

Lymphoma patient- initiated follow-up

Your guide to supported
self-management after lymphoma



Follow-up care after treatment for cancer is a necessary precaution, as sometimes the cancer can return (this is called a cancer recurrence or relapse). It's a way to pick up problems early and act quickly enough to be able to treat them.

This booklet contains:

- a summary of patient-initiated follow-up (PIFU) for lymphoma, supported self-management and what is meant by your surveillance plan
- information on how and when to contact our team to arrange a follow-up appointment
- useful information and contacts to support you as you recover from your treatment for lymphoma

Contact us

If you or your general practitioner (GP) have any questions or concerns, please contact us using the details below.

Lymphoma nurse specialist team

Telephone: **023 8120 5059** (Monday to Friday, 8am to 4pm)

Email: **lymphomaPTFU@uhs.nhs.uk**

In an emergency situation, call our acute oncology 24-hour emergency phone line: **023 8120 1345**.

Introducing patient-initiated follow-up (PIFU)

In the past, people living with or after lymphoma have been seen at regular intervals by their clinical team for follow-up care. Although some people find these pre-arranged appointments useful and reassuring, many more find them a source of great anxiety and not particularly helpful, unless they have something specific they wish to discuss.

There is strong evidence that:

- having pre-arranged follow-up appointments does not increase a person's life expectancy or prevent cancer from returning
- symptoms and concerns are addressed more quickly if people report them as and when they occur, rather than waiting for a routine appointment

We have therefore changed the way we manage follow-up care, and this new system is called **patient-initiated follow-up (PIFU)**.

What PIFU means for you

Instead of having pre-booked follow-up appointments, your PIFU will comprise of two main areas. These are:

Supported self-management: This allows you to take control of your care and recovery with the support of our lymphoma nurse specialist team.

Your surveillance plan: This is the term used to describe the tests we'll plan for you when you start the PIFU pathway.

During PIFU:

- we will ask you to complete a health questionnaire. This questionnaire is important because it makes us aware of any potential relapse symptoms you may be experiencing, as well as giving you the opportunity to discuss any other health concerns you have with us. There's more information about this in the 'When to contact us for a follow-up appointment' section.

- you may need to have yearly blood tests as part of your surveillance. We will discuss this with you, if it is appropriate.

You and your GP will be given a summary of all the tests included in your surveillance plan when you start PIFU.

The PIFU workshop

Once you have received this booklet and understand what PIFU and your surveillance plan are, we'll invite you to attend a workshop (this may be a face-to-face, telephone or online workshop). Attendance at this workshop is important because it will help you to understand your surveillance and pathway, and what you need to be aware of to manage your own care effectively.

Once you have been to the workshop, you will no longer need to attend routine follow-up appointments at the hospital. Instead, you will be able to contact our team directly to discuss any concerns, as and when they occur. If an appointment is needed after having a discussion with us, our team will arrange this for you.

How long does PIFU last?

How long you will need surveillance for will depend on the type of lymphoma you had. However, people recovering from lymphoma will typically need surveillance for three to ten years. We will send you a surveillance pack, which will give you more information about this.

When you have completed your surveillance, we will discharge you from our PIFU service. If you have any concerns after this time, you should contact your GP who can then refer you back to us if needed.

If you change your contact details or GP during PIFU, it is important that you let us know.

My Medical Record

My Medical Record is an online service provided by University Hospital Southampton NHS Foundation Trust (UHS) that gives you access to your own digital health record.

On My Medical Record, you will be able to:

- access useful information on our lymphoma PIFU page
- manage your surveillance
- complete your health questionnaire
- contact us via a messaging service

You can register for My Medical Record at any time. For more information about this, speak to your clinical nurse specialist (CNS) team or visit:

www.uhs.nhs.uk/for-patients/my-medical-record

If you do not have a My Medical Record account, we will send you the health questionnaire in the post to complete and return to us by post as soon as possible. Please note that we are unable to provide pre-paid envelopes, so you will need to pay for postage.

When to contact us for a follow-up appointment

You need to arrange a follow-up appointment if you have any **new** symptoms, including:

- swollen glands
- sweats
- unexplained discomfort or pain
- shortness of breath
- tiredness
- any new symptom in any part of your body that goes on for more than two weeks

Symptoms can vary depending on which parts of the body are involved. For example, an enlarged lymph node might cause pain in the area around it, and lymphoma in the stomach might cause a stomach ache. It is important that you contact us for an appointment if you notice any new symptoms in any part of your body – even if the symptoms are not affecting the same part of your body as before.

