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# Living Well with Acute Myeloid Leukaemia (AML)

**A Guide for  
Patients**

**Leukaemia Care**  
YOUR Blood Cancer Charity

# Introduction

**Being diagnosed with acute myeloid leukaemia (AML) can be a shock, particularly when you may have never heard of it. This booklet covers a range of topics to help you cope a little better.**

Experiences vary from person to person. You may experience all of the things featured in this booklet, some of them, or maybe none of them at all. This booklet, and the organisations listed in it, are available to help you whatever you may be facing.

Remember, you can also find tailored advice for your particular situation by talking to your GP or your medical team.

This booklet was originally compiled by Flora Dangwa, Monica Figueiredo, Anne Crook,

Alison Kyle, Sandra Gates, Moez Dungarwalla, Anne Johnson, Genevieve Isaacson, Andrew Nye, Molly Clavering, Steve Knapper, Julia Williams and Caroline Hoffman who also peer reviewed the booklet along with Natasha Jones, Hannah Tramaseur, Lizzy Davies, Una Farrell, Catia Oliveira, Marie Krnakova, Gemma Trout, Joanne Murfett and Laura Barr. We are also grateful to Julie Quigley for her valuable contribution as patient reviewer. This booklet has since been updated by our Patient Information Writer, Isabelle Leach.

If you would like any information on the sources used for this booklet, please email [communications@leukaemiacare.org.uk](mailto: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 magazine includes inspirational patient and carer stories as well as informative articles by medical professionals: **www.leukaemiacare.org.uk/communication-preferences/**

# Changes in appearance and body image

There can be many changes to your body and appearance when you are going through your leukaemia journey, from diagnosis to treatment and beyond. In this chapter, we talk about some of the common changes that you may experience as well as offering suggestions on how to cope with them.

## Hair loss

Hair loss or alopecia is a common and well-known side effect experienced by people receiving high-dose chemotherapy. Body hairs including the scalp, eyelashes, armpit as well as pubic hair can fall out. Hair loss occurs because some chemotherapy drugs may affect actively dividing cells including hair follicles as well as leukaemia cells.

Hair loss may begin a few days to weeks after starting treatment. It is usually temporary, and normally reverses on completion of treatment. Hair may even start to grow back before treatment is completed. People receiving low-dose chemotherapy or other anti-leukaemia drugs like azacitidine may experience hair thinning but not total hair loss.

Hair loss can have a physical as

well as psychological impact on you and the value of hair loss cannot be underestimated. Some people describe hair loss as one of the most distressing physical and psychological side effects of cancer treatment, often reporting loss of self-confidence, feelings of sadness or even depression.

There are many ways that can help you to cope with the loss of hair. A holistic needs assessment (HNA) can help identify some of your physical and psychological needs, including a solution for your hair loss, in a timely and appropriate way. The NHS has a provision of wigs for those who may need them. There are several options available for wigs, which include human hair wigs or synthetic wigs.

Wigs are available on the NHS, but you will be charged for them unless you qualify for help with

**Holistic Needs Assessments:** The HNA is seen as a key tool used by healthcare professionals. Your clinical nurse specialist (or an Allied Health Professional) will aim to offer you an HNA at different times within treatment. Your cancer centre will agree internally when they think it is most appropriate for your HNAs to be carried out. Some departments will offer you an HNA a few weeks after being diagnosed, after your first cycle of chemotherapy and at the end of treatment, but there is no right or wrong time to complete them. It is important for you to know that you are able to talk to your clinical nurse specialist about any topic covered on the HNA at any time, not only when it is offered to you.

charges. For more information, please see the NHS website at <https://www.nhs.uk/using-the-nhs/help-with-health-costs/wigs-and-fabric-supports-on-the-nhs/>

Alternatively, you may choose to shave off your hair before it starts to fall out rather than waiting for this to happen, or you may choose to do nothing at all or something other than a wig. For example, patients may find wearing headscarves or hats more comfortable. There are professionals and websites available to show you how to tie head scarves.

## Weight

It is usual for you to experience

weight loss. There are several factors that can contribute to weight loss during treatment. These include gastrointestinal symptoms such as:

- Nausea and/or vomiting (it is estimated that up to 70% of people receiving high-dose chemotherapy can experience chemotherapy-induced nausea and vomiting)
- Diarrhoea
- Treatment-related mucositis (sore mouth)
- Loss of appetite

Changes in taste sensations can also affect the ability to maintain weight during treatment. These factors can all result in eating

# Changes in appearance and body image (cont.)

less and affect your weight. You will usually find that treatment will always be tailored to your weight. The dose of chemotherapy given to you will be calculated based on your weight. You may have access to a specialised dietitian that will work with you to improve your eating/drinking and your overall weight before, during and after your treatment.

Anybody starting treatment for leukaemia is weighed prior to starting treatment as a matter of protocol. Baseline weight is important because it is used to calculate your body mass index (BMI) and because, traditionally, chemotherapy dosages are based on your body surface area (BSA) or body mass index (BMI). There are guidelines for approximate dosing for adult patients with high BMIs; however, no differences in treatment-related toxicities or outcomes have been found. If you are concerned that your weight might impact on your treatment, speak to your medical team.

