Jascap

FIGHTING CANCER – LIVING WITH IT

Chronic Lymphocytic Leukaemia

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Contents

About this booklet

This booklet is about chronic lymphocytic leukaemia (CLL). It is for anyone who has been diagnosed with CLL. There is also information for carers, family members and friends.

The booklet explains:

- what chronic lymphocytic leukaemia is
- symptoms and diagnosis
- the different treatment options
- coping with chronic lymphocytic leukaemia.

We hope it helps you deal with some of the questions or feelings you may have. We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

How to use this booklet

The booklet is split into sections to help you find what you need. You don't have to read it from start to finish. You can use the contents list to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

The blood and CLL

What is leukaemia?

Leukaemia is a cancer of the white blood cells. People with leukaemia usually have more or fewer white blood cells than

normal. Leukaemia cells behave differently from healthy white blood cells.

The four main types of leukaemia are:

- acute lymphoblastic (ALL)
- acute myeloid (AML)
- chronic myeloid (CML)
- chronic lymphocytic (CLL).

Each type of leukaemia is different. We have separate information about these different leukaemias.

The blood

To help you understand CLL and its treatment, it is useful to know a bit about your blood, how it is made and what it does.

Blood is made up of blood cells, which move around in a liquid called plasma. Blood cells are made in the bone marrow. The bone marrow is a spongy material in the middle of our bones, mainly in the pelvis, backbone (spine) and breast bone (sternum). Normally, millions of new blood cells are made every day to replace old and worn-out blood cells.

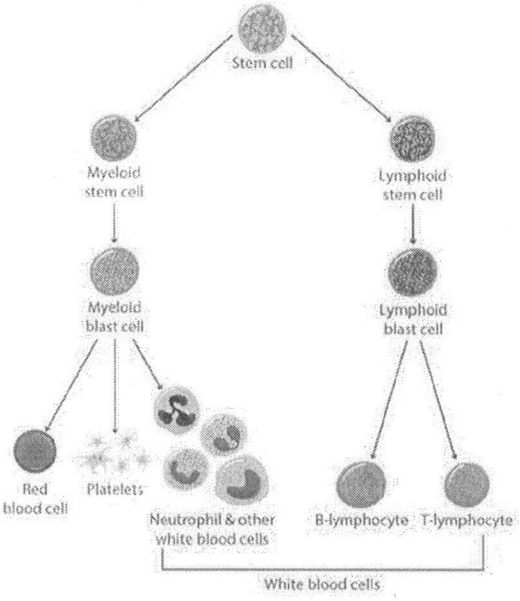
All blood cells are made from blood stem cells. There are two types of blood stem cell:

- Lymphoid stem cells make a type of white blood cell called lymphocytes.
- Myeloid stem cells make all the other types of blood cell. These include red blood cells, platelets, and other types of

white blood cells, such as neutrophils.

Blood stem cells in the bone marrow divide and grow to make new blood cells. The new, developing blood cells are called blast cells. They do not look like fully developed cells and they cannot do the jobs that fully developed cells do. Usually, blast cells stay in the bone marrow until they have developed into red blood cells, platelets or white blood cells. The next page has a diagram that shows blood cells dividing.

Blood cells dividing



The developed cells are then released into the blood to carry out different functions:

- Red blood cells contain haemoglobin (Hb). This carries

oxygen from the lungs to all the cells in the body.

- Platelets are very small cells that help the blood to clot. They prevent bleeding and bruising.
- White blood cells fight and prevent infection. There are several types of white blood cell. The two most important types are neutrophils and lymphocytes.

The levels of these cells in your blood are measured in a blood test called a full blood count (FBC). The figures below are a guide to the levels usually found in a healthy person.

Type of cell	**Levels found in a healthy person**
Red blood cells – measured in haemoglobin (Hb) levels in red blood cells	130 – 180 g/l (men) 115 – 165 g/l (women)
Platelets	150-400 x 10^9 /l
White blood cells (WBC)	4.0 – 11.0 x 10^9/l
Neutrophils	2.0 – 4.5 x 10^9/l
Lymphocytes	1.5 – 4.5 x 10^9/l

These figures can vary slightly between hospitals. Your doctor or nurse can tell you the levels they use. The levels can also vary slightly between people from different ethnic groups.

The figures might look complicated when they are written down, but doctors and nurses use them in a straightforward way. For example, you will hear them saying things like, 'Your haemoglobin (Hb) is 140,' or, 'Your neutrophils are 4'.

Most people with CLL quickly get used to these figures and what they mean. But if you do not understand, you can always ask your

medical team to explain in more detail. Your doctors will look at how your blood test results change over time. This helps them know if you need treatment, and what type you should have.

Lymphocytes and the lymphatic system

Lymphocytes

Lymphocytes are a type of white blood cell. They move around the body in the blood and the lymphatic system (see below). Lymphocytes are an important part of the body's defence. They fight against germs such as bacteria, fungal infections and viruses. They do this by:

- killing germs directly
- making special proteins called antibodies that stick to germs and make it easier for other white blood cells to find and kill them
- remembering and recognising germs – lymphocytes can live for a very long time, so they can quickly fight any infection you have had before.

