

Follicular lymphoma

This page is about follicular lymphoma, the most common type of low-grade non-Hodgkin lymphoma.

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We have separate information about the topics in **bold font**. Please get in touch if you'd like to request copies or if you would like further information about any aspect of lymphoma. Phone 0808 808 5555 or email information@lymphoma-action.org.uk.

What is follicular lymphoma?

Lymphoma is a type of blood cancer that develops when white blood cells called **lymphocytes** grow out of control. Lymphocytes are part of your **immune system**. They travel around your body in your **lymphatic system**, and blood, helping you fight infections. There are two types of lymphocyte: **T lymphocytes (T cells)** and **B lymphocytes (B cells)**.

Lymphomas can be grouped as **Hodgkin lymphomas** or **non-Hodgkin lymphomas**, depending on the types of cell they contain. Follicular lymphoma is a common type of slow-growing (low-grade) non-Hodgkin lymphoma that develops from B cells. It is called ‘follicular’ lymphoma because the abnormal B cells usually develop in clumps called ‘follicles’ inside **lymph nodes**.

Who gets follicular lymphoma and what causes it?

Follicular lymphoma is the most common type of low-grade non-Hodgkin lymphoma. About 2,200 people are diagnosed with follicular lymphoma every year in the UK. It can develop at any age, but it is more common in people over 60.

In most cases, there is no known cause for follicular lymphoma. Some genetic changes are common in follicular lymphoma, but scientists don’t know what causes them. There is not normally any family history of follicular lymphoma.

Symptoms

Follicular lymphoma is usually very slow-growing so **symptoms** develop gradually over time. Many people have few symptoms and some have none at all. Sometimes follicular lymphoma is noticed during tests for a different health issue. However, follicular lymphoma can be very variable and some people might have faster-growing follicular lymphoma that causes more symptoms.

The most common symptom of follicular lymphoma is a lump or several lumps. These typically develop in your neck or just above your collar bones but they can develop in other places, such as your armpits or groin. The lumps are caused by lymphoma cells building up in your lymph nodes, which makes the lymph nodes swell. The **swollen lymph nodes** are usually painless. They might stay swollen or they might shrink a little and then come back from time-to-time. Most people have no other symptoms.

Some people have other common symptoms of lymphoma, such as:

- **unexplained weight loss**
- **fevers** (temperature above 38°C)
- **drenching sweats**, especially at night
- frequent **infections**, or having difficulty getting over infections
- **fatigue** (overwhelming tiredness).

Weight loss, drenching sweats and fevers often occur together. These three symptoms are called 'B symptoms'.

Rarely, follicular lymphoma is found outside of the lymph nodes. This is called 'extranodal' lymphoma. Extranodal lymphoma can cause a **variety of symptoms** depending where the lymphoma is growing.

Around 1 in 2 people with follicular lymphoma have lymphoma cells in their **bone marrow** (the spongy centre of larger bones where blood cells are made) when they are diagnosed. This might lead to:

- **anaemia** (low red blood cell count), which can cause tiredness and shortness of breath
- **thrombocytopenia** (low platelet count), which makes you more likely to bruise and bleed
- **neutropenia** (low neutrophil count – a type of white blood cell), which makes you more prone to infection.

Diagnosis and staging

The main way to diagnose follicular lymphoma is to remove a sample of cells from your body and look at it under a microscope. This involves a procedure called a **biopsy**, which is usually done under a local anaesthetic. You might have a 'needle core biopsy', when a doctor uses a hollow needle to remove a 'core' of tissue from a lymph node. Sometimes a whole lymph node needs to be removed. This involves a small operation. It is usually performed under local anaesthetic.

The biopsy sample is examined by an expert lymphoma **pathologist**. The pathologist might also test the lymphoma cells for particular proteins and genetic changes. This can help your medical team decide on the most appropriate **treatment** for you.



I had no idea what follicular lymphoma was. I was in proper panic mode – fearful and horrified. My wife, Brenda, found out as much information as she could from Lymphoma Action, and in fact we were given one of the charity’s leaflets at the hospital when I was diagnosed. But it was really hard for me to take in information at that point. Your brain’s still in shock I think.