There are ways to help you maintain a steady weight similar to your baseline throughout. These

include screening and assessing your weight and nutrition status on a daily or weekly basis as required. Appropriate dietary advice is important. A neutropenic diet, which includes high calorie and high protein food and drinks, is usually recommended. You may also be encouraged to eat whatever you want, as and when you can. If you experience extreme weight loss, you should be referred to a specialist dietitian.

## Memory and concentration changes

Difficulty in concentration and changes in memory have been reported in people with leukaemia. These cognitive changes can have a limiting effect on quality of life. There are several factors that can contribute to memory and concentration changes. Pain, lack of sleep or difficulty in sleeping, worrying and sadness have been mentioned as some of the physical and psychological factors that can affect concentration and memory.

Your environment such as prolonged periods as an in-

patient and psychological distress associated with the diagnosis of leukaemia have also been identified as contributing factors to changes in concentration. Other factors associated with concentration changes include financial and social difficulties.

Treatment for AML usually takes months and there are ways to help changes in memory and concentration during this time. Information on disease, treatment and management as well as an HNA from the beginning is important. Having this type of routine screening at diagnosis can help identify any complex psycho-social care factors that are likely to contribute to memory and concentration changes for you. Healthcare professionals like social workers and counsellors within local teams can then plan for psycho-social support and assistance for you according to your needs.

Complementary therapies and psychological interventions such as meditation and mindfulness have been found to be beneficial for some people. More

information about meditation and mindfulness is available later in the booklet in the section on complementary therapies.

## **Skin changes and nail care**

Chemotherapy may induce skin and nail changes during or after treatment. Although not life threatening, skin toxicity can be visible and affect quality of life. People report skin sensitivity with symptoms of itchiness, dryness, rash or hyperpigmentation. Skin toxicity may also result in bacterial infections which can affect treatment.

Changes to fingernails and toenails are also common during chemotherapy. Nails can become brittle, change colour, crack or show partial breakages from the nail bed.

People receiving anti-leukaemia treatment via subcutaneous injection like azacitidine or low-dose cytarabine, may also experience skin changes. A common side effect of chemotherapy is an injection site

# Changes in appearance and body image (cont.)

reaction. This can be anything from a bruise to a large, painful, red mark or scar. Injection site reactions usually go away after several days but they need to be managed to prevent serious problems like necrosis of the skin (premature death of skin cells).

There are some ways to help maintain good skin and nail care. Your nurse will do an HNA from the start of treatment, which can help identify some pre-existing physical skin and nail problems and how to help manage them. Skin care is important during and after treatment.

It is recommended to maintain good personal hygiene. Some useful tips include:

- Use skin moisturisers or emollients as well as cuticle cream.
- Avoid alcohol based or perfumed products which may dry the skin.
- Protect yourself from direct sunlight.
- Apply skin protection creams (SPF 40 at least is

recommended) and cover up when going in the sun.

- Use gloves when washing dishes.

## Physical pain

Pain is multidimensional, but physical pain is a commonly reported symptom in AML patients. Pain can have a significant impact on quality of life and is associated with increased emotional distress. Pain can vary over time and it can present itself acutely or can be chronic.

It has been reported in up to 20% of patients with haematological malignancies. More specifically, bone and joint pain is more commonly reported in patients with AML and this is thought to be related to the build-up of leukaemia cells in these areas. Certain procedures and treatments can be associated with pain, including bone marrow biopsies.

Intense pain has also been found to be associated with a lack of appetite, fatigue, nausea

and psychological distress, as well as chemotherapy-related toxicities, such as mucositis and gum disease, and pain related to diarrhoea or haemorrhoids. If you experience pain, it can be treated with painkillers. Other approaches include complementary therapies, psychological interventions such as mindfulness and meditation, nerve blocks and TENS (transcutaneous electrical nerve stimulation) used for blocking pain signals from the nerves to the brain.

Where pain is not adequately controlled, or there is no response from standard interventions, specialist palliative care teams can play an important role in managing pain symptoms.

If you need any help in dealing with pain, speak to your medical team. It is important to report any pain you have to maintain an accurate assessment of how you are doing.

## Neuropathy

Neuropathy is where the nerves in the body's extremities – such as the hands, feet and arms – are

damaged. This has been linked to certain drugs, dosages and regimes, including high-dose chemotherapy for AML patients. Those who are over the age of 60 years are known to be at a higher risk of experiencing it. Neuropathy does not always respond to opioids; however, there are other drugs that can be specifically used including gabapentin. Physiotherapy interventions can also be used to help treat and manage neuropathy.

## Mouth care

Sore mouth, or mucositis, is a common side effect often associated with high-dose chemotherapy as a treatment for AML patients. Maintaining good basic mouth care helps promote oral cleanliness.

Evidence shows that the efficacy of alcohol-based mouthwashes is similar to neutral saline mouthwashes. If your mouth does not have any sores and you are using a mouthwash to prevent the development of mucositis, alcohol-based mouthwashes can be used, although they may cause

# Changes in appearance and body image (cont.)

your mouth to be drier.

To achieve good oral hygiene, ensure you brush your teeth after every meal, if possible, using a soft toothbrush. A saline mouthwash that consists of dissolving one teaspoon of salt in a pint of boiled water is effective and inexpensive. Leave it to cool down, store in the fridge for 24 hours and use during the day after brushing your teeth.

