
Watch and wait (also known as active monitoring)

A Guide for
Patients

Introduction

Some blood cancers progress rapidly and require immediate treatment. Others progress slowly, and you may not experience any symptoms for a while or at all. Therefore, the presence of these blood cancers does not cause any symptoms or affect your quality of life. They only require treatment when it is absolutely necessary. These blood cancers can be managed using watch and wait, also referred to as ‘active monitoring’ or ‘watchful waiting’.

This booklet helps you to understand:

- What is watch and wait?
- Which blood cancers can be 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

This booklet was written by Hannah Cunliffe, a former Nurse Advisor at Leukaemia Care, and the rewrite was put together by Lisa Lovelidge. The booklet has since been updated by our Patient Information Writer, Isabelle Leach and medically reviewed by Clinical Nurse Specialist Helen Knight. We are also grateful to Erica Farmer and Marc Auckland for their contributions as patient reviewers.

If you would like any information on the sources used for this booklet, please email communications@leukaemiare.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 8:30am – 5:00pm Monday - Friday and 7:00pm – 10:00pm on Thursdays and Fridays. If you need someone to talk to, call **08088 010 444**.

Alternatively, you can send a message via WhatsApp on **07500068065** on weekdays 9:00am – 5:00pm.

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 or over the phone on **08088 010 444**.

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@leukaemiacare.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.leukaemiacare.org.uk**.

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@leukaemiacare.org.uk**

Patient magazine

Our magazine includes inspirational patient and carer stories as well as informative articles by medical professionals: **www.leukaemiacare.org.uk/communication-preferences/**

What is watch and wait?

Watch and wait, also known as active monitoring, is the close monitoring of a patient with a slow-growing cancer without treatment until symptoms appear or worsen.

You will be actively monitored, but how often this happens will depend on the stability of your condition. You will have regular visits to see your hospital consultant or GP where you will have blood tests to monitor your condition. 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 being managed using watch and wait, you will still be receiving all the support and monitoring you need. This form of management is chosen because your condition is either progressing very slowly and remaining stable, or you may feel well and have no symptoms.

Blood cancers usually managed by watch and wait

Blood cancers typically occur when the blood cells start growing out of control and interrupt the function of normal blood cells. These cancers start in the bone marrow or the lymphatic system, and the cells are usually abnormal and do not work properly. The lymphatic system includes the spleen, thymus gland, tonsils and lymph nodes, linked by a network of lymphatic vessels. The lymphatic system transports lymph, a fluid containing infection-fighting white blood cells, throughout the body.

Patients with an acute leukaemia or high-grade lymphoma that progress rapidly require immediate treatment. However, slow-growing types of blood cancer can be managed using watch and wait.

Blood cancers can be divided into three main types: leukaemia,

lymphoma and myeloma. They all affect different types of blood cells and act in different ways.

Leukaemia

These blood cancers begin in the bone marrow. Leukaemia is classified according to the type of blood cell it affects (either myeloid or lymphoid) and whether it grows quickly (acute) or slowly (chronic).

Chronic lymphocytic leukaemia (CLL), small lymphocytic lymphoma (SLL), hairy cell leukaemia (HCL) and large granular lymphocytic leukaemia (LGLL) can be managed using watch and wait.

Monoclonal B-cell lymphocytosis is the presence of less than $5 \times 10^9/L$ of identical B-cell lymphocytes in the blood with no signs of increase in cell numbers. As the condition is known to progress into CLL, it can also be managed using watch and wait.

Lymphoma

Lymphomas are cancers that start in the lymphocyte white blood cells within the lymphatic system.

Only low-grade lymphomas such

as indolent (slow growing) non-Hodgkin lymphoma, follicular lymphoma, lymphoplasmacytic lymphoma (Waldenström macroglobulinemia) and mantle cell lymphoma and marginal zone lymphoma can be managed using watch and wait.

Myeloma

These cancers of the plasma cells start in the bone marrow. Plasma cells are a type of white blood cell that makes antibodies. When cancerous, they multiply uncontrollably and spread throughout the bone marrow, crowding out healthy blood cells and the antibodies they make cannot fight off infections.