The lymphatic system

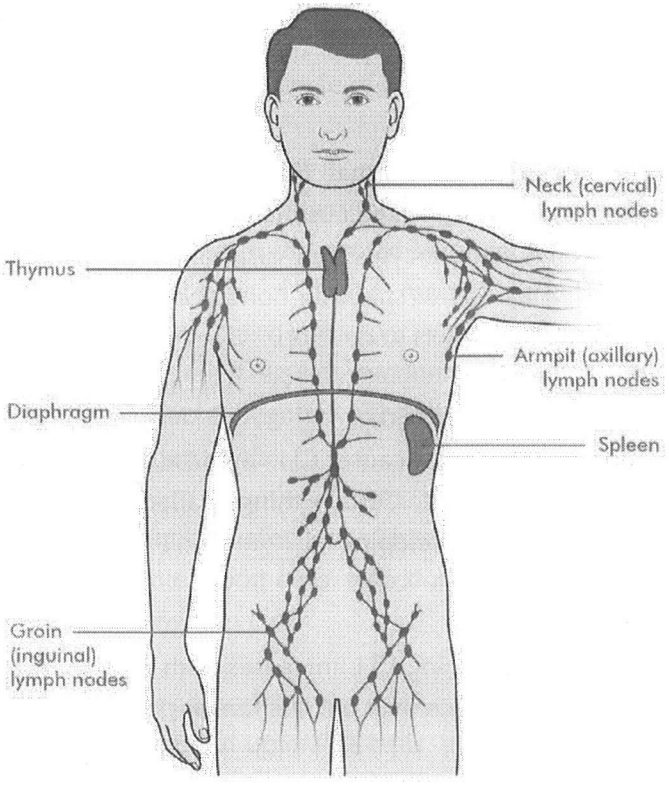
The lymphatic system is part of the immune system. It helps to protect us from infection and disease. It also drains fluid from the tissues of the body before returning it to the blood.

It is made up of lymphocytes and organs such as the bone marrow, thymus, spleen and lymph nodes. There are lymph nodes throughout the body connected by a network of fine tubes called lymphatic vessels. The lymph nodes filter disease and

germs (bacteria and viruses) from lymph, a liquid that travels through the lymphatic vessels. If you have an infection, lymph nodes close by often swell as they fight the infection.

There are lymph nodes in the neck, armpits and groin. Doctors can feel them when they look at these parts of the body. There are also lymph nodes in the chest and the tummy (abdomen).

The lymphatic system



Chronic lymphocytic leukaemia (CLL)

It is more common in older people. CLL usually develops very

slowly, which is why it is called a chronic leukaemia. Acute leukaemias develop more quickly.

Many people with CLL do not need treatment for months or years. But if people have symptoms, they may need treatment sooner.

CLL is a cancer of the white blood cells, which develop from the lymphoid stem cells. In people with CLL, the bone marrow (see page 7) makes too many abnormal white blood cells called lymphocytes. These cells look normal under a microscope. But they are not fully developed (immature) and do not work properly.

Over time, these abnormal lymphocytes build up in the lymphatic system and may cause large, swollen lymph nodes. The abnormal lymphocytes can also build up in the bone marrow. This leaves less space for normal white blood cells, red blood cells and platelets to develop.

Causes and risk factors

We do not know what causes CLL, but research is going on to find out more about it. Certain things called risk factors can increase the risk of developing it.

Age

The risk of developing CLL increases with age. Most people diagnosed with CLL are over 60. It is rare in people under 40.

Sex

CLL is more common in men than women.

Family history

Most people with CLL have no family history of it. But studies show that there is an increased risk of developing CLL if you have a close relative (parent, sibling or child) who has it. If anyone else in your family has CLL, it is important to let your specialist know. But most people who have a relative with CLL will never develop it themselves.

CLL is not infectious and cannot be passed on to other people.

Ethnicity

CLL is most common in people of European origin.

Signs and symptoms

CLL develops slowly and many people have no symptoms in the early stages. It is often discovered by chance after a routine blood test. The symptoms of CLL can include the following:

- Feeling very tired (fatigued), becoming breathless easily and getting headaches regularly. This is caused by a lack of red blood cells (anaemia).

- Having frequent infections. This is caused by a lack of healthy white blood cells. Infections may be more severe and take longer to clear.

- Swollen lymph nodes in the neck, armpits or groin. This is caused by a build-up of CLL cells. It is usually painless.

- Bruising and bleeding easily. This may happen if there are not enough platelets in the blood. You may have

nosebleeds that take a long time to stop (more than 10 minutes). You may get big bruises in unexpected places.
- A tender lump in the upper left-hand side of the tummy (abdomen). This is caused by an enlarged spleen.

- Heavy sweating at night.
- Weight loss.
- A high temperature (fever) without any obvious cause.

Diagnosing CLL

How CLL is diagnosed

CLL is often diagnosed after a routine blood test, and you may have had no symptoms at all.

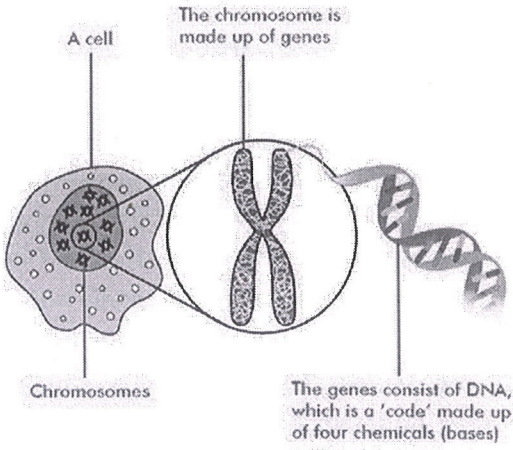
If you do have symptoms, your GP will examine you and take a blood test. If they think you have CLL, they will refer you to a doctor who specialises in diagnosing and treating blood problems (haematologist). The haematologist will arrange further tests for you.

Understanding CLL cell changes

To help you understand some of the tests used to diagnose CLL, it can be helpful to know a bit more about cells.

The organs and tissues of our body are made up of cells. Every cell contains all the biological information we inherit from our parents. This information is stored in our genes in the centre (nucleus) of every cell. Genes control what the cell does. They are grouped together in chromosomes.

Genes and chromosomes



CLL can behave differently in different people. Most often, CLL progresses slowly over many years, sometimes 20 years or more. But in some people, CLL develops more quickly.