Patients report that this tends to offer some relief if they have severe mucositis (extensive painful mouth sores). Different hospitals have different mouthcare protocols, so speak to your medical team about any precautions you should be taking to prevent any oral infections.

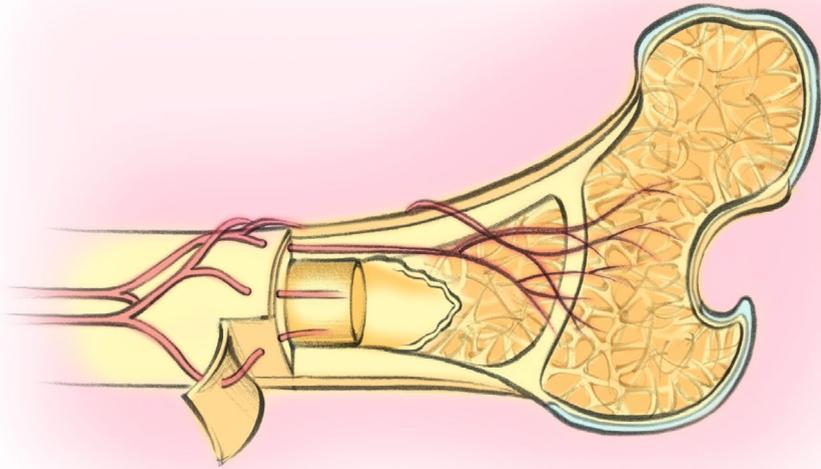
## Bone density

When it comes to maintaining the right level of bone density, there are two types of cell at work:

1. Osteoclasts - cells that are responsible for the breakdown and reabsorption of bone.
2. Osteoblasts - cells responsible for the formation of bone.

It is important that these two work together to create a balance in your bones. If there are too many osteoclasts your bones become too soft, and if there are too many osteoblasts then your bones may become brittle.

It has been suggested that leukaemia may affect this, which can be problematic. However, bone mineral density remains an unidentified aspect in patients with AML. At the moment, bone density is not measured in patients completing treatment for AML as there is no standard guidance on it. However, it is something that is monitored following a bone marrow transplantation.



# Sex, pregnancy, breastfeeding and fertility

## Sex life and libido

Sexuality varies from person to person and is an individual experience. It is lived, experienced and expressed in different ways, via thoughts, fantasies, desires, beliefs, attitudes, values, practices, roles and relationships.

Hormones alone do not affect your sex life and libido. There are many other factors that influence your sex life and libido in a permanent or temporary way, including AML diagnosis and treatment.

## At diagnosis

The news of AML may impact your wellbeing and create anxiety and fear which may lead to loss of interest in sex and reduced libido. It is important to communicate your feelings and emotions with your haematologist, clinical nurse specialist and partner rather than to isolate yourself.

Your medical team will discuss fertility with you at diagnosis. For male patients they will be offered the opportunity to store sperm. For female patients preserving fertility is more challenging as egg/ovarian tissue cryopreservation is logistically a longer process and commencing

chemotherapy is the priority. This will be discussed with sensitivity and understanding. The Fertility experts can be contacted for female patients and they may recommend a medication that puts the female ovaries to sleep whilst receiving chemotherapy.

## During treatment

Some surgeries and treatments may put you off having sex and reduce your desire for sex. If you are feeling this at the moment, that's perfectly normal. There are many ways to express your emotions and feelings. Your first priority is your health, so you may find alternatives to sexual intercourse to express your emotions which are just as valuable. With this, it is important to involve your partner.

## After treatment

It is normal if after treatment it takes some time to adjust to the new reality, and this will also affect your relationships. You might have less interest in sexual contact, not only because treatments will potentially affect your hormonal system, but also due to a change in your body image. It is important that you

talk to your partner and the healthcare professionals that are involved in your care as they will be able to provide further support.

## Contraception

After you start your AML treatments, your haematologist or clinical nurse specialist may advise you to abstain from unprotected sexual activity.

This is to protect both you and your partner. Chemotherapy and radiotherapy affect the cells that produce sperm and eggs and are also toxic for the unborn baby. Avoiding a pregnancy while on treatment is important and you should seek medical advice before you decide to conceive naturally.

Protecting your partner from fluids that may contain traces of chemotherapy is also important. Men should use a condom in sexual intercourse and oral sex. There are no contraindications on having sex while on treatment, but it is important to use contraception during treatment and for a minimum of three months after treatment has ended. Your team will be able to get your fertility assessed at this point so you are able to make informed decisions and plan for

the future.

Unfortunately, after receiving high-dose chemotherapy, it is common for patients to find it difficult to conceive. Overall, it is recommended to wait six months to a year after stopping all medications before trying to conceive. If you are likely to remain on life-long medication but are thinking about wanting to start a family, please talk to your haematologist or clinical nurse specialist.

## Pregnancy

When facing your diagnosis of AML, your priority is survivorship. However, depending on the stage of your pregnancy when you are diagnosed, your treatment will vary. Every case is different and your whole medical team (including your obstetrician and midwife), as well as you and your partner, should be involved. Decisions may need to be made so it is important that you and your partner obtain all the information you need to make an informed choice that you are both comfortable with. Don't be afraid to ask questions.

During the first trimester of

# Sex, pregnancy, breastfeeding and fertility (cont.)

pregnancy, all drugs are generally to be avoided, but particularly chemotherapy which is highly toxic and can cause genetic abnormalities in your unborn child. After 14 weeks of pregnancy, it is possible that chemotherapy can be given to women with AML.

