbal supplements, and show it to your healthcare provider.

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**GET MORE INFORMATION**

- This is only a brief summary of important information about ZYDELIG. Talk to your healthcare provider or pharmacist to learn more

- Go to ZYDELIG.com or call 1-800-GILEAD-5

- If you need help paying for your medicine visit ZYDELIGAccessConnect.com for program information
ZYDELIG® AccessConnect™: your partner in therapy.

Now that your doctor has prescribed ZYDELIG for you, we want to help you access, afford and adhere to your therapy. And that’s precisely what ZYDELIG AccessConnect was designed to do. This support program can help:

- Evaluate your insurance coverage options for ZYDELIG
- Evaluate any financial assistance options available for your situation
- Ensure you receive ZYDELIG in a timely manner
- You adhere to ZYDELIG, as prescribed, through useful tips provided by a Patient Support nurse

You can register for this important program at your doctor’s office, or by visiting the AccessConnect website, at www.zydeligaccessconnect.com/supportnetwork

Please see full Prescribing Information, including Medication Guide with important warnings available at zydelig.com.
Many people are fearful about the types of side effects they may experience with certain types of cancer treatment. These fears grow from a belief that the side effects cannot be relieved. However, it is now possible to prevent or manage many common side effects of cancer treatment.

Preventing and managing side effects is extremely important for the success of your treatment because the better you feel, the more likely you’ll be able to complete your treatment as planned, which offers a greater chance for a successful outcome. Your doctor can help you anticipate the most common side effects, so that you are prepared if they occur.

MANAGING THE SIDE EFFECTS OF CANCER DRUGS

Although the side effects from systemic therapies, such as chemotherapy, immunotherapy and targeted therapy, have some differences, several of their most common side effects are the same. It is extremely important to talk openly with your doctor about any side effects you experience and to call your doctor’s office immediately if a side effect occurs suddenly.

It may be helpful to keep a diary of your symptoms so that your doctor can assist you in managing them. Write down when your symptom started and what you were doing at the time it started. Include where the symptom occurs, how long it lasts and how severe it is. Also include if any activities make the symptom better or worse.

Fatigue

Treatment-related fatigue occurs primarily because the body needs extra energy to repair the healthy tissue damaged by cancer treatment. Additionally, other side effects of treatment, such as pain, nausea and vomiting, can cause or worsen fatigue. Although most people think more rest will help relieve fatigue, increasing activity and performing regular exercise (such as walking or bike riding) are the best ways to combat it. If your fatigue is severe, your doctor may prescribe a drug to improve alertness.

Fever

Fever, which occurs when the body’s temperature is abnormally high, is the body’s response to infection. Fever can develop in a person who is receiving drug therapy. It can be particularly concerning if it occurs when a person’s white blood count is low. If you recently received chemotherapy and develop a fever, call your doctor immediately. If you know a medication you are taking has fever as a side effect or if you know your white blood count is low, check your temperature if you feel warm or unwell.

Your doctor may recommend trying over-the-counter medications, such as acetaminophen, to treat the fever related to flu-like syndrome. Avoid non-steroidal anti-inflammatory (NSAID) drugs, as well as aspirin, if you have a bleeding disorder. Discuss all of your options with your doctor before treatment begins to know the best way to manage a fever that develops after you begin treatment.

Cough

Coughing can be a symptom of follicular lymphoma or it can be caused by a treatment for follicular lymphoma. When coughing occurs due to follicular lymphoma, it’s typically caused when lymph vessels become blocked and fluid begins to accumulate around the lungs. Coughing is a side effect of some chemotherapy drugs. Your doctor may prescribe medications or recommend over-the-counter medications you can take to treat a cough, such as an antitussive, expectorant or decongestant.

Nausea and vomiting

Nausea and vomiting occur as the result of a series of reactions between your stomach and your brain, which start when cancer drugs damage the cells lining the inside of the stomach. The cells send signals to an area in your brain that sends signals to trigger nausea and vomiting. It is much easier to prevent nausea and vomiting than to control them once they’ve started.

Recent advances have led to the development of prescription drugs called antiemetics, which can prevent and control nausea and vomiting. To further protect yourself, you may want to try some nondrug approaches, including progressive muscle relaxation, biofeedback, guided imagery, self-hypnosis and acupuncture. Eating several small meals rather than a few big meals a day, staying hydrated and avoiding unpleasant odors can also help.