All CLL cells have abnormal gene changes. This is what makes them behave differently from normal blood cells. These gene changes happen when something goes wrong when the body is making new blood cells. The gene changes in CLL cells vary from person to person. This is why CLL can behave differently in different people.

Abnormal gene changes are not inherited and they cannot be passed on to any children you have.

At the hospital

The haematologist will ask you about any illnesses or health problems you have had. They will check whether your lymph nodes, spleen or liver are enlarged. They will also do more

detailed blood tests to check whether you have CLL cells in your blood.

In many people with CLL, the leukaemia cells are mainly in the bloodstream and the bone marrow. If the leukaemia cells are mainly in the lymph nodes, the disease is called small lymphocytic lymphoma (SLL). CLL and SLL are now considered to be the same disease.

Blood tests

The blood tests you may have include the following:

- Fluorescent in situ hybridisation (FISH) testing – this is an important cytogenetic test used to look for a small number of specific changes in genes or chromosomes in the CLL cells.
- Cytogenetic testing – this looks at all the chromosomes in the leukaemia cells.
- Immunophenotyping – this checks for CLL cells in the blood.
- Immunoglobulin testing – this checks the levels of antibodies you have in your blood for fighting infection.
- Direct Coombs test – these check if your CLL cells are making antibodies that can damage your red blood cells.

FISH testing

FISH testing gives information about the gene changes in chromosomes, such as whether a part is missing or 'deleted'. Information from these tests helps doctors know how well certain drugs may work. This helps them plan your treatment.

The most important change is when a gene called TP53 is missing or does not work. This can happen when part of chromosome 17 (17p) where the gene is usually found is missing (deleted), or when the gene has changed (mutated). You may hear this called a 'del 17p'. Often, doctors call this a 'p53 deletion', or 'p53 mutation'.

Fewer than 1 in 10 (10%) people with CLL have a p53 deletion or p53 mutation when they are first diagnosed. But the deletion is more common in CLL that has come back after treatment.

CLL with a p53 deletion or p53 mutation does not usually respond well to standard chemotherapy treatment. Doctors use different types of drug to treat this type of CLL.

Further tests

Chest x-ray

A chest x-ray takes a picture of your chest, to check your lungs and heart. The x-ray also looks at lymph nodes in your chest.

CT scan

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. The scan takes 10 to 30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with.

A CT scan is sometimes used to check how many lymph nodes are affected by CLL. It can also be used to see whether the spleen is enlarged.

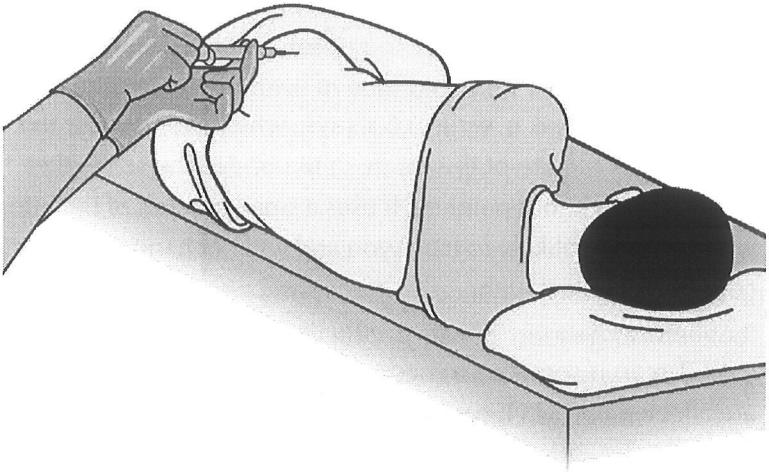
You may be given a drink or injection of a dye, which allows some areas to be seen more clearly. This may make you feel hot all over for a few minutes. It is important to let your doctor know if you are allergic to iodine or have asthma, because you could have a more serious reaction to the injection. You will probably be able to go home as soon as the scan is over.

Bone marrow biopsy

A bone marrow biopsy is used to check how much CLL is in the bone marrow.

The doctor or nurse takes a small sample (biopsy) of bone marrow from the hip bone. They usually do this under a local anaesthetic in the outpatient department. It usually takes about 10 minutes. It can feel quite uncomfortable, but you can take painkillers if you need to.

A sample of bone marrow being taken from the back of the hip bone



Lymph node biopsy

People do not usually need a lymph node biopsy. But some people may have an enlarged lymph node removed so it can be examined under a microscope. You may have this done under a local or general anaesthetic. It is a small operation and most people can go home on the same day. After the operation, you have a small wound with a few stitches. The stitches are usually taken out after 7 to 10 days.

Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend.

Staging

Doctors use staging to find out how much leukaemia there is in the body. This helps them know when you may need treatment and which treatment is best for your situation.

There are 2 staging systems commonly used for CLL – the Binet system and the Rai system. The Binet system is most commonly used in the UK.

Binet staging system

This looks at the number of white blood cells, red blood cells and platelets in the blood. It also looks at how many areas of lymph nodes are enlarged. These areas are in the neck, armpits, groin, liver and spleen. If the lymph nodes in both armpits are enlarged, it is only counted as one area.

There are 3 stages in the Binet system:

- Stage A – there are fewer than 3 areas of enlarged lymph nodes.
- Stage B – there are 3 or more areas of enlarged lymph nodes.
- Stage C – there are a reduced number of red blood cells, platelets or both.

Transformation

In up to about 10% of people with CLL, the leukaemia can change. It can start to grow more quickly and become harder to treat. This is called transformation.

CLL may change into:

- another type of leukaemia called prolymphocytic leukaemia
- a type of lymphoma (cancer of the lymphatic system) called diffuse large B-cell lymphoma (DLBCL) – this transformation is called Richter's syndrome
- a type of lymphoma called Hodgkin lymphoma (but this is rare).