Drugs that might be used in the treatment of AML and the recommendations for their use in pregnancy are summarised below. Your haematologist will explain the treatments, their side effects and the risks to your unborn child. Their clinical experience in these situations will be helpful in providing the options you may have.

## Treatments and their recommendations during pregnancy

### Liposomal cytarabine-daunorubicin (Vyxeos)

No studies on the use of Vyxeos in pregnant women are available; however, animal studies indicate that it should not be used unless the clinical condition of the pregnant woman requires treatment and justifies the potential risk to the unborn child.

### Daunorubicin

There is no data on the effect of daunorubicin in humans. Daunorubicin is known to cross the placenta and has been shown to cause birth defects in animals.

In a few reported cases, women who received daunorubicin during the second and third trimesters of pregnancy have delivered healthy infants.

### Idarubicin

There are no adequate studies on the use of idarubicin in pregnant women. However, potential birth defects in animals have been demonstrated. Idarubicin should only be used if the potential benefit to the mother justifies the potential risk to the unborn child.

### Cytarabine

Data of birth defects due to cytarabine are only available in animals. It should not be used in pregnant women (especially during the first trimester), unless the possible benefits outweigh the potential risks.

### Hydroxycarbamide

Hydroxycarbamide affects the formation of DNA synthesis and

is capable of causing mutations. In pregnant women, it has been shown to harm the unborn child and should not be given to pregnant women unless the potential benefits to the mother outweigh the possible harm to the unborn child.

### **Azacitidine**

There are no adequate studies of the use of azacitidine in pregnant women. However, based on animal studies, azacitidine should not be used during pregnancy, especially during the first trimester, unless absolutely necessary. The advantages of treatment should be weighed against the possible risk to the unborn child in every individual case.

### **Decitabine**

There is no information on the use of decitabine in pregnant women, but it is known to cause birth defects in animals. It should not be used during pregnancy.

The most recent guidelines of AML in pregnancy recommend that pregnant women should be treated without delay and that if given chemotherapy, it should be daunorubicin for three days and

cytarabine for 10 days (also known as the standard 3+10 schedule).

If you are in the last trimester of pregnancy when you are diagnosed with AML, your haematologist will discuss your possibilities and potential outcomes. You may need to consider whether to start treatment before or after delivery. Your haematologist and medical team, particularly your oncologist and obstetrician, will help with this decision, factoring in both the wellbeing of you and your unborn baby. Pregnancy and chemotherapy can be exhausting so it is important that you also rest and take time for yourself.

### **Breastfeeding**

There is very little clinical information about whether the drugs used for AML are transferred to breast milk during treatment. However, as a general precaution, it is normally recommended that breastfeeding should be avoided during treatment and for a certain amount of time after treatment is finished depending on the drug you are on.

Regardless of your chemotherapy

# Sex, pregnancy, breastfeeding and fertility (cont.)

treatment, once the baby is born, milk will be produced. Given it is not recommended to breastfeed while receiving treatment for AML, you can ask your medical team or midwife to help you suppress the breast milk.

Led by your obstetrician and gynaecologist/midwife, there are two methods of suppressing your breast milk:

1. Stopping your breast milk naturally. This involves only expressing enough breast milk for comfort, because the more milk that is expressed, the more breast milk will be produced.
  - In the first two days after delivery, express each breast every four hours for five minutes.
  - In the following days, express your milk every five hours for three to four minutes.
  - Thereafter, express your milk a few times a day to keep your breasts from feeling full. It may take several days to weeks for breast milk to stop being produced completely.

2. Take drugs such as cabergoline (Dostinex) or bromocriptine. This method is sometimes used if it would be distressing for the mother to stop her breast milk naturally.

Depending on the timing of your chemotherapy, in certain circumstances you may be able to breastfeed. This includes:

- If your chemotherapy ceases weeks before your baby is born, there will be no problem in breastfeeding.
- If your chemotherapy treatment finishes, you may be able to re-initiate breastfeeding depending on the drug you were taking.

If you are unsure about whether you are allowed to breastfeed, speak to your medical team.

## Fertility after AML

As a part of the treatment for AML, patients will be exposed to a number of treatments that may put them at risk of infertility. Chemotherapy is designed to kill cells in our body that divide rapidly and, unfortunately, this includes testicular cells

(responsible for producing sperm) and ovarian cells (responsible for producing eggs). As a result, both men and women are at risk of permanent or temporary infertility when they undergo this type of treatment.

Radiation therapy which uses high-energy radiation to kill cancer cells is usually not part of the main treatment pathway for people with AML, but it may be used against leukaemia cells that have spread outside of the bone marrow and bone. This can include the brain and spinal fluid, or the testicles, for example. Radiation to the whole body is also often part of treatment before a stem cell transplant. Therefore, radiation, particularly of the ovaries or testes, can lead to infertility.

In the UK, there are restrictions to the types of fertility treatments you can access according to the Clinical Commissioning Group (CCG) in your area. To find your nearest CCG, go to the NHS website to search by location.

As soon as possible after you are informed that you will be receiving treatment, you should

seek information from both your haematologist and fertility specialists in order to make some informed decisions about fertility. Since AML is an acute leukaemia, treatment normally starts relatively quickly after diagnosis, so speak to your medical team about timeframes.

