CLL

Handheld

Record 2017

Contains- Patient information booklet, details of haematology clinic assessment and ongoing clinical assessment at GP surgery

Stockport NHS Foundation Trust

You have been diagnosed with CLL on \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

The results of your blood tests and physical examination done on

\_\_\_\_\_\_\_\_\_\_\_\_\_ are as follows-

Hb- \_\_\_\_\_\_\_\_\_\_\_

WCC-\_\_\_\_\_\_\_\_\_\_\_\_

Lymphocytes \_\_\_\_\_\_\_\_\_\_\_\_ Neutrophils \_\_\_\_\_\_\_\_\_\_\_\_\_\_

Platelets \_\_\_\_\_\_\_\_\_\_\_\_\_\_

YOUR EXAMINATION FINDINGS

|  |  |  |
| --- | --- | --- |
| Lymphatic area | Left | Right |

Cervical( neck)

Axillary( armpits)

Inguinal ( groin

Spleen

What is chronic lymphocytic leukaemia (CLL)?

Chronic lymphocytic leukaemia (CLL) is the most common type of leukaemia. About 2,700 people in the UK are diagnosed with it each year.

CLL usually develops very slowly and many people don’t need treatment for months or years. However, some people need to have treatment straight away.

In people with CLL, the body makes too many white blood cells called lymphocytes. When examined under a microscope, the lymphocytes look normal, but they aren’t fully developed (immature) and don’t work properly. Over time, these abnormal lymphocytes build up in the lymphatic system (see below) and may cause large, swollen lymph nodes. They may also fill the bone marrow (see below), reducing the number of normal white blood cells, red blood cells and platelets that can be made.

Blood

Blood is made in the bone marrow. This is a spongy material that’s found in the middle of your bones, particularly in your pelvis and backbone (spine). All blood cells are made from stem cells. The bone marrow is a safe place for the stem cells to divide and grow into fully developed (mature) red blood cells, white blood cells and platelets.

These are then released into your blood to carry out different functions:

 x Red blood cells contain haemoglobin (Hb), which carries oxygen from your lungs to all the cells in your body.

 x White blood cells fight and prevent infection. There are several types of white blood cell. The two most important types are neutrophils and lymphocytes.

 x Platelets are very small cells that help the blood to clot and prevent bleeding and bruising.

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 blood cell  Levels found in a healthy person

Haemoglobin (Hb) 130–180g/l (men)

115–165g/l (women)

|  |  |
| --- | --- |
| Platelets | 150–400 x 10/l |
|  | 9 |
|  |  |

White cells (WBC)  4.0–11.0 x 109/l

|  |  |
| --- | --- |
| Neutrophils | 2.0–7.5 x 109/l |
|  |  |
| Lymphocytes | 1.5–4.5 x 109/l |
|  |  |

These figures can be slightly different in people of African-Caribbean and Middle Eastern origin. The figures might look complicated when they’re written down, but in practice they’re used in a straightforward way. For example, you’ll hear doctors or nurses saying things like ‘your haemoglobin is 140’ or ‘your neutrophils are 4’. Many people with CLL soon get used to these figures and what they mean.

Your doctors will often look at the way your blood test results change over time (trend) to decide what, if any, treatment is needed.

Lymphocytes

People with CLL make too many lymphocytes (a type of white blood cell). Normally, lymphocytes are an important part of the body’s defence against bugs such as bacteria, fungal infections and viruses. They fight infections in several ways:

 x they kill bugs directly

 x they make special proteins called antibodies that stick to bugs and make it easier for other white blood cells to find and kill them

 x they remember and recognise bugs - lymphocytes can live for a very long time so they can mobilise quickly to fight any infection you’ve had before.

Lymphocytes travel around the body in the blood and the lymphatic system.

Symptoms of chronic lymphocytic leukaemia (CLL)

Chronic lymphocytic leukaemia (CLL) develops slowly and many people have no symptoms in the early stages.

It’s often discovered by chance when a blood test is taken for another reason, such as before an operation or as part of a routine health check.

The signs and symptoms of CLL can include the following:

 x Feeling tired (fatigued) or unwell.

 x Frequent infections due to a shortage of healthy white blood cells that make antibodies and fight off infections. Infections may be more severe and take longer to clear.

 x Enlarged lymph nodes in the neck, armpits or groin, caused by a build-up of CLL cells. The swollen lymph nodes are usually painless.

 x Breathlessness, tiredness and headaches caused by too few red blood cells (anaemia). x Bruising and bleeding easily, which may happen if there aren’t enough platelets in the blood. You may have nosebleeds that take a long time to stop (more than 10 minutes).

