
Mixed Phenotype Acute Leukaemias (MPALs)

**A Guide for
Patients**

Leukaemia Care
YOUR Blood Cancer Charity

Introduction

Being diagnosed with a mixed phenotype acute leukaemia (MPAL) such as bilineal leukaemia or biphenotypic leukaemia can be a shock. Due to their rarity, you may have never heard of them. If you have any questions about MPALs – including what causes them, who they affect, how they affect your body, what symptoms to expect and likely treatments – this booklet covers the basics for you.

For more specialised, tailored advice, speak to your GP or medical team.

This booklet has been compiled by our Patient Information Writer Isabelle Leach and peer reviewed by Prem Mahendra, Consultant Haematologist from University Hospitals Birmingham NHS

Foundation Trust. We are also grateful to Christine Cozart for their contribution as patient reviewer.

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

What are MPALs?

Most acute leukaemias can easily be recognised as being either myeloid or lymphoid (B-lymphoblastic or T-lymphoblastic).

Lymphoid cells give rise to lymphocyte cells which are the white blood cells that help fight infections as part of the immune system. There are three types of lymphocytes:

1. B-lymphocytes (B-cells)
2. T-lymphocytes (T-cells)
3. Natural killer lymphocyte (NK-cells)

Myeloid cells give rise to neutrophils and monocytes.

Patients with acute leukaemia are normally divided into acute lymphoblastic leukaemia (B-cell or T-cell ALL) if the origin of the leukaemia cells is lymphoid, or acute myeloid leukaemia (AML) if the origin of the leukaemia cells is myeloid.

A small minority of acute leukaemias (<5%) show no clear origin of their leukaemia cells, and are called leukaemias of

ambiguous lineage. They include:

Mixed phenotype acute leukaemias (MPALs)

Leukaemia cells which have antigens of more than one origin. There are two distinct groups of leukaemia within the very rare MPALs:

- **Bilineal leukaemias** - These acute leukaemias are characterised by having two separate populations of blast cells of myeloid and lymphoid origin at diagnosis. Bilineal means two lineages.
- **Biphenotypic leukaemias** - These acute leukaemias have a single population of leukaemia cells which express antigen markers of both lymphoid and myeloid origin. Biphenotypic means both types.

Acute undifferentiated leukaemias

In these leukaemias, it is not possible to differentiate the origins of the cell populations or the antigen markers on the leukaemia cells.

The term biphenotypic leukaemia is sometimes used more generally to include the bilineal leukaemias. In practice, the distinction between bilineal and biphenotypic leukaemias is often unclear. In addition, in some cases of leukaemia, features of both biphenotypic leukaemia and bilineal leukaemia are combined.

Moreover, bilineal leukaemias can transform into biphenotypic leukaemias over time, and vice versa. The mechanism by which this switching occurs is unknown, but patients in which this phenomenon occurs have a very poor prognosis. These bilineal/ biphenotypic leukaemias are still included in the MPALs category.

For these reasons, the 2008 World Health Organisation (WHO) Classification grouped bilineal and biphenotypic acute leukaemias together under the new heading of MPALs. The classification of leukaemias of ambiguous lineage remains a challenge and the term MPALs represents a good working solution.

Who is affected by MPALs?

Because it is such a rare group of leukaemias, details of MPALs (including incidence, disease characteristics and treatment) have mainly been gathered from analyses of case reports.

However, it must be noted that since the 2008 WHO grouping of bilineal and biphenotypic acute leukaemias as MPALs, studies of acute leukaemias have not always separated the characteristics for the bilineal and biphenotypic acute leukaemias.

Who is affected by bilineal leukaemia?

Bilineal leukaemia has been estimated to correspond to 1%-2% of acute leukaemias.

In an analysis of patients with acute leukaemia, 1.2% of the patients were classified as having bilineal leukaemia. Their ages ranged from 0.3 to 69 years with a median age of 18 years. The ratio of male to female patients was 65% to 35%.

What are MPALs? (cont.)

Who is affected by biphenotypic leukaemia?

Biphenotypic leukaemia represents 0.5 to 2% of all acute leukaemias. It can occur at any age, but is more common in adults. The median age of patients with biphenotypic leukaemia is 53 years, but the incidence of biphenotypic leukaemia in children is not known.

Biphenotypic leukaemia is slightly more common in males than females (approximately 60% to 40%) and its incidence is similar among races.

What causes MPALs?

