

Keeping track of my Lymphoma and CLL

PATIENT DIARY

www.lymphoma.org.au



This diary is personal and confidential. If found, please contact:

Name

Number.....

Email

.....



Lymphoma Australia

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About Lymphoma Australia

**Our mission: Raising awareness.
Giving support. Searching for a cure.**

Lymphoma Australia is an incorporated charity and is providing education, support and awareness across Australia.

Lymphoma Australia relies on grants, fund raising initiatives, donations and sponsorships to continue our work, support research, and to develop our free resources for patients, hospitals and cancer clinics. We are a member of the Lymphoma Coalition which provides global support to the millions of people around the world living with cancer of the lymphatic system.

Lymphoma Australia is endorsed with deductible gift recipient (DGR) status from the ATO and receives no government funding. The feather in our logo symbolises a guardian angel because our founding patient group wanted to make sure no one felt alone in their lymphoma journey. It is also a symbol of hope to those with lymphoma, and reflects the fact that people are searching for cures for this group of cancers everyday.

Lymphoma Care Nurses

Lymphoma Australia is dedicated to raising funds to ensure specialist lymphoma care nurses are available wherever they are needed.

Our Lymphoma Care Nurses will help patients and their families from the time of diagnosis, throughout treatment and survivorship. This support is available for free, regardless of where you live in Australia.

Lymphoma Nurse Support Line 1800 953 081

Patient Support

The following free resources are also available by visiting Lymphoma Australia at www.lymphoma.org.au

- Lymphoma: What You Need to Know
- Living with CLL
- Patient & Carer Newsletters
- Patient & Carer Education Days
- What is new for lymphoma and CLL - Know your treatments
- Fact sheets: subtypes, management & supportive care
- Video presentations & expert interviews

Keep Connected

Join our closed Facebook group '**Lymphoma Down Under**'

Keeping track of your journey

Receiving a lymphoma or CLL diagnosis for many people is scary and confusing, as you have no idea of what to expect moving forward. The type and stage of your cancer can also determine the treatments and medicines used. However, it is important that you understand and record your journey as much as possible.

Based on the collective experiences of many patients we were able to design Your Treatment Diary.

Your lymphoma treatment has been developed so that it will:

- Be easy to take with you to any appointments
- Encourage you to ask for details and explanations of all aspects of your treatment
- Record information and responses from your medical team so that it will assist you with understanding your treatments and talking about it with your support network
- Keep a track of the drugs that have been given to you
- Allow you to record any side effects you may experience. This will also help your healthcare team and may assist them to make any changes in treatment or medications that may be needed



When I was admitted to hospital while on holidays my own treatment diary provided a wealth of information to the healthcare team that had never seen me before.

- Provide a place to
 - » Jot down questions and record your experiences between appointments or treatments
 - » Keep a diary of your personal thoughts/feelings

Personal information

This section will help you remember the details that you will probably be asked every time you have a new health related appointment.

Title..... First Name Surname

Address

.....

State Postcode.....

Email.....

Country of Birth.....

Religion

Emergency Contact

Relationship to you Mobile.....

Second Emergency Contact

Relationship to you Mobile.....

GP's Name

Address

State Postcode PH.....

Specialist Name

Address

State Postcode PH.....

My Blood Type Pensioner No. (if applicable).....

Ambulance Cover (Y/N)..... Subscriber No. (if relevant)

Dept of Veteran Affairs (Y/N)..... DVA No.

Medicare No..... Expiry Date

Health Care Card (Y/N)..... Health Care No.....

Health Insurance Company.....

Level of Cover Excess (Y/N)

Policy No. Date joined

My type of Lymphoma or CLL

It is very important that you know the exact type, stage and grade of Lymphoma/CLL that you have.

Type of Lymphoma/CLL

Date of Diagnosis Stage..... Grade

My Haematologist

Haematologists (also called haematologist/oncologists) treat diseases of the blood, including cancers such as Lymphoma/CLL

My Haematologist/Oncologist.....

Address

State Postcode PH.....

Floor and Room No.....

Email.....