In order to give you and your partner the option to have biological children in the future, in the event your fertility does not recover after the treatment, if possible based on access and timeframes, it is sensible to freeze (cryopreserve) your eggs or sperm prior to receiving treatment.

## Options for women

Women are born with all the eggs they will ever have. After the onset of puberty, one egg is released from alternate ovaries each month, and travels through the fallopian tube until it reaches the uterus. If this egg is not fertilised by a sperm, then the pregnancy will not occur.

An option for you is to freeze your eggs or, in some cases, your ovarian tissue. This involves freezing the eggs in liquid

# Sex, pregnancy, breastfeeding and fertility (cont.)

nitrogen (vitrification) in order to be used later. It is important to be aware that the success in freezing eggs is reduced in women over the age of 35 years. In fact, the younger you are when your eggs are frozen, the greater your chance of success.

If you have any further questions about this procedure, including whether this is a feasible option, you should consult your haematologist and obstetric consultant within your medical team.

## Options for men

Chemotherapy directly affects the cells that produce sperm. Therefore, before undergoing treatment for your AML, you should have your sperm frozen to give you the option of fathering a biological child in the future.

Prior to the procedure, you will have had some blood count results and a referral from your haematologist or clinical nurse specialist. On your arrival, you will be asked to produce a fresh sperm sample that will then be analysed and frozen in liquid nitrogen. You will also be asked

to fill in consent forms as a legal requirement. You can store your sample for up to a maximum of 55 years.

For more information about egg freezing or sperm storage, go to the Human Fertilisation and Embryology Act (HFEA) website at [www.hfea.gov.uk](http://www.hfea.gov.uk).

## How to try for a child after your treatment

If you are planning to start a family in the future, you should check your fertility status as soon as possible so that you are aware of your options and can make any necessary arrangements.

If you are fortunate and your fertility is intact, you can try for a child after a safe period following the end of your treatment. This is usually six months to make sure there are no longer any effects of your treatment on your eggs or sperm.

In the event that your fertility hasn't recovered, but you have

frozen your eggs or sperm, you can seek a referral to an in-vitro fertilisation (IVF) clinic, and you will be able to receive assistance with getting pregnant.

The following options are available:

**3.** IVF: The sperm and egg are placed close to one another in a test tube, allowing the sperm to swim and fertilise the egg. More information about this procedure can be found on the NHS website: <https://www.nhs.uk/conditions/ivf/>

**4.** Intra-cytoplasmic injection (ICSI): This is a specialised type of IVF, often used when the sperm are low in numbers or of poor quality. Under the microscope, a single sperm, which has been specifically selected, is injected directly into an egg to fertilise it. More information about this procedure can be found on the HFEA website: <https://www.hfea.gov.uk/treatments/explore-all-treatments/intracytoplasmic-sperm-injection-icsi/>

In both of these techniques,

the embryo is created in the laboratory environment and implanted into the woman's womb in order to start a pregnancy.

It is often a good idea to seek advice from your doctor, or ask to be referred to a fertility counsellor. Talking through your fears and doubts will ease the pressure and help you to cope with the uncertainty.

If you are in a relationship, involve your partner as soon as possible. Be open, transparent and upfront. If your partner asks questions that you struggle to answer or if they have their own questions and want to voice their concerns, bring them to your consultations. This way you and your partner can go through the difficulties together with the support of a medical professional.

If you haven't frozen your eggs or sperm, you may need to cover the costs of donated eggs or sperm. You may be able to secure funding for the procedure depending on your CCG. In the UK, there are restrictions on the types of fertility treatments you can access according to the CCG for

# Sex, pregnancy, breastfeeding and fertility (cont.)

your area.

The policies for each CCG can be found on the Fertility Fairness Website at: [www.fertilityfairness.co.uk](http://www.fertilityfairness.co.uk). Once you are on the website, click on 'compare your area' and you will find the policy for each CCG. Some areas of England do not fund fertility treatment and, generally speaking, egg and sperm freezing is not available on the NHS.

You can also refer to the NHS England Clinical Commissioning Policy for Assisted Conception, which gives details of what CCGs should provide in accordance with NICE guidelines.

For leukaemia patients, however, your GP or haematologist can submit an individual Funding Request on your behalf.

If you have any questions about NHS funding for fertility treatment or would like some advice or emotional support, you can find information at [www.fertilitynetworkuk.org](http://www.fertilitynetworkuk.org).

Finally, if the above options are not possible for you, adoption is also an alternative.

## Changes in relationships

Following an AML diagnosis, its impact can vary from person to person, including partners and family. You should seek as much information as possible about your treatment and prognosis. This will allow you to make the best decisions regarding your future.

The chemotherapy for AML and its duration can involve a period when you will suffer from physical symptoms such as pain, tiredness, decreased libido, as well as all kinds of emotional feelings. You may feel weak, unattractive and afraid. You may think that your body is different because of the side effects of chemotherapy, including weight loss. Changes to your body can affect your self-esteem and your sense of feeling desired. Sex can become the thing you don't want to do, or something that you don't want to talk about.