You should also contact us if you notice:

- possible side effects from your chemotherapy or radiotherapy
- problems related to your original treatment for lymphoma (for example, feeling low or fertility concerns)

How to arrange an appointment

To arrange a follow-up appointment, please contact us **via the online messaging service on My Medical Record**.

If you don't have a My Medical Record account, please contact us using the details below:

Lymphoma nurse specialist team

Telephone: **023 8120 5059** (Monday to Friday, 8am to 4pm)

Email: **lymphomaPTFU@uhs.nhs.uk**

If we are unable to answer your call, please leave a message on our answer machine with your name, hospital or NHS number, contact number, and a brief message.

One of our team will then contact you (usually within one working day). We will briefly discuss your concern and arrange for you to have an appointment within two weeks. Your GP can also use these contact details if they think you need to be seen by our team.

In an **emergency situation**, call our acute oncology 24-hour emergency phone line: **023 8120 1345**.

Reaching the end of your treatment

Everyone recovers from lymphoma and lymphoma treatment at different times and in different ways. There is no right or wrong way, just what works for you.

Reaching the end of your treatment is a great relief for most people, but it can also be a difficult time for some people. Although you will be pleased that your treatment is over, you may have a feeling of 'what now?' and miss the security of being seen at the hospital.

You may find it helpful to get some extra support dealing with your feelings, for example, talking about your experiences with someone. Your GP or our team can arrange this for you. Please let us know if you think extra support would be helpful. There are also some useful contacts at the back of this booklet.

We have also outlined some information below which may be of interest to you while you are recovering.

Tiredness

Tiredness affects almost everyone who has treatment for cancer. It's important to understand that energy levels can take up to 18 months to return to normal. Resting when you are tired will help your recovery but it is also important to build up your strength by doing regular gentle exercise, such as walking.

Feeling low

It's natural to look forward to finishing your treatment. However, it can also be a time to reflect on what you have just been through. It's possible you may be left feeling anxious and low after finishing your treatment. If you feel this way, please talk to your GP or contact us and we will find the best way to support you.

Recovering the feeling in your fingers and toes

Some chemotherapies can cause pins and needles or a feeling of numbness in the fingers and toes. These sensations should improve with time but, on rare occasions, can be permanent. If you experience this, please contact our team for advice.

Fertility

Treatment for lymphoma can affect your fertility temporarily (for up to a year or more) or even permanently. We are here to offer advice if you would like to talk about this.

Long-term risks of chemotherapy

There is a very low risk that people treated with chemotherapy or radiotherapy can develop different unrelated cancer in the future. If you have concerns about this, please contact us for advice or discuss it with your GP.

Returning to work or college

If you're returning to work or college, it may help to have a meeting first with your employer, course tutor, human resources department or occupational health team. It can be useful to take someone with you to help take notes (for example, a work colleague, students' union or student representative).

If you're still experiencing side effects from your treatment, you should discuss any reasonable changes that can be made to aid your return, such as a gradual return (in stages) or extra exam time.

Some useful questions to ask are:

- What adjustments could your employer or college arrange that would make work or college easier for you?
- Could you reduce your hours, work flexibly or work more from home?
- Can you have extended assignment times or extra exam time?
- What facilities are available if you need to rest at work or college during the day?
- Are there any counselling or student support services available?

It is your decision as to who you tell about your cancer diagnosis. However, you may find it helps to talk to friends and work colleagues about your diagnosis, as then they can offer additional support.

The Disability Discrimination Act (DDA)

The Disability Discrimination Act (DDA) covers all types of cancer and exists to protect against unfair treatment compared to others, harassment, victimisation and unfair dismissal. If you think you are being treated unfairly when you are trying to get back to work or college, the DDA is there to protect you.

Disability employment advisors are based at Jobcentre Plus and can help you if you are having problems.

Financial concerns

Being diagnosed with cancer can have an effect on your income, but you may be able to get help through grants and certain benefits. There are a number of resources available to see if you are entitled to any additional help. If financial issues are worrying you, ask us to refer you to Macmillan Cancer Support, Citizen's Advice Bureau (CAB) or social services for more information.

