
Watch and Wait

**A Guide for
Patients**

Introduction

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

If you are diagnosed with a slow progressing blood cancer and are recommended the watch and wait approach, we understand this can be hard to comprehend as it's probably not what you were expecting to be told upon a diagnosis of cancer.

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're on watch and wait

Booklet written by Hannah Cunliffe, former Nurse Advisor at Leukaemia Care.

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/resources/filter-by-resource-type/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/our-support-groups**

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 **care@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/resources/subscribe-to-journey-magazine

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; how often will depend on how stable your condition is. You will attend regular hospital visits or see your GP where you will have regular blood tests which will be reviewed by your GP, consultant haematologist or specialist. They will also 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. Treating it would only make you feel more unwell as a result of the cancer drugs.

Blood cancers usually managed by Watch and Wait

Patients with high-grade lymphomas and acute leukaemias which 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
- MGUS
- Myeloproliferative neoplasms (MPN)
- The myelodysplastic syndromes (MDS)

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 occur during these treatments earlier than necessary.

Lots of patients enjoy a long period of feeling well and carry on living their normal lives. If, or when, treatment does start, patients respond to the chemotherapy well because it has been given at the right stage in their disease. Clinical trials have shown that patients who are on a watch and wait approach have the same outcomes as patients who have treatment immediately.

Disadvantages

Receiving a diagnosis of a blood cancer can be a very difficult time. 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 condition is incurable, however this is not the case.

Coping with Watch and Wait

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

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

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

You can find out more about these in our booklet on the emotional impact of a blood cancer, which is downloadable from our website or you can request one by calling **08088 010 444**.

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.
- Consider reducing your hours at work (if financially possible) to help manage 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 helpful to learn more about their condition and the different treatment types available. However this is not the case for

everyone.

Patient support groups

You may find it helpful to attend a local support group in your area and meet with 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 they can relate to. 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 this 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.

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.

Changes that may indicate you need to start treatment

Even when you're not having any active treatment, you'll still have regular appointments with your GP or haematologist.

At each appointment they'll 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, too.

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're 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 **care@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. 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 which need to be mentioned to my consultant?
- 6.** Are there any precautions I need to take whilst on watch and wait?

Glossary

Chemotherapy

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

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.

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 disoreder in which the bone marrow does not make 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.

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
care@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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Leukaemia Care
YOUR Blood Cancer Charity