Drink plenty of fluids in small amounts throughout the day. Try bland, easy-to-digest foods like crackers. Ginger and peppermint also can help with nausea, so you may try ginger ale or peppermint tea. Avoid eating your favorite foods after your chemotherapy is completed; they might not be your favorite foods anymore if you associate them with receiving this type of treatment.

Diarrhea

Diarrhea is the passing of loose or watery stools three or more times a day, which may cause cramps in the abdomen and pain or discomfort in the rectum. When mild, diarrhea is an inconvenience. If left untreated, diarrhea can lead to serious problems, such as dehydration, loss of important nutrients, weight loss and fatigue. Your doctor may check you for a Clostridium difficile (C. diff) infection.

Once diarrhea occurs, consuming only clear liquids may help the lining of your intestines heal. Clear liquids include water, cranberry juice, ginger ale, clear broth, popsicles, decaffeinated tea and gelatin. As diarrhea improves, you can slowly add solid foods to your diet, starting with low-fiber foods like white rice or potatoes. Some foods can worsen diarrhea, including dairy products; spicy, greasy or fried foods; raw fruits or vegetables; or foods that are high in fiber.

Over-the-counter medicines and fiber

SURVIVOR VOICE  "Faye J. | Follicular lymphoma survivor"

I was pleasantly surprised that I never got sick or vomited while on treatment. My only side effect problems were losing my leg strength as well as being tired, bloated and incontinent. I was able to work throughout my treatment and could eat almost anything."
supplements are available to control diarrhea, but ask your doctor before taking anything. If diarrhea is severe, your doctor may prescribe other medications or choose to stop your cancer treatment temporarily until your diarrhea is controlled.

You might even know when to anticipate bouts of diarrhea based on prior episodes you have experienced during your chemotherapy treatments. If so, mark your calendar so that you aren't scheduling yourself to be out for a walk or having company when it is most likely to happen.

Abdominal pain
The abdomen is located between the chest and pelvis, and some treatments can cause pain in this area of the body. The pain can be the result of increased or decreased motility (movement) of the intestines, the destruction of beneficial (good) bacteria in the gut; ulcers; an intestinal perforation; or cramping of the bowel. Dull aches and cramping are common, but a sharp pain that does not go away in a few minutes may indicate a more serious problem. If that occurs, call your doctor immediately.

Mouth sores
Mouth sores, also known as oral mucositis, are small cuts or ulcers that can affect the gums, tongue, roof of the mouth or lips. Mouth sores sometimes begin as mild pain or burning, followed by white patches or redness that may become large red lesions. Pain may range from mild to severe, making it difficult to talk, eat or swallow. Taking good care of your teeth and gums is essential to managing mouth sores, and you should brush and floss several times a day. Your doctor may suggest rinsing your mouth with special solutions and may prescribe a medication that coats the lining of your mouth or pain medications that can be applied topically.

To manage mouth sores, keep your mouth and lips moist by using lip balm, sipping water, sucking on ice chips and drinking through a straw. Choose soft, moist foods that are easy to swallow, and consider letting your food cool to room temperature before you eat. It is also a good idea to avoid alcoholic beverages and tobacco products, as well as hot, spicy, citric, greasy, fried, coarse or rough-textured foods.

Skin reactions
Skin reactions can include redness and irritation (similar to sunburn), skin rash or dry, flaky skin. These reactions often cause itchiness and discomfort. Although most reactions are mild to moderate, some can become severe if not treated early. If a rash develops and causes itchiness or pain, your doctor may prescribe a mild corticosteroid cream or an antibiotic gel. Severe rashes are usually treated with an oral antibiotic and perhaps an oral corticosteroid. When a rash is severe, the dose of the cancer drug(s) is often reduced or temporarily stopped until the rash improves.

Cognitive dysfunction (“chemo brain”)
People being treated for cancer often refer to “chemo brain” when they can’t think clearly or have trouble remembering details, such as names and dates. This cognitive dysfunction is associated with chemotherapy, but it can occur in people receiving all types of treatments. Even though it is treatment-related, some people don’t experience it until months or even years after treatment ends. If you have this side effect, use a daily planner to keep track of things. Solve crossword puzzles or number games to help strengthen your mental ability. Record memory and attention problems to determine when you’re most affected. Don’t multitask; instead, focus on one thing at a time. Let friends and family know you’re having trouble, and ask them to help you remember and repeat information. Make a list each day of what needs to happen that day. As you complete each task, draw a line through it and then go on to the next task.

