

Patient-initiated follow-up (PIFU) for CLL, SLL, LMZL and HCL

Your guide to supported self-management



Follow-up care after treatment for cancer is a necessary precaution as sometimes the cancer can return (this is called a cancer recurrence), or in some cases, the cancer can progress (grow and spread in the body). 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 chronic lymphocytic leukaemia (CLL), small lymphocytic lymphoma (SLL), leukaemic marginal zone lymphoma (LMZL) and hairy cell leukaemia (HCL)
- information on how and when to contact our team to arrange a follow-up appointment
- useful information and contacts to support you

Contact us

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

Lymphoid PIFU team

Telephone: **023 8120 8892**

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

In **an emergency situation**, call our 24-hour Macmillan acute oncology service (MAOS) support line on telephone: **023 8120 1345**.

Introducing patient-initiated follow-up (PIFU)

In the past, people living with a diagnosis of CLL, SLL, LMZL and HCL 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 find them to be 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)**.

Your eligibility for PIFU

You will be eligible for the PIFU pathway if:

- you are in complete or partial remission
- you have a stable disease (confirmed on a CT scan or following a clinical examination and blood test results two years after your treatment or two years after your initial diagnosis, if untreated)

What PIFU means for you

Instead of having pre-booked follow-up appointments, your PIFU pathway will be made up of two main areas:

- **Supported self-management:** This puts you in control of your care and allows you to take an active and leading role in your recovery, with the support of our team. Instead of having routine follow-up appointments, 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.

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

While you are on the PIFU pathway, we will ask you to complete a health questionnaire via My Medical Record each time a follow-up appointment is due. 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.

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. For more information about My Medical Record, please visit: www.uhs.nhs.uk/for-patients/my-medical-record

While you are on the PIFU pathway, we will continue to carry out regular blood tests (you can choose to have these blood tests at the hospital, your GP surgery or a local blood-taking service) to check your:

- full blood count
- liver, bone, and kidney function
- immunoglobulins (antibodies)
- LDH (lactate dehydrogenase) level - a rise in this enzyme can indicate the presence of cancer (please note that a normal LDH reading doesn't necessarily mean that the cancer hasn't returned or progressed, so it is important that you look out for any new symptoms as outlined in the 'When to contact us for a follow-up appointment' section later in this booklet)

We will give you and your GP a summary of all the tests included in your surveillance plan when you start the PIFU pathway. Alternatively, you can access your surveillance plan via your My Medical Record account.

The PIFU workshop

Once we have given you this booklet and have explained what PIFU and your surveillance plan are, we will invite you to attend a workshop (this may be a face-to-face workshop, a telephone workshop, or a virtual presentation). This workshop will provide you with more information about how to maintain a healthy lifestyle.

After 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 the PIFU pathway last?

Following a cancer diagnosis or treatment, you will receive follow-up care from the hospital for 25 years in total. The first two years will involve you coming into hospital for regular follow-up appointments. After two years, you will then be enrolled on the PIFU pathway (if both you and your consultant agree to this).

When the PIFU pathway is completed, your GP will become your main point of contact if you have any concerns or notice anything unusual.

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

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
- recurrent night sweats
- unexplained fever (a high temperature of 38°C or above)
- unexplained weight loss
- loss of appetite
- abdominal discomfort (such as feeling full without eating or after eating a small amount of food)
- unexplained discomfort or pain
- change in bladder or bowel habits
- shortness of breath at rest or when exercising
- ongoing tiredness or fatigue (extreme tiredness)
- unexplained rash or itching
- unexplained facial swelling and/or bulging neck veins
- any new symptom in any part of your body that goes on for more than two weeks

You should also contact us if you notice:

- possible long-term side effects from your chemotherapy or radiotherapy (for example, lung and heart issues, kidney problems, chronic pain, neuropathy (numbness or tingling in the fingers and/or toes) or forgetfulness)
- problems related to your condition (for example, feeling low or fertility concerns)

How to arrange a follow-up 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:

Lymphoid PIFU team

Telephone: **023 8120 8892**

Email: **LymphoidPIFU@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 within two working days. We will briefly discuss your concern and arrange for you to have an appointment within four 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 24-hour Macmillan acute oncology service (MAOS) support line on telephone: **023 8120 1345**.

If you experience sudden chest pain and/or difficulty breathing, call 999 for an ambulance immediately.

Reaching the end of your treatment

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. Please see pages 12 to 15.

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 cancer 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 or radiotherapy

There is a very low risk that people treated with chemotherapy or radiotherapy can develop a 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

If you're returning to work, it may help to have a meeting first with your employer, human resources department, or occupational health team. It can be useful to take someone with you to help take notes, such as a work colleague.

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).

Some useful questions to ask are:

- What adjustments could your employer arrange that would make work easier for you?
- Could you reduce your hours, work flexibly, or work more from home?
- What facilities are available if you need to rest at work during the day?

