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Nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL)

Nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL) is a rare type of Hodgkin lymphoma.

On this page

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 NLPHL?

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, helping you fight infections. There are two types of lymphocyte: T lymphocytes (T cells) and B lymphocytes (B cells).

There are lots of different types of lymphoma. Nodular lymphocyte predominant Hodgkin lymphoma (NLPHL) is listed as a type of Hodgkin lymphoma. However, it is different to classical Hodgkin lymphoma and may be referred to as "nodular lymphocyte predominant B cell lymphoma".

NLPHL is a slow-growing type of lymphoma.

Who gets NLPHL?

NLPHL is rare. Around 220 people are diagnosed with it in the UK every year. It can develop at any age, although it's most common in people in their 30s to 50s. It can also affect children and young adults.

NLPHL is much more common in males than females, but scientists don't know why.

There is no known cause for most cases of NLPHL.

3 in 4 people with NLPHL are male

Symptoms

The most common symptom of NLPHL is a lump or lumps. These typically develop in your neck, armpits or groin. They can develop in other places, too. 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.

> I had raised lymph nodes in my neck, and could feel small lumps which felt very small and very mobile. At the time I thought it was just my lymphatic system doing its job.
>
> *Surinder, diagnosed with NLPHL*

Read Surinder's story.

Swollen lymph nodes are often the only symptom. Sometimes, people have other symptoms, such as:

- losing weight without trying to
- fevers (temperature above 38°C)
- drenching sweats, especially at night.

These three symptoms are called 'B symptoms'.

Diagnosis and staging

NLPHL is diagnosed by a small procedure called a biopsy. A sample of tissue, such as a swollen lymph node or part of one, is removed, usually under local anaesthetic. An expert lymphoma pathologist examines the sample under a microscope to check for lymphoma cells. They usually also run specialist tests to help them find out the exact type of lymphoma it is.

You also have scans to find out if you have lymphoma in any other parts of your body. This is called staging. Staging usually involves having a CT scan or a PET/CT scan. Children might have an MRI scan instead.

Depending on the results of your other tests, you might have a bone marrow biopsy to check for lymphoma cells in the spongy tissue in the centre of your bones where

blood cells are made. This involves having a sample of cells taken from your hip bone or, occasionally, your breastbone under local anaesthetic.

You also have blood tests to look at your general health, check your blood cell counts and make sure your kidneys and liver are working well. Blood tests can also check for infections that could influence your treatment.

You usually have your tests done as an outpatient. It can take a few weeks to get all the results back. Waiting for the results of your tests can be difficult. Our Helpline (freephone 0808 808 555, 10am to 3pm, Monday to Friday) can offer support if you'd like to talk things through. It is important for your medical team to find out exactly what type of lymphoma you have and where it is. This helps them plan the most appropriate treatment for you.

Outlook

Treatment for NLPHL is very effective. Most people either go into complete remission (disappearance of the lymphoma) or a partial remission (significant shrinkage of the lymphoma) and usually have a long period without any symptoms. Although NLPHL can come back (relapse), treatment is usually successful. For most people, having NLPHL will have little or no effect on how long they live.

Your medical team are best placed to advise you on your outlook based on your individual circumstances. They can use the results of your tests and other factors (for example, your age and physical fitness) to help choose the best treatment for you.

Transformation

Occasionally, NLPHL can change (transform) into a faster growing type of lymphoma. This is uncommon. It happens in around 1 in 100 people with NLPHL each year.

Transformed lymphoma needs stronger treatment than NLPHL. It is usually treated like a type of fast-growing (high-grade) non-Hodgkin lymphoma called diffuse large B-cell lymphoma (DLBCL). Transformed NLPHL often responds well to treatment and many people go into complete remission.

Treatment

Treating NLPHL in a similar way to classical Hodgkin Lymphoma can be very effective, but it is now recognised that most patients (adults and children) with NLPHL do not require as intensive treatment.

The treatment your medical team will recommend for you depends on several factors, including:

- the stage of your lymphoma
- your symptoms
- your age and general health
- your feelings about the treatment options
- whether or not you plan to have children in the future.

Your medical team also take into account the possible side effects or late effects (health problems that develop months or years after treatment) of the different treatment options. They should discuss these with you.

If appropriate, your consultant can refer you to a fertility specialist before you start treatment.

Treatment of early stage NLPHL

Most people with NLPHL have early stage lymphoma (stage 1 or stage 2 without any B symptoms) when they are diagnosed. This means the lymphoma is only growing in one place, or a few places close together. If you have early stage NLPHL, you might only need treatment to the area affected by lymphoma.