Transformation may cause:

- a sudden swelling of affected lymph nodes, especially in the tummy (abdomen)
- heavy sweats at night
- weight loss
- high temperatures (fever) with no obvious cause.

There may be other reasons for these symptoms. But always tell your doctor if you notice any of them.

Doctors can diagnose transformation of CLL with a bone marrow Biopsy or a lymph node biopsy.

It is important to remember that transformation is unusual and does not happen for most people with CLL.

Treating CLL

Treatment overview

Only a small number of people with CLL need to start treatment straight away. Doctors usually wait until there are signs the CLL is progressing before suggesting you have treatment. There is no evidence that starting treatment before this helps, and it can cause side effects.

CLL usually develops very slowly, so you may not need treatment for months or years. Some people will never need treatment. Even if you are not having any treatment, you will see your haematologist or GP regularly for check-ups and blood tests. This is called monitoring (watch and wait).

Aims of treatment

The aim of treatment is to reduce the number of CLL cells to as few as possible. This is called remission. It is not usually possible to cure CLL, but it can be well controlled. Most people with CLL can have long periods of time when they have a normal life with no symptoms.

Types of remission

There are different levels of remission:

- Complete remission (CR). No CLL cells or enlarged lymph nodes can be found by standard tests and scans.

- Minimal residual disease (MRD). There are so few CLL cells remaining that they can only be found with special tests on the blood or bone marrow.
- Partial remission (PR). There are still CLL cells in the blood or bone marrow, but their number has reduced and the lymph nodes are smaller.

For most people, treatment is very successful at getting the leukaemia into complete or partial remission. This may last for years.

If the leukaemia does not respond well to the first treatment you have, your doctors can change the treatment. There are many different treatment options available for CLL.

When the leukaemia starts to grow again and starts to cause problems, you can have more treatment to put the leukaemia back into remission. This can be done several times.

If treatments to control CLL do not work, or stop working, you can have supportive therapy to manage symptoms.

Deciding when to start treatment

Stages of CLL and treatment

If you have stage A CLL, you do not usually need treatment when you are diagnosed. Often, stage A CLL does not cause any symptoms and develops very slowly. Some people with stage A

CLL may never need treatment. You will usually only start treatment if there are signs the CLL is progressing.

Some people with stage B CLL may not need to start treatment straight away. This depends on what signs and symptoms you have.

If you have stage C CLL, you usually need treatment soon after being diagnosed.

Reasons you may need treatment

There are a number of signs and symptoms your doctors will check for when they decide if you need treatment. These include:

- very enlarged or fast-growing lymph nodes
- a low level of red blood cells (anaemia) or platelets
- severe night sweats
- weight loss
- whether the number of white blood cells is high and increasing quickly.

Your doctor will check these symptoms are being caused by the CLL and not something else. This helps them decide whether to start your treatment.

Your doctor will also ask you about your general health and check your fitness when planning your treatment. They can explain the benefits and disadvantages of treatment to you.

Before starting treatment, you will have some blood tests to check for the hepatitis B virus and HIV. These are routine tests people have before starting treatment for CLL. Your doctor will

talk to you about these tests.

Types of treatment

Most people are treated with a combination of 2 types of treatment. These are:

- chemotherapy
- targeted therapy.

Other treatments that are sometimes used include the following:

- **Supportive therapy.** You may have this to help control any symptoms caused by CLL, such as infections or anaemia.

- **Donor stem cell transplant.** Doctors may suggest this treatment if the CLL has not responded to other treatments or if it is a type of CLL that is unlikely to respond. It is only suitable for a small number of people. This is because it is an intensive treatment that can have serious side effects.

- **Radiotherapy.** This is only used in certain situations. For example, you may have it if you have enlarged lymph nodes or an enlarged spleen.
- **Surgery.** This is occasionally used to remove an enlarged spleen (splenectomy).

There are many new treatments being developed to improve the outcomes for people with CLL. You may be invited to take part in a clinical trial of one of these treatments. Ask your doctor about any clinical trials you could join.

How treatment is planned

In most hospitals, a team of specialists will meet to plan your treatment. This multidisciplinary team (MDT) may include:

- haematologists (doctors who specialise in diseases of the blood)
- a radiologist (a doctor who specialises in reading scans and x-rays)
- a pathologist (a doctor who specialises in looking at cells under a microscope and diagnosing the cell type)
- specialist nurses who give information and support.

It may also include other healthcare professionals, such as a dietitian, physiotherapist, occupational therapist, psychologist or counsellor.

The MDT will take a number of factors into account when deciding which treatment is best for you. These include the stage of the leukaemia, test results and your general health.

Haematologists follow national and international guidelines for treating CLL. Your treatment will be based on these guidelines but will be adapted to your particular situation.

Giving your consent

Before you have any treatment, your doctor will explain its aims. They will usually ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent. Before you are asked to sign the form, you should be given full information about:

- the type and extent of the treatment
- its advantages and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

If you do not understand what you've been told, let the staff know straight away so they can explain again. Some leukaemia treatments are complex, so it is not unusual to need repeated explanations. It is a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment.

People sometimes feel that hospital staff are too busy to answer their questions. But it is important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions.

You can always ask for more time if you feel that you cannot make a decision when your treatment is first explained to you.

You are also free to choose not to have the treatment. The staff can explain what may happen if you do not have it. It is essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You do not have to give a reason for not wanting treatment, but it can help to let the staff know your concerns so they can give you the best advice.

If you choose not to have treatment, you can have supportive (palliative) care, with medicines to control any symptoms.

Second opinion

Your multidisciplinary team (MDT) uses established treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion.

Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information. If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

Monitoring (watch and wait)

Monitoring is used when you do not need to start treatment straight away. It is also called watch and wait. Your GP or haematologist monitors you regularly to check for any swollen lymph nodes and check your blood cell count.