Pain management
Untreated pain, even if it’s minor, can get out of hand quickly. In all cases, it is very important that your health care team know what is happening and reporting pain is the first step to feeling more comfortable and having a good quality of life.

RECOVERING FROM RADIATION THERAPY
Because radiation therapy is delivered from the outside of the body, the skin and underlying tissues in the area being treated may develop redness, dryness, peeling or itchiness. This sensitivity is short-term and usually resolves gradually within two months after treatment stops. Other side effects might include fatigue, anemia, hair loss in the area treated, nausea and vomiting. Management techniques for these side effects are very similar to those for managing the side effects from cancer drugs.
Although follicular lymphoma may go into remission, the disease may relapse (come back) after initial treatment. For this reason, follow-up care and healthy living are extremely important. Monitoring your health will be key to achieving these goals. Although follicular lymphoma is difficult to cure, it is highly treatable. Doctors typically will focus on maintaining or controlling the disease while minimizing any symptoms related to the follicular lymphoma.

**MONITORING YOUR HEALTH**

After your initial treatment for follicular lymphoma is complete, your doctor will design a follow-up care plan to monitor your health and check for a potential relapse. For this plan to be useful, you must understand and follow it exactly. If you have any questions or concerns as your follow-up care plan is being developed, don’t hesitate to talk to your doctor.

Your follow-up care plan likely will include regular physical examinations, blood tests and/or computed tomography (CT) (See page 2 for more information about these procedures). If signs of relapse are detected, your doctor will talk to you about new treatment options (See Treatment for Relapsed Disease, page 4). It is important to keep personal health care records of all of your medications and doctor appointments. One way to keep track is to use the “My Medical Journal” (see page 17).

In addition to follow-up appointments, it is important to report any side effects or symptoms to your doctor. Honest and timely reporting of how you feel can assist your doctor in managing your disease. Record and describe any changes you experience that are unexplained and persistent, such as pain, fatigue, abnormal bowel and kidney function, fevers and sweats.

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**UNDERSTANDING GOOD NUTRITION**

→ Treating follicular lymphoma may cause a loss of appetite, nausea or vomiting, or a change in your sense of taste, which could make it difficult to eat and maintain your weight. Eating enough high-quality food that is rich in nutrients is important for good health and can support you in your recovery. If you find it difficult to eat, consider eating small portions instead of three big meals a day.

A healthy diet is made up of different food groups that give your body nutrients. These include carbohydrates, protein, fat, fiber, and vitamins and minerals. Carbohydrates are starchy foods, such as rice, bread and pasta. For a healthier option, choose brown, whole grain or whole meal varieties.

A diet high in protein is often recommended for people receiving treatment. Protein helps your body grow and repair itself as you are healing. Foods high in protein include meat, fish, eggs, beans and lentils. Dairy products also contain some protein, calcium and zinc. If you are trying to gain weight, choose full fat options instead of low-fat or non-fat options.

Fats provide an important source of energy and vitamins and often help you feel full. Unsaturated fats are considered heart healthy and may lower your cholesterol. Good examples of food containing unsaturated fats include avocados, Brazil nuts and oily fish. Saturated fats are found in foods such as butter, meat and many processed foods, such as sausage, and should be limited in your diet.

Vitamins and minerals help boost your immune system and keep your bones, teeth and skin healthy. Fruits and vegetables are good sources of vitamins and minerals. It is recommended that you eat at least five servings of fruits and vegetables a day. Fruits and vegetables are also a good source of fiber, which helps your digestive system to function best. Fiber can also be found in cereals and potatoes.

Vitamin D is recommended for people with follicular lymphoma because a lack of vitamin D can contribute to bone loss and other types of cancers. Your doctor can perform a blood test to determine if your vitamin D level is low. To increase your vitamin D level, doctors typically recommend 15 minutes in the sun three days a week or taking supplements. Your doctor will recommend how much to take on a daily basis.

Although sugar may be a good source of energy, it generally is recommended to limit the amount you eat. However, if you are losing weight, adding sugar to your diet may help slow weight loss or gain weight.