As with acute leukaemias, the exact cause of MPALs is unknown.

Chromosomal abnormalities have been associated with all forms of acute leukaemia. Abnormal development and maturation of white blood cells are thought to result from alterations in the patient's chromosomes. Nevertheless, no specific chromosome abnormality has been identified in patients with

MPALs, as yet.

The chromosome abnormalities common in MPALs include the Philadelphia chromosome and chromosome 11q23 abnormalities.

The Philadelphia chromosome is an abnormal chromosome resulting from the fusion of a portion of chromosome 9 on chromosome 22, and is present in approximately a third of patients with MPALs. The Philadelphia chromosome is particularly common in the MPALs that combine B-cell lymphoid and myeloid cells.

The second most common chromosome abnormality associated with MPALs is abnormalities of chromosome 11q23 which is seen in approximately 8% of patients.

Both these chromosome abnormalities are associated with a poorer prognosis.

Symptoms and diagnosis of MPALs

What are the symptoms of MPALs?

Patients with an MPAL have similar symptoms to patients with AML or ALL.

These symptoms include:

- Anaemia
- Bruising and bleeding
- Fever and infections
- Lymphadenopathy (enlarged lymph nodes)
- Joint pain
- Swelling of the gums
- Enlargement of the liver and spleen
- Headaches
- Nausea and/or vomiting

Patients with MPALs often have a higher white blood cell count and involvement of the central nervous system (brain and spinal cord) at diagnosis than patients with AML and ALL. Leukaemia cells are present in the central nervous systems of approximately 25% of patients with MPALs.

How are MPALs diagnosed?

MPALs are a very rare group of acute leukaemias that are difficult to diagnose.

The diagnosis of MPALs is based on immunophenotyping of a bone marrow or blood sample. The preferred technique for immunophenotyping is flow cytometry which analyses the sample to detect the various antigen markers on the leukaemia cells.

According to antigen markers identified on the leukaemia cells, their origins can be determined as myeloid (AML), B-cell (ALL) or T-cell (ALL). This will indicate if an AML chemotherapy regimen or an ALL chemotherapy regimen will be more appropriate for the patient's treatment.

Chromosome analysis of the leukaemia cells can also help to support the diagnosis, but its main advantage is to detect if the patient has a Philadelphia chromosome or chromosome 11q23 abnormality as these

Symptoms and diagnosis of MPALs (cont.)

patients will need more intensive treatment.

Diagnosing bilineal leukaemia

In bilineal leukaemia, two separate populations of leukaemia cells of different origins must be present for a diagnosis. In addition, the sum of all the leukaemia cells from both populations of cells must be 20% or more of the cells in the sample. Occasionally, one population of cells is smaller than the other; however, this does not matter as long as the total of cells from both populations is 20% or more.

The most common combination seen in bilineal leukaemia is a population of cells of myeloid origin and a population of B-cell lymphoid origin. Population of cells of B-cell lymphoid origin and T-cell lymphoid origin are rarely seen together in bilineal leukaemia, and population of cells of all three origins, myeloid, B-cell lymphoid and T-cell lymphoid origin, are extremely rare.

Diagnosing biphenotypic leukaemia

The diagnosis of biphenotypic leukaemia requires finding both lymphoid and myeloid antigen markers on the same cell.

What are the treatment options for MPALs?

MPALs are generally treated with a chemotherapy regimen for ALL or a combined ALL/AML regimen, followed by an allogeneic stem cell transplant (allo-SCT), which is a transplant of stem cells from a matching donor.

The chemotherapy regimen will be selected according to the findings at diagnosis. Your haematologist will discuss with you which chemotherapy treatment is likely to be best for you based on your results. It is likely to be intensive as MPALs are difficult to treat.

Treatment regimens

In patients without the Philadelphia chromosome or a chromosome 11q23 abnormality, there are no approved chemotherapy regimens to date because the chemotherapy is selected on the findings at diagnosis. However, it has been found that in patients with an MPAL, an ALL regimen of therapy or an ALL/AML combined regimen appears to achieve the best rates of remission.

Patients with a Philadelphia chromosome or chromosome

11q23 abnormality need more intensive treatment as having these chromosome abnormalities is linked to a poor outcome.

Patients with the Philadelphia chromosome

For patients with a Philadelphia chromosome, an ALL chemotherapy regimen together with a tyrosine kinase inhibitor such as imatinib or dasatinib is generally required, followed by an allo-SCT. An allo-SCT during the first complete remission is the treatment of choice because of their usual poor outcome with chemotherapy.

