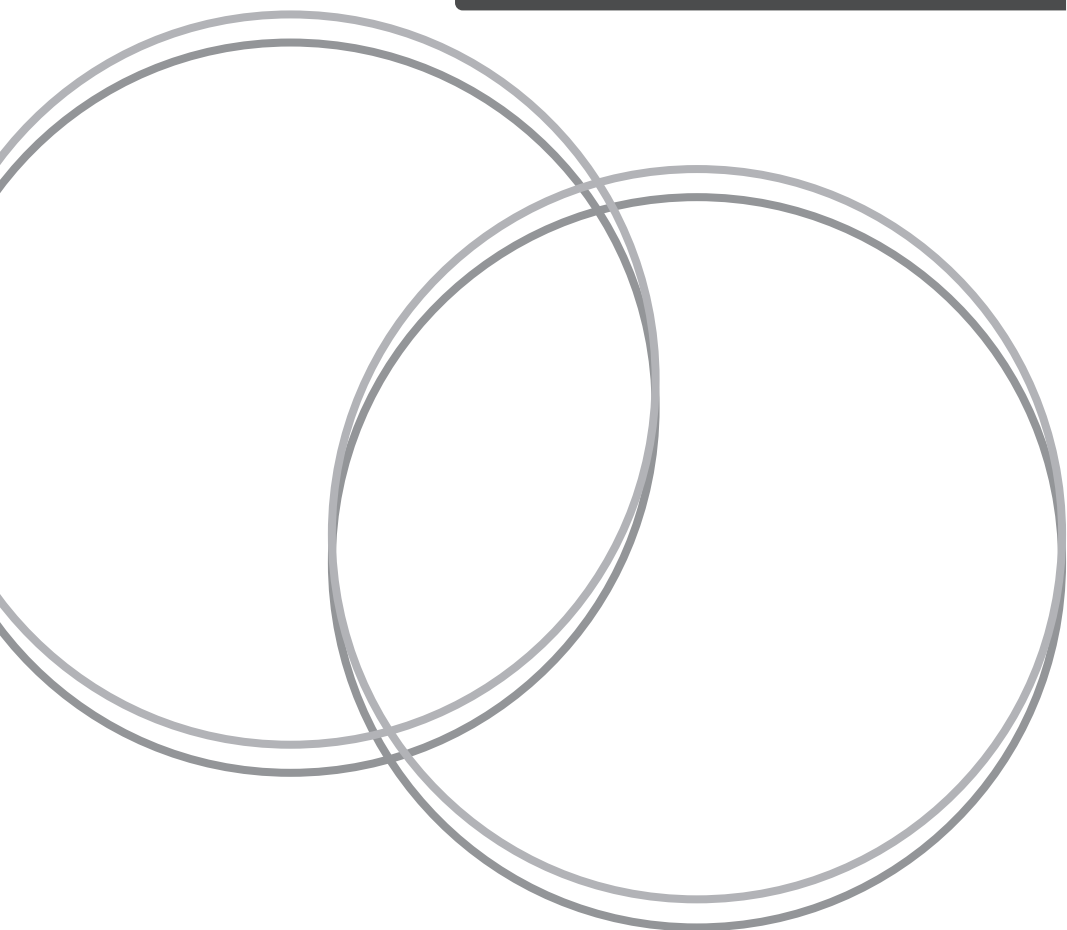




Oxford University Hospitals
NHS Foundation Trust

Chronic Lymphocytic Leukaemia (CLL)

**The OUH monitoring service and
practical guidance for patients**



Introduction

This leaflet is for people who have been diagnosed with Chronic Lymphocytic Leukaemia (CLL). This information also applies to people with a diagnosis of SLL (Small Lymphocytic Lymphoma) and MBL (Monoclonal B-cell Lymphocytosis).

This leaflet provides information about your care at Oxford University Hospital NHS Trust Clinical Haematology Department. It provides information about the symptoms you need to look out for.

This leaflet does not include detailed information about CLL or its treatments. You will find this information in the recommended websites listed at the end of this leaflet. You are also encouraged to talk to your clinical team if you have any questions about your condition.

Please get in touch with us using the numbers at the end of this leaflet if you have any questions about your care.

What is CLL?

Chronic Lymphocytic Leukaemia (CLL) is a common type of cancer that affects the blood and the bone marrow. CLL is the most common blood cancer in adults.

The bone marrow is a spongy tissue in the centre of your large bones. The bone marrow is where your blood cells are made – red blood cells, white blood cells and platelets. These include white blood cells called lymphocytes, which are part of your immune system.