Malcolm, diagnosed in 2007

You also have **blood tests** to look at your general health, check your **blood cell counts**, make sure your kidneys and liver are working well, and test for viral infections that could reactivate during treatment.

You have other tests to find out which areas of your body are affected by lymphoma. This is called **staging**. Staging usually involves having a **CT scan** and often also a **PET scan**. You might have a sample of your bone marrow cells taken (a **bone marrow biopsy**), to check if you have lymphoma cells in your bone marrow.

You usually have your tests done as an outpatient. It takes a few weeks to get all the results. **Waiting for test results** can be a worrying time, but it is important for your medical team to have all the information they need so they can plan the most appropriate treatment for you.

Because follicular lymphoma typically grows slowly and might not cause any symptoms, it is often **advanced** (stage 3 or 4) by the time it is diagnosed. There are treatments for all stages of follicular lymphoma, which can usually keep the lymphoma under control for many years.



I noticed a dull ache in my groin and felt a lump. After tests, a haematologist told me I had follicular B-cell non-Hodgkin lymphoma, probably stage 3. A month before, I didn't even know there was anything wrong with me, and now I am diagnosed with a stage 3 cancer. How does that work?

Andy, diagnosed in 2009

Grading of follicular lymphoma

Your doctor might tell you the grade (1, 2, 3A or 3B) as well as the stage of your lymphoma. The grade relates to the number of large lymphocytes that the pathologist can see under a microscope. Grade 1 has the fewest large lymphocytes and grade 3B has the most. Grades 1 and 2 are often grouped together. Your doctor might call this 'grade 1 to 2' follicular lymphoma.

Grades 1 to 2 and 3A follicular lymphoma are all slow-growing and are treated in the same way. The grade does not affect the likely outcome of treatment.

Grade 3B follicular lymphoma is usually fast-growing. Under a microscope, it looks like a type of high-grade non-Hodgkin lymphoma called **diffuse large B-cell lymphoma (DLBCL)**. It is treated the same way as DLBCL.

Your 'prognostic score'

Your doctor might use your test results to give you a score that can help predict your response to treatment. This is called a 'prognostic score'. There are a number of different scoring systems for follicular lymphoma. One of the most common in the UK is the 'FLIPI', which gives you a score based on:

- your age
- how widespread your lymphoma is
- the results of some of your blood tests.

Other scoring systems are based on the particular genetic changes your lymphoma cells have.

Your doctor might use your prognostic score to help decide on the most appropriate treatment for you.

Types of follicular lymphoma

Most people who have follicular lymphoma do not have a particular type. However, there are some rare variants of follicular lymphoma that behave, and are treated, differently. These include:

- duodenal-type follicular lymphoma
- paediatric-type follicular lymphoma.

We have separate information on [primary cutaneous follicle centre lymphoma](#). This is a type of low-grade B-cell skin lymphoma that used to be classified as a type of follicular lymphoma.

Duodenal-type follicular lymphoma

Duodenal-type follicular lymphoma grows in the small intestine (small bowel or gut). It is slow-growing and is usually diagnosed at an early stage. Duodenal-type follicular lymphoma is unlikely to spread to other parts of your body or change (transform) into a faster-growing type of lymphoma. People with duodenal-type follicular lymphoma might be observed ([active monitoring](#)), treated with [rituximab](#) (on its own or with [chemotherapy](#)) or treated with [radiotherapy](#). Treatment is usually very successful.

Paediatric-type follicular lymphoma

Paediatric-type follicular lymphoma is a very rare form of follicular lymphoma. It typically affects children but it occasionally develops in adults. It is more common in males than females.

Paediatric-type follicular lymphoma most commonly develops in lymph nodes in the head or neck. It is typically diagnosed at an early stage and is usually cured with treatment. Most people have surgery to remove the affected lymph nodes. Occasionally, some people need **radiotherapy** or **chemotherapy**. Paediatric-type follicular lymphoma does not usually come back (relapse) after successful treatment.

Outlook

Follicular lymphoma often grows slowly, although in some people it can develop more rapidly. Treatment is generally successful, but at some point, the lymphoma usually comes back (relapses) and needs more treatment to keep it under control. It is hard to predict how long it might be before you need more treatment.

