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Non-Hodgkin lymphoma

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Non-Hodgkin lymphoma: the care you should expect

This information explains the care that NICE has said works best for people aged 16 and over who have, or may have, non-Hodgkin lymphoma. It will help you, your family and carers know what to expect from health and care services.

Why is this important for you?

NICE aims to help people to get the best care, no matter who they are or where they live. This NICE advice is about:

- finding out if you have non-Hodgkin lymphoma, and which type you have
- deciding which treatment, or combination of treatments, would work best for you
- getting the support and information you need when you are diagnosed, during your treatment and afterwards.

Your healthcare team should know what NICE has said. Talk to them if you don't think you are getting the care NICE has said you should have.

What this advice covers

There are many types of non-Hodgkin lymphoma. The sections about diagnosis, making decisions about your care, which type of non-Hodgkin lymphoma you have, where it is in your body and after your treatment are for people with any type.

Different types of non-Hodgkin lymphoma need different treatments. This information doesn't tell you about every test and treatment that might be used for every kind of non-Hodgkin lymphoma. For this guideline, NICE looked at the most common types, which are:

- follicular lymphoma
- MALT lymphoma
- mantle cell lymphoma
- diffuse large B-cell lymphoma
- Burkitt lymphoma
- peripheral T-cell lymphoma.

Speak to your healthcare team for advice about specific tests and treatments that may be right for you. See also where can I find out more?

Medical words used in this information are described in medical terms explained.

What is non-Hodgkin lymphoma?

Non-Hodgkin lymphoma is a cancer of the lymphatic system, which is part of your immune system. Your immune system contains white blood cells and antibodies which help fight infection. Sometimes the body starts to make abnormal white blood cells. These cells can form a lump, usually in the glands (called lymph nodes) in your neck, armpit or groin. They can also grow in other parts of the body, outside the lymph nodes.

Non-Hodgkin lymphomas are called B-cell or T-cell lymphomas depending on which type of white blood cell they began to grow from.

See where can I find out more? if you would like to know more about the different types of non-Hodgkin lymphoma.

How is non-Hodgkin lymphoma diagnosed?

Non-Hodgkin lymphoma is diagnosed by taking a piece of tissue from an affected lymph node or other area – this is called a biopsy.

You may be offered a type of biopsy called an excision biopsy, where a surgeon removes part or all of your lymph node, usually under general anaesthetic. An excision biopsy gives your care team the best chance to find out as much as possible about your lymphoma.

If you don't have an excision biopsy your doctor can still take a small piece of tissue using a needle – this is called a core biopsy. But if diagnosis isn't possible after a core biopsy, you should then be offered an excision biopsy (unless this isn't suitable for you) rather than another core biopsy.

Questions you could ask about diagnosis

- Please tell me more about tests for diagnosing non-Hodgkin lymphoma
- What does having a biopsy involve?
- How long does it take to get the biopsy results? Who will tell me the results?
- Might I need more tests after a biopsy?

Making decisions about your care

You should be part of all decisions about your care so you can agree which treatments are likely to suit you. Your care team should involve you by:

- talking to you about non-Hodgkin lymphoma and listening to your concerns, so that they understand what is most important to you

- making sure you have all the information you need to help you make decisions about your treatment and care
- giving you information in the right way for you, at the times when you need it
- explaining if they think something that is mentioned here won't work for you and why, and discussing other options you could try instead
- making sure you have a named 'key worker' as soon as you are diagnosed, who you can talk to about any concerns or questions during your treatment
- giving you contact details for the care team after your treatment finishes, in case you need to get in touch.

There is more information about how you should be involved in your care on our website.

Who will look after me?

A range of professionals may be part of your care team. These could include:

- haematologists – doctors who specialise in blood conditions, including lymphoma
- oncologists – doctors who specialise in cancer, including lymphoma
- specialist nurses
- pharmacists
- radiologists – doctors who examine scans of the body
- surgeons.

Information about tests and scans

Your care team should explain the tests and scans that you might have and tell you:

- what each one is for and why it is important
- what it involves.

They should also explain this information to any family members or carers who are supporting you, if you are happy with this.

Talking about how lymphoma will affect your life

Non-Hodgkin lymphoma can affect many parts of your life. Your care team should talk to you about this. Having lymphoma affects people in different ways, and what is very important to one person may be less important to another. You may want to discuss things like:

- keeping up a healthy lifestyle, including exercise, from your diagnosis onwards
- support with money and any benefits you might be entitled to
- what support groups are available
- wellbeing services, and how to get psychological support if you need it
- any worries about how your illness may affect your sex life
- your fertility (whether you can have children) after treatment.

