
Watch and Wait

**A Guide for
Patients**

Leukaemia Care
YOUR Blood Cancer Charity

Introduction

Some blood cancers progress rapidly and therefore require treatment straightaway. Others progress slowly, and you may not experience any symptoms for a while. Therefore, the presence of the blood cancer does not affect your general wellbeing or quality of life and only requires treatment when it is absolutely necessary. This is called 'Watch and Wait', or sometimes referred to as 'active monitoring' or 'watchful waiting'.

This booklet helps you to understand:

- What is Watch and Wait?
- Which blood cancers are managed with Watch and Wait
- Some advantages and disadvantages of Watch and Wait
- Coping with Watch and Wait
- Helping yourself when you are on Watch and Wait

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If you would like any information on the sources used for this booklet, please email communications@leukaemiacare.org.uk for a list of references.

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About Leukaemia Care

Leukaemia Care is a national charity dedicated to ensuring that people affected by blood cancer have access to the right information, advice and support.

Our services

Helpline

Our helpline is available 9.00am - 10.00pm on weekdays and 9.00am - 12.30pm on Saturdays. If you need someone to talk to, call **08088 010 444**

Nurse service

We have two trained nurses on hand to answer your questions and offer advice and support, whether it be through emailing **nurse@leukaemicare.org.uk**, over the phone on **08088 010 444** or via LiveChat.

Patient Information Booklets

We have a number of patient information booklets like this available to anyone who has been affected by a blood cancer. A full list of titles – both disease specific and general information titles – can be

found on our website at **www.leukaemicare.org.uk/support-and-information/help-and-resources/information-booklets/**

Support Groups

Our nationwide support groups are a chance to meet and talk to other people who are going through a similar experience. For more information about a support group local to your area, go to **www.leukaemicare.org.uk/support-and-information/support-for-you/find-a-support-group/**

Buddy Support

We offer one-to-one phone support with volunteers who have had blood cancer themselves or been affected by it in some way. You can speak to someone who knows what you are going through. For more information on how to get a buddy call

08088 010 444 or email
support@leukaemicare.org.uk

Online Forum

Our online forum, **www.healthunlocked.com/leukaemia-care**, is a place for people to ask questions anonymously or to join in the discussion with other people in a similar situation.

Patient and carer conferences

Our nationwide conferences provide an opportunity to ask questions and listen to patient speakers and medical professionals who can provide valuable information and support.

Website

You can access up-to-date information on our website, **www.leukaemicare.org.uk**, as well as speak to one of our care advisers on our online support

service, LiveChat (9am-5pm weekdays).

Campaigning and Advocacy

Leukaemia Care is involved in campaigning for patient well-being, NHS funding and drug and treatment availability. If you would like an update on any of the work we are currently doing or want to know how to get involved, email **advocacy@leukaemicare.org.uk**

Patient magazine

Our free quarterly magazine includes inspirational patient and carer stories as well as informative articles by medical professionals. To subscribe go to **www.leukaemicare.org.uk/communication-preferences/**

What is Watch and Wait?

Watch and Wait refers to the time when you have no active treatment following a blood cancer diagnosis.

You will be actively monitored, but how often this happens will depend on the stability of your condition. You will attend regular hospital visits or see your GP where you will have regular blood tests that will be reviewed by your GP, consultant haematologist or specialist. They will ask how you are feeling, monitor any symptoms you may be experiencing and check for any changes or developments in your cancer.

Some patients may never need treatment for their blood cancer because it does not progress to a stage where treatment is required.

It is important to know that even though you are on a Watch and Wait policy, you will still be receiving all the support you need. This form of management is chosen because the condition is either progressing very slowly and remains stable or you may feel well and have no symptoms from your cancer. This also prevents you from experiencing any possible side effects that

may come with treatment if it is not necessary.

Blood cancers usually managed by Watch and Wait

Patients with acute leukaemias and high-grade lymphomas that progress rapidly require treatment straightaway. The Watch and Wait policy does not apply to these patients. However, the Watch and Wait approach is commonly used for the treatment of:

- Chronic lymphocytic leukaemia (CLL)
- Indolent non-Hodgkin lymphoma
- Lymphoplasmacytic lymphoma
- Follicular lymphoma
- Marginal zone lymphoma
- Mantle cell lymphoma
- Smouldering myeloma
- Monoclonal gammopathy of unknown significance (MGUS)

- Myeloproliferative neoplasms (MPN)
- Myelodysplastic syndromes (MDS)
- Large granular lymphocytic leukaemia (LGLL)
- Monoclonal B cell lymphocytosis (which can then transform into CLL)

You can find out more about some of these types of blood cancer, such as CLL and MDS, in our disease specific booklets, which are downloadable from our website or you can request them by calling **08088 010 444**.

Advantages and disadvantages to Watch and Wait

Advantages

When patients are given chemotherapy too early they can build up a resistance to chemotherapy drugs, which can affect treatment options at a later date.

One advantage of the Watch and Wait approach is that it ensures patients are not exposed to high-dose chemotherapy and the side effects that can occur during these treatments earlier than necessary.