Before deciding on treatment, your health care team will consider:

- The exact type, stage and grade of your lymphoma/CLL
- Your age
- Your general health status
- Any other medical problems you may have
- Your personal wishes and input

All of this information is important in deciding which treatment option is best for you.



Don't be worried about asking questions. Knowing your subtype is very important.

Current Medical Conditions

Name of Condition	Medication Taken

Known Allergies

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Past Medical Conditions

Name of Condition	Medication Taken

Surgery to Date

Type of Surgery	Date	Hospital	Surgeon

Medical appointments and tests

In this section you can record the dates of medical and other health related consultations, the key points discussed, and your questions and answers given by your doctor/health team.

Appointment	Main points discussed
Date: Appointment with:	
Date: Appointment with:	
Date: Appointment with:	
Date: Appointment with:	

Appointment	Main points discussed
Date: Appointment with:	
Date: Appointment with:	
Date: Appointment with:	
Date: Appointment with:	
Date: Appointment with:	

Appointment	Main points discussed
Date: Appointment with:	
Date: Appointment with:	
Date: Appointment with:	
Date: Appointment with:	
Date: Appointment with:	

Treatments and tests

There are some lymphomas and types of CLL that will be successfully treated over many years and the following tables will assist you with keeping a record of the treatments that you have had, drugs used and any side effects that you may have experienced as a result of this treatment.

You may find it helpful to keep track of all this information in case you need to access this in an emergency or you are travelling away from your treatment team.

Types of Treatments/Tests	Notes
Blood tests	
Surgery	
Radiotherapy	

Types of Treatments/Tests	Notes
Chemotherapy	
Maintenance Therapy	
Immunotherapy	
Stem Cell/ Bone Marrow Transplant	
Clinical Trials	
Oral Targeted Therapies e.g. tablet or capsule	

Blood Tests

Because lymphoma and the effects of your treatment can be monitored closely by your haematologist with blood tests such as a full blood count (FBC) this section will help you record and understand these tests. Because a FBC is very detailed and can be requested often, it is best to keep a copy of your results in a folder.

The following table will help you record dates, where the test was performed and any action needed as a result of this test. e.g. blood transfusion.

Your blood is made up of 3 types of cells which are constantly being produced in the bone marrow: red blood cells, white blood cells and platelets. Red blood cells carry oxygen to

Date	Place of test	Action Needed

body tissues and remove carbon dioxide. White blood cells fight infections and harmful substances that invade the body. Platelets help stop bleeding by plugging leaks in the blood vessels.

Chemotherapy may reduce the production of these vital blood components and if this happens, anaemia, bruising or infection may occur. During some courses of chemotherapy, your white blood cell count can drop to dangerously low levels. This condition is called 'neutropenia'. Since white cells help the body to fight infections, your body is less able to protect itself when you have Neutropenia. Even a simple case of the flu can become a serious, potentially life threatening problem which may require hospitalisation. Infections can start in almost any part of your body including your mouth, skin, lungs, urinary tract, colon, rectum and reproductive tract.

Date	Place of test	Action Needed

Signs of Infection

Always be on alert for the common signs of infections such as:

- Chills and/or shaking
- Cough or sore throat
- Loose stools or diarrhoea over 24 hours
- Change in urination (frequency or burning sensation)
- Vaginal discharge or itching
- Redness, swelling or sore on your skin
- Earache, difficult or painful breathing, wheezing

If you notice any sign of infection, no matter how small, call your treating team immediately.



Be alert!

Surgery

Before you leave hospital, make sure you have the hospital's contact details in case you have any concerns when you are at home.

My Surgery Team

During Office Hrs (Name) PH.....

After Office Hrs (Name) PH.....

Surgeon

Anaesthetist.....

Hospital where surgery was performed

Your hospital UR No..... Is this surgery a biopsy? (Y/N).....

Results of the biopsy (e.g. Lymphoma type)

Is this surgery part of a clinical trial? (Y/N)

Name of Trial

My surgery experience and questions for my health care team

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Surgery

Date	Where	Details/Outcomes

Radiotherapy

Some patients may need to have radiotherapy. This record will help you keep track of your treatment and experiences. You may want to note any side effects to discuss with your radiation oncologist or nurse.

