
Relapse in Acute Myeloid Leukaemia (AML)

**A Guide for
Patients**

Leukaemia Care
YOUR Blood Cancer Charity

Introduction

A relapse is the return of leukaemia after treatment. Specifically, this booklet is about a relapse in acute myeloid leukaemia (AML).

You may be feeling frightened, disappointed and upset after going through your treatment course only for it to return. This booklet aims to help you understand better what relapse means, what the next steps are, what your options are regarding treatment, how to deal with loved ones, how to manage your emotions, and what help and support is available to you.

This booklet was written by Bilal Bham, and updated by our Patient Information Writer, Isabelle Leach. The booklet was reviewed by Victoria Grandage. Thank you to Julie Quigley for providing valuable feedback as a patient reviewer.

If you would like any information on the sources used for this booklet, please email communications@leukaemicare.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@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**.

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

What is AML?

All blood cells are made from blood stem cells in the bone marrow. Myeloid stem cells are derived from blood stem cells, and develop into healthy white blood cells, red blood cells and platelets.

New immature white blood cells are called myeloblast cells, and can't perform the functions that mature cells can. Normally, these blood cells are made in a controlled way in the bone marrow. When this process goes out of control, many immature and abnormal cells (leukaemia cells) are produced. These cells overcrowd the bone marrow and prevent healthy mature blood cells from being made. Some of the leukaemia cells flow into the blood and circulate through the bloodstream around the body. These leukaemia cells don't function like healthy white blood cells, which leads to an increased risk of infection.

Myeloid leukaemia becomes acute when the cells progress quickly.

How common is AML?

AML is diagnosed in around 3,100 people annually in the UK. AML is

more common in people over 75, but can affect people at any age, including children.

How is AML treated?

Your treatment for AML depends on the type of AML you have, your age, medical fitness, risk of relapse, and length of remission.

You may have already received either intensive or non-intensive treatment:

- 1. Intensive therapy** involves two phases of chemotherapy, called remission induction therapy and consolidation therapy, which may or may not involve a stem cell transplant.
- 2. Non-intensive treatment**, given to patients who can't tolerate invasive treatment, involves gentler chemotherapy, given either in hospital or at home to give patients an excellent quality of life for as long as possible.



What is a relapse?

You may have successfully completed treatment for AML. However, as can happen sometimes, the leukaemia has returned. When the levels of leukaemic cells have risen beyond those considered remission (when all tests show absence of leukaemia), this is called a relapse or recurrence of leukaemia.

AML relapse affects about 50% of all patients who achieved remission after initial treatment, and can occur several months to several years after treatment. However, every patient carries the risk of relapse, and the majority of relapses occur within two to three years of initial treatment.

Your AML may have relapsed for a variety of reasons:

- It could be that your AML was resistant to your initial treatment
- The treatment may not have removed all leukaemic cells
- The leukaemic cells have spread to other parts of the body and were initially too small for detection

When looking down the microscope, haematologists

can only detect one leukaemia cell in every 100 cells. However, using specialist techniques such as flow cytometry (which involves detecting the cells using antibodies) or molecular techniques (which involve detecting DNA/RNA) means that they are able to detect very low levels of leukaemia (one leukaemia cell in every 100,000 cells) called minimal residual disease (MRD). The lower the level of MRD, the better the prognosis.

Experiencing relapse after treatment will be very disappointing and upsetting.

Your leukaemia specialist will advise you on how best to have it treated, and map out the most beneficial approach for you, in terms of treatment, quality of life, and support.

Signs and symptoms of a relapse

You may be experiencing some of the same symptoms as you did at your initial AML diagnosis.

Your symptoms may include:

- Anaemia
- Bruising
- Infections
- Aching bones
- Swollen glands
- Feeling tired and run down
- Fever and sweats
- Headaches
- Blurred vision
- Breathlessness

You might also experience fewer common symptoms, such as swollen lymph nodes showing up as lumps and bumps on your neck, armpit and groin.

Between 2% and 9% of AML patients also develop chloromas, which are a collection of leukaemia cells, which appear as a solid lump or nodule. This can be in the skin or within other areas of the body including lymph nodes and solid organs such as the brain or testes.