Only the slow-growing smouldering myeloma and monoclonal gammopathy of unknown significance (MGUS) can be managed using watch and wait.

Other proliferative disorders of the blood include myelodysplastic syndromes (MDS) and myeloproliferative neoplasms (MPNs) which may also be managed using watch and wait.

What is watch and wait? (cont.)

MDS

In this group of cancers, bone marrow cells of all types reproduce uncontrollably and have abnormal (dysplastic) changes. MDS are characterised by a poorly functioning bone marrow and a likelihood to progress to acute myeloid leukaemia (AML).

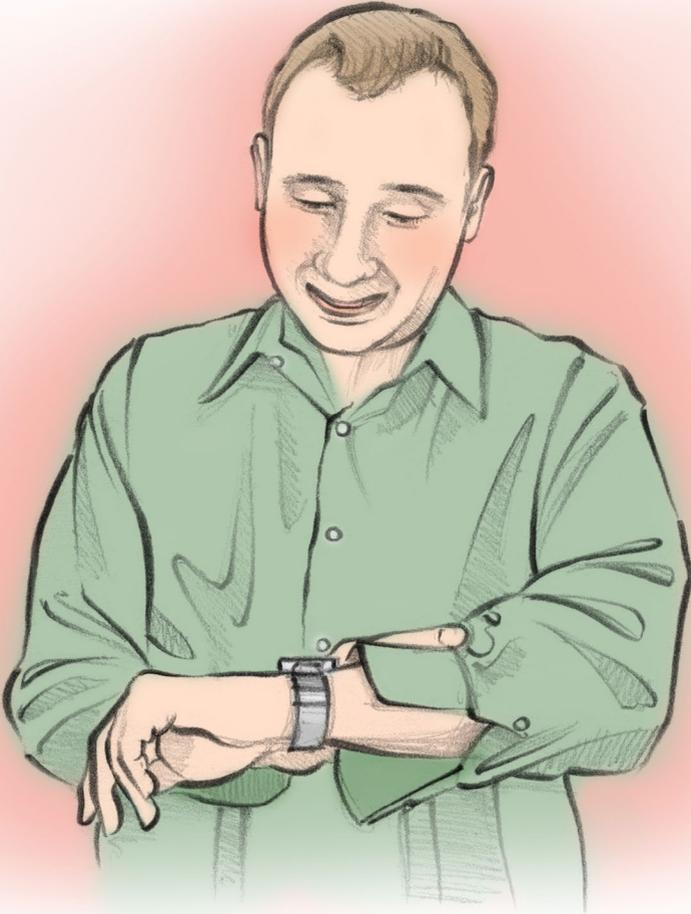
MPNs

These chronic disorders are characterised by the myeloid stem cells in the bone marrow making too many abnormal red blood cells, white blood cells, or platelets which do not function properly. The main MPNs are:

- Chronic myeloid leukaemia (CML)
- Essential thrombocythaemia (ET)
- Polycythaemia vera (PV)
- Primary myelofibrosis (MF)

Some MPNs are also likely to transform into acute myeloid leukaemia (AML).

You can find out more information about some of these types of blood cancers in our dedicated booklets. To see our full range, you can go to our website at www.leukaemiacare.org.uk or you can request hard copies by calling **08088 010 444** or emailing support@leukaemiacare.org.uk.



Advantages and disadvantages to watch and wait

Advantages

For most types of leukaemia and other blood cancers such as high-grade lymphomas, early treatment is advisable. However, this is not the case for CLL and the other blood cancers mentioned previously because their clinical course can vary.

For patients who do not have any symptoms, watch and wait is the current standard of care. For example, a large proportion of people diagnosed with CLL are diagnosed due to an incidental finding from a blood test taken for another reason. In these circumstances they are well, with no symptoms, so exposing them to treatment with possible side effects would not be beneficial. Instead, waiting until there is a need for treatment, such as becoming symptomatic, is preferential.