Patients with chromosome 11q23 abnormality

For patients with a chromosome 11q23 abnormality, the first treatment option is similar to those patients with normal chromosomes or no Philadelphia chromosome. However, if chemotherapy and an allogeneic SCT are not successful, or the patient cannot withstand an

What are the treatment options for MPALs? (cont.)

intensive chemotherapy regimen, then a clinical trial should be considered.

The new monoclonal antibody blinatumomab has shown promising results in patients with Philadelphia chromosome positive ALL who have relapsed. Although there is very limited data available, blinatumomab may be beneficial for patients with an MPAL and the Philadelphia chromosome.

Allogeneic Stem Cell Transplant (SCT)

As with all other types of acute leukaemia, an allogeneic SCT has the potential to improve the treatment of patients with MPALs. Whether an allogeneic SCT should always follow induction chemotherapy remains controversial.

While the allogeneic SCT can reduce a patient's risk of relapse, there are a number of potential side effects including Graft versus Host Disease (GvHD) and infections. GvHD is a reaction against the donor T-cells.

For more information about allogeneic stem cell transplants - including its possible side effects such as GvHD - you can order our booklet by going to our website www.leukaemiacare.org.uk or by calling the helpline on 08088 010 444.

In some cases, the decision to carry out an allogeneic SCT is based on the availability of a closely matched donor which will reduce complications.

Despite the limited data available, it appears that positive outcomes are generally seen in patients who receive the allogeneic SCT after their first complete remission.

For patients with an MPAL and the Philadelphia chromosome, an allogeneic SCT during the first complete remission is the treatment of choice because of their poor outcome with chemotherapy.

Some haematologists recommend that allogeneic SCTs should be

restricted to the following specific patients:

- Patients with an MPAL and the Philadelphia chromosome
- Infants particularly those with 11q23 abnormalities
- Patients who have responded poorly to early treatment

Intrathecal treatment

In patients with MPALs, there is a high incidence of patients who have leukaemia cells present in the central nervous system (brain and spinal cord) when they are first seen. Therefore, chemotherapy is injected into the cerebrospinal fluid that surrounds the brain and spinal cord which is called intrathecal treatment. This will help eradicate the leukaemia cells from the central nervous system.

What is the prognosis for MPALs?

The prognosis for patients with an MPAL is poorer than that for patients with AML and ALL. Bilineal leukaemia tends to have a poorer prognosis than biphenotypic

leukaemia and shows less response to chemotherapy.

Factors which predict a poor prognosis for MPALs include:

- Age (>60 years)
- High white blood cell count at diagnosis
- The presence of a Philadelphia chromosome and/or a chromosome 11q23 abnormality

It is very difficult to predict the overall survival for patients with an MPAL as there are very few studies about it. More research on the chromosomes involved in MPALs will allow the development of treatments better suited for patients.

Seeing your doctor

Your symptoms

Whatever symptoms you have, make sure you write a list of all of them to share with your doctor as they may be important to the treatment.

Your appointment

Arranging an appointment with your GP will be one of the first things you will need to do when you start to notice symptoms. Pick a time convenient for you that you know you will be able to attend.

Your preparation

It is important to know exactly what you would like to ask your doctor. Make a list of your questions and leave spaces for the answers so you can write them down when you see the doctor. This way you can go into the appointment ready and prepared.

Examples of questions to ask the doctor are:

- What tests will be needed?
- What will the tests show?

- How long will it take to get the results back?
- How common is this condition?
- What sort of treatment will be needed?
- How long will the treatment last?
- How will I know if the treatment has worked?
- What will the side effects be?
- Are there any foods or medications that need to be avoided?
- Will I be able to go back to work?
- Where can I get help with claiming benefits and grants?
- Where can I get help dealing with my feelings?

Talking to your doctor

Be honest with your doctors; there is no need to feel embarrassed about anything. If you saw your healthcare team before seeing your doctor, be sure to share with your doctor everything your healthcare team told you about

your condition, the blood tests that were performed and the next steps. Ask also if any intensive treatment or palliative care will be needed.

Your support

If it helps, take a family member or friend in with you for support. Some people take a pen and paper in to make notes, and repeat back to their doctor everything they have been told to ensure that they are on the same page, and that nothing has been missed or forgotten.