Diagnosis

How AML relapse is diagnosed

In the same way that you were initially diagnosed with AML, you will undergo the same tests to confirm an AML relapse.

At the hospital

Your haematologist will take you through general questions about your health, ask you about any illnesses and symptoms consistent with relapsed AML and check you for enlarged lymph nodes, spleen or liver. They will also arrange for you to have some more tests, including:

- **Blood tests** - to look at the numbers of normal cells (red cells, white cells and platelets) as well as the number of circulating leukaemia cells.
- **Bone marrow test** - where samples are taken from your bone marrow to count the numbers of leukaemia cells. These samples will be sent for cytogenetic and immunophenotyping testing. These tests help to tell what sort of leukaemia cells are

involved, as well as give some indication as to how easy it will be to treat. These will help your healthcare team decide on the best treatment for you.

- **Lumbar puncture** - where a small sample of the fluid that surrounds your brain and spinal cord is taken to check for leukaemia cells.
- **Chest X-ray** - to see if there are any swollen lymph nodes in your chest.
- **Immunophenotyping** - several laboratory tests are done on your blood and bone marrow samples, which are then analysed under a microscope, and subjected to immunophenotyping. This counts the number of leukaemia cells and determines whether these cells are myeloid or lymphoid leukaemia cells. AML will be confirmed if the cells are myeloid.
- **Cytogenetics** - chromosomes, of which we have 46, carry your genetic information in the form of genes consisting of your DNA. Under a microscope, your

chromosomes are checked for genetic abnormalities such as breaks and rearrangements that may be, in part, responsible for the development of your leukaemia. Not all the genetic errors can be detected this way.

- **Further tests** - once the results of your diagnostic tests have been received back from the laboratory, you and your healthcare team will have much more information about your AML, which will help with future treatment decisions.

Treatment

Treatment plan

Before deciding on the next course of treatment, you will discuss your options with your healthcare team to work out the best treatment plan for you. Many factors will influence your team of specialists on the best way forward for your treatment, such as taking a closer look at your leukaemia cells, your age, medical fitness, risk of relapse and length of remission.

More treatment

After having gone through treatment already, your next main decision will be like before, in that you and your healthcare team will have to decide if you want to opt for a) intensive treatment, which aims to achieve remission, or b) non-intensive treatment, which aims to give you the best quality of life for as long as possible.

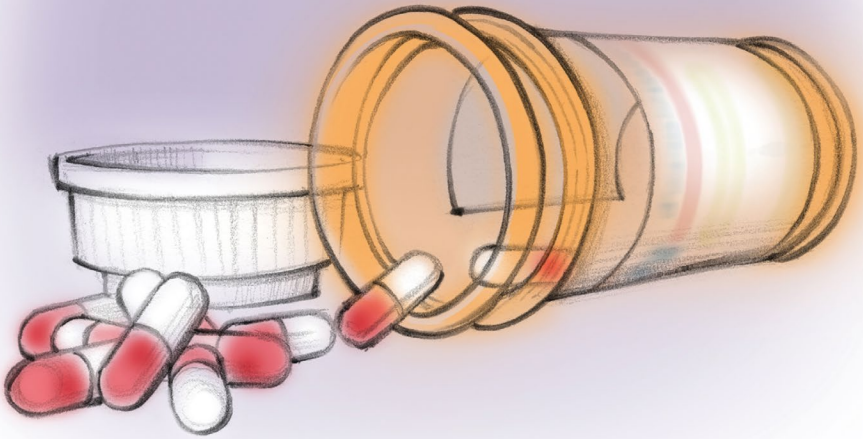
Relapse treatment might involve more intensive chemotherapy with different drugs, or a stem cell transplant. Achieving a remission can be more difficult at relapse but is more common if your first remission lasted a while (several years), if you are medically fit, and can have a stem cell transplant.

Clinical trials

You may have the opportunity to take part in a clinical trial. Clinical trials can involve chemotherapy drugs, drug combinations, and different delivery schedules. There can be many advantages to taking part for you personally, as well as for the wider community by contributing to cutting edge medical research. You will be carefully monitored during and after the study.