It is important to be honest and frank. You may have loads of thoughts about the disease, your future and relationships. It

is okay to feel confused, afraid and uncertain about it all. It is important to talk to your partner and seek support. You are not alone, and you shouldn't be. If you need it, try to seek help from your medical team when it comes to talking to your partner. If you have surgery for any reason, this also may have an impact on your body image and potentially your sex life. You should discuss it with your clinician. The more information you gather, the better for you to make decisions and/or inform your partner. Ideally, bring your partner to the consultation.

You may feel more emotional and you may even have difficulties in processing all the information that is given to you. Feel free to enquire as many times as you need about information concerning your treatment and your future, even if you need to ask the same questions several times.

# Emotional impact of AML

This chapter describes some of the more challenging emotional responses you may experience as you adjust to life following a diagnosis of AML. Everyone is different and what follows may or may not apply to you. There is no right or wrong way to live with AML. As you gradually adjust to this major change in your life, you will find what is most helpful and feels right for you.

## Feelings

Living with AML is often described like being on an emotional rollercoaster ride because of the range of emotions at different times. Following the shock of being told about your diagnosis, facing the challenges of going through treatment and then adjusting to life after treatment ends, your emotions can catch you by surprise and may sometimes feel overwhelming.

It is common to feel low, sad, angry or anxious. Feeling down or worried is a normal reaction and does not mean that you are weak or failing to cope. Your feelings may come and go. There may be times when you are not sure how you are feeling and other times when you feel okay.

## Hope and determination

Hope and determination will help you to face AML. Identify your reasons to get through treatment and remind yourself of them when you feel that you are struggling. Notice what helps you to feel strong. Set yourself realistic goals to help your recovery process and draw on the support of others. We are resilient beings and with time and good support, you can adjust to this enormous change in your life.

## Anger

Anger is an emotion that we naturally feel when we are challenged and under threat and so it is not unusual for illness to provoke an angry response. You may be angry with your body for becoming ill in the first place. Thoughts like, 'why me? It's not

fair, I don't deserve this' can make you feel angry.

You may be annoyed with healthcare professionals and with the lack of control over your life. It may be frustrating that it is taking so long to recover from your treatment. This is particularly so if you have had a transplant and/or are struggling with physical weakness and fatigue.

Anger makes us feel uncomfortable. Some of us shout and rage but for others, feeling and expressing anger is a struggle. It can be a physical feeling of restlessness and frustration and of not being able to settle. It may leak out as irritability or impatience with the people around us.

It helps to acknowledge your anger at the time rather than hold onto it and let it build up; otherwise, it may burst out and leave you feeling helpless and out of control. Buy yourself some time to let the tension go by leaving the room, getting some fresh air, listening to some music, doing something physical or putting your angry thoughts down on paper.

Try and identify what it is that is making you angry so you can direct the energy that comes with anger in ways that help you to feel more in control. This could be setting some recovery goals for yourself, doing some exercise or physical activity to shift your pent-up tension or talking through your frustrations with someone who is a good listener. Often, if your frustrations are relayed they can be resolved or at least improved by a member of your clinical team.

## Feeling alone

There are times when you are going through AML that you may feel alone. This can be despite having good support from your family, friends and healthcare team.

Worrying about how others might respond if you tell them what's really on your mind, feeling that you need to hide your feelings to protect others or because they may not understand can leave you feeling isolated and alone. Feeling different from those around you whose lives are continuing as before can be a challenge.

You will most likely have your treatment in hospital in an

# Emotional impact of AML

## (cont.)

'isolation' room. You won't be in complete isolation as you will be able to have some visitors and the staff will be in and out of your room. However, when your blood cell counts are low and the time seems to be going by slowly, you may sometimes feel vulnerable and alone.

When you are going through treatment, you become used to the hospital environment and the healthcare team looking after you. Once your treatment is finished, it can feel disconcerting to be on your own and not to have the same reassurance and support on hand. Some people describe this time as feeling lost and abandoned. The transition after treatment is another big adjustment to make so give yourself time to regain your self-confidence.

### Loss, sadness and depression

The experience of AML brings with it many losses. You might long for the life that you had before the illness, and for the hopes and plans that have been put on hold for now.

There may be activities and

people that you miss. You may feel a sense of loss for the healthy you and feel sad and vulnerable because of the changes to your body. It is normal to grieve for these losses and to feel sad when you think about the impact that AML has had on you and those close to you. Give yourself permission to allow these feelings of grief to surface. It isn't self-indulgent or weak to feel sad as you adjust to your new reality.

Sadness can often make our mood feel low. People sometimes worry that feeling low can affect their recovery from AML. They can put themselves under pressure or are encouraged by others to remain 'positive' and to 'fight' the illness. This becomes a way of coping for some people and it works for them.

It is important, though, to know that everyone copes in their own way and that you don't have to be positive all the time. A hopeful and determined outlook will help you to get through the challenges but it is alright to feel low from time to time, particularly when your energy is low or you experience setbacks.

Feelings of being low usually

pass, but if your low mood persists over a couple of weeks, you feel depressed and it is affecting your day to day life, then you may be suffering from depression. It can be hard to separate out the physical and psychological causes but the feeling of depression is deeper, longer and more unpleasant than the short episodes of feeling low and unhappy that everyone sometimes experiences.