The next steps

Always ensure that you leave the GP surgery, or the hospital, having shared everything you know about your condition, with all of your questions answered, and knowing exactly what the next steps are, whether it is more tests, further treatment or palliative care. You can ask for a summary letter of the consultation to have everything in writing. Your doctor will generally send a letter like this to your GP.

Furthermore, be sure to access all of the other support available

to you as this may be able to help you with your feelings towards the diagnosis and treatment.

Telling your family

Planning who to tell

Telling your family and friends what is happening can be difficult.

You may want to create a list of people you want to tell, starting with close family and friends, and then extending it beyond, from your colleagues at work to friends in your neighbourhood.

Planning what to say

It is important to know what you want to say and exactly how much you want people to know. Being clear in your mind about that before speaking to anyone will make this a much smoother experience. Know the story that you want to tell, the diagnosis, the prognosis, the next treatment steps, and what you expect will happen physically and emotionally. Be sure to speak to people in an environment where both of you can hear each other clearly and where there are likely to be no interruptions.

How to say it

Using a conciliatory tone will help

keep both yourself and the other person calm.

Deliver what you have to say slowly, calmly, concisely, and sentence by sentence to allow the other person time to take in the information. Be sincere, and hold their hands if you need to.

You can use the following sentences to help you articulate what you need to say:

- "This is going to be difficult, but I need to tell you something."
- "I've had some bad news but there's a chance that everything will be okay after treatment."
- "You know I have been feeling unwell for a while. Some tests have been done and they've found out what's wrong."

How to respond

Naturally people will feel sad and concerned for you. Everyone deals with this type of news in their own way, from shock and silence, to questions and support.

Invariably, people respond positively, which in turn means

you will respond back positively.

Accepting help

Sometimes people feel guilty if they get cancer, that it's their fault, and that they will be a burden on those around them. This is where your loved ones come in, so make sure you do ask for and accept offers to help and support you. Do not try to cope on your own. If they offer to help, tell them that you will get in touch when you need them.

Repeating yourself to different people can become burdensome. Your network of family and friends can help you out by telling those beyond them about your current situation. You can receive help from us on how to deal with telling your family and friends. You can visit **www.leukaemiacare.org.uk**, or call **08088 010 444**, to find out more.

Managing your emotions

Being told that you have cancer may be difficult for you to deal with.

You may have a positive demeanour, which will obviously be helpful to you during the next steps in the management of the condition. However, you may experience a range of emotions, including uncertainty, isolation, anxiety, anger, sadness and depression. Understanding each emotion and developing ways that help you deal with them will help you move forward with your life.

Uncertainty

You may think "What happens next?". You may be unsure about your health and what the future holds for you. You may or may not have had meetings with your healthcare team to discuss the next steps. Once you have a clear path set out in front of you, you will be able to develop a clearer picture of where you are headed. Gaining a sensible balance between being vigilant about your symptoms and carrying on with your life will help ease any anxieties. Help, care, kindness and support will be available to you from your healthcare team,

and you will have access to counsellors and therapists if and when you need it.

Isolation

If you have received a diagnosis of an MPAL, you may feel alone.

Alternatively, you may feel dealing with your cancer allows you to be around those closest to you. Being around your family and friends can be positive and negative.

Let them know what you do and don't want to do, how you do and don't wish to be treated, and what you do and don't feel comfortable talking about. Sometimes, it is difficult for your family, friends and colleagues to understand what you are feeling and going through. Being clear will help create the kind of positive, supportive, and caring environment that will help as you move forward with your life.

Anxiety

Being fearful of the unknown, especially when we are feeling threatened, is natural. You may experience an increased heart rate, rapid breathing, and muscle tension. These things help us to

face a danger or run away. These changes in you are part of the 'fight or flight' response. Any feeling of discomfort, pain or even another appointment with your healthcare team may elicit such responses, and give you sleepless nights or feelings of worry. This is completely natural.

Such reflexes and responses will ease over time with the building of daily routines and planning things for the future, which will help you to cope with the physical effects of anxiety. Cognitive behavioural therapy can help you deal with your worrying thoughts.

Anger

Feeling angry at the cancer diagnosis is natural and normal. You may be angry with yourself, with the healthcare team or with family and friends. You may display your anger as impatience, irritability and frustration with people and things that would not normally bother you.

Understanding exactly what is making you angry will help you deal with your feelings effectively. In addition, setting yourself achievable, but demanding, goals will help reduce the anger and

impatience, especially with each passing success.