They usually see you at least twice in the first year of being diagnosed. If your blood cell count changes or you develop symptoms, your doctors will think about whether you need to start treatment.

If you are worried about not having treatment, here are some helpful tips from people who have experienced monitoring:

- Make sure you understand why your doctor is recommending watch and wait. If you have any worries, talk to your doctor.

- Think of your time without treatment as an opportunity to make the most of your quality of life. Use it to do things you enjoy, and to get as fit and healthy as you can.
- Try to focus on the present rather than what might happen in the future.
- Talk about how you feel. You could do this by talking to family and friends, or joining a support group or online forum.

Watch and wait can be difficult to adjust to at first, but many people find it gets easier with time.

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy or damage leukaemia cells. These drugs interfere with the way leukaemia cells grow and divide.

How chemotherapy is given

You can have the drugs as tablets (oral chemotherapy) or into a vein (intravenously). The chemotherapy moves around the body through the blood. It can reach leukaemia cells all over the body.

You may have either a single chemotherapy drug or a combination of different drugs given together. Chemotherapy is usually given with a targeted therapy. This is called chemo-immunotherapy.

You usually have chemotherapy as several sessions of treatment. Each treatment is followed by a rest period. This lets your body recover from any side effects. The treatment and the rest period together make up a cycle of treatment.

The chemotherapy drugs most often used to treat CLL are:

- fludarabine
- cyclophosphamide
- chlorambucil
- bendamustine.

Fludarabine and cyclophosphamide are usually given together with a targeted therapy called rituximab. This combination is called FCR or RFC. The chemotherapy drugs can be given into a vein or as tablets.

Chlorambucil chemotherapy is given as tablets. It is often given along with a targeted therapy. Bendamustine is given into a vein. It is usually given with rituximab. This treatment is called BR.

There are lots of different drugs available to treat CLL. Your doctors may use other drugs and combinations of drugs. They will tell you what treatment they think is best for your situation.

You can usually have chemotherapy for CLL as an outpatient.

Side effects of chemotherapy

We have listed some of the most common side effects of chemotherapy over the next few pages. Different chemotherapy drugs have different side effects. Your doctor, nurse or pharmacist will give you more information about the chemotherapy you are having.

Your nurse will give you phone numbers for the hospital. If you feel unwell or need advice, you can call them at any time of the day or night. Save these numbers in your phone or keep them somewhere safe.

Risk of infection

This treatment can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is called neutropenia.

If you have an infection, it is important to treat it as soon as possible. Contact the hospital straight away on the 24-hour contact number you have if:

- your temperature goes over 37.5°C (99.5F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection.

Symptoms of an infection include:

- feeling shivery
- a sore throat
- a cough
- diarrhoea
- needing to pass urine often.

It is important to follow any specific advice your cancer treatment team gives you.

The number of white blood cells will usually return to normal before your next treatment. You will have a blood test before having more treatment. If your white blood cell count is low, your doctor may delay your treatment for a short time.

Anaemia (low number of red blood cells)

Chemotherapy can reduce the number of red blood cells in

your blood. These cells carry oxygen around the body. If the number of red blood cells is low, you may be tired and breathless. Tell your doctor or nurse if you feel like this. If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

Increased bruising and bleeding

Chemotherapy can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. Contact your doctor or the hospital straight away if you develop any unexplained bruising or bleeding. This includes nosebleeds, bleeding gums, blood spots or rashes on the skin.

If your red blood cells or platelets take a while to recover, you may need a blood transfusion or a platelet transfusion. You can have transfusions as an outpatient.

Feeling sick

You may feel sick in the first few days after chemotherapy. Your doctor will give you anti-sickness drugs to help prevent or control sickness. Take the drugs exactly as your nurse or pharmacist tells you. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluids and eat small amounts often. If you continue to feel sick, or if you vomit more than once in 24 hours, contact the hospital as soon as possible. They will give you advice and may change the anti-sickness drug to one that works better for you.

Sore mouth

You may get a sore mouth or mouth ulcers. This can make you

more likely to get a mouth infection. Use a soft toothbrush to clean your teeth or dentures in the morning, at night and after meals. If your mouth is sore:

- tell your nurse or doctor – they can give you a mouthwash or medicines to help
- try to drink plenty of fluids
- avoid alcohol, tobacco, and foods that irritate your mouth.

Feeling tired

Feeling tired is a common side effect. It is often worse towards the end of treatment and for some weeks after it has finished. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy. If you feel sleepy, do not drive or operate machinery.

Hair loss

Some chemotherapy drugs may cause hair loss. You may notice your hair thinning. Some people may have total hair loss, including eyelashes and eyebrows, but this is not common. It depends on what chemotherapy drugs you have. Your doctor or nurse can tell you what to expect.

If you do have hair loss, your hair should start to grow back about 3 to 6 months after you finish treatment. Your nurse can give you advice about coping with hair loss and how to look after your scalp.

Contraception

Your doctor will advise you not to get pregnant or father a child while having this treatment and for some time afterwards. The

drugs may harm the developing baby. It is important to use effective contraception.

Fertility

Some of the drugs used to treat CLL may cause infertility (being unable to become pregnant or father a child). This may be temporary or permanent.

If you think you may want to have children in the future, talk to your doctors about this before starting chemotherapy treatment. They can tell you whether your fertility is likely to be affected.

If you have a partner, it is a good idea for both of you to be there during these discussions. You can then make an informed decision about your options.

If you have high-dose chemotherapy, or radiotherapy before a stem cell or bone marrow transplant, you are likely to become permanently infertile.

Men may be able to have sperm stored before they start treatment (sperm banking).

Sometimes women may be able to have eggs collected and frozen It is important to speak to your medical team about this before your treatment starts.