It is important to remember that not all new treatments work as effectively as existing treatments, or may lead to side effects that outweigh the benefits. If you decide not to take part in a clinical trial, your decision will be respected, and you will not have to provide any reasons for your decision.

However, do speak to healthcare staff, and share any concerns you may have so that they can provide you with the best advice moving forward. If you decide not to take part in a clinical trial, you will not be treated any differently by hospital staff, and you will be offered the standard available treatment for your stage of your AML.



Seeing your doctor

Your symptoms

Whatever symptoms you have, make sure you know all of them and make a list that you can share with your doctor.

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. If there is a chance that you might be experiencing a relapse, you will be referred to the hospital who will be able to confirm this through tests.

Your preparation

It is important to know exactly what you would like to ask your doctor. Think of all the questions you would like to ask. Make a list of 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 meeting ready and prepared.

Examples of questions to ask the doctor:

- How would I know if I had AML again?
- What tests will I need to have?
- What will the tests show?
- How long will it take to get the results back?
- How common is it to have a relapse?
- What sort of treatment will I need?
- How long will my treatment last?
- Will my treatment work this time?
- What will the side effects be?
- Are there any foods or medications that I need to avoid?
- 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 doctor, they have seen and heard everything before, so 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 relapse, the blood tests you had performed, and the next steps in your AML journey. Ask also if there will be more intensive treatment or if you will move on to palliative care.

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 both 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. Furthermore, be sure to access all of the support available to you as this may be able to help you with your feelings towards your diagnosis and treatment.

Telling your family

Planning who to tell

Telling your family and friends that you have suffered a relapse can be difficult, especially since you already went through it with your initial AML diagnosis. One positive aspect to this is that you already have your team in place, so once they know what the situation is, they can help and support you like they did before. 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 equally knowing 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 your story that you want to tell, the diagnosis, the prognosis, the next treatment steps, and what you expect to be going through

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 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 good chance that everything will be okay after I've had treatment."
- "You know I've been feeling unwell for a while. I've had some

tests and they've found out what's wrong."

How to respond

You may receive similar responses to when you told people about your initial AML diagnosis. Naturally they will feel sad, and concerned about you. Everyone deals with such news in their own way, from shock and silence, to questions and support. Overwhelmingly, people respond positively, which in turn will mean you will respond back positively.

Accepting help

Sometimes people feel guilty for their cancer relapsing, that they weren't strong enough, 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 in the next stages of your AML journey. Do not try to cope with this on your own.

If your loved ones 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 about your relapse. You can visit www.leukaemiacare.org.uk, or call **08088 010 444**, to find out more.

Managing your emotions

Being told that your cancer has returned may be difficult for you to deal with, especially after all your time and effort during treatment and remission.

Indeed, you may have a positive demeanour, which will obviously be helpful to you during the next steps in the management of your AML, and life beyond. However, you may experience a range of emotions, including uncertainty, isolation, and 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?" and 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 following your relapse. 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 following relapse and carrying on with your life will help ease any anxieties you feel. Help, care, kindness and support will be available to you from your healthcare team, and you will have access to counsellors and therapists as needed.

Isolation

If you have received a diagnosis of relapse, and the next steps don't involve intensive treatment, you may feel a break in routine. You may feel alone because you will no longer enjoy regular meetings with your healthcare team who provide you with information and reassurance, or fellow patients who can provide you with empathy and compassion. Alternatively, you may feel the break in routine from your normal life in remission allows you to be around those closest to you.

Being around those closest to you, such as your family and friends, can be positive and negative.

However, being clear with them about what you do and don't want, how you do and don't wish to be treated, and what you do and don't feel comfortable talking about, will help create the kind of positive, supportive, and caring environment that will help as you move forward with your life.

Anxiety

Feeling fear of the unknown, especially when we are feeling threatened, is natural. You may experience increased heart rate, rapid breathing, and muscle tension. These things help us to face a danger or run away and this response is known as 'fight or flight'. 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.