Questions you could ask your care team

- Who will I see at my appointments?
- Who should I contact if I have any questions or worries?
- What changes could I make to my lifestyle to improve my wellbeing?
- Can you give me more information, like a leaflet, or a website I can go to?
- Are there any support organisations in my local area?
- What support and information is available for my family and carers?

Which type of non-Hodgkin lymphoma do I have?

Your care team will use your biopsy, along with blood tests and scans, to find out:

- which type of non-Hodgkin lymphoma you have – this is vital to getting the best care, because different types need different treatments
- which parts of your body are affected (see finding out where the lymphoma is in your body)
- how fast the lymphoma is growing – non-Hodgkin lymphoma is called either high-grade (sometimes called aggressive) or low-grade (sometimes called indolent).

Genetic testing for people with high-grade B-cell lymphomas

Looking at gene changes in cancer cells can give helpful information about your lymphoma and how it is likely to develop. It can also sometimes be used to work out your outlook (prognosis) and which treatments are likely to help you the most.

NICE says this testing can be helpful if you have a high-grade B-cell lymphoma. It is important that your care team tell you what the test results mean for your treatment options and outlook.

Questions you could ask about types of non-Hodgkin lymphoma

- Can you explain more about my type of non-Hodgkin lymphoma?
- What are 'high-grade' and 'low-grade' lymphomas?
- Is genetic testing suitable for me?
- What does genetic testing involve? How is it helpful?
- How long does it take to get the test results? What might they show?

Finding out where the lymphoma is in your body

Your care team will use the results of your biopsy, blood tests and scans to find out where the lymphoma is in your body. This is called 'staging'. Doctors describe lymphoma using stages numbered from 1 to 4, where stage 1 is early-stage lymphoma and stage 3 and stage 4 are advanced-stage lymphoma. Stage 2 lymphoma is usually treated as an early lymphoma, but this depends on the type, where it is in your body and if you have symptoms. Your doctor will explain how the stage of your lymphoma affects your treatment.

PET-CT scans

A type of scan called a PET-CT scan is sometimes used to show where cancer cells are in the body.

When you are diagnosed

A PET-CT scan is particularly useful for people who have been diagnosed with stage 1 and some stage 2 lymphomas. It is less useful if your lymphoma is advanced (stages 3 or 4) or if you have MALT lymphoma or mantle cell lymphoma. You should only be offered this scan if your care team believes it will give information that might affect your treatment.

After your treatment

A PET-CT scan is sometimes done after treatment has finished, to see how well the treatment has worked. This is usually only helpful for people with certain types of non-Hodgkin lymphoma – ask your care team for more information.

Before a stem cell transplant

You may be offered a PET-CT scan if you have a high-grade non-Hodgkin lymphoma, to see if treatment has worked before you have a stem cell transplant.

Questions you could ask about staging and PET-CT scans

- Please explain more about staging non-Hodgkin lymphoma
- What types of scans might I have?

- What stage of lymphoma do I have? What does this mean for my outlook (prognosis)?
- Why are you advising that I have a PET-CT scan? What will it show?
- What does having a PET-CT scan involve?
- Will a PET-CT scan show if my treatment has worked?

How is non-Hodgkin lymphoma treated?

The following sections explain the treatments that NICE has looked at for the 6 most common types of non-Hodgkin lymphoma. If you would like to know more about these and other treatments, see where can I find out more? and talk to your care team.

Talking to you about treatment options

There may be different ways to treat your lymphoma, and more than 1 option may be suitable for you. Your care team should explain the treatments they think will be best for you. They should tell you the pros and cons of each treatment and about any possible late effects of treatment.

They should also explain about treatments to any family members or carers who are supporting you, if you are happy with this.

At the time of publication, some medicines may be recommended for 'off-label' use in this guideline. Your doctor should tell you this and explain what it means for you.

What is 'watch and wait'?

Deciding to watch and wait for a while before starting treatment can be a good option for some people with low-grade lymphoma who are feeling well. It means that treatment is given when it can make the most difference, and side effects of treatment are avoided for longer.

Many people feel worried if a period of watch and wait is suggested. Talk to a member of your care team if you feel anxious – they should make sure you understand what is involved and why this approach is being advised.