Many patients enjoy a long period of feeling well and carry on living their normal lives. If, or when, treatment does start, patients tend to respond to the chemotherapy well because it has been given at the right stage in their disease. Clinical trials have shown that there is no advantage to starting treatment earlier than necessary as this

has been found to have no improvement in outcome.

Disadvantages

Receiving a diagnosis of a blood cancer can be very difficult. Watch and Wait is sometimes referred to by patients as 'watch and worry' because waiting for treatment after a cancer diagnosis can be extremely stressful, adding to the anxieties you will naturally already have about your condition.

Some people also assume being put on Watch and Wait is because their cancer is incurable; however, it is not as simple as this. Although it is not curable, it is treatable, but you will only require treatment when you become symptomatic. This will become noticeable in either blood test results, or through physical symptoms.



Coping with Watch and Wait

The Watch and Wait approach can be a worrying time for patients. The uncertainty about whether your condition will progress and its impact on you can provoke anxiety. You might feel helpless or out of control, which are common feelings that you will ultimately need to learn to live with.

Human beings are actually incredibly resilient and good at coping with adversity. It is a good idea to learn some coping strategies to help you feel less overwhelmed by anxiety.

If you are worried about delaying treatment, there are some things you can do to help you cope with this prospect.

How can I help myself?

There is some evidence to suggest that people who are generally healthy and fit when their treatment begins have a lower risk of complications. The following lifestyle suggestions

might help you in the future:

- Try to eat a healthy diet with plenty of fruit and vegetables.
- Maintain a healthy weight.
- Take regular, gentle exercise.
- Give up smoking.
- Try not to drink more than the recommended amount of alcohol.
- Adopt strategies to help manage your fatigue (more information about coping with fatigue can be found on our website at www.leukaemicare.org.uk/support-and-information/information-about-blood-cancer/living-well-with-leukaemia/fatigue/).
- Ensure you make time for relaxation and doing things that you enjoy.

Some people find it useful to use the time whilst on Watch and Wait to learn more about

their condition and the different treatment types available. However, this is not the case for everyone.

At Leukaemia Care we have a freephone helpline service available for patients and carers who are affected by a blood cancer. We can provide emotional and practical support as well as medical advice. The telephone number of the helpline is **08088 010 444**.

Patient support groups

You may find it helpful to attend a local support group in your area and meet other people who are facing a similar situation. Our support groups are an informal environment where

people can talk openly about how they are feeling and meet other people to whom they can relate. Guest speakers come and talk on helpful topics about treatment and other areas that may affect your life.

Buddy support

We offer a one-to-one Buddy Support service where you can be put in contact with one of our volunteers who has the same diagnosis and treatment plan as you. Many patients find it beneficial to talk to someone in the same situation as themselves.

Talk it through

It is important to know that you are never alone at any stage in your treatment and there is always support available through your GP, clinical nurse specialist or haematologist. Talking through your treatment can help ease any anxieties you may have.

Coping with Watch and Wait (cont.)

Managing practical issues

It might also be helpful to inform your place of work of your cancer diagnosis and treatment plan so that they can help to put any necessary adjustments into place, such as flexible working hours. If you feel like you can no longer work, you may be entitled to receive benefits to help with the cost of living, such as Personal Independence Payment (PIP).

If you are struggling to come to an agreement with your employer or are unsure of how to fill in an application form for benefits, we can offer advice and support from our in-house Advocacy Caseworker. To get in touch, email advocacy@leukaemicare.org.uk

For more information about work and finances, there is a designated chapter in our booklet *The Next Stage* which can be ordered by emailing support@leukaemicare.org.uk or calling **08088 010 444**. Alternatively, you can find out more on our website at www.leukaemicare.org.uk/support-and-information/information-about-blood-cancer/living-well-with-leukaemia/practical-issues/



Changes that might indicate you need to start treatment

Even when you are not having any active treatment, you will still have regular appointments with your GP or haematologist.

At each appointment they will check for signs that show you may need to start treatment. Treatment will start either if you begin to experience significant symptoms or when the results of tests suggest that your condition is progressing.

It is important that if you notice any changes in your condition that you tell your GP, clinical nurse specialist, consultant or the cancer centre that you attend straightaway, especially if:

- You are experiencing new symptoms.
- You have a loss of appetite and/or weight loss.
- You are experiencing worsening fatigue.
- You are having unexplained, persistent fevers.

Are you a carer?

Caring for someone who is on Watch and Wait can evoke some very strong feelings. Even though you are not the patient, it is inevitable that the journey of a blood cancer will have an effect on everyone and it is important that you find the time to look after yourself.

You may experience feelings of helplessness, worry, loneliness, stress and uncertainty and you may feel scared about what the future might hold. It is important to keep in mind that being a carer can affect different people in different ways and however you are feeling, it is very normal to go through a mixture of emotions and there is support available.