Some of the common symptoms of depression include:

- Feeling sad or low, most of the time
- Losing interest or enjoyment in people and things
- Finding it harder to concentrate or make decisions
- Feeling helpless, hopeless or worthless
- Feeling restless, agitated and irritable
- Feeling easily moved to tears
- Thinking negative thoughts about yourself, the world and the future
- Difficult getting to sleep or waking up very early

- Having thoughts about self-harm or suicide

Depression does not mean that you can't cope or are weak. It is a common medical condition and there is support available to help you get through it. You can't simply 'snap out of it' or 'pull yourself together'.

Talk to your GP or healthcare team if you think that you may be depressed. Some hospitals have access to specialist cancer psychologists/counsellors which you could be referred to. Depression can be treated with both medication and talking therapies such as cognitive behavioural therapy (CBT) and counselling. Your doctor may also recommend self-help books or an online course. Depression can make you feel less inclined to ask for help, so be guided by those close to you.

If you are having suicidal thoughts or feelings, you can call the Samaritan 24-hour helpline free on **116 123**. Further information and links to support you can be found at **[www.mind.org.uk](http://www.mind.org.uk)** and **[www.nhs.uk](http://www.nhs.uk)**.

# Emotional impact of AML

## (cont.)

### Anxiety and worrying about your health

AML brings with it the challenge of living with uncertainty. You might be worrying about what will happen to you, if your treatment will work or if the AML will come back. It is natural to feel anxious when faced with fears for ourselves. Anxiety is like an internal alarm system going off. Being anxious will not affect the AML or harm your recovery but do ask for support if it is making it difficult for you to have medical procedures.

We feel anxious when we feel threatened. The brain releases adrenaline to tell the body to run away from or to fight a danger and this is called the 'fight or flight' response. It is helpful when we need to escape quickly from a physical threat such as a fire but less helpful when the brain interprets stressful life events, such as illness, in the same way.

Because we can't physically run away, those same 'fight or flight' physical symptoms can persist and make you feel uncomfortable. It causes that familiar feeling of lying awake at night and the mind won't switch off because

it's focussed on the threat, and with it comes a racing heart, tight chest and tense muscles. When we feel constantly stressed and we struggle to relax, it is difficult to concentrate and we can feel impatient, irritable and restless.

Worrying is something we do to try and cope with uncertainty. We try to predict and control future events by thinking about them, preparing ourselves if the worst happens. Worry can be useful to take action to sort out a difficult problem. However, more often, these thoughts focus on what could go wrong in the future. All that worry does is keep our attention focussed on the threat and this keeps the anxiety going. It's helpful to remember that our brain is responding to something that may happen in the future and that it may never happen.

If you notice that you are constantly checking, seeking reassurance or you avoid doing things, it may be a sign that your anxiety is becoming a problem. If you feel that the uncertainty is making you feel so anxious and worried that it is affecting your daily life, you may find it helpful to talk to your healthcare team.

There is much information about anxiety and helpful links on the NHS website: [www.nhs.uk](http://www.nhs.uk).

## Managing stress

You cannot remove the stress completely but there are things you can do to help yourself manage when you are feeling stressed:

- Exercise is an excellent way to reduce the impact of stress. It could be any physical activity – walking, exercise or dance classes, yoga, gardening, housework etc. It helps us to use up some of that extra adrenaline that comes from worrying, helping us to feel calm. For more information, go to the exercise chapter of this booklet on page 56.
- Relaxation and breathing exercises can help to calm the mind and release muscle tension.
- Doing an activity that you enjoy can help you to stay in the present moment and enjoy life in the now rather than jumping ahead in your mind to predicting the future.
- Talking about what's on your mind to someone who is a good listener or writing worries down can make them feel less overwhelming. When we hear ourselves out loud, we are more able to rationalise and put our worries into perspective. We can ask ourselves: "is this a problem that I can do something about or is this an uncertainty that may never happen?"
- Mindfulness is a great way to be in the present. It is simply bringing our attention into the present moment and being fully aware of what we are experiencing – noticing what is going on using your senses rather than thinking about the past or worrying about the future. For more information, go to the mindfulness chapter of this booklet, starting on page 86.
- Complementary therapies can help you relax and feel more in control, but make sure you are seeing a qualified therapist who has experience of treating people with cancer. For more information, go to the complementary therapies chapter of this booklet on page 78.
- Talking therapies such as

# Emotional impact of AML (cont.)

counselling can help you to talk through your experience to try and make sense of it all. Talking to someone you don't know and in confidence can be helpful to understand and process feelings as normal responses to a difficult situation. Counselling may be available to you through your doctor or local cancer support centre.

- Connect with others who have been affected by AML through a support group or online forum. Each person's experience is unique, but it can help to hear from others who know what it is like to have AML.
- Do the things that work for you - maintain the activities and hobbies that were important to you before your diagnosis and try to keep these interests going if they are not too tiring and you are still enjoying them.
- See the people you want to see and talk about what you feel comfortable with. It is fine to change the subject if you don't want to talk about something. For more information go to the telling others about AML chapter of this booklet on page 32.

## A new normal

Reaching the end of treatment can bring a whole set of new challenges as you begin to recover from the physical, practical and emotional demands that treatment brings. It will probably feel like a relief that the intense treatment has ended even though there may be ongoing side effects to deal with. Getting through treatment can take up all of your energy and it is only when it has stopped that you may begin to deal with the emotional impact of it all.

Your family and friends might expect you to feel back to normal once your treatment finishes, but your body and your emotions need time to recover and to work through all that has happened. You may have gone through treatment with the goal of getting back to normal. Now, it is not so much getting back to normal, as finding out what is normal for you now. Your new normal.