Don't forget to congratulate yourself for each successfully completed task, however small.

Physical exercise is a great way to release your anger and frustrations, and channel energy positively with no negative impact on the body. Talking about feelings and letting them out will also help stop you lashing out at people and keep things calm.

Sadness and depression

You may feel a sense of loss about how safe you once felt. You may also feel that your illness is a heavy burden on those around you. You might be feeling low, which is a natural effect of your situation and the illness, treatment and recovery process. However, if this low mood persists for more than several weeks, and you feel hopeless, and lose interest and pleasure with things in life, then you may have depression.

Your first steps should be to speak to your loved ones around you about your mood and state

Managing your emotions (cont.)

of mind, and then contact your GP. You may lift the way you feel by engaging in activities that you were enjoying before the diagnosis and connecting back with your life. Only do as much as you can and try and talk about your thoughts and feelings. This will help lighten your burden and put things into perspective. If you have made any acquaintances or friends in the same position as you, talk to them over coffee as they will understand what you are facing.

Self-confidence

Being forced to adjust from your daily routine during the visits to the hospital for treatment can take its toll. This interruption of your life can impact on how you feel about your appearance and how you feel emotionally. In turn, this can knock your self-confidence and self-esteem. Your feelings of relief, hope and optimism have just been replaced with their polar opposites.

You can gradually build your self-confidence and self-esteem back up by engaging in the activities you did before the diagnosis, and socialising with family, friends,

and those in the same position as you. This will help create a supportive atmosphere to get you back to your old self.

Mindfulness and relaxation

Simple practices from mindfulness and relaxation techniques can help you calm the mind, release tension and ease any pain.

- Put yourself in a relaxing environment, sitting or lying down comfortably.
- Loosen your clothing so you can move more freely.
- Calmly breathe in through your nose, and out through your mouth, developing a steady natural rhythm, focusing on your chest and abdomen as you do so.
- Visualise that you are inhaling positivity and exhaling negativity.

By taking some time out of your day to do these exercises, you can help quieten your mind and remove the stress of coming to terms with your diagnosis, so you feel calmer and more relaxed.



Survivorship

Someone who is living with or beyond a cancer diagnosis can be considered a cancer survivor.

Survivorship can be defined as:

"...cover[ing] the physical, psychosocial and economic issues of cancer, from diagnosis until the end of life. It focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, secondary cancers and quality of life. Family members, friends and caregivers are also part of the survivorship experience."

When living with cancer, you will face new challenges to cope with from physical to psychological and social ones. Survivorship aims to provide personalised care based on improving your health, wellbeing, quality of life, and your confidence and motivation, to help you manage. Survivorship also focuses on your health and life with cancer after the end of treatment until the end of life. At

this point, your routine of meeting frequently with your healthcare professionals also ends, so you may feel a mixture of emotions from relief to fear, anxiety and uncertainty about the future. You may wonder how you will slot back into your life after coming through the treatment period.

Your survivorship pathway began at the point when you were diagnosed with an MPAL. By this point, you will have been starting to receive support for work, finance, and personal relationships through to managing pain, fatigue and making positive lifestyle changes, such as starting a healthy diet and gentle exercising.

Your individual needs will be identified and addressed, including:

- Dealing with the emotional impact of receiving a diagnosis, which may have created feelings of uncertainty, fears of recurrence and difficulties in planning for the future. These will be discussed with you to develop an individualised care

plan with support from social care staff and therapists, as you need it.

- Improving your quality of life through efficient and co-ordinated care during treatment, with effective communication within the treatment team, and a positive attitude.
- Taking care of any comorbidities – that is, other medical conditions and diseases – and offering a cancer rehabilitation based on your clinical needs as assessed by informed professionals, and ensuring compliance with the National Cancer Rehabilitation Pathways and Rehabilitation Peer Review requirements.
- Providing you with a treatment summary from the diagnosis of your condition to the end of treatment. This would include any ongoing medication and noting possible symptoms that may occur in the future. You would also be provided details of who to contact in addition to your GP for any concerns you may have.
- Preparing you fully for the impact of the treatment, the physical and physiological side effects of treatments and the psychological impact of your diagnosis in general. You will be provided physical equipment, and taught about various coping strategies to adapt to your new situation.
- Supporting you with advice for social and financial difficulties, including caring responsibilities, your inability to participate in social activities, any debt and financial worries from not being able to work, and perhaps the need to return to work before you feel ready.
- Receiving health and nutrition advice from a nutritionist on following a healthy and balanced diet to help improve your general health and wellbeing. The World Cancer Research Fund published a report for cancer survivors which suggests that even small dietary and lifestyle changes can produce large health benefits.