Side effects experienced during treatment can affect the ability and joy of eating. Nausea, sore mouth and changes in taste can prevent you from eating. For nausea, antiemetics (anti-sickness medications) are available, and you can try dry, plain foods, such as toast, crackers or rice. For mouth sores, some mouthwashes may be available to try. Many people report changes in how food tastes, saying it is too bland or bitter or has a metallic taste. Adding extra flavoring to foods may help improve the taste. Consider using different herbs, spices and sauces.

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Although follow-up care is important for survivors of all types of cancer, it's especially important for people who have had follicular lymphoma because multiple relapses often occur.

**LIVING A HEALTHY LIFESTYLE**

Perhaps as important as sticking to your follow-up care schedule and managing side effects is staying healthy and active. It's important to maintain good nutrition, be as active as you can, get enough rest and be emotionally healthy. Taking these actions can help you feel better both physically and psychologically, allowing you to better cope with the day-to-day challenges of living with follicular lymphoma.
Maintain good nutrition
It's important to make healthy choices before, during and after treatment. This can be a challenge if you have side effects, such as loss of appetite, nausea or vomiting. A healthy diet rich in protein can help you gain strength, which is especially needed during treatment cycles. In general, try to eat a wide variety of nutrient-rich foods and drink plenty of liquids. Because some cancer treatments can cause loss of bone mass, it is helpful to eat dairy foods and other foods high in calcium. Talk to your doctor or a registered dietitian about the need for calcium and vitamin D, either in your diet or as supplements. (See Understanding Good Nutrition, page 14).

Be active
Participating in physical activities or regular exercise can help you feel better overall. Although it may not seem to make sense, physical exercise is actually the best treatment for fatigue. Studies have shown that people with cancer who exercise regularly feel less tired and have more energy. Weight-bearing activities, such as walking, can help strengthen bones, which is important if you have bone metastasis. Think about what type of physical activity you enjoy most, and engage in it daily, or as often as you can tolerate. Try to modify your favorite form of exercise if you experience any pain or discomfort, rather than discontinue it.

Get enough rest
Sleep disturbances are common among people with cancer. One reason is that fatigue related to cancer and its treatment leads people to take frequent naps during the day, which then makes it difficult to sleep at night. You can still set aside time in your day to rest or take naps, but limit them to 20 to 30 minutes each, and avoid napping in the late afternoon or early evening. Your doctor may review the medications you are taking and change them if drug interactions or side effects are contributing to your sleep problems. Your doctor may also recommend a medication to help you sleep.

Stay emotionally healthy
Living with cancer can often feel like being on an emotional rollercoaster. Allow yourself to express your emotions freely. Finding ways to reduce and manage stress will strengthen your coping abilities. Some possibilities are journaling, meditation, guided imagery, muscle relaxation and yoga. Ordinary “escapes,” such as reading, television and games, can help you relax. You must also be alert to depression and seek help if you’re experiencing a depressed mood and a loss of interest or pleasure in normal activities. Maintaining relationships and participating in support groups — either in-person or online — can go a long way toward helping you stay emotionally healthy.

ADDITIONAL RESOURCES
- American Cancer Society: www.cancer.org
  Depression
  Nutrition for the Person with Cancer During Treatment
  Sleep Problems
- American Society of Clinical Oncology: www.cancer.net
  Caring for the Symptoms of Cancer and its Treatment
  Fatigue
  Lymphoma - Non-Hodgkin - Late Effects of Treatment
- National Cancer Institute: www.cancer.gov
  Coping – Late Side Effects
  Nutrition in Cancer Care

MANAGING LATE EFFECTS

In addition to watching for signs of disease relapse, your doctor will use your follow-up care visits to check for long-term side effects, which are also called late effects. These can begin weeks, months or even years after your treatment ends, and they vary based on your overall health and the type of treatment you received.

Each treatment option offers its own possible late effects. Before you begin treatment, ask your health care team about what symptoms, including late effects, to expect. Be prepared to call your doctor right away if you have any concerns.

Some common late effects of follicular lymphoma treatments include reduced fertility, fatigue, peripheral neuropathy, heart problems, stroke, lung damage, shortness of breath, thyroid problems and increased risk for infection.

One late effect from high-dose chemotherapy is the risk for a second cancer, which is different from cancer than follicular lymphoma. The second cancers that have been linked to chemotherapy treatment for lymphoma include leukemia, lung cancer, brain cancer, kidney cancer, bladder cancer, melanoma and Hodgkin lymphoma.