Another reason for this is that because there is no treatment available to cure these conditions, the best option is managing them with the treatments available to help patients lead the best life

possible. Many patients enjoy a long period of feeling well and carry on living their normal lives, with no need for treatment.

If treatment is necessary, patients tend to respond well to treatment because it has been given at the right stage in their disease. Watch and wait is the right management approach for a number of reasons, including:

- Clinical trials have shown that there is no evidence of a clinical or survival benefit for patients with no symptoms who are treated early.
- When patients are given treatment too early they can build up a resistance to treatments over time. This will reduce the options when symptoms appear and active treatment is needed.
- Most treatments have side effects with the possibility of treatment-related complications. These side effects are avoided until treatment is necessary by using watch and wait.

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 that having the condition causes. It is understandable to want to start treatment and deal with the condition straight away.

Additionally, some people assume that if they are being managed using watch and wait, it is solely because their cancer is considered incurable; however, this is not the case. Although your condition is not curable, it is treatable and you will only require treatment when you become symptomatic. This stage will become noticeable from the result of your blood tests or the emergence of physical signs and symptoms.

Coping with watch and wait

Watch and wait can be a worrying time for patients. The uncertainty about whether your condition will progress and how its symptoms may affect you can leave you feeling anxious. You might feel helpless or out of control, which are common feelings that you need to learn to live with.

Human beings are actually incredibly resilient and good at coping with adversity. It might be beneficial for you 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.leukaemiacare.org.uk).
- Ensure you make time for relaxation and doing things that you enjoy.
- If you are experiencing minor symptoms, develop personal coping strategies to help you manage them. Remember, if you start to experience any new symptoms, tell your GP or medical team.

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.

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 with whom you 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 a similar 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 plan can help ease any anxieties you may have.

Managing practical issues

It might also be helpful to inform your place of work of your 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.

For more information about work and finances, there is a dedicated chapter in our booklet *The Next Stage* which can be ordered by emailing support@leukaemiacare.org.uk or calling **08088 010 444**. Alternatively, 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, you can receive advice and support from our Advocacy Team. To get in touch, email advocacy@leukaemiacare.org.uk.

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 and symptoms 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 you tell your GP, clinical nurse specialist, consultant or the cancer centre that you might 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 condition requiring watch and wait 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. However you are feeling, it is very normal to go through a mixture of emotions and there is support available.

You can download our Caring for Carers booklet, which provides information on dealing with the feelings you may be experiencing, from our website at www.leukaemiacare.org.uk. Alternatively, you can order the booklet by emailing Patient Services at support@leukaemiacare.org.uk or calling the helpline on **08088 010 444**.

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:

- Is it possible to estimate how long I will be on watch and wait for before I need to start treatment?
- Are there any specific tests that can tell when I might need treatment?
- If I do need treatment, what will it involve?

- How often will my appointments be and what happens during them?
- Are there any specific symptoms that need to be mentioned to my consultant?
- Are there any precautions I need to take whilst on watch and wait?

It is important to bear in mind that some of the answers will be generalised as it can be quite hard to predict how a particular condition will progress or exactly when treatment will be required.

At Leukaemia Care we offer a freephone helpline service available for anyone who is affected by blood cancer. We can provide emotional and practical support as well as medical advice. To use the helpline and speak to a member of our Patient Services team, call **08088 010 444**.

Glossary

Acute leukaemias

Leukaemias which progress rapidly and are generally aggressive. There are two main types: acute lymphoblastic leukaemia and acute myeloid leukaemia.

Acute lymphoblastic leukaemia (ALL)

A leukaemia in which lymphocytes start multiplying uncontrollably in the bone marrow, resulting in high numbers of abnormal, immature lymphocytes. Lymphocytes are a type of white blood cell involved in the immune response.

Acute myeloid leukaemia (AML)

A rapid and aggressive cancer of the myeloid cells in the bone marrow.

Antibodies

A blood protein produced in response to and counteracting a specific antigen. Antibodies combine with substances which they recognise as alien, such as bacteria, viruses and foreign substances in the blood.