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 move forward with your life. You may find that relaxation exercises can help with the physical effects of anxiety, and cognitive behavioural

therapy (CBT) can help bring your thoughts of worry under control.

Anger

Feeling angry after a relapse is natural and normal. You may be angry with yourself, the healthcare team or with family and friends. You may display your anger through impatience, irritability and frustration with people and things around you that would not normally bother you.

Understanding exactly what is making you angry will help you deal with those feelings effectively. In addition, setting achievable goals that stretch you will help reduce the anger and impatience you feel, especially with each passing success. Physical exercise is a great way to release your anger and frustrations and channel those energies positively without negatively impacting your body. Talking about your feelings and letting them out will also help to curb you lashing out at people and help calm you.

Managing your emotions (cont.)

Sadness and depression

Relapsing will bring back some, if not all, of the feelings you felt upon your initial AML diagnosis. You may be feeling a sense of loss for the person you used to be and how safe you felt. You may feel that your illness is a heavy burden on those around you. You might be feeling low, which is part of your illness, treatment and recovery. However, if this low mood persists for 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 contact your GP and speak to your loved ones around you about your mood and state of mind. You may lift the way you feel by engaging in activities that you were enjoying before your relapse and initial diagnosis, as much as you can, to connect back with your life. Again, talking about your thoughts and feelings can lighten your burden and help bring things into perspective and help you deal better with your situation.

Self-confidence

Being forced to readjust from your daily routine during remission back into one involving multiple visits to the hospital for further treatment, or moving into palliative care, can take its toll. This interruption of your life, along with your lack of energy because of your AML and the effects of your treatment, can impact on how you feel about your appearance and feel emotionally. In turn, this can knock your self-confidence and self-esteem and your feelings of relief, hope and optimism are 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 your diagnosis, and socialising with family, friends, and fellow patients. This will help create a supportive atmosphere to rehabilitate you back to your old self.

Mindfulness and relaxation

Using simple techniques from mindfulness along with relaxation

Leukaemia Care offers nationwide support groups for people affected by a diagnosis of a blood cancer. Visit www.leukaemiacare.org.uk, or call **08088 010 444**, to find out more and to find a group near you.

and simple exercises can help calm the mind, release tension and ease any pain in your muscles.

1. Put yourself in a relaxing environment, sitting or lying down comfortably.
2. Loosen your clothing so you can move more freely.
3. 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.

4. 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 to calm and relax you and to de-stress you from coming to terms with your diagnosis.

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 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, second cancer and quality of life. Family members, friends and caregivers are also part of the survivorship experience."

When living with cancer, especially relapsing after remission, you will face new challenges to cope with various needs from the physical through to the psychological and social.

Survivorship aims to provide personalised care based on your need to improve your health, wellbeing, quality of life, and your confidence and motivation to help you manage your own health and wellbeing. Survivorship 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 treatment.

Your survivorship pathway began at the point when you were diagnosed with AML. 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 physical activity.

Your individual needs as a patient will be identified and addressed, including:

- Dealing with the emotional impact of receiving a diagnosis of relapse, which may have created feelings of uncertainty, fears of recurrence and difficulty 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 required.

- Improving your quality of life from efficient and co-ordinated care during your 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 you 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 diagnosis of your relapse to the end of your 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 relapse and treatment, about the physical and physiological side effects of treatments and the psychological impact of AML relapse in general, by being provided with physical aids and being taught about various coping strategies to adopt to your new situation.
- Supporting you with advice for social and financial difficulties, including caring responsibilities, inability to participate in social activities, debt and financial worries due to not being able to work for a long time, and perhaps needing to return before you feel ready.
- Receiving health and nutrition advice from your nutritionist about 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 in relapsed AML

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

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

Who provides palliative care?

Your palliative care will be provided by a team of health and social care professionals trained in palliative medicine who will coordinate your 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. Your 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 experienced a cycle of relapses and remissions, and be prone to frequent infections because of the disease and your treatments. Your chemotherapy may continue because of potential remission and/or useful palliation.