Targeted therapies

Targeted therapies (also called biological therapies) are drugs that target something that is helping the cancer cells grow and survive. Because these drugs only 'target' the cancer cells, they

have less effect on healthy cells.

There are different types of targeted therapy. They all act in different ways and have different side effects. They are often given with chemotherapy. Your haematologist can tell you which treatments may be suitable for you.

Monoclonal antibodies

Monoclonal antibodies treat CLL by targeting proteins on white blood cells called B-lymphocytes (B- cells). This makes the B-cells die.

Monoclonal antibodies are usually given with chemotherapy. They are usually given as a drip into a vein.

Monoclonal antibody treatments used for CLL include:

- rituximab
- obinutuzumab (Gazyvaro®)
- ofatumumab (Arzerra®).

Alemtuzumab is also occasionally used to treat CLL.

How monoclonal antibodies are given

Monoclonal antibodies are usually given into a vein as a drip. You can have them as an outpatient. Some people may be asked to stay in hospital overnight for their first treatment.

Some people may have a reaction during the infusion. A reaction is more likely with the first infusion, so it is given slowly over a few hours. Reactions are usually milder after the first

infusion. You are also given medicines before each infusion to help prevent or reduce any reaction.

Symptoms of a reaction can include:

- a high temperature
- shivering and shakes
- a rash
- blood pressure
- feeling sick (nausea).

If you have any of these symptoms or feel unwell during or soon after an infusion, tell your nurse or doctor immediately.

Alemtuzumab may be given as an injection under the skin (subcutaneously). In this case, it is less likely to cause a reaction.

B-cell receptor (BCR) inhibitors

BCR inhibitors are another type of targeted therapy. They work by targeting proteins called B-cell receptors on the surface of the CLL cells. B-cell receptors control how CLL cells grow. If they are switched off, the CLL cells die. Two drugs that can be used for CLL are ibrutinib (Imbruvica®) and idelalisib (Zydelig®).

BCR inhibitors target the B-cell receptors to stop the cancer growing and dividing. You may be given a BCR inhibitor:

- if CLL comes back after chemo-immunotherapy treatment
- as a first treatment instead of chemo-immunotherapy if you have CLL with a p53 deletion or p53 mutation.

You take BCR inhibitors as tablets or capsules every day. You

usually continue taking them for as long as they are working.

BCL2 inhibitors

One of the reasons that CLL cells continue to grow is that they make too much of a protein called BCL2. BCL2 inhibitors work by blocking (inhibiting) this protein. This helps kill the CLL cells.

Your haematologist may suggest treatment with a BCL2 inhibitor called venetoclax (Venclyxto®) if:

- you have CLL with a p53 deletion or p53 mutation, and BCR inhibitors are not suitable for you or are no longer working
- chemotherapy and other targeted therapy treatments have not worked for you.

You take venetoclax as tablets. You may have it with other treatments. This drug may only be available in some situations. Your haematologist can tell you if it is suitable for you.

Side effects of targeted therapies

Different targeted therapies can have different side effects. Your doctor, nurse or pharmacist will explain the possible side effects of the specific drugs you are having before you start your treatment.

Stem cell transplant

Stem cells are early blood cells that are inside the bone marrow. They make all the red blood cells, white blood cells and platelets in the blood.

A stem cell transplant is a very intensive treatment. It is only usually used to treat CLL when other standard treatments are not suitable, or have not worked. Having a stem cell transplant may result in a long period of remission. But only a small number of people with CLL have one. This is because it can cause very serious side effects and there are many other effective treatment options available. Your doctor will tell you if it might be suitable for you.

People who have a stem cell transplant to treat CLL usually have a type called a donor stem cell transplant (allogeneic). Stem cell transplants are also called bone marrow transplants.

Donor stem cell transplant

For this treatment, you are given stem cells from someone else (a donor). This lets your doctor give a higher dose of chemotherapy than usual. The donor's stem cells will give you a new immune system, which can fight the CLL cells.

The transplant uses stem cells from a brother or sister who is genetically similar to you (a match). If you do not have a brother or sister who can donate stem cells, another donor may be found who has stem cells that genetically match you. This is called a volunteer unrelated donor.

Before you are given donor stem cells, you have intensive chemotherapy. Sometimes radiotherapy is also used. This destroys any remaining leukaemia cells and prepares your immune system for the donor stem cells.

Some types of donor stem cell transplant use less chemotherapy

and radiotherapy. They are called reduced-intensity transplants.

Stem cell transplants are only done in specialist cancer treatment centres.

Radiotherapy

Radiotherapy uses high-energy x-rays to destroy leukaemia cells, while doing as little harm as possible to normal cells. Radiotherapy is not often used to treat CLL. This is because radiotherapy usually only targets specific areas in the body.

Radiotherapy is sometimes used to target a specific area of the body where CLL cells have built up. For example, it might be used to treat the spleen or a group of enlarged lymph nodes.

You have radiotherapy in the hospital radiotherapy department. You have it as an outpatient. Treatment is usually given daily, from Monday to Friday with a rest at the weekend. You may have it over 1 or 2 weeks. Each session may last a few minutes and is painless.

CLL is very sensitive to radiotherapy. If just one area of your body is being treated, you only need a low dose. This means that side effects are not common. Your doctor, nurse or radiographer will tell you about the treatment plan and the possible side effects of the radiotherapy.

Radiotherapy is also sometimes given before a stem cell transplant. This is called total body irradiation (TBI).

Supportive therapy

Supportive therapies are treatments that help control any

symptoms caused by CLL or its treatment. This section explains the more common problems that some people with CLL have, and the treatments that can help.

Infections

People with CLL are more at risk of getting infections. This is because both CLL and the treatments used affect the immune system.