The use of certain chemotherapy drugs also has been associated with heart problems because they can weaken or damage the heart muscle. Higher doses and more frequent use increase the risk. This late side effect typically occurs 10 years or more after treatment.

Some uncommon late effects from chemotherapy include problems with your teeth and eyes, including cataracts and glaucoma.

Late effects from radiation therapy also are possible and can include problems with your lungs, teeth, eyes, heart and thyroid.

If you stay on top of your follow-up care plan, these late effects often can be managed, allowing you to maintain a high quality of life. Attend follow-up appointments, get to know what is normal for you, get regular check-ups with your dentist and eye doctor, and discuss other cancer screening programs that you may need in addition to your treatments.
**ASSISTANCE & SUPPORT RESOURCES**

**BLOOD CANCER**
- American Society of Hematology: [www.hematology.org](http://www.hematology.org)
- The Angiogenesis Foundation: [www.angiogenesis.org](http://www.angiogenesis.org)
- Delete Blood Cancer/DKMS: [www.deletebloodcancer.org](http://www.deletebloodcancer.org)
- Headstrong Foundation: [www.headstrong.org](http://www.headstrong.org)

**CAREGIVERS & SUPPORT**
- 4th Angel Patient & Caregiver Mentoring Program: [www.4thangel.org](http://www.4thangel.org)
- Bloch Cancer Hotline: [800-433-0464](tel:800-433-0464)
- CanCare: [www.canercare.org](http://www.canercare.org)
- CANCER101: [www.cancer101.org](http://www.cancer101.org)
- Cancer Action: [www.canceractiontc.org](http://www.canceractiontc.org)
- CancerCare: [www.cancercare.org](http://www.cancercare.org)
- Cancer Connection: [www.cancerconnection.org](http://www.cancerconnection.org)
- Cancer Hope Network: [www.cancerhopenetwork.org](http://www.cancerhopenetwork.org)
- Cancer Wellness Center: [www.cancerwellness.org](http://www.cancerwellness.org)
- CaringBridge: [www.caringbridge.org](http://www.caringbridge.org)
- Family Caregiver Alliance: [www.caregiver.org](http://www.caregiver.org)
- Fighting Chance: [www.fightingchance.org](http://www.fightingchance.org)
- Friend for Life Cancer Support Network: [www.friend4life.org](http://www.friend4life.org)
- The Hope Light Foundation: [www.hopelightproject.com](http://www.hopelightproject.com)
- Immerman Angels: [www.imermanangels.org](http://www.imermanangels.org)
- The LGBT Cancer Project – Out With Cancer: [www.lgbtcancer.com](http://www.lgbtcancer.com)
- LIVESTRONG Foundation: [www.livestrong.org](http://www.livestrong.org)
- MyLifeLine.org Cancer Foundation: [www.mylifeline.org](http://www.mylifeline.org)
- Patient Empowerment Network: [www.powerfulpatients.info](http://www.powerfulpatients.info)
- Patient Power: [www.patientpower.info](http://www.patientpower.info)
- PeerPoint Cancer Support: [https://my.peerpoin.org](http://https://my.peerpoin.org)
- SHARE Caregiver Circle: [www.sharecancersupport.org/support](http://www.sharecancersupport.org/support)
- Strike Out Cancer: [www.strikeoutcancer.com](http://www.strikeoutcancer.com)
- Stronghold Ministry: [www.stronghold.org](http://www.stronghold.org)
- Triage Cancer: [www.triagecancer.org](http://www.triagecancer.org)
- Turning Point: [www.turningpointic.org](http://www.turningpointic.org)
- Vital Options International: [www.vitaloptions.org](http://www.vitaloptions.org)
- Well Spouse Association: [www.wellsopurse.org](http://www.wellsopurse.org)

**CLINICAL TRIALS**
- ACCESS: [www.access.cantria.com](http://www.access.cantria.com)
- ACT (About Clinical Trials): [www.learnaboutclinicaltrials.org](http://www.learnaboutclinicaltrials.org)
- Center for Information and Study on Clinical Research Participation: [www.searchclinicaltrials.org](http://www.searchclinicaltrials.org)
- ClinicalTrials.gov: [www.clinicaltrials.gov](http://www.clinicaltrials.gov)
- Coalition of Cancer Cooperative Groups: [www.cancerrтайlhelp.org](http://www.cancerrтайlhelp.org)
- LIVESTRONG Foundation: [www.livestrong.org](http://www.livestrong.org)
- PeerPoint Cancer Support: [https://my.peerpoin.org](http://https://my.peerpoin.org)
- MolecularMatch: [http://molecularmatch.com](http://molecularmatch.com)
- My Clinical Trial Locator: [http://myclinicaltriallocator.com](http://myclinicaltriallocator.com)
- National Cancer Institute: [www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials)
- Stand Up To Cancer: [www.standup2cancer.org](http://www.standup2cancer.org)
- TrialCheck: [www.trialcheck.org](http://www.trialcheck.org)