Lymphoma that changes from low-grade to high-grade

Sometimes a low-grade lymphoma can start to grow more quickly and turn into a high-grade lymphoma. This is called 'transformation'. If you have a low-grade lymphoma, a member of your care team should tell you about the possibility of transformation and explain what it means. They should also explain it to your family or carers if you are happy with this.

Transformation happens most often with follicular lymphoma and will mean you need a different type of treatment. See the section on transformed follicular lymphoma for more information.

Questions you could ask your care team

- Which treatment do you think is best for me, and why?
- What are the benefits of watching and waiting before starting treatment?
- What does having this treatment involve?
- What are the side effects of this treatment?
- Are there any other treatments I could try?
- Are there any long-term effects ('late effects') of this treatment?
- What does it mean for my outlook (prognosis) if treatment doesn't completely get rid of the lymphoma?
- What happens if my low-grade lymphoma transforms to a high-grade lymphoma?

Treating follicular lymphoma

NICE did not look at treatments for stage 1 follicular lymphoma. Ask your care team if you would like more information, or see where can I find out more?

Stage 2A follicular lymphoma

If you have stage 2A follicular lymphoma in 1 area of your body ('localised'), you should be offered radiotherapy as your first treatment.

Radiotherapy is not suitable for everyone. If it isn't right for you, and your lymphoma is not causing symptoms, your care team may advise a period of watch and wait before starting treatment.

If you are having symptoms, you should be offered treatment – ask your care team about treatment options.

Stage 3 or 4 follicular lymphoma

Many people have stage 3 or stage 4 (advanced-stage) follicular lymphoma when they are diagnosed, but not everyone has symptoms. If you are symptom-free you can stay well for longer before needing chemotherapy by taking a drug called rituximab.

If you do have symptoms you should be offered chemotherapy with rituximab. If your lymphoma improves after this treatment you may then be offered ongoing regular treatment with rituximab – this is called 'rituximab maintenance'.

Follicular lymphoma that comes back after treatment

If your lymphoma comes back you will usually be offered more treatment with chemotherapy and rituximab. Your care team will look at the treatment you had last time to help decide what would work best.

If your lymphoma improves after treatment and you are well enough, you should be offered high-dose chemotherapy, which helps to kill any cancer cells left in your body, followed by a stem cell transplant (as long as you haven't had a transplant before). This is called 'consolidation' treatment.

Transformed follicular lymphoma

Follicular lymphoma is a low-grade lymphoma, but sometimes it can start to grow more quickly and turn into a high-grade lymphoma. This is called 'transformed' follicular lymphoma (see lymphoma that changes from low-grade to high-grade for more details).

Your care team will talk to you about the best treatment for transformed follicular lymphoma. Depending on how it responds to 1 or more rounds of chemotherapy, you may be offered high-dose chemotherapy with a stem cell transplant.

Questions you could ask about treating follicular lymphoma

- Why are you advising we watch and wait before starting treatment?
- What is rituximab – is it suitable for me?
- What is high-dose chemotherapy?
- If I am not well enough to have high-dose chemotherapy or choose not to have it, what options can you suggest?
- Is a stem cell transplant suitable for me? What type of transplant could I have?
- What happens if my follicular lymphoma transforms into a high-grade lymphoma?

Treating MALT lymphoma

MALT lymphoma is a slow-growing (low-grade) lymphoma that usually, but not always, starts in the stomach.

MALT lymphoma involving the stomach may be triggered by a bacterial infection. Some people with this type of MALT lymphoma just need antibiotics – these treat both the infection and the lymphoma.

If you need other treatment, you should be offered chemotherapy with rituximab, or radiotherapy. Your care team will explain which treatment is most suitable for you. They may suggest a period of watch and wait if you feel well and the lymphoma is not causing you problems.

Questions you could ask about treating MALT lymphoma

- Why are you offering me antibiotics to treat the lymphoma?
- Why are you advising we watch and wait before starting or continuing treatment?
- What is rituximab – is it suitable for me?

Treating mantle cell lymphoma

For stage 1 or stage 2 mantle cell lymphoma, you may be offered radiotherapy if the lymphoma is in 1 area of your body (localised).

Radiotherapy is not suitable for everyone. If it isn't right for you, and your mantle cell lymphoma (of any stage) is not causing symptoms, your care team may suggest a period of watch and wait before starting treatment.