CLL happens when you have changes to the bone marrow. These changes result in the production of abnormal blood cells. When you have CLL, your bone marrow makes abnormal lymphocytes.

CLL can mean that your body doesn't make the healthy blood cells it needs. This can mean changes to your immune system, your red blood cells, and your platelets.

CLL is usually found when you have a blood test. Many people with CLL will have no symptoms and will need no treatment, sometimes for many years.

For more information about CLL please visit one of the recommended websites listed on pages 9 and 10. You will find information that you can view online, download, or order in print.

Will I need treatment?

Many people with CLL do not need any treatment and will feel well for long periods of time before any treatment becomes necessary. You will have regular appointments and blood tests to see if your condition changes. This is known as 'active monitoring' or 'watch and wait.'

You might need treatment in future if you experience any or all of the following symptoms. They are also known as **'B' symptoms**:

- Your lymph nodes are getting too large or uncomfortable
- You start to feel flu-like symptoms, night sweats, loss of appetite or unexplained weight loss
- You are experiencing frequent infections requiring antibiotics
- You notice an obvious reduction in your energy level or increasing fatigue

And/or

- You have significant changes to the cells in your blood count.

If you have had had treatment for CLL in the past, we will monitor you for these symptoms too.

How will my CLL be monitored?

Your condition will be monitored with:

- Regular blood tests
- Regular appointments with our team
- Being aware of your symptoms.

There are two teams within our Haematology Department that look after people with CLL.

The Oxford Community clinic (OxCom) monitors people who:

- Are newly diagnosed but feeling well and not needing treatment
- Have had CLL for some time but have been looked after by their GP
- Have visited us in the past but have been looked after by the GP.

If you have had CLL for some time, and it has remained stable under the care of your GP, your care will be transferred from your GP to the OxCom service.

The CLL service monitors people who:

- need treatment
- have recently had treatment.

Regardless of who is managing your care, you will have access to a Nurse Specialist and a Consultant Haematologist if you need it.

Face to face appointment

All newly diagnosed patients are offered a face-to-face appointment in the Haematology Department outpatient clinic. This clinic is at the Churchill Hospital or the Horton Hospital for people in the Banbury area.

You will see a doctor and have contact from a specialist nurse. You will have a physical examination, and you can discuss your diagnosis and ask questions.

Some people will continue to see us face-to-face.

Follow up

After you have seen us in the clinic, you will have regular appointments with a specialist nurse or doctor. The precise nature and timing of these appointments will depend on your individual circumstances.

These appointments will usually be by telephone. We will arrange these regularly, usually twice a year. We may also offer appointments via video-link.

We can always see you in person if you have changes in your condition.

Telephone appointments are very important for both you and your clinical team and you should prepare for them in the same way as you would for a face-to-face appointment.

These appointments are to ask you if you have any of the 'B' symptoms described on page 3. We recommend that you keep a record of your symptoms in between appointments. This is so that you don't forget details that might be important for your care. We will also discuss your blood test results.

These appointments are an opportunity to talk about your CLL, and we want to make sure we have time to focus on this. We would be grateful if you could ask your GP about any health problems that are not related to your CLL.

Blood tests

You will have blood tests before all telephone or face to face appointments.

We will send you the forms for your blood tests. You can have blood taken at the GP surgery or at the Churchill Hospital.

You should arrange the blood tests for about one week before your appointment.

What do I need to know about looking after myself?

'B' Symptoms

We will monitor you for the symptoms listed above – the 'B' Symptoms (see page 3). If you experience any or all of these symptoms in between your appointments, please get in touch with your nurse specialist.

We may arrange to see you in person in the clinic or arrange further investigations.

Increased risk of infection

You might find you pick up infections (including Covid 19) more easily, or that it takes longer to recover from infections. This is because your immune system is not working as well as it should. You may be prone to chest infections in particular. Some symptoms may resemble a heavy cold or be similar to flu.

If you have signs of infection or feel generally unwell, please get in contact with your GP surgery without delay as you may require antibiotics. Sometimes people with CLL will need longer courses of antibiotics if they have an infection.

If you remain worried, or develop a high temperature above 37.5°C then you should contact the triage assessment unit at the Churchill Hospital on 01865 572192. The Triage service is available 7 days a week, 24 hours a day. It is staffed by nurses who will ask you questions and provide advice about what to do next.

If you are on treatment for your CLL, and develop a high temperature of 37.5°C or above, please call Triage.