You may experience various pains and other clinical complications such as:

- **Bone pain:** Radiotherapy and/or oral steroids, and sometimes non-steroidal anti-inflammatory drugs may be included, although these are used with caution because they

can interfere with your 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 fracture and reduce the likelihood of complex pain syndromes developing.
- **Spinal cord compression:** Immediate high single daily-dose oral steroids are required.
- **Back pain from wedge and crush fractures of the spinal column:** Treatment can include analgesics, anti-depressants 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 you have relapsed and are going through palliative care, you may be offered end of life care. End of life care begins when you need it 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 you enjoy a good quality of life until you die, and to die with dignity. The professionals looking after you will ask you 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 you are, 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 your end of life care, including hospital doctors and nurses, your GP, community nurses, hospice staff and counsellors, social care staff, physiotherapists, occupational therapists, complementary therapists and religious leaders, if you would like this. Your GP will have overall responsibility for your care if you are being cared for at home or in a care home, and community nurses, along with family and friends, will be involved in your care.

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 and seeing what services are available to you can help to make the decision a little

easier.

- **Staying at home** - a place of familiarity, surrounded by your loved ones, may be something that you will find reassuring. External care professionals will be able to visit you at home to make sure your symptoms are looked after.
- **Hospices** - 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 your symptoms are controlled and offer you a number of services to make your stay as comfortable as possible. For more information on the care that they can provide, go to **www.hospiceuk.org**
- **Residential care/nursing homes** - if you think that your stay may be a few months or so, 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 specifically to you as it is often busy. 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 to your GP or healthcare team who will be able to help you put everything into place.

End of Life Care (cont.)

Where can I seek support about end of life care?

Coming to terms with end of life care can take some time and you may feel like you need some support with this. There are a number of external organisations that can help you.

Marie Curie

Marie Curie offer care and support for anyone with a terminal or life-threatening illness as well as their families. They are able to offer you information as well as being able to provide expert nursing care in the home or through one of their hospices.

www.mariecurie.org.uk

Tel: **0800 090 2309**

If you think that counselling might be beneficial for you, your GP or medical team may be able to put you in touch with a suitable therapist. To find one local to your area, go to www.bcap.co.uk

Where can my loved ones seek support?

As well as yourself, you may find that your loved ones may need some help coping with you starting end of life care. Charities are available that can provide support specifically for the people who care for you.

Carers UK

Carers UK is available to provide expert advice for carers all around the UK. They offer support in local communities and help to campaign for changes to policies and services that affect carers and the loved ones they care for.

www.carersuk.org

Tel: **0808 808 7777**

Email: **advice@carersuk.org**

Carers Trust

Carers Trust work to directly impact on the lives of unpaid carers through the support, services and advice that is available to them. They also offer tailored help to suit whatever circumstances you may be in to try and makes things a little easier to cope with through activities and replacement care to offer respite.

www.carers.org

Tel: **0844 800 4361**

Email: **info@carers.org**

If you or your loved ones need any more information or support, contact the National Council for Palliative Care – responsible for the Dying Matters coalition – on **020 7697 1520** or go to **www.ncpc.org.uk**

Glossary

Acute Myeloid Leukaemia (AML)

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

Chloromas

Tumours of myeloid leukaemic cells occurring outside of the bone marrow, usually associated with acute or chronic myeloid leukaemia. Chloromas can occur anywhere in the body.

Cytogenetics

A test to check the chromosomes in your DNA for abnormalities.

Immunophenotyping

A process that uses antibodies to identify cells based on the types of antigens or markers on the surface of the cells. This process is used to diagnose specific types of leukaemia and lymphoma by comparing the cancer cells to normal cells of the immune system.

Palliative care

Also known as supportive care, this is a type of care that focusses on improving the quality of life for a patient with a life-threatening illness and their loved ones.

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.

Remission

When all tests indicate the absence of an illness.

Stem cell transplant

A transplant of stem cells derived from part of the same individual or a donor.

Survivorship

A focus on the life of someone with cancer after diagnosis and treatment.

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.leukaemicare.org.uk
support@leukaemicare.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

care@leukaemicare.org.uk

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

Registered charity
259483 and SC039207

Leukaemia Care
YOUR Blood Cancer Charity