Blood cells

Cells present in the blood and bone marrow which include red blood cells, white blood cells and platelets. These three types of blood cell make up 45% of the blood volume, with the remaining 55% being plasma, the liquid component of blood.

Bone marrow

The soft blood-forming tissue that fills the cavities of bones and contains fat, immature and mature blood cells, including white blood cells, red blood cells and platelets.

Chemotherapy

Drugs that work in different ways to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing.

Chronic leukaemias

Leukaemias which progress slowly and are less aggressive than acute leukaemias. There are two main types: chronic lymphocytic leukaemia and chronic myeloid leukaemia.

Glossary (cont.)

Chronic lymphocytic leukaemia (CLL)

A leukaemia in which the B-lymphocytes (B-cells) in the bone marrow start multiplying excessively leading to large numbers of small, mature lymphocyte cells, which are unable to fight infection, and their presence prevents the bone marrow from producing healthy blood cells of all types.

Chronic myeloid leukaemia (CML)

A leukaemia in which the myeloid cells start multiplying in the bone marrow leading to large numbers of abnormal, immature myeloid cells called blasts, which prevent the bone marrow from producing enough healthy blood cells of all types.

Clinical Trials

Trials designed and planned to determine a specific answer or aim; for example, whether treatment A is better than treatment B. The study will be conducted in patients who meet

particular criteria, and the results are collected and analysed to provide an answer.

Essential thrombocythaemia (ET)

An increased production in the bone marrow of the platelets by the megakaryocytes, which are the platelet-forming cells. This condition leads to abnormal blood clotting or bleeding.

Fatigue

Tiredness and weakness rendering the patient unable to work or perform usual activities.

Follicular lymphoma

Normally a slow-growing form of a non-Hodgkin's lymphoma that arises from B-cells. This subtype of lymphoma represents 20% to 30% of all non-Hodgkin's lymphomas.

Haemoglobin

The protein molecule in red blood cells that carries oxygen from the lungs to the body's tissues and returns carbon dioxide from

the tissues back to the lungs. Haemoglobin is made up of four protein molecules (globulin chains) that are connected together.

High-grade lymphomas

Lymphomas that grow and spread quickly. High-grade lymphomas have a quicker and longer lasting response to treatment than the low-grade lymphomas do.

Hodgkin lymphoma

A lymphoma characterised by the presence of a type of cell called the Reed-Sternberg cell which has a particular appearance under a microscope. Reed-Sternberg cells are a type of B-cell that has become cancerous. Hodgkin lymphoma accounts for approximately 10% to 30% percent of all lymphomas depending on the age of the patient.

Large granular lymphocytic leukaemia (LGLL)

A rare leukaemia characterised by an excessive production of large granular T-lymphocytes and

natural killer cells which infiltrate the bone marrow, spleen and liver.

Leukaemia

A group of cancers that usually begin in the bone marrow and result in high numbers of abnormal blood cells. These cells are not fully developed and are called blasts or leukaemia cells. Depending on the type of blood cell involved, there are different types of leukaemia with varying characteristics, such as being acute (develops quickly) or being chronic (develops slowly).

Lymph nodes

A component of the lymphatic system (part of the body's immune system) that contains lymphocytes which produce antibodies and macrophage cells which digest dead cells. Lymph nodes are swollen with cell fragments in the event of infection or cancer. They can be located anywhere in the body, but are mainly noticeable in the spleen but also in the neck, armpit and groin.

Glossary (cont.)

Lymphocytes

A type of white blood cell that is vitally important to the immune response. There are three types of lymphocytes: B-cells, T-cells and natural killer (NK)-cells. B-cells produce antibodies that seek out invading organisms. T-cells destroy the organisms that have been labelled by the B-cells, as well as internal cells that have become cancerous. NK-cells attack cancer cells and viruses.

Lymphoid

Relates to lymphocyte white blood cells.

Lymphoma

A blood cancer originating from lymphocytes within the lymphatic system, and include Hodgkin and non-Hodgkin's lymphoma.