**FINANCIAL ASSISTANCE**
- BenefitsCheckUp: [www.benefitscheckup.org](http://www.benefitscheckup.org)
- Bringing Hope Home: [www.bringinghopehome.org](http://www.bringinghopehome.org)
- CancerCare: [www.cancercare.org](http://www.cancercare.org)
- Cancer Financial Assistance Coalition: [www.cancerfac.org](http://www.cancerfac.org)
- The CHAIN Fund: [www.thechainfund.org](http://www.thechainfund.org)
- HealthWell Foundation: [www.healthwellfoundation.org](http://www.healthwellfoundation.org)
- Hope Lodge: [www.cancer.org/treatment/support programaservicest/hopelodge](http://www.cancer.org/treatment/support programaservicest/hopelodge)
- Medicare.gov: [www.medicare.gov](http://www.medicare.gov)
- NeedyMeds: [www.needymeds.com](http://www.needymeds.com)
- Partnership for Prescription Assistance: [www.ppaox.org](http://www.ppaox.org)
- Patient Access Network Foundation: [www.panfoundation.org](http://www.panfoundation.org)
- Patient Advocate Foundation: [www.patientadvocate.org](http://www.patientadvocate.org)

**LyMOMA**
- Be the Match: [www.bethematc.org](http://www.bethematc.org)
- Blood & Marrow Transplant Information Network: [www.bmtnetfonet.org](http://www.bmtnetfonet.org)
- Headstrong Foundation: [www.headstrong.org](http://www.headstrong.org)
- The Leukemia & Lymphoma Society: [www.lls.org](http://www.lls.org)
- Lymphoma Foundation of America: [www.lymphomahelp.org](http://www.lymphomahelp.org)
- Lymphoma Information Network: [www.lymphomainfo.net](http://www.lymphomainfo.net)
- Lymphoma Research Foundation: [www.lymphoma.org](http://www.lymphoma.org)
- National Bone Marrow Transplant Link: [www.nhtlink.org](http://www.nhtlink.org)
- Patients Against Lymphoma: [www.lymphomation.org](http://www.lymphomation.org)

**PAIN MANAGEMENT**
- American Chronic Pain Association: [www.theacpa.org](http://www.theacpa.org)
- Cancer Pain Research Consortium: [www.cancerpainresearchconsortium.org](http://www.cancerpainresearchconsortium.org)
- LIVESTRONG Foundation: [www.livestrong.org](http://www.livestrong.org)
- The Resource Center of the Alliance of State Pain Initiatives: [www.trc.wisc.edu](http://www.trc.wisc.edu)
- U.S. Pain Foundation: [www.uspainfoundation.org](http://www.uspainfoundation.org)

**PRESCRIPTION EXPENSES**
- The Bone Marrow Foundation: [www.bonemarrow.org](http://www.bonemarrow.org)
- CancerCare Co-Payment Assistance Foundation: [www.cancercarecopt.org](http://www.cancercarecopt.org)
- Cancer Financial Assistance Coalition: [www.cancerfac.org](http://www.cancerfac.org)
- The CHAIN Fund Inc: [www.thechainfund.com](http://www.thechainfund.com)
- Foundation for Health Coverage Education: [www.coverageforall.org](http://www.coverageforall.org)
- GoodDays: [www.gooddaysfromcf.org](http://www.gooddaysfromcf.org)
- HealthWell Foundation: [www.healthwellfoundation.org](http://www.healthwellfoundation.org)
- Leukemia & Lymphoma Society: [www.lls.org](http://www.lls.org)
- NeedyMeds: [www.needymeds.com](http://www.needymeds.com)
- Partnership for Prescription Assistance: [www.ppaox.org](http://www.ppaox.org)
- Patient Access Network Foundation: [www.panfoundation.org](http://www.panfoundation.org)
- Patient Advocate Foundation Co-Pay Relief: [www.copays.org](http://www.copays.org)
- Patient Services, Inc: [www.patientsviesinc.org](http://www.patientsviesinc.org)
- ReAssist: [www.rassocist.org](http://www.rassocist.org)
- ReHope: [www.rehope.com](http://www.rehope.com)
- RoOutreach: [www.rooutreach.org](http://www.rooutreach.org)
- Together Rx Access: [www.togetherhaxccess.org](http://www.togetherhaxccess.org)