Charities such as Macmillan also give grants and have access to low cost holiday schemes. You will need to apply for these through a care professional, such as your specialist nurse or social worker.

Living well after your treatment for lymphoma

Although there is no known cause for most lymphomas, it is important to follow a healthy lifestyle after your treatment to help your recovery. A healthy lifestyle can also help reduce the risk of other conditions such as heart disease and diabetes. For more information on living well after your cancer treatment, please visit the cancer-specific pages on My Medical Record.

Stop smoking

Stopping smoking is one of the most important things you can do to keep yourself well. We realise this can be a difficult thing to do, so if you need help, take a look at the useful contacts information at the back of this booklet or ask one of the specialist nurses.

Eat a healthy, balanced diet

Everyone should try to eat a healthy, balanced diet but it is especially important when you are recovering from lymphoma.

To achieve a healthy, balanced diet, you should try to:

- eat plenty of fresh fruit and vegetables
- eat plenty of foods rich in fibre and starch – these should form the main part of your diet
- avoid eating too many fatty foods (such as fast food or fried food)
- avoid having sugary foods and drinks (things like cakes, biscuits and fizzy drinks should form only a small part of your diet)
- avoid drinking excessive amounts of alcohol (only drink alcohol in moderation)

In the long term, a healthy diet may reduce the chances of getting heart disease and diabetes, as well as certain types of cancer. For more useful information about healthy eating, please visit: www.nhs.uk/live-well

If you find eating a balanced diet difficult after your treatment, please let your specialist nurse know.

Be more active

Physical activity is good for both your body and mind. Regularly doing 150 minutes of moderate physical activity over the course of a week has been shown to help prevent and manage over 20 chronic conditions, including cancer. Examples of moderate physical activity include walking, yoga, and Pilates.

To help you stay fit and healthy, we recommend that you do at least three 20-minute sessions of moderate physical activity each week. You may need to gradually build up to this after finishing your treatment. Going for a daily walk is a good starting point and you can slowly increase how far you walk each day. See the back of the booklet for local contacts who can help you to become more active.

Travelling abroad after your cancer treatment

After you finish your treatment for lymphoma, we recommend that you only travel to Europe or North America for the first year, making sure you can get to a hospital if you need to.

After one year, your immune system will have had more time to recover and will be able to protect you when travelling to other places. If you're thinking of going anywhere that requires you to have travel vaccinations, make sure you speak to us first. It is important that you do not have any live vaccinations (ones which contain the bacteria or virus they are designed to protect against). We will be able to give you more advice about this.

Travel insurance

It is very important to get health insurance when you travel. Unfortunately, some people can find this difficult after treatment for lymphoma. The Macmillan Cancer Information and Support Centre at Southampton General Hospital and the Macmillan website have a list of insurers specialising in the cover of those who have had cancer (see the information at the back of this booklet). Your medical and nursing teams are happy to write letters to insurers to give details of your illness and treatment if needed.

Dealing with worries about lymphoma returning

Am I cured?

As much as we'd like to, we cannot give you a 100% guarantee that your lymphoma will never return. The treatment that you have had to date has given you the greatest chance of being well in the long term. Your surveillance plan is designed to ensure that any problems are detected early. It is important that you contact us if you have any concerns, so we can see you and take any action quickly, if necessary.

What is the chance of the lymphoma returning?

The risk of the lymphoma coming back is different for everyone. However, by having the treatment recommended by your oncologist, you have minimised your personal risk of having any further problems from lymphoma as much as possible.

Eating a healthy, balanced diet and taking regular exercise can have a positive effect on your health and reduce your risk of getting cancer again in the future.

I am worried that the lymphoma will come back, what can I do?

It is very normal to feel worried that the lymphoma could come back. You may also feel very uncertain about your future and find it difficult to 'get on with life' after completing your treatment. We understand this and are here to help you. Please get in touch with your specialist nurse if you would like more support with dealing with worries about your cancer returning.

Why won't I need regular blood tests on the PIFU pathway?

We understand that you may feel worried about not having regular blood tests while on the PIFU pathway. However, recent research has shown that symptoms are a much more reliable indicator of a relapse for lymphoma than blood tests. This is why it is so important that you attend our PIFU workshop and complete your health questionnaire on time. These will both help you to recognise signs of a potential relapse, so you can then contact us for advice straight away.