- Are there any counselling or support services available?

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, 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 with NHS costs through grants and certain benefits. There are a number of people you can talk to for information 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, Citizens 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 cancer treatment

A healthy lifestyle is important after cancer treatment. It 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 on pages 12 to 15 or ask one of your specialist nurses for advice.

Eat a healthy, balanced diet

Everyone should try to eat a healthy, balanced diet, but it is especially important when you are recovering from cancer. This means eating a wide variety of foods in the right proportions and consuming the right amount of food and drink to achieve and maintain a healthy body weight.

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
- avoid eating too many fatty foods (such as fast food or fried food)
- avoid having sugary foods and drinks
- 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 page 14 for local contacts who can help you to become more active.

Travelling abroad after your cancer treatment

After you finish your treatment for cancer, 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 cancer. 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 useful contacts section on pages 12 to 15). 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 cancer progressing or returning

Am I cured?

As much as we'd like to, we cannot give you a 100% guarantee that your cancer will never progress or return. 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 cancer progressing or returning?

The risk of the cancer 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 the cancer 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 cancer will progress or come back, what can I do?

It is very normal to feel worried that the cancer could progress or come back. You may also feel very uncertain about your future and find it difficult to 'get on with life'. 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.

Further information and 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

Leukaemia Care

A charity offering support to people with cancer.

Telephone: **0808 801 0444** (Monday to Friday, 9am to 5pm and Thursday and Friday evenings, 7pm to 10pm)

Website: **www.leukaemiacare.org.uk**

Lymphoma Action

A charity offering support to people with lymphoma, including a helpline, a live web forum and a 'buddy' system (a system that can put you in touch with someone else who has had similar experiences).

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

Email: **information@lymphoma-action.org.uk**

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

Blood Cancer UK

A community dedicated to beating blood cancer by funding research and supporting those affected.

Telephone: **0808 208 0888** (Monday, 10am to 7pm, Tuesday to Friday, 10am to 4pm, and weekends and bank holidays, 10am to 1pm)

Website: **www.bloodcancer.org.uk**

Macmillan cancer support

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

Telephone: **0808 808 0000** (everyday, 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**

Turn2us

A national charity providing practical help to people who are struggling financially.

Telephone: **0808 802 2000** (Monday to Friday, 9am to 5pm)

Website: **www.turn2us.org.uk**

NHS Live Well

NHS advice about healthy living.

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

WW (WeightWatchers)

A points system weight loss programme that calculates your personal nutrition needs based on your height, weight, age, and activity level.

Website: **www.weightwatchers.com/uk**

NHS Quit smoking

Support for people who want to stop smoking.

Smokefree National Helpline: **0300 123 1044** (Monday to Friday, 9am to 8pm, Saturday and Sunday, 11am to 4pm)

Website: **www.nhs.uk/better-health/quit-smoking**

Drink Aware

An independent charity helping people to make better choices about their drinking.

Website: **www.drinkaware.co.uk**

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)

Maggie's is 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, 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**

Hampshire Macmillan citizens advice service

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

Telephone: **0344 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**

Macmillan centre (Portsmouth)

A peaceful, welcoming and confidential space for people affected by cancer. The centre is located at Queen Alexandra Hospital.

Telephone: **023 9228 3323** (Monday to Friday, 10am to 4pm)

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

Website: **www.porthosp.nhs.uk/departments/macmillan**

Smokefree Hampshire

Support for people living in Hampshire who want to stop smoking.

Telephone: **01264 563039** (Monday to Friday, 9am to 5pm)

Email: **smokefree.hampshire@nhs.net**

Website: **www.smokefreehampshire.co.uk**

Citizens Advice

Southampton

Telephone: **0808 278 7863** (Monday to Friday, 9.30am to 4pm)

Website: **www.citizensadvicesouthampton.org.uk**

New Forest

Telephone: **0808 278 7860** (Monday to Friday, 10am to 4pm)

Website: **www.newforestcab.org.uk**

Fareham

Telephone: **0808 278 7964** (Monday to Friday, 9am to 5pm)

Website: **https://public.citafareham.org/citizensadvicefareham**

Eastleigh

Telephone: **0808 278 7862** (Monday to Thursday, 10am to 4pm)

Website: **www.citizensadvicееastleigh.org.uk**

Romsey

Telephone: **0808 278 7862** (Monday, Wednesday and Friday, 10am to 12pm)

Website: **www.testvalleycab.org.uk**

Winchester

Telephone: **0808 278 7861** (Monday to Friday, 10am to 4pm)

Website: **www.citizensadvicewinchester.org.uk**

University Hospital Southampton NHS Foundation Trust

Tremona Road
Southampton
Hampshire
SO16 6YD

Main switchboard: **023 8077 7222**

Some of the sections in this booklet have been adapted with permission from information by Macmillan cancer support.

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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