Most people live with follicular lymphoma for many years. You might have periods when you feel well and don't need treatment, and other periods when your symptoms get worse and you need more treatment.

Your doctor is best placed to advise you on your outlook (prognosis) based on your individual circumstances.

Transformation

Sometimes, follicular lymphoma changes (**transforms**) into a faster-growing type of lymphoma. This happens in around 2 to 3 in every 100 people with follicular lymphoma each year.

If your doctor thinks your lymphoma might have transformed, you are likely to have a **biopsy** to check for faster-growing cells. Transformed follicular lymphoma is usually treated like a high-grade lymphoma such as **diffuse large B-cell lymphoma (DLBCL)**.

Treatment

Follicular lymphoma is slow-growing and there is rarely an urgent need for treatment. Some people might not need treatment for many years. Your medical team will consider carefully whether you need treatment straightaway and what treatment is best for you.

The treatment your medical team recommends for you depends on the stage of your lymphoma and the signs and symptoms you have. **Stage 1** or **stage 2** follicular lymphoma is known as 'early-stage' lymphoma. **Stage 3** or **stage 4** follicular lymphoma is known as 'advanced-stage' lymphoma. Most people have advanced stage follicular lymphoma when they are diagnosed.

When choosing your treatment, your team also takes into account:

- where your lymphoma is growing
- how big the lumps of lymphoma are
- how the lymphoma is affecting you, including any symptoms you're experiencing and the results of your blood tests
- your general health and fitness
- your age
- your feelings about treatment.

Your team also considers any potential **side effects**, long-term or **late effects** (health problems that develop months or years after treatment) of the treatment.

Treatment of early-stage follicular lymphoma

Around 1 in 5 people with follicular lymphoma are diagnosed when it is at an early stage. Early-stage follicular lymphoma that is only growing in one part of your body can sometimes be very effectively treated with **radiotherapy** to the affected area. Some people might even be cured with this approach. Low doses of radiotherapy have few **side effects**.

Sometimes radiotherapy is not suitable – for example, if your lymphoma is close to important organs that could be damaged by the radiotherapy, or if you have other medical conditions that make radiotherapy unsuitable. If this is the case, and you are not experiencing troublesome symptoms, you might not need treatment straightaway. Instead, you might be monitored during regular visits to your doctor. This is called **active monitoring** or ‘watch and wait’. This approach keeps treatment for when it is needed and allows you to avoid the side effects of treatment for as long as possible. Alternatively, you might have **antibody therapy** with **rituximab** on its own, or you might be treated in the same way as people with advanced-stage follicular lymphoma.

Treatment of advanced-stage follicular lymphoma

Most people have advanced-stage follicular lymphoma when they are diagnosed. Advanced-stage follicular lymphoma can be treated very successfully. Treatment aims to keep the lymphoma under control for as long as possible with as few side effects as possible. Although the lymphoma usually comes back (**relapses**) and needs more treatment at some point, most people with follicular lymphoma have long periods of feeling well between courses of treatment.

If you have advanced-stage follicular lymphoma that is not causing troublesome symptoms, you might not need treatment straightaway. Instead, your doctors might recommend an approach called ‘**active monitoring**’ (or ‘watch and wait’). This involves having regular check-ups with your medical team to monitor your health and to see how the lymphoma is affecting you. Active monitoring means that while you are well, you avoid the side effects of chemotherapy for as long as possible. Treatment is still available when you need it, but this might not be for months or years. Even if you don’t have any symptoms, your medical team might recommend a short course of an **antibody treatment** (for example **rituximab**). This can help to delay your need for chemotherapy.

If your lymphoma is causing problems, your medical team are likely to recommend a course of **chemotherapy** combined with **antibody therapy**. This is sometimes called chemo-immunotherapy.



I was diagnosed with stage 4 follicular lymphoma and had six cycles of R-CHOP chemotherapy. I think I had prepared myself for a horrible experience, so, although I felt queasy at times, treatment wasn't as bad as I had expected. I had been warned that I would lose my hair, but this wasn't something I really worried about – in fact, I have more hair now that it has grown back than I did before.