You can request a copy of our Caring for Carers booklet which provides information on dealing with the feelings you may be experiencing by calling **08088 010 444** or emailing **support@leukaemiacare.org.uk**

Questions to ask your medical team

When Watch and Wait is recommended, it is natural for you to have a number of concerns and questions. Below are some questions you may wish to ask your medical team. It is important to bear in mind that some of the answers will be generalised as it can be quite hard to predict how the cancer will progress or exactly when treatment will be required.

- 1.** How long will I be on Watch and Wait before I need to start treatment?
- 2.** Are there any specific tests that can tell when I might need treatment?
- 3.** If I do need treatment, what will it involve?
- 4.** How often will my appointments be and what happens during them?
- 5.** Are there any specific symptoms that need to be mentioned to my consultant?
- 6.** Are there any precautions I need to take whilst on Watch and Wait?

Glossary

Acute Leukaemia

Leukaemia is a cancer of the white blood cells. Acute leukaemia means it progresses rapidly and aggressively, and usually requires immediate treatment.

Chemotherapy

A type of cancer treatment that uses one or more drugs with a powerful chemical to kill growing cancer cells.

Chronic Leukaemia

A type of blood cancer that affects the white blood cells. This tends to progress over many years.

Chronic Lymphocytic Leukaemia

A cancer that effects the blood and bone marrow derived from lymphocytes.

Clinical trial

A highly regulated research study which assigns patients and non-patients to participate in the study and to evaluate the efficacy of a drug or a combination of drugs.

Fatigue

Extreme tiredness, which is not alleviated by sleep or rest.

Fatigue can be acute and come on suddenly or chronic and persist.

Large Granular Lymphocytic Leukaemia (LGLL)

T-cell large granular lymphocyte (LGLL) leukaemia is the reproduction of cytotoxic (toxic to living cells) T-cells, which causes neutropenia, anaemia, and/or thrombocytopenia. This condition is often associated with autoimmune disorders, especially rheumatoid arthritis, and other lymphoproliferative disorders.

Leukaemia

A cancer of the blood with many different subtypes. Some forms are acute (develop quickly) and others are chronic (develop slowly). Leukaemia is an excess number of abnormal cells in the blood, usually white blood cells, which stop the bone marrow working properly.

Lymphocyte

A type of white blood cell which forms the body's immune system.

Myelodysplastic Syndrome (MDS)

A disorder in which the bone marrow does not make

Glossary (cont.)

enough healthy blood cells, the maturation of the cells is abnormal and there may be blast cells visible in the marrow. It may be a precursor to the development of acute leukaemia.

Platelets

A disc-shaped element in the blood that assists in blood clotting. During normal blood clotting, the platelets clump together (aggregate).

Radiotherapy

The use of high energy x-rays to treat cancer. The radiotherapy field is the area of the body being treated. Cancer cells are killed within the radiotherapy field.

Red blood cells

The blood cell that carries oxygen. Red cells contain haemoglobin, which permits them to transport oxygen (and carbon dioxide) around the body.

White blood cells

One of the cells the body makes to help fight infections. There are several types of white blood cells. The two most common types are the lymphocytes and neutrophils.

Tell us what you think!

If you would like to give us some feedback about this patient information booklet, please hover over the code to the right using your phone or tablet's camera. Click the link as it appears and this will take you to a short web form to fill in.

Suitable for Android, iPhone 7 and above.



Useful contacts and further support

There are a number of helpful sources to support you during your diagnosis, treatment and beyond, including:

- Your haematologist and healthcare team
- Your family and friends
- Your psychologist (ask your haematologist or CNS for a referral)
- Reliable online sources, such as Leukaemia Care
- Charitable organisations

There are a number of organisations, including ourselves, who provide expert advice and information.

Leukaemia Care

We are a charity dedicated to supporting anyone affected by the diagnosis of any blood cancer.

We provide emotional support through a range of support services including a helpline, patient and carer conferences, support group, informative website, one-to-one buddy service and high-quality patient information. We also have a nurse on our help line for any medical queries relating to your diagnosis.

Helpline: **08088 010 444**
www.leukaemiacare.org.uk
support@leukaemiacare.org.uk

Bloodwise

Bloodwise is the leading charity into the research of blood cancers. They offer support to patients, their family and friends through patient services.

020 7504 2200
www.bloodwise.org.uk

Cancer Research UK

Cancer Research UK is a leading charity dedicated to cancer research.

0808 800 4040
www.cancerresearchuk.org

Macmillan

Macmillan provides free practical, medical and financial support for people facing cancer.

0808 808 0000
www.macmillan.org.uk

Maggie's Centres

Maggie's offers free practical, emotional and social support to people with cancer and their families and friends.

0300 123 1801
www.maggiescentres.org

Citizens Advice Bureau (CAB)

Offers advice on benefits and financial assistance.

08444 111 444
www.adviceguide.org.uk

Leukaemia Care is a national charity dedicated to providing information, advice and support to anyone affected by a blood cancer.

Around 34,000 new cases of blood cancer are diagnosed in the UK each year. We are here to support you, whether you're a patient, carer or family member.

Want to talk?

Helpline: **08088 010 444**

(free from landlines and all major mobile networks)

Office Line: **01905 755977**

www.leukaemicare.org.uk

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