Useful contacts

In addition to your clinical team, there are a number of other organisations you may wish to contact for further information, support and advice.

National contacts

Lymphoma Action

A charity offering support to people with lymphoma.

Freephone helpline: **0808 808 5555** (Monday to Friday, 10am to 3pm)

Telephone: **01296 619400** (for general enquiries)

Website: **www.lymphoma-action.org.uk**

Macmillan Cancer Support

Support for people with cancer and information about cancer types and treatments.

Helpline: **0808 808 0000** (every day, 8am to 8pm)

Website: **www.macmillan.org.uk**

Cancer Research UK

Information about cancer types, diagnosis, prevention, clinical research trials and statistics.

Telephone: **0808 800 4040** (Monday to Friday, 9am to 5pm)

Website: **www.cancerresearchuk.org**

Mind

Free mental health information and support.

Telephone: **0300 123 3393**

Website: **www.mind.org.uk**

NHS Live Well

NHS advice about healthy living.

Website: **www.nhs.uk/live-well**

Teenage Cancer Trust

A UK cancer charity that offers unique care and support for young people facing cancer.

Telephone: **020 7612 0370** (Monday to Friday, 9am to 5pm)

Website: **www.teenagecancertrust.org**

Trekstock

A UK charity that provides wellbeing support services for young adults living with cancer and its after-effects.

Telephone: **020 4541 7601**

Website: **www.trekstock.com**

Local contacts

Macmillan Cancer Information and Support Centre (Southampton)

A peaceful, welcoming and confidential space for people affected by cancer. You can come in to relax or take up the services on offer. The centre is located on B level at Southampton General Hospital.

Telephone: **023 8120 6037** (Monday to Thursday, 10am to 4pm)

Email: **macmillancentre@uhs.nhs.uk**

Website: **www.uhs.nhs.uk/departments/cancer/living-with-cancer-information-and-support/macmillan-cancer-information-and-support-centre**

Maggie's (Southampton)

A charity that provides free cancer support and information in centres across the UK and online.

Telephone: **023 8212 4549** (Monday to Friday, 9am to 5pm)

Email: **southampton@maggies.org**

Website: **www.maggies.org/our-centres/maggies-southampton**

Wessex Cancer Trust

A local charity providing information, grants, counselling and complementary therapies for people affected by cancer.

Telephone: **023 8067 2200** (Monday to Friday, 9am to 5pm)

Website: **www.wessexcancer.org.uk**

Waterside Cancer Support Centre

A non-clinical support centre in Hythe for people with cancer.

Telephone: **023 8178 0409** (Monday to Friday, 10am to 1pm)

Email: **waterside@wessexcancer.org.uk**

Website: **www.wessexcancer.org.uk/support-services/waterside**

Jane Scarth House

A cancer support centre providing emotional and practical support to anyone whose life is affected by cancer.

Address: **Jane Scarth House, 37a The Hundred, Romsey, SO51 8GE**

Telephone: **01794 830374** (Monday to Friday, 9am to 4pm)

Website: **www.janescarthhouse.co.uk**

Hampshire Macmillan Citizens Advice Service (HMCAS)

A confidential service for advice on welfare benefits, employment, finance, housing and general advice for people living in Hampshire and the Isle of Wight. An outreach service is also available at Southampton General Hospital.

Telephone: **0844 847 7727** (Monday to Friday, 9am to 4pm)

Email: **macmillan.cahampshire@cabnet.org.uk**

Website: **www.macmillan.org.uk/in-your-area/local-dashboard/detail/Benefit%20advice%20services/9832/Hampshire-Macmillan-Citizens-Advice-Service**

University Hospital Southampton NHS Foundation Trust
Southampton General Hospital
Tremona Road
Southampton
SO16 6YD

Main switchboard telephone: **023 8077 7222**

Some of the sections have been adapted with permission from information by Macmillan Cancer Support and Lymphoma Action.

If you are a patient at one of our hospitals and need this document translated, or in another format such as easy read, large print, Braille or audio, please telephone **0800 484 0135** or email **patientsupporthub@uhs.nhs.uk**

For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **www.uhs.nhs.uk/additionalsupport**

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