If your lymphoma is in a place where it can be removed, you might be offered surgery. If you have no signs of lymphoma left after surgery, you might not need any more treatment. Instead, your medical team might recommend that you have regular check-ups to make sure the lymphoma stays under control. This is called active monitoring (active surveillance or 'watch and wait'). If there are lymphoma cells left behind after your surgery, your medical team are likely to recommend a course of radiotherapy, too.

If you have early stage NLPHL that can't be removed, you might have radiotherapy to the part of your body affected by lymphoma. This is usually very successful.

Your consultant might ask you if you'd like to take part in a clinical trial, if there is one suitable for you.

If these options aren't suitable for you, your team are likely to suggest the same treatment options used for people with advanced-stage NLPHL.

Treatment of advanced stage NLPHL

Around 1 in 4 people have advanced stage NLPHL (stage 2 with B symptoms, stage 3 or stage 4) when they are diagnosed. Advanced NLPHL still responds very well to treatment. The main difference is that you have treatment to your whole body rather than just one area.

If you have advanced-stage NLPHL but your symptoms aren't interfering with your day-to-day life, you might not need treatment straightaway. Instead, your medical team might recommend active monitoring (active surveillance or 'watch and wait'). This involves having regular check-ups to monitor how the lymphoma is affecting you.

Active monitoring means that you avoid the side effects of treatment for as long as possible. Treatment is still available if your lymphoma starts to cause problems or if you develop symptoms that are hard to cope with. Treatment is just as successful in people who save it until they need it as in people who have treatment straightaway.

> It was explained to me that I could have a period of active monitoring (watch and wait) or they could consider starting treatment with R-CHOP chemotherapy straightaway. Although radiotherapy can be an option for NLPHL, they said it was not appropriate in my case. I felt very strongly that I wanted to start treatment straightaway and made my preference very clear to my treating team.
>
> *Surinder, diagnosed with NLPHL*

If your lymphoma needs treatment, you are most likely to have chemotherapy combined with the antibody treatment rituximab (R). There are a range of chemotherapy regimens available. These include:

- R-CHOP
- R-CVP

- R-ABVD.

Your medical team will recommend the one best suited to your individual circumstances.

People who are not well enough to have chemotherapy might have rituximab on its own.

Your consultant might ask you if you'd like to take part in a clinical trial, if there is one suitable for you.

Follow-up

When you finish treatment, you have a scan to check how well your lymphoma has responded. This is usually a CT or PET/CT scan, but children might have an ultrasound or MRI scan instead.

> I had six cycles of chemotherapy over a 6 month period and had another scan at the end. The scan came back clear. I remember crying when I heard the news. It was such a relief for me and for my family.
>
> *Adam, diagnosed with NLPHL*

Read Adam's story.

You have regular follow-up appointments with your medical team after you finish your treatment. These are to check that:

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

At first, your follow-up appointments are approximately every 3 months. If you stay well, they gradually become less frequent. Your medical team should explain how follow-up works at your hospital.

Relapsed or refractory NLPHL

Treatment for NLPHL is usually effective. However, it can sometimes come back (relapse) and need more treatment. This can be after a very long period of time. Occasionally, it doesn't respond well to initial treatment (refractory lymphoma).

If NLPHL 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 more scans and another biopsy to make sure it hasn't changed (transformed) to a faster-growing type of lymphoma.

Relapsed NLPHL usually responds very well to treatment.

If your lymphoma comes back but it isn't causing problems, you might not need treatment straightaway. Instead, you might have a period of active monitoring (active surveillance or 'watch and wait').

If you need treatment, your medical team might recommend:

- radiotherapy if the lymphoma is only in one part of your body
- chemotherapy, usually with different drugs if you had chemotherapy before, although your consultant might consider using the same drugs again if they worked well for you
- rituximab, either on its own or with chemotherapy.

If your lymphoma comes back very soon after treatment, comes back several times, or transforms to a high grade lymphoma, your medical team might suggest a stem cell transplant. This is a very intensive treatment and you have to be fit enough to have it. Most people with NLPHL do not need a stem cell transplant.

Research in NLPHL

NLPHL is rare. There are not many clinical trials looking at new treatment options. However, existing treatment is usually very successful. Most research is looking at ways of using treatments more effectively to make sure side effects and late effects are as low as possible.

Your consultant might offer you the chance to take part in a clinical trial if there is one suitable for you. You can find out more about clinical trials and search for a trial that might be suitable for you at 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.

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