Douglas, diagnosed in 2010

The most common **chemotherapy regimens** (combinations of drugs) used to treat follicular lymphoma are:

- bendamustine
- CVP – cyclophosphamide, vincristine and prednisolone
- CHOP – cyclophosphamide, doxorubicin (also known as hydroxydaunorubicin), vincristine (also known as Oncovin®) and prednisolone)
- chlorambucil.

They are usually given with antibody therapy. At the time of writing, two antibody therapies are available to treat follicular lymphoma in the UK:

- **rituximab** – in which case an 'R' is added to the name of your chemotherapy regimen (for example R-CHOP)
- **obinutuzumab** – in which case an 'O' is added to the name of your chemotherapy regimen (or sometimes a 'G', after the trade name of obinutuzumab: Gazyvaro®).

If you respond well to your course of chemo-immunotherapy, you are likely to be offered **maintenance treatment**. This aims to keep your lymphoma under control and make your **remission** (the time when your lymphoma has shrunk or gone completely) last as long as possible. Maintenance treatment involves having an injection of your antibody therapy (either rituximab or obinutuzumab) every 2 months for up to 2 years.

In retrospect, I am pleased that I did not know anything about the side effects of my chemotherapy. I was aware that I might feel sick but, surprisingly, I never did. As the weeks progressed though, my 'dip' days became harder alongside the fatigue, the aching in my bones, the loss of appetite and most of all the mouth blisters. I never realised how difficult it is to keep your tongue still...

I can reflect now about how hard it was, particularly the last two cycles, and I am in awe of myself and how I managed to survive, let alone manage to smile occasionally! It is a very difficult thing to go through in so many ways but having wonderful support, both medical and at home, was key to keeping me going.

Debbie, diagnosed in 2010

Follow-up

If you are on active monitoring (watch and wait) or you're in **remission** after treatment, you'll have regular **follow-up appointments** in the clinic. Your follow-up appointments are to check that:

- you are recovering well from treatment
- you have no signs of the lymphoma relapsing or getting worse
- you are not developing any **late effects** (side effects that develop months or years after treatment).

At each appointment, your doctor or nurse specialist examines you and asks if you have any concerns or symptoms. You might have blood tests. You are unlikely to have a scan unless you have troubling symptoms.

Some people go onto a **self-management scheme**. Your medical team gives you information on what to look out for and how to book an appointment if you need one. You might have blood tests at your GP surgery. If you are worried about your health at any time, you can contact your medical team.



My last chemotherapy was 13 years ago and check-ups are now annual. I have been lymphoma free for 13 years and have done things I could barely have dreamed of doing before I was diagnosed. I realise how getting older really is a privilege, and I am so grateful for being able to look forward to the next stage in my life.

Caroline, diagnosed in 2006

Relapsed or refractory follicular lymphoma

Treatment for follicular lymphoma is usually effective. However, follicular lymphoma usually comes back (**relapses**) and needs more treatment at some point. Most people with follicular lymphoma need several courses of treatment during their illness.

The length of **remission** after successful treatment can vary widely, so it can be difficult to predict how long it might be before you need more treatment. Some people stay in remission for several years but others need more treatment sooner.



A diagnosis isn't necessarily as bad as it may seem at first. Since by all accounts I should not have had this type at a young age I feel very lucky that each time it has relapsed new treatments were offered and that many years later I am able to tell my story.

Carole, diagnosed in 1984

Occasionally, lymphoma doesn't respond well to your first treatment. This is called 'refractory' lymphoma. Refractory lymphoma is usually treated in a similar way to relapsed lymphoma.

If you have follicular lymphoma that comes back, you might have the same symptoms you had before or you might have different symptoms. If your medical team suspects your lymphoma has come back, they are likely to recommend that you have another **biopsy** to make sure it has not changed (transformed) to a faster-growing type of lymphoma. You are also likely to have more scans to check the stage of your lymphoma.

Treatment for relapsed or refractory follicular lymphoma

If your lymphoma is not causing troublesome symptoms, you might have a period of **active monitoring** (watch and wait) before starting any treatment. If you need treatment, several different options are available for relapsed and refractory follicular lymphoma. Your medical team will consider all of the same factors they considered before as well as:

- the treatment you've already had
- how well your lymphoma responded to previous treatment
- how you coped with your previous treatment
- how quickly your lymphoma relapsed.