Who to contact with concerns related to radiotherapy treatment

During Office Hrs (Name) PH.....

After Office Hrs (Name) PH.....

Radiation received at

Your hospital UR No.....

Radiation Oncologist (Name).....

No. of treatments plannedNo. of treatments planned

Dose received Areas treated.....

Is this treatment part of a clinical trial? (Y/N).....

Name of Trial

My radiotherapy experience and questions for my health care team

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Radiotherapy

Date	Where	Side effects/Notes

Chemotherapy

From the moment your chemotherapy treatment begins, you will find yourself learning the names of different drugs that will be administered and how they can possibly affect you physically. Each of these drugs has a list of possible side effects. To counteract some of these side effects, you can find yourself on a source of other support medication. This can be overwhelming as you start to get an idea of the challenging journey you are about to embark on. The following tables will help you keep track of your chemotherapy drugs as well as the all important support drugs that make the treatment so much easier

Who to contact with concerns related to chemotherapy treatment

During Office Hrs (Name) PH.....

After Office Hrs (Name) PH.....

Chemotherapy received atYour hospital UR No.....

Haematologist (Name).....

Oncologist (Name)

Chemotherapy drugs

No. of cycles planned No. of cycles received.....

My chemotherapy experience and questions for my health care team

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Chemotherapy

Date	Drugs Used	Side effects/Notes

Immunotherapy

Some patients may need to have immunotherapy. This record will help you keep track of your treatment and experiences.

Who to contact with concerns related to immunotherapy treatment

During Office Hrs (Name) PH.....

After Office Hrs (Name) PH.....

Immunotherapy received at.....

Your hospital UR No.....

Radioimmunologist (Name).....

No. of treatments plannedNo. of treatments planned

Dose received

Is this treatment part of a clinical trial? (Y/N).....

Name of Trial

My immunotherapy experience and questions for my health care team

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Immunotherapy

Date	Type of immunotherapy	Side effects/Notes

Stem Cell/Bone Marrow Transplant

A transplant is a very complex treatment and depending on your lymphoma or CLL, there can be different drugs and treatment regimens that can be used.

Use the following tables to record what is relevant for your transplant.

Chemotherapy given prior to transplant

Who to contact with concerns related to chemotherapy treatment

During Office Hrs (Name) PH.....

After Office Hrs (Name) PH.....

Chemotherapy received at

Your hospital UR No.....

Haematologist (Name).....

Oncologist (Name)

Name of chemotherapy drugs.....

No. of cycles planned No. of cycles received

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Mobilisation Chemotherapy

This is the chemotherapy that is used prior to the collection of stem cells. (If you are having an autologous transplant i.e. using your own stem cells)

Chemotherapy can also be given prior to an allogeneic transplant (using a donor's stem cells)

Date	Name of chemotherapy	Side effects

Stem Cell Mobilisation Dates

In order to undergo an autologous transplant, you must have enough stem cells collected to proceed to transplant.

Stem cell mobilisation is a process whereby stem cells are stimulated out of the bone marrow space (e.g., the hip bones and the chest bone) into the bloodstream, so they are available for collection for future reinfusion.

The cells are then preserved, frozen and stored until the time of transplant.



I was scared about being connected to the machine for my stem cell mobilisation but it didn't hurt and millions of stem cells were collected.

Date	Name of Growth and amount	My Notes
Day 1		
Day 2		
Day 3		
Day 4		
Day 5		
Day 6		
Day 7		
Day 8		
Day 9		
Day 10		
Day 11		
Day 12		
Day 13		
Day 14		

Stem Cell Harvest

Date/s for harvest (number of days needed can vary from person to person)

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Number of stem cells collected.....

Name of hospital/institution where your stem cells are stored

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Notes to remember about my harvest

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Chemotherapy Given Prior to Transplant

Date	Chemotherapy	Side effects/Notes

Transplant

Date.....

Side effects (if any) Notes.....

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Clinical Trials

Some patients throughout the treatment journey will be given the opportunity to participate in a clinical trial. Important information about your clinical trial can be recorded here.