**REIMBURSEMENT & PATIENT ASSISTANCE PROGRAMS**
- Amgen Assist 360: [www.amgenassistanceonline.com](http://www.amgenassistanceonline.com)
- Amgen First Step: [www.amgenfirststep.com](http://www.amgenfirststep.com)
- Boehringer Ingelheim Cares Foundation: [www.boehringer-ingelheim.com](http://www.boehringer-ingelheim.com)
- Celgene Patient Support: [www.celgenepatientsupport.com](http://www.celgenepatientsupport.com)
- Cephalon Cares Foundation: [www.cephaloncares.com](http://www.cephaloncares.com)
- Eisai Reimbursement Resources: [www.eisaiereimbursement.com](http://www.eisaiereimbursement.com)
- Genentech Access Solutions: [www.genentech-access.com](http://www.genentech-access.com)
- Janssen Prescription Assistance: [www.janssenprescriptionassistance.com](http://www.janssenprescriptionassistance.com)
- Johnson & Johnson Patient Assistance Foundation, Inc: [www.jfapf.org](http://www.jfapf.org)
- Merck Access Program: [www.merckaccessprogram.com](http://www.merckaccessprogram.com)
- Merck Helps: [www.merckhelps.com](http://www.merckhelps.com)
- Novartis Patient Assistance Now: [www.patientassistantcnow.com](http://www.patientassistantcnow.com)
- Patient Rx Solutions: [www.patientrxsolutions.com](http://www.patientrxsolutions.com)
- Pfizer RxFibrates: [www.pfreizimeter.com](http://www.pfreizimeter.com)
- Revlimid Co-Payment Assistance: [www.revlimid.com/mds-patient-resources](http://www.revlimid.com/mds-patient-resources)
- Sandor One Source: [www.sandoronesource.com](http://www.sandoronesource.com)
- Sanofi Patient Connection: [www.sanofipatientconnection.com](http://www.sanofipatientconnection.com)
- Takeda Patient Assistance: [www.takeda.us/responsibility/patient_assistance_program.aspx](http://www.takeda.us/responsibility/patient_assistance_program.aspx)
- Teva Cares Foundation Patient Assistance Programs: [www.tevacares.org](http://www.tevacares.org)
- Teva Oncology Core Reimbursement Assistance & Support: [www.tevaoare.com](http://www.tevaoare.com)
- Zydigil AccessConnect: [www.zydigilaccessconnect.com](http://www.zydigilaccessconnect.com)
A medical journal can help you keep track of all of your medications, appointments and health care contacts. Note the name and contact information for each health care professional and any drugs they have prescribed. You can share this list with your health care team so they can help you manage your medications and avoid drug interactions.

### JOURNAL ENTRIES

**MY APPOINTMENTS**

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<tr>
<th>DATE</th>
<th>HEALTH CARE PROFESSIONAL</th>
<th>REASON FOR VISIT</th>
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### DAILY REMINDERS

**MY MEDICATIONS**

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<thead>
<tr>
<th>MEDICATION</th>
<th>DOSAGE</th>
<th>DIRECTIONS</th>
<th>PURPOSE</th>
<th>NEXT REFILL</th>
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<tbody>
<tr>
<td>Ex: Drug name</td>
<td>350 mg</td>
<td>Once every 4 hrs.</td>
<td>Pain management</td>
<td>8/31/2017</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>MEDICATION</th>
<th>DOSAGE</th>
<th>DIRECTIONS</th>
<th>PURPOSE</th>
<th>NEXT REFILL</th>
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### MY MEDICAL TEAM CONTACTS

**PHYSICIAN AND PHARMACY INFORMATION**

**Physician:**

Address

City

State

ZIP

Phone

Fax

**Nurse Navigator:**

Address

City

State

ZIP

Phone

Fax

**Pharmacy:**

Address

City

State

ZIP

Phone

Fax

**Lab:**

Address

City

State

ZIP

Phone

Fax