Vaccinations

You should not have live vaccines. Live vaccines use live or weakened viruses to give you immunity. Live vaccines include:

- yellow fever
- oral polio
- measles, mumps and rubella (MMR)
- the live shingles vaccine (Zostavax).

Talk to your GP about vaccinations if you are planning to travel. Always ask if a vaccine is live.

Flu vaccination

You should have the flu vaccination every year. People who live with you should also have the flu vaccination.

If you know children aged between 2 and 18 who are having the flu vaccination, you should avoid them for one week after they have it. This is because children usually get a 'live' version of the flu vaccine.

Pneumonia vaccinations

You should have vaccinations against pneumonia. It is recommended that you have the pneumonia vaccine called PCV13 or Prevnar® followed by PPV23 or Pneumovax II® at least two months later. PPV23 should be repeated every 5 years.

If you have had only PPV23 Pneumovax II® before, you should have a “catch up” dose of PCV13, Prevnar®.

Shingles vaccinations

You should have the non-live Shingrix shingles vaccine if you are eligible. If you have had shingles before, you should take Aciclovir 200mg tablets three times a day to prevent it coming back.

COVID 19 vaccinations

You should stay up to date with vaccinations against COVID 19 according to the advice of the Government and your medical specialists, including any booster vaccinations that may be offered. All of the approved vaccines are safe for you. The people you live with should also be vaccinated against COVID-19 to reduce the risk of giving it to you.

People with CLL do not always produce COVID antibodies in response to the vaccinations. However, we advise that you have the vaccinations so that you have the best chance of protection from the virus.

Good quality, up to date information about COVID19 can be found on the websites listed at the end of this booklet.

General health advice

If you smoke, you should stop smoking. For assistance with this please consult your GP or ask your nurse specialist to direct you to help from the Here’s for Health or smoking cessation team.

People with CLL are at increased risk of skin damage from the sun. You are advised to use sunscreen every day with an SPF of at least 30, and a 5-star UVA rating.

Travel insurance

You are advised to arrange insurance before you travel. Some bank accounts or financial products such as home insurance will include travel insurance. You will find more information on the CLL Support website and from other organisations listed at the end of this booklet.

Keeping up to date

Please make sure we have the most up to date contact details for you – including a mobile number, next of kin and email address if you use one. You can also let us know the best way to contact you.

Please ensure that you tell us if you have hearing or visual impairment, or any difficulties that will make it difficult to have telephone appointments.

Sources of further information

CLL Support Association

www.clisupport.org.uk/

0800 977 4396

Blood Cancer UK

www.bloodcancer.org.uk/understanding-blood-cancer/leukaemia/chronic-lymphocytic-leukaemia/

0808 169 5155

Leukaemia Care

www.leukaemiacare.org.uk/support-and-information/information-about-blood-cancer/blood-cancer-information/leukaemia/chronic-lymphocytic-leukaemia/

0808 801 0444

Macmillan

www.macmillan.org.uk/cancer-information-and-support/leukaemia/chronic-lymphocytic-leukaemia-cll

0808 808 0000

Cancer Research UK

www.cancerresearchuk.org/about-cancer/chronic-lymphocytic-leukaemia-cll

0300 123 1022

Lifestyle, emotional support and wellbeing information

Here for Health

www.ouh.nhs.uk/patient-guide/here-for-health/

Talking space

www.oxfordhealth.nhs.uk/talkingspaceplus/

Maggie's centre

www.maggies.org/our-centres/maggies-oxford/

Travel insurance advice

www.cllsupport.org.uk/information-support/faqs/

Macmillan benefits advice

macmillan@cab-oxford.org.uk

01865 227083

Contact information

If we don't answer your call, please leave a message. We will aim to respond to your call within 24 hours.

All appointment and administrative queries:

01865 235185

OxCom Service

Julia Evans, Specialist Nurse

Telephone: 01865 223846

Julia.evans@ouh.nhs.uk

Or: ouh-tr.oxcomcllservice@nhs.net

CLL Service

Lianne Palmer, CLL Clinical Nurse Specialist
(Monday, Wednesday & Thursday)

Lianne.palmer@ouh.nhs.uk

Telephone: 01865 235284

Triage

Triage assessment unit: 01865 572192

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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November 2022
Review: November 2025
Oxford University Hospitals NHS Foundation Trust
www.ouh.nhs.uk/information



Making a difference across our hospitals

charity@ouh.nhs.uk | 01865 743 444 | hospitalcharity.co.uk

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