You can usually be treated for infections as an outpatient. But some infections can be life-threatening. If you get one of these, you will need to stay in hospital for treatment. It is important to contact your doctor or specialist nurse straight away for advice if you develop:

- a cough
- a sore throat
- a fever
- any other sign of infection.

Shingles

People with CLL are at a higher risk of developing an infection called shingles. This is an infection of a nerve and the area of skin around it. It is caused by the same virus that causes chickenpox. Anyone who has had chickenpox may develop shingles.

The virus usually affects one nerve in one area of the body. The most common areas to be affected are one side of the chest, or one side of the tummy (abdomen). A nerve in the face can also be affected, but this is less common.

The first symptom is often a tingling or burning feeling in the affected area. This is followed by pain and a red rash. This develops 2 to 3 days later.

Contact your GP or the hospital immediately if you:

- think you have shingles
- come into contact with someone who has shingles or chickenpox.

Effective treatment can prevent or limit the infection. Shingles usually gets better within 2 to 5 weeks.

People over 70 are routinely offered a vaccine against shingles. But if you have CLL, this vaccine is not suitable for you because it is a live vaccine. Your haematologist can give you more information about this.

Vaccines

Most people with CLL are advised to have a yearly flu vaccine. This is to give them as much protection as possible. Your doctors may also recommend two specific vaccines when you are first diagnosed. These are to protect against:

- pneumonia
- a type of infection called streptococcus.

There are some types of vaccine that you should avoid. These are called live vaccines, because they contain the live virus in a weakened form. People with CLL have a weakened immune system, so a live vaccine may cause them harm. Your haematologist can tell you which vaccines are safe and if there

are any you should avoid.

Low levels of antibodies

Many people with CLL have very low levels of infection-fighting antibodies (immunoglobulins) in their blood. This may mean they keep getting infections. Some people who are affected may need regular immunoglobulin treatment. A nurse gives the immunoglobulins:

- as a drip (infusion) into a vein
- as an injection under the skin.

Most people feel fine when they are having an immunoglobulin infusion, but sometimes it can cause a reaction. This can feel similar to the reaction a monoclonal antibody infusion may cause. A reaction is more likely with the first infusion, so it is given more slowly.

Auto-immune reactions in CLL

CLL can sometimes cause the immune system to act against normal, healthy red blood cells or platelets. If red blood cells are affected, this is called auto-immune haemolytic anaemia (AIHA). If platelets are affected, this is called immune thrombocytopenic purpura (ITP).

If you have AIHA, the number of red blood cells in the blood can fall very quickly. This can cause:

- breathlessness
- tiredness
- a yellowish tinge to the whites of your eyes
- dark-coloured urine.

If you suddenly become very tired or breathless, contact the hospital straight away. You may need to have a blood test, and possibly treatment.

With ITP, the number of platelets in the blood can fall suddenly. This can cause:

- bruising
- areas of tiny, dark, purple-red dots on the shins or arms
- unusual bleeding from the gums
- a nosebleed that takes a long time to stop.

If you have any of these symptoms, contact the hospital straight away for advice.

Transfusions

If your bone marrow is not making enough red blood cells or platelets, you may need to have a blood or platelet transfusion. You can have this as an outpatient.

If you are treated with fludarabine or bendamustine, you should only be given blood and platelet transfusions that have been treated with radiation (irradiated).

Irradiated transfusions should always be used during and after you have finished your treatment. This lowers the risk of the donated blood cells reacting against your own blood cells. Your hospital team should give you a card to carry or a MedicAlert ID tag to wear. This is so hospital staff are aware of this if you ever need a blood transfusion in an emergency.

Steroids

Steroids (sometimes called corticosteroids) are substances that are made naturally in the body. They control different functions in our bodies, such as the immune system or the way the body uses food. Steroids can also be man-made and used as part of your treatment.

The steroids most commonly used to treat CLL include:

- dexamethasone
- methylprednisolone
- prednisolone.

You may have treatment with steroids if the number of red blood cells in the blood falls very quickly, because of a condition called auto-immune haemolytic anaemia (AIHA).

Occasionally, people have high-dose steroid treatment called high-dose methylprednisolone (HDMP). With HDMP, you can have the steroids as tablets or as a drip into a vein. Your doctor may prescribe antibiotics, anti-viral drugs or anti-fungal drugs to help prevent infection during your treatment.

Research – clinical trials

Cancer research trials are carried out to try to find new and better treatments for leukaemia. Trials that are carried out on patients are called clinical trials. These may be carried out to:

- test new treatments, such as new chemotherapy drugs or targeted therapies
- look at new combinations of existing treatments or change

the way they are given, to make them more effective or reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how cancer treatments work
- find out which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different type of treatment is better than what is already available.

Taking part in a trial

You may be asked to take part in a treatment research trial. There can be many benefits to this. Trials help to improve knowledge about leukaemia and develop new treatments. You will be carefully monitored during and after the study.

Usually, several hospitals around the country take part in these trials. But some treatments that look promising at first are later found not to be as good as existing treatments, or have side effects that outweigh the benefits. This is something for you to think about.

If you decide not to take part in a trial, your decision will be respected and you don't have to give a reason. But it can help to let the staff know your concerns so they can give you the best advice. There will be no change in the way you are treated by the hospital staff, and you will be offered the standard treatment for your situation.

Blood and biopsy samples

Blood and biopsy samples may be taken to help make the right

diagnosis. You may be asked for your permission to use some of your samples for research into cancer. If you take part in a trial you may also give other samples, which may be frozen and stored for future use when new research techniques become available. Your name will be removed from the samples so you can't be identified.

The research may be carried out at the hospital where you are treated, or at another one. This type of research takes a long time, and results may not be available for many years. The samples will be used to increase knowledge about the causes of cancer and its treatment, which will hopefully improve the outlook for future patients.