Your medical team might discuss several treatment options with you. You should have time to consider the options carefully and discuss the risks and benefits with your team to help you decide what treatment is best for you. We outline some of the more common approaches here but your medical team might recommend a different option.

- If you have not had rituximab as part of your treatment before, or you had a long remission after rituximab-based treatment, you might have rituximab again, combined with chemotherapy. This might be the same **chemotherapy regimen** you had before, or a different one. If you have not had **maintenance therapy** before, you might have a course of rituximab maintenance therapy afterwards.
- If you have had rituximab as part of your treatment before but you did not respond to it, or you relapsed within 6 months of having it, you might be offered **obinutuzumab** plus bendamustine, followed by obinutuzumab maintenance therapy.
- You might have treatment with **rituximab** combined with a **targeted drug** called **lenalidomide** (also known as **Revlimid®**). This combination is sometimes called R².
- If your lymphoma has relapsed more than once, you might be offered treatment with a targeted drug called **idelalisib**. At the time of writing, idelalisib is available on the NHS in Scotland but it is not currently available on the NHS in other parts of the UK except as part of a clinical trial.

If you respond well to more treatment, your medical team might recommend a **stem cell transplant** to help your remission last as long as possible. Stem cell transplants are a very intensive form of treatment and you have to be fit enough to have one.

If chemotherapy or targeted therapy isn't suitable for you, your medical team might suggest that you have rituximab on its own.

If your lymphoma is causing problems in one particular area of your body, you might be offered **radiotherapy** to the affected area to help control your symptoms.

Research and targeted treatments

Scientists are testing many different **targeted treatments** in **clinical trials** for follicular lymphoma, including some treatments that are already approved for other types of lymphoma. Many of these new targeted drugs work by helping your own immune system get rid of the lymphoma. They might offer the possibility of more chemotherapy-free treatments in the future.



It was clearly explained to me that the drug was being trialled and that it was impossible to know at that stage if it was the best course of treatment, although the clinical team seemed to think it would be. But they stressed it had to be my decision.

Although the information I was given was easy enough to read and understand, I took it to my GP to discuss. She pointed out that my progress would be well monitored, in terms of the number of check-ups, blood tests and opportunities to see the treating team.

Sue, diagnosed in 2007. She experienced a relapse in 2010 and had treatment as part of a clinical trial.

New types of treatment that are being tested in people with follicular lymphoma include:

- New **antibody therapies**, including antibodies that bind to two different targets (one on lymphoma cells and one on T cells, which helps the T cells find and destroy the lymphoma cells). These are called 'bispecific' antibodies.

- **Antibody–drug conjugates** (antibodies joined to chemotherapy drugs). The antibody sticks to a protein on the surface of lymphoma cells and carries the chemotherapy drug directly to it.
- **Checkpoint inhibitors**, which stop lymphoma cells blocking the pathways your immune system uses to recognise and destroy cancer cells.
- **Cell signal blockers**, which block signals that B cells send to help them divide or stay alive. Cell signal blockers include targeted drugs such as BTK inhibitors, PI3K inhibitors and BCL-2 inhibitors, named after the particular proteins they block.
- **CAR T-cell therapy**, which involves genetically modifying your own T cells so they can recognise and kill lymphoma cells.
- Drugs that block proteins linked to particular genetic changes in lymphoma cells.

Some of these might be available to you through a clinical trial. If you are interested in taking part in a clinical trial, ask your doctor if there is a trial that might be suitable for you. To find out more about clinical trials or to search for a trial that might be suitable for you, visit [Lymphoma TrialsLink](#).

References

The full list of references for this page is available on our website. Alternatively, email publications@lymphoma-action.org.uk or call 01296 619409 if you would like a copy.

Acknowledgements

- Dr Kirit Ardeshta, Divisional Clinical Director for Cancer and Consultant Haematologist, University College Hospital, London.
 - Dr William Townsend, Consultant Haematologist and Lead for Early Phase Lymphoma Trials, University College London Hospitals NHS Trust. Dr Townsend has received honoraria and consultancy fees from Roche and Gilead.
 - We would like to thank the members of our Reader Panel who gave their time to review this information.
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Content last reviewed: August 2020
Next planned review: August 2023
LYMweb0092FollicularLymph2020v4

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