Chronic Lymphocytic Leukaemia

You have just been diagnosed with 'chronic lymphocytic leukaemia'.

'Leukaemia' means that you have too many of a certain kind of white blood cells. Leukaemia may take any of several forms, of various degrees of seriousness. This is one of the least serious forms.
'Lymphocytic' refers to the white blood cells involved in the immune system whose role is to protect your body against infections.
'Chronic' refers to a disease which progresses slowly, usually over several years.

Medecin's notes :

Chronic lymphocytic leukaemia (CLL) causes abnormal lymphocytic cells to multiply and accumulate in the blood, the lymph nodes, the spleen and the bone marrow, which accounts for the higher level of these cells in your blood and possibly the enlargement of one or more of those organs.
In France a little over 2,000 people are diagnosed with chronic lymphocytic leukaemia each year. Men are slightly more likely than women to develop CLL. It is neither contagious, nor hereditary, even though some forms appear to run in families.

Diagnosis

CLL is a disease affecting blood cells; therefore its diagnosis is made from a simple blood test.

- **Lymphocyte count**

First a haemogram, or full blood count, is made to count the different types of blood cells. A lymphocyte count above the normal range is suggestive of CLL.

- **Immunophenotyping / flow cytometry**

Immunophenotype determination consists in examining the disease-specific molecules (markers) present on the surface of the lymphocytes. This investigation allows to confirm the CLL diagnosis. Immunophenotyping is made by a specialised laboratory.

More often than not no other investigation is required to diagnose CLL. However, your doctor may require a CT (computerised tomography) scan, especially if enlarged lymph nodes have been felt on examination. A bone marrow biopsy may sometimes be useful, as well as the study of the chromosomes and genes of the pathological lymphocytes.

Management

Simple medical supervision by your doctor may be enough for a long period of time, but sometimes treatment may need to be started.

The main kinds of treatment used are chemotherapy and monoclonal antibodies. Sometimes corticosteroids are combined with chemotherapy. These drugs are administered either as intravenous infusions, or as injections into the skin, or still by mouth (tablets or capsules to be swallowed).

If a treatment is started it is administered as regular courses of targeted therapy products that your doctor thinks suitable for you. These courses are usually spaced out by a few weeks. The drugs can also be taken orally on an everyday basis. Treatment completion takes 3 to 12 months depending on each patient's case. More often than not the treatment requires you to make appointments with your doctor or to attend an outpatient clinic.

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Chronic Lymphocytic Leukaemia (suite)

Signs to watch out for

It is important to get in touch with your GP or your haematologist if you experience any of the following:

- fever,
- weight loss,
- problem breathing

These symptoms may be the sign of an infection requiring adapted treatment, or they may be the sign of the evolution of the disease.

Your treatment may induce adverse effects and carry risks. Your doctor will keep you informed and tell you what symptoms to watch out for before you start on the suggested treatment.

Participating in a clinical trial

The best way to contribute to the improvement of disease management is to treat patients in the context of clinical trial. If your doctor suggests this could apply to you, he will explain its purpose, protocol, expected benefits, potential risks and will give you an information leaflet.

Participating in a trial of course means you will first have to give your written informed consent.

Even though current treatments enable to eliminate all visible signs of the disease, they cannot, however, eradicate all of the diseased cells. This explains why, after an event-free period of various duration, symptoms reappear in most patients, requiring a new treatment to be started.

The adverse effects due to the treatment vary with the products used :

- immune deficiency will persist because of the disease, but may paradoxically get temporarily worse because of the treatment, thus requiring antibiotics to be prescribed preventively.
- In spite of such precautions infections may occur with some of these treatments and may require hospital stays for antibiotic infusions. You may also need red blood cell or platelet infusions.

Medical follow up

Regular visits with your doctor and blood tests are usually enough to monitor the disease and its treatment.

Whether your doctor suggests a treatment or not (depending on the stage of the disease and your own general health condition) complications may occur within the course of the disease. Here are some of the most frequent ones:

- infections due to deficient immune defences
- anaemia, i.e. a lower red blood cell count. Anaemia may sometimes be haemolytic, i.e. your red blood cells are spontaneously destroyed, which requires a treatment to be started urgently.

In all cases it is a slowly-growing disease which may not affect your everyday life at all. However, it requires supervision at regular intervals determined by your doctor, whether you need to be on a treatment or not.

The best thing is to learn to live with this disease as it is entirely possible to forget about it.

Useful contacts:

- **Secretarial / appointment:**
- **Nursing consultation:**
- **Consulting psychologist:**
- **Social worker:**
- **In an emergency:**

Patients association → SILLC (Association de Soutien et d'Information à la LLC et à la Maladie de Waldenström)
Site Internet : www.sillc-asso.org