You may get bruises in unexpected places and they may be much bigger than they should be.

 x A tender lump in the upper left-hand side of the abdomen caused by an enlarged spleen.

 x Severe sweating at night.

 x Weight loss.

Stages of chronic lymphocytic leukaemia

Doctors use staging to assess the extent of a leukaemia. This helps them know when treatment is needed and which treatment is appropriate for each person.

There are two staging systems commonly used for CLL: the Binet system and the Rai system.

The Binet system is the one most commonly used in the UK.

Binet staging system

This looks at the number of white cells, red cells and platelets in the blood and 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 swollen this is only counted as one area.

There are three stages in the Binet system:

 x Stage A - There are fewer than three areas of enlarged lymph nodes.

 x

 x

Stage B - There are three or more areas of enlarged lymph nodes.

Stage C - There are a reduced number of red blood cells, platelets or both.

Transformation

In a small number of people with CLL, the leukaemia can change and start to grow more quickly. This is called transformation.

In about 1 in 10 people, CLL may change into another type of leukaemia (prolymphocytic leukaemia). In less than 1 in 10 people, CLL may develop into a particular type of lymphoma (cancer of the lymphatic system) known as Richter’s syndrome.

Transformation can be found by a blood test that shows a high number of leukaemia cells.

Sometimes, the first sign of transformation is an increase in symptoms. These include a high temperature (fever), sweats and weight loss, and a sudden swelling of affected lymph nodes, especially in the tummy (abdomen). However, symptoms such as a high temperature and weight loss can occur for many other reasons.

It’s important to remember that transformation is unusual and doesn’t happen for most people with CLL.

Follow-up and monitoring after treatment for chronic lymphocytic leukaemia (CLL)

Chronic lymphocytic leukaemia (CLL) is an illness that you can live with for a long time, as it often progresses very slowly.

If treatment is needed, it’s usually very effective and can keep the leukaemia under control for many years. You will need to have regular check-ups and blood tests.

Let your doctor know as soon as possible if you have any problems or notice any new symptoms that don’t go away within a couple of weeks - you don’t need to wait until your next appointment.

**When to see your Gp**

**Please ensure you make an appointment with your GP as soon as possible if you have any of the following symptoms-**

1. **Unexplained weight loss.**
2. **Drenching night sweats**
3. **Unexplained fever**
4. **Fatigue**
5. **Sudden appearance of or rapidly increasing lumps in neck, armpits or groins**
6. **Unexplained bleeding ( for example from gums, mouth etc)**

**If any of the above are present, please do not wait till your next appointment, make an appoinment to see your GP in the next 1-2 weeks.**

Other important things to be aware of-

1. You are at a higher risk of infection, please see your GP promptly for assessment and antibiotics, if needed for cough, suspected urinary infections or diarrhoea.
2. Please get you flu jabs each year!

RECOMMENDATIONS FOR FOLLOW UP

 † 4 monthly FBC and examination for lymphadenopathy/splenomegaly for first year, then if stable, 6 monthly for second year, then annually.

 † Prompt treatment of infective episodes with antibiotics.

 † Routine immunisation with Influenza vaccine.

REFERRAL TO HAEMATOLOGY

 † If hb< 100 g/dl

 † Platelets<100 x 10 ^9/l

 † Lymphocytes >30 and doubling within 12 months † Rapidly enlarging or bulky lymphnodes

 † B symptoms- Unintentional weight loss >10% of body weight in 6 months, drenching night sweats, unexplained fever.

 † Refer back as proforma.

 FURTHER INFORMATION

Can be found on www.macmillan.org.uk .

ONGOING ASSESSMENT RECORD AT GP PRACTICE

Date

Hb

WCC

Neutrophils

Lymphocytes

Platelets

Date

Cervical Left

Cervical

Right

Axillary Left

Axillary

right

Inguinal left

Inguinal

right

Spleen

ONGOING ASSESSMENT RECORD AT GP PRACTICE

Date

Hb

WCC

Neutrophils

Lymphocytes

Platelets

Date

Cervical Left

Cervical

Right

Axillary Left

Axillary

right

Inguinal left

Inguinal

righ

Spleen

ONGOING ASSESSMENT RECORD AT GP PRACTICE

Date

Hb

WCC

Neutrophils

Lymphocytes

Platelets

Date

Cervical Left

Cervical

Right

Axillary Left

Axillary

right

Inguinal left

Inguinal

right

Spleen