Palliative care

Palliative care, also known as supportive care, involves a holistic or "whole person" approach, which includes the management of pain and symptoms as well as psychological, social and spiritual support for you and your loved ones.

Palliative care aims to reduce the symptoms, control the MPAL, extend survival, and give you and your loved ones the best quality of life possible. Your doctor will discuss the options with you in detail before you decide the next steps.

Who provides palliative care?

Palliative care will be provided by a team of health and social care professionals trained in palliative medicine who will coordinate the care.

These professionals can include your GP, hospital doctors and nurses, community nurses, hospice staff and counsellors, social care staff, physiotherapists, occupational therapists, complementary therapists, and

religious leaders, if you would like this. The palliative care services may be provided by the NHS, local council or a charity. You may receive day-to-day care at your home and at the hospital.

What is the clinical course?

You will have a number of treatments, and be prone to frequent infections because of the leukaemia and the impact of the treatments. The therapy may continue because of potential remission and/or useful palliation.

Various pains and other clinical complications can occur such as:

- **Bone pain:** Radiotherapy and/or oral steroids, and sometimes non-steroidal anti-inflammatory drugs (NSAIDs), may be used with caution, because they can interfere with the immune system and kidney function.
- **Bone marrow failure:** Blood and platelet transfusions are provided to prevent and fight recurrent infections and bleeding episodes.

- **Oral problems:** Analgesic mouth washes and topical ointments may help with ulceration. Chewing gum, and mouth washes, have been shown to help with dry mouth, tooth decay and oral thrush.
- **Night sweats and fever:** These can also place a heavy burden on carers because of so many changes of night clothes and bedding.
- **Pathological fractures:** Orthopaedic intervention and subsequent radiotherapy, with consideration given to prophylactic pinning of long bones and/or radiotherapy to prevent fractures will be performed. This will reduce the likelihood of complex pain syndromes developing.
- **Spinal cord compression:** Immediate high single daily dose oral steroids will be given.
- **Back pain from wedge and crush fractures of the vertebrae of the spinal column:** Treatments can include analgesics, antidepressants and/or anticonvulsant

medication used in tandem with opioids.

- **Hypercalcaemia:** Treatment is usually with intravenous hydration and intravenous bisphosphonates.
- **Loss of appetite:** Low-dose steroids may temporarily boost the appetite, while small, frequent and appetising meals and supplement drinks will also help.

End of life care

When does end of life care begin?

If the treatment hasn't worked and you are going through palliative care, end of life care may be offered. End of life care begins when it is needed and may last a few days, months or years.

What does end of life care involve?

End of life care is support for people who are in the last few months or years of their life. The aim is to help patients enjoy a good quality of life until they die, and to die with dignity. The professionals looking after you will ask about your wishes and preferences on how to be cared for and put these into action. They will also provide support to your family, carers and loved ones. You will be able to decide where you will receive end of life care, be it at home or in a care home, hospice or hospital. The same will be true of where you would like to die. Wherever this is, you will receive high quality end of life care.

Who provides end of life care?

A team of health and social care professionals may be involved in the end of life care, including hospital doctors and nurses, your GP, community nurses, hospice staff and counsellors, social care staff, physiotherapists, occupational therapists or complementary therapists, and religious leaders, if you would like this. If you are being cared for at home or in a care home, your GP will have overall responsibility for your care with the support from community nurses, along with your family and friends.

What choices do I have in terms of end of life care?

Deciding where you want to die can be a difficult choice to make. Working out what you and your loved ones want, together with seeing what services are available can help to make the decision a little easier.

- **Staying at home:** A place of familiarity, surrounded by loved

ones, may be something that will be reassuring. External care professionals will be able to visit your home to make sure the symptoms are looked after.

- **Hospices:** These are specialised in looking after those with life-limiting illnesses and those who are coming to the end of their life. Hospices are staffed with care professionals who are able to keep an eye on you, make sure that symptoms are controlled and offer a number of services to make the stay as comfortable as possible. For more information on the care that they can provide, go to <https://www.hospiceuk.org/>
- **Residential care/nursing homes:** If you think that your stay may be a few months or more, then a nursing home may be more suitable than a hospice. These can be private or run by a charity or the local council so be sure to check if there are any fees.
- **Hospitals:** Although you may be used to staying in a hospital ward, the care routine cannot always be tailored to patients'

specific needs. Pressures on the NHS mean that your stay will only be as long as strictly required. As soon as the condition requiring hospital admission has been resolved, you will need to go back to your home or nursing home. However, a number of specialists will be available to help look after specific problems, and a number of hospitals also have a designated palliative care team for patients who require them.