Name of Trial

Drugs used on this trial

My contact person for the trial

Name

PH

Email

Questions and notes about my trial

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New Oral Targeted Therapies

Some new treatments that are being prescribed to treat some types of lymphoma and CLL are taken as a tablet or capsule and treatment usually continues until the lymphoma or CLL comes back. Tablets, like Ibrutinib, block either the signal or key pathway, can make cells die or stop them from growing. It is important to remember that even though this treatment is an oral medication there can be side effects that you may need to tell your doctor about.

The table below will help you record your medication and any side effects that you need to discuss with your treatment team.

Name of Medication	Side Effects

Additional Information

Treatment as a Public or Private Patient

Even if you have private health insurance, you are also entitled to be treated for your lymphoma or CLL as a public patient in a public hospital, if you so wish. You may also find that members of your medical team e.g. haematologist, may be treating patients in both the public and private hospitals. However, some doctors may only treat at certain hospitals and you should find out this information at your first consultation with your primary specialist.

Public Patient

As a patient in a public hospital you are normally treated by doctors nominated by the hospital and will not be charged for most treatments and care costs. Some pharmacy costs or other aspects of your care may not be covered but you will be informed about this on admission/at discharge by your hospital.

You can also choose to pay for treatment as a private patient even if you don't have private health insurance. Your doctors and the hospital will be able to assist you with working out this cost.

Private Patient

Step one is to check with your insurance company that you will be fully covered for all aspects of your care. Some

insurance companies may have exclusion clauses for certain conditions therefore make sure you are covered for your condition.

If you have an excess on your policy this is different to exclusions and this excess can be applied depending on the conditions of your insurance policy. Your health fund should be able to provide you with all the relevant information.

If you decide to be treated as a private patient, you will be able to choose your doctor and hospital. However, your doctor will not be treating at all hospitals, but the doctor/receptionist will be able to advise you which hospitals your doctor attends.

Before your treatment starts, as a private patient you may want to find out how much it will cost you, as there are often out-of-pocket expenses that will be your responsibility. Your doctor may be able to provide a quote and you should check the following with your private health fund.

1. Which treatments are covered by my insurance?
2. Will there be a gap in how much I am charged and how much is paid by my private health fund?

You will need the cost and item numbers from your doctor to check this out with your fund. For example, radiotherapy may not always be fully covered by the health fund.

Which other services are covered by my insurance? e.g. wig, home help

Some patients will find that even with private health insurance there are significant gaps between the charge and the benefit provided by the fund. You will be responsible for paying these gap amounts, as they are not covered by Medicare.

Please Note

Private health insurance only covers treatments carried out in hospital when you are admitted as an inpatient. This includes day admissions for chemotherapy.

Private health insurance does not cover treatment in the emergency department of a private hospital. This can only be claimed on Medicare and there is often a large gap for this consultation unless you are treated in the emergency department of a public hospital. In this case your consultation will be free.

Out patient care, such as radiology, pathology tests and visits to specialists in their rooms, is not covered by private insurance. Medicare rebates do apply and sometimes cover the whole fee. However, in some cases there could also be a gap that will be your responsibility to pay.

Professional and Support Contacts

Throughout your lymphoma/CLL journey you will meet a variety of important and helpful people but there might be one or two people including the Lymphoma Care Nurse with Lymphoma Australia who are there to help when you need them. Record their details here

Name

Position

Address

PHEmail

How you know them

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Name

Position

Address

PHEmail

How you know them

Name

Position

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How you know them

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How you know them

Name

Position

Address

PHEmail

How you know them

Questions and notes

In this section, you can list any questions that you may have for your health care team or keep a journal of general notes for future reference.

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Stay connected

it's easy!

1

Visit www.lymphoma.org.au

Order your free resource book: 'Lymphoma: What You Need To Know' or fact sheets.

2

Subscribe to the eNewsletter

Keep up-to-date with all our latest eNews.
Subscribe at www.lymphoma.org.au

3

Join the Facebook Group

Share experiences, information and research by joining our lymphoma patients and carers Facebook group. Search Facebook groups for Lymphoma Down Under

Lymphoma

Nurse Support Line

1800 953 081

We are here to help.

Please call or email:
nurse@lymphoma.org.au,
as fear of the unknown
should not be part of the
Lymphoma experience.