Current research

Some trials are testing new combinations of existing treatments, to find out if this makes them more effective. Other trials are looking for more effective treatments for CLL that is either difficult to treat or no longer responding to standard treatments. Some trials are looking at the possible causes of chronic leukaemias, including genetics.

Your haematologist will know if there are any trials you might want to take part in.

Follow-up and monitoring

CLL often progresses very slowly. This means that people who have CLL can live with it for a long time. If you do need treatment, it is usually very effective and can keep the leukaemia under control for many years. You will need to have regular check-ups and blood tests.

If you have any problems or notice any new symptoms, let your doctor know as soon as possible. Do not wait until your next appointment.

Living with CLL

Well-being

You may want to make changes to your lifestyle and find out more about healthy living. This will help you stay as well as possible. Even if you had a healthy lifestyle before your diagnosis, you may want to focus more on making the most of your health.

Having a healthy lifestyle is about making small, manageable changes to the way you live. This will improve your health and well-being, and lower your risk of getting other illnesses and some cancers.

Some examples of having a healthy lifestyle include:

- having a well-balanced diet
- being physically active
- reducing stress
- being involved in your healthcare.

When you plan changes, you need to consider how the side effects of treatment might affect you. Try not to do too much, too soon.

There are many benefits of having a healthy lifestyle. It does not have to be difficult or expensive.

Eat well

Eating well will help you keep your strength, increase your energy levels and improve your well-being. It can also help reduce the risk of new cancers and other diseases, such as heart disease, stroke and diabetes.

A well-balanced diet should include:

- plenty of fresh fruit and vegetables – aim to eat at least 5 portions a day
- foods high in fibre, such as beans and cereals
- plenty of water or other non-alcoholic drinks.

You should also try to reduce your intake of:

- red meat and animal fats
- alcohol
- salted, pickled and smoked foods.

Stop smoking

If you smoke, choosing to stop will benefit your health. Speak to your doctor or call a stop-smoking helpline for advice on how to stop smoking. They can also tell you where your local stop smoking service is.

Reduce stress

There are different ways of reducing stress. They will vary from person to person. Some people find it relaxing to meditate or pray, or you might decide to take up a new hobby. You could try a complementary therapy, such as aromatherapy or reflexology.

Some people find it helpful to talk about their feelings to reduce stress. Being in contact with other people who have been through a similar experience can help. Other people find it helpful to write a journal or blog.

Get physically active

Physical activity can improve your sense of well-being and help build up your energy levels. It also reduces the risk of heart disease, strokes, diabetes and bone thinning (osteoporosis). Being active does not mean you have to exercise intensely. You can start gently and build up the amount you do.

Get involved in your healthcare

This includes taking your medicines as prescribed and always going to your hospital appointments. If you have any problems or notice any new symptoms between appointments that do not go away within a couple of weeks, let your doctor know as soon as possible.

Understanding more about CLL and its treatment can also help you cope. It can help you talk to your doctors and nurses about your treatment, tests and check-ups. It can also help you be involved in making decisions. This can make you feel more confident and give you back a feeling of control.

Talk to someone or share your experience

Talking about your feelings can help reduce stress, anxiety and isolation. There are lots of different ways to communicate, and they can all help people feel less alone. Self-help or support groups offer you a chance to talk to other people who may be in a similar situation and facing the same challenges as you. Joining

a group can be helpful if you live alone or do not feel able to talk about your feelings with the people around you. Not everyone finds it easy to talk in a group, so it might not be for you. Try going along to see what the group is like before you decide.

Online support

Many people now get support on the internet. There are online support groups, social networking sites, forums, chat rooms and blogs for people affected by leukaemia. You can use these to ask questions and share your experience. You can ask your nurse for advice if you are unsure of which sites might be useful.

Specialist help

It is common to still have difficult feelings after treatment is over, but most people find these get better as they recover. Some people only experience a few of these feelings and may be able to deal with them easily. Others may have more, and find them harder to cope with. Try to let your family and friends know how you are feeling so that they can support you. Talking about your feelings is not always easy.

Often it is easier to talk to someone who's not directly involved with your illness. You can ask your hospital consultant or GP to refer you to a specialist doctor or counsellor who can help.

Your feelings and relationships

Your feelings

Relationships

Talking to children

What you can do

If you are a relative or friend

JASCAP has a range of booklets listed below with detailed information on the above subjects.

JASCAP has a series of booklets on the following topics relating emotional aspects of cancer.

Talking about cancer
Talking to children and teenagers when an adult has cancer
Talking with someone who has cancer
Making or changing your Will
When Cancer Returns
Looking after someone with cancer

JASCAP has a series of booklets on the following topics relating physical aspects of cancer.

Dietary advice for cancer patients
Eating Hints Before During and After Cancer Treatment
Cancer and your sex life
Cancer pain

Control of common cancer symptoms
Other symptoms and side effects of cancer and its treatments
Life After Cancer Treatment
Side effects of cancer treatment
Coping with fatigue
Physical activity and cancer treatment

Please also note that all these booklets (PLUS this booklet itself), in various Indian languages are available on our website www.jascap.org for free download.

Work and financial support

Financial help and benefits

The hospital social worker will help you in identifying sources for financial assistance and guide you the procedures for obtaining such help.

Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager early on. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others carry on working, perhaps with reduced hours or other changes to their job.

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to take on too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

JASCAP is a charitable trust that provides information various aspects of cancer. This can help the patient and his family to understand the disease and its treatment and thus cope with it better.

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Contact: **Mr. Prabhakar Rao or Ms. Neera Rao**

JASCAP - we need your help

We hope that you found this booklet useful

To help other patients and their families we need and intend to extend our Patient Information Services in many ways.

Our Trust depends on voluntary donations. Please send your donation by cheque or D/D payable in Mumbai in favour of "JASCAP".

Important

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