For stage 3 or stage 4 mantle cell lymphoma that is causing symptoms, you should be offered chemotherapy with rituximab. Your care team should see how well you are before deciding what type of chemotherapy might work best for you. You may then be offered high-dose chemotherapy, which helps to kill any cancer cells left in your body, followed by a stem cell transplant. This is called 'consolidation' treatment.

Another possible treatment is a drug called bortezomib – you may be offered bortezomib as a first treatment if high-dose chemotherapy with a stem cell transplant is not suitable for you.

Some people are not well enough to have high-dose chemotherapy. Ongoing regular treatment with rituximab may slow down any spread of the lymphoma and keep you well for longer. This is called 'rituximab maintenance' – ask your care team for more information.

If you are in remission after high-dose chemotherapy, you may be offered rituximab maintenance to help stop the lymphoma from coming back.

Questions you could ask about treating mantle cell lymphoma

- Why are you advising that we watch and wait before starting treatment?
- What is rituximab – is it suitable for me?
- What is high-dose chemotherapy?
- Is a stem cell transplant suitable for me? What type of transplant could I have?
- If I am not well enough to have high-dose chemotherapy or choose not to have it, what options can you suggest?

Treating diffuse large B-cell lymphoma

Most people with diffuse large B-cell lymphoma (sometimes called DLBCL for short) are offered chemotherapy with rituximab as their first treatment. This may be followed by radiotherapy. Your care team will discuss treatment options with you.

Stopping the lymphoma from developing in your brain and spinal cord

DLBCL can sometimes develop in the brain and spinal cord. There is more chance of this happening if you have the lymphoma in your testicles, breast, adrenal gland or kidney. To lower this risk, you should be offered an additional type of chemotherapy that can reach the brain.

You should also be offered this treatment if 4 or 5 of the following apply to you:

- you are over 60
- you have stage 3 or stage 4 DLBCL
- your lymphoma is in more than 1 place outside your lymph nodes
- you can't carry on with your normal daily activities because of your illness
- you have high blood levels of an enzyme called lactate dehydrogenase (LDH).

If only 2 or 3 of the above apply to you, you might still be offered this treatment – ask your care team for more information.

Check-ups after your treatment

If your symptoms come back or you get new symptoms, tell your care team straight away – you should be given an urgent appointment.

If you are in complete remission after your first treatment for DLBCL, you should have regular check-ups for 3 years – after this time your doctor may decide you no longer need them. You don't need regular scans or X-rays to check for signs of lymphoma if you don't have symptoms.

What if DLBCL comes back after treatment?

If your DLBCL comes back or the first treatment hasn't worked very well, you should be offered high-dose chemotherapy with rituximab, followed by a stem cell transplant, if you are well enough. This is called 'consolidation' treatment.

Questions you could ask about treating DLBCL

- What are the chances that DLBCL will spread to my brain?
- Can you explain more about the type of chemotherapy that will help prevent this? What does it involve?
- What is rituximab – is it suitable for me?
- What signs should I look out for that the lymphoma is coming back?
- If the lymphoma comes back, what options can you suggest?

Treating Burkitt lymphoma

Burkitt lymphoma is usually treated with intensive chemotherapy with rituximab, which involves staying in hospital for several weeks. This is offered even for early-stage (stage 1 or stage 2) lymphoma because Burkitt lymphoma grows quickly and needs to be treated intensively. Your care team should choose a combination of chemotherapy drugs that suits how well you are.

Questions you could ask about treating Burkitt lymphoma

- Can you explain which treatment might work best for me, and why?
- Why are you offering me intensive chemotherapy? What does it involve?
- How long will I need to stay in hospital?
- What is rituximab – is it suitable for me?

Treating peripheral T-cell lymphoma

Peripheral T-cell lymphoma is usually treated with chemotherapy first.

If you are well enough you may then be offered high-dose chemotherapy, which helps to kill any cancer cells left in your body, followed by a stem cell transplant. This is called 'consolidation' treatment.

Questions you could ask about treating peripheral T-cell lymphoma

- Can you explain which type of chemotherapy might work best for me?
- What is high-dose chemotherapy?
- Is a stem cell transplant suitable for me? What type of transplant could I have?

After your treatment

At the end of your treatment you should be given a written summary. It should say which type of non-Hodgkin lymphoma you had, the tests and treatments you had and whether you may get ongoing side effects or late effects of treatment. Your care team should talk to you about your summary when they give it to you, and send a copy to your GP.

Your care team should give you information about how to spot signs that might suggest your lymphoma is coming back or you have late effects of treatment.