Lymphoplasmacytic lymphoma

A low-grade (slow-growing) non-Hodgkin's lymphoma that develops from B-cells that grow out of control and are abnormal.

Mantle cell lymphoma

An aggressive type of non-

Hodgkin's lymphoma which develops from the B-cells in the mantle region, which is the outer layer of the lymph node.

Marginal zone lymphoma

A slow-growing non-Hodgkin's lymphoma of the B-cells that begins at the edge of normal lymphoid tissues (collections of lymphocytes) called the marginal zone.

Monoclonal B-cell lymphocytosis

A condition in which a higher-than-normal number of identical B-cells are found in the blood. To confirm a diagnosis, there must be a presence of less than $5 \times 10^9/L$ (that is, five billion cells per litre of blood) of identical B-cell lymphocytes in the blood with no signs of increase in cell numbers. This condition is known to progress into CLL.

Monoclonal gammopathy of unknown significance (MGUS)

A condition characterised by the presence of an abnormal protein called M-protein produced by plasma cells in the bone marrow. The protein is present in the

blood and bone marrow. MGUS is normally a benign condition as there is only a very small risk that it will develop into myeloma. Watch and wait is required to detect any progression into myeloma.

Myelodysplastic syndromes (MDS)

MDS occur when the bone marrow does not make enough normal blood cells. The blood cells made are not fully developed and not able to work normally. These blood cells include red blood cells which supply oxygen to the body's tissues, white blood cells which fight infection and platelets which help blood clot.

Myeloid

Relates to bone marrow.

Myeloma (multiple myeloma)

A cancer of the plasma cells in the bone marrow, which are derived from B-cells and produce antibodies. Myeloma accounts for approximately 15% of blood cancers. It affects multiple places in the body which is why it is often called multiple myeloma.

Myeloproliferative cancer

A disease of the bone marrow in which excess cells are produced.

Neoplasm

The medical term for cancer, meaning a new and abnormal growth of tissue anywhere in the body.

Non-Hodgkin's lymphoma

A group of blood cancers that includes all types of lymphoma except Hodgkin lymphomas. Lymphoma is a cancer that starts in lymphocytes of the lymphatic system, which are part of the body's immune system. Non-Hodgkin's lymphoma account for approximately 80% percent of all lymphomas.

Plasma cell

A type of white blood cell that produces antibodies and is derived from B-cells. It is an ovoid (egg-shaped) cell with an off-centre nucleus.

Platelets

One of the types of blood cell which helps to stop bleeding.

Glossary (cont.)

Polycythaemia vera (PV)

A chronic increased production of red blood cells, white blood cells and platelets in the bone marrow. When the increased production is only of the red blood cells, the condition is erythrocytosis.

Prognosis

An indication of how well a patient is expected to respond to treatment based on their individual characteristics at the time of diagnosis or another timepoint in the disease.

Proliferation

A rapid increase, for example, in the number of cells.

Red blood cells

Small blood cells that contain haemoglobin and carry oxygen and other substances to all tissues of the body.

Spleen

The largest organ of the lymphatic system whose function is to help clear the body of toxins, waste and other unwanted materials. The spleen is located under the ribs on the left of the abdomen.

Thymus gland

The main organ of the lymphatic system, located behind the sternum and between the lungs, where the T-cell lymphocytes develop and mature.

White blood cells

White blood cells create an immune response against both infectious disease and foreign invaders. Granulocyte white blood cells include the neutrophils (protect against bacterial infections and inflammation), eosinophils (protect against parasites and allergens) and basophils (create the inflammatory reactions during an immune response). Other white blood cells include the lymphocytes (recognise bacteria, viruses and toxins, to which they produce antibodies) and monocytes (clear infection products from the body).

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.leukaemicare.org.uk
support@leukaemicare.org.uk

Blood Cancer UK

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

0808 2080 888
www.bloodcancer.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

support@leukaemicare.org.uk

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Leukaemia Care is registered as a charity in England and Wales (no.1183890) and Scotland (no. SC049802).
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Leukaemia Care
YOUR Blood Cancer Charity