Whatever your choice, speak with your GP or healthcare team who will be able to help you put everything into place.

Glossary

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.

Allogeneic Stem Cell Transplant (allo-SCT)

The transplant of stem cells from a matching donor.

Anaemia

A condition where the number of red blood cells are reduced. Red blood cells contain haemoglobin and transport oxygen to body cells. This may be due to a lack of iron, leukaemia, or sickle cell disease.

Antibody

A large Y-shaped protein produced by B-cell lymphocytes in response to a specific antigen, such as a bacteria, virus, or a foreign substance in the blood.

Antigen

A toxin or other foreign substance which induces an immune response in the body, especially the production of antibodies.

Biphenotypic

This describes a cell which has antigen markers of two separate phenotypes.

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.

Complete remission

Complete remission has occurred when blood cell counts have returned to normal, and/or less than 5% of blasts (abnormal, immature leukaemia cells) are still present in the bone marrow.

Chromosomes

X-shaped, thread-like structures which carry the genes, and are located in the nuclei of every cell in the body. There are 46 chromosomes (23 pairs) in

humans.

Leukaemia

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

Lineage

Originating from a specific cell or organism.

Lymph nodes

The components of the lymphatic system (part of the body's immune system) that contain the lymphocytes which produce antibodies and macrophages to digest dead cells. Lymph nodes are swollen with cell fragments in the event of infection or cancer. They are located mainly in the spleen but also in the neck, armpit and groin. They are commonly called 'swollen glands'.

Lymphocytes

Lymphocytes are a type of white blood cell that are 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

The tissue responsible for producing lymphocytes.

Minimal Residual Disease

A measure of the presence of leukaemia at a molecular level rather than at a cell level. It is measured using molecular techniques such as flow cytometry and polymerase chain reaction analysis which can detect if there is any trace of leukaemia left in the body.

Monoclonal Antibody Drugs

Antibodies created in the laboratory from the same original cell and which target specific proteins on the cancerous cells

Myeloid

Tissue relating to the bone marrow.

Phenotype

The description of an organism's actual physical characteristics. This includes

Glossary (cont.)

visible characteristics, for example blue eyes, and invisible characteristics, for example predisposition to diabetes. The phenotype is influenced by the organism's genotype as well as the environment in which the organism has lived. This is often referred to as 'nature' (genotype) and 'nurture' (environment).

Philadelphia Chromosome (BCR-ABL1 - Breakpoint Cluster Region - Abelson Murine Leukaemia Viral proto oncogene 1)

The Philadelphia chromosome is a cancer gene formed by the fusion of a portion of chromosome 9 on chromosome 22 to form the BCR-ABL fusion gene [t(9;22)(q34;q11)]. It is the most common genetic abnormality associated with adult CML and ALL and has a very poor prognosis for both children and adults.

Refractory

A condition for which treatment does not result in a remission.

Relapse

A relapse occurs when a patient initially responds to treatment, but after six months or more, the response stops. This is also sometimes called a recurrence.

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.

Stem Cell

The most basic cell in the body that has the ability to develop into any of the body's specialised cell types, from muscle cells to brain cells. However, what makes these stem cells reproduce uncontrollably, as in cancer, is thought to be linked to chromosome abnormalities.

Stem Cell Transplant (SCT)

The transplant of stem cells derived from part of the same individual (autologous SCT) or a donor (allo-SCT).

Tyrosine Kinase Inhibitor

A drug that inhibits the tyrosine kinase enzymes which activate many of the proteins for cell growth. Inhibiting or blocking tyrosine kinases can prevent cancer cell growth.

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

Leukaemia Care,
One Birch Court,
Blackpole East,
Worcester,
WR3 8SG

Leukaemia Care is registered as a charity in England and Wales (no.1183890) and Scotland (no. SC049802).
Company number: 11911752 (England and Wales).
Registered office address: One Birch Court, Blackpole East, Worcester, WR3 8SG

Leukaemia Care
YOUR Blood Cancer Charity