At 3 years after your treatment has finished you may be able to go back to the care of your GP or practice nurse for monitoring of late effects of treatment.

Questions you could ask your care team

- What should I do if I'm worried that my lymphoma might be coming back?
- What are late effects of treatment? What should I look out for?
- What will happen at my follow-up appointments?
- Where will they be, and how often? Who will I see?

Where can I find out more?

- Lymphoma Association, 0808 808 5555
  www.lymphomas.org.uk
- Bloodwise, 0808 208 0888
  www.bloodwise.org.uk
- Macmillan Cancer Support, 0808 808 0000
  www.macmillan.org.uk
- Cancer Research UK, 0808 800 4040
  www.cancerresearchuk.org
- Anthony Nolan, 0303 303 0303
  www.anthonynolan.org/patientinfo
- Teenage Cancer Trust, 0207 612 0370
  www.teenagecancertrust.org

You can also go to NHS Choices for more information.

NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

You may also like to read NICE's information for the public on:

- patient experience in adult NHS services – this sets out what adults should be able to expect when they use the NHS
- improving supportive and palliative care for adults with cancer
- care of dying adults in the last days of life.

Medical terms explained

Chemotherapy

A treatment that uses anticancer drugs to destroy cancer cells. In non-Hodgkin lymphoma it is often used together with an antibody drug called rituximab – this is sometimes called 'immunochemotherapy'.

High-grade

Non-Hodgkin lymphomas are divided into 2 types, high-grade and low-grade. A high-grade ('aggressive') lymphoma is made up of large cells and usually grows quickly.

Late effects

These are side effects of treatment that can appear months or even years after treatment has finished.

Low-grade

Non-Hodgkin lymphomas are divided into 2 types, high-grade and low-grade. A low-grade ('indolent') lymphoma is made up of small cells, and usually grows slowly and can take a long time to develop. Sometimes a low-grade lymphoma can transform into a high-grade lymphoma.

Off-label medicines

In the UK, medicines are licensed to show that they work well enough and are safe enough to be used for specific conditions and groups of people. Some medicines can also be helpful for conditions or people they are not specifically licensed for. This is called 'off-label' use. There is more information about licensing medicines on NHS Choices.

PET-CT scan

A combination of a CT scan and a positron emission tomography (PET) scan. A CT scan gives a 3-dimensional picture of the internal organs, and a PET scan shows the most active cells in the body. This helps to show which cells in your body are cancerous because lymphoma cells are usually very active.

Radiotherapy

A treatment that uses high-energy rays to destroy cancer cells.

Remission

If you are in remission it means that most or all signs of the lymphoma have gone. 'Complete' remission means that no signs of the lymphoma can be seen.

Rituximab

A type of antibody drug that helps your immune system to destroy cancer cells. In non-Hodgkin lymphoma it is often used together with chemotherapy.

Stage 1

The lymphoma is affecting only 1 group of lymph nodes or 1 area of the body.

Stage 2

The lymphoma is affecting 2 or more groups of lymph nodes either above or below your diaphragm (the spleen counts as a lymph node in this definition). If your lymphoma is 'stage 2A' it means that you don't have any of the following symptoms: weight loss, heavy sweating (especially at night) or a high temperature that is not caused by infection.

Stage 3

The lymphoma is affecting lymph nodes both above and below your diaphragm (the spleen counts as a lymph node in this definition).

Stage 4

The lymphoma is found in organs outside the lymph nodes and spleen – for example, the liver or bone.

Stem cell transplant

Having high-dose chemotherapy damages stem cells in your bone marrow – these cells are needed to make new blood cells. To help your bone marrow recover, you can be given a transplant of stem cells after your chemotherapy. In an autologous stem cell transplant, you have some stem cells collected from your blood before your chemotherapy – these are stored and then replaced after your treatment. In an allogeneic transplant the stem cells come from another person (called a donor).

Watch and wait

This means not starting treatment straight away, but waiting until it is needed. This can work well for some people with low-grade lymphoma who are feeling well, because treatment is given when it can make the greatest difference, and the side effects of treatment are avoided for longer. You will have regular check-ups to look out for signs that you might need treatment.

What are NICE guidelines?

NICE gives advice to staff working in health and social care. Our guidelines help them to give the best care to people with different conditions and needs. We wrote this guideline with people who have been affected by non-Hodgkin lymphoma and staff who treat it. All the decisions are based on the best research available. You can read the guideline written for people who work in health and care services.

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