AML is a devastating experience and it may seem hard to imagine life ever feeling ordinary again. You can feel very out of touch with your life before AML because so much has happened. The

emotions which have been building up as you have been going through the intense treatment may now come bubbling up and catch you by surprise.

Some of your relationships may feel stronger whereas other relationships might have changed. Perhaps you have discovered that you or those around you are more resilient than you could have ever imagined.

Your outlook on life may be very different because of AML and you may be faced with making difficult adjustments. Continue to seek support from those close to you. You might find that making decisions and plans with those around you helps you feel more prepared for what the future may hold.

Coming through successful treatment brings hope for the future, and life inevitably takes on a new meaning. People sometimes think about what is most important to them in life and make changes for the better. As you work through your process of recovery, you can gradually incorporate all that you have

experienced into your new view of yourself and your life.

# Telling others about AML

Your relationships are unique to you and so there is no one way to tell others about AML. Relationships can be a great source of support when we are ill and can bring people closer together. They are often complicated and the challenge of illness can open up difficulties. Communication is at its best when it is as open and honest as possible. This chapter offers some guidance to help you think about what feels right for you.

## Should I tell others about my AML?

When you are first diagnosed, there is a lot of information to take in and you may be feeling shocked and overwhelmed by different emotions. You may need to give yourself some time to think about what is happening to you before you decide when and how to tell others about it.

People may be anxious to know what is happening and this can make you feel under pressure to pass on information before you are ready. Let them know that you need some time to process the information yourself before you are ready to talk about it in more detail. It is up to you who you tell and how much you tell them, but going through treatment for AML is not something you can hide from the people closest to you.

You may be concerned about how family and friends will react and be tempted to protect them from upset and worry by not telling them. It is usually harder for them to manage when they sense that something is wrong and try to guess what it is. Take some time to plan how you will tell children and elderly parents.

It may help to sit down with someone else first and rehearse what you are going to say. Hearing yourself say the words out loud first will help you to feel calm when you come to talking about it.

## How to tell a partner

Your partner may have been with you when you heard about the AML. If not, they will most likely want to know as soon as possible to be able to support you. It can be hard talking to them about it

because they will have their own concerns and emotions and they will also need time to adjust to the shock of the diagnosis.

As you go through treatment, your partner and family will be affected in their own way. They will also need the support of family and friends. They can access support for themselves such as counselling and support for children through helplines and cancer support centres. Ask your healthcare team about what is available locally.

It can be helpful to have your partner with you for hospital appointments so that you are both able to hear the information being given and have the opportunity to ask questions. One of you may prefer to have lots of information and ask lots of questions and the other may prefer to know less or to quietly think things through. One may like to talk about feelings and the other not. Finding ways to manage your different needs can be a challenge throughout your experience of AML.

Some couples describe the challenge of illness as an experience that brings them

closer together. For others, the stresses can put a strain on the relationship and it can become difficult to find your way together. The more open and honest you are able to be with each other, the more you will be able to work together as a team to get through it. If you are struggling to communicate your needs to your partner, or are having issues with intimate relationships, then contact an organisation such as Relate **[www.relate.org.uk](http://www.relate.org.uk)**.

When you are going through treatment, it can be hard to find time for yourselves as a couple. When you are feeling relatively well, you may want to set aside time to catch up and give each other a chance to say how you are. Take time to discuss what helps each of you and what is difficult, either on an emotional or practical level.

It is also helpful to set aside some time when you can do something normal like watch TV, have a trip out together or decide to have an AML-free day where you talk about other things.

# Telling others about AML (cont.)

## How to tell a friend or family member

Telling people that you have a rare condition like AML can be hard to explain. Keep it simple and explain that AML is a type of blood cancer. It means that the bone marrow does not function properly and this affects the blood cells it produces. The treatment will involve chemotherapy and the aim will be to cure the AML.

You may find it easier to direct your family and friends to our information booklets or the Leukaemia Care website. Alternatively, you might find it easier over the phone or by letter or email. It is exhausting to have to keep repeating the same difficult conversation and you could ask someone else to tell people for you. People will have their own ideas and possible misunderstandings and it can create more uncertainty for you if you cannot answer all of their questions.

People will often want to help and support you. Think about practical things that will help such as lifts to and from hospital appointments and help with shopping, housework or childcare.

As treatment goes on, you will have a better idea about what you need and what works for you.

Your family and friends will be keen to know how you are and for updates about your progress. Keeping in touch can be hard work when you are not feeling well and you may want to consider having someone else as a point of contact or to pass on your information via texts or social media. However, do consider who you want to see your posts, check privacy settings and remember that information stays on the internet unless you remove it.

## Coping with other people's emotional reactions

People will have a wide range of reactions about your illness. Some may be upset and distressed and may need time to adjust. However, most people will be supportive and want to help you by following your lead on your approach to your AML.

You may find that not everyone is sensitive to your needs and this can be upsetting and frustrating. Often people make assumptions and say what they think is helpful.

They might say that you look well, recount stories of others they know with a similar diagnosis or even a completely different type of cancer. They may encourage you to stay positive and look ahead. They may have advice about particular diets and supplements you can take.

Where possible, try to let people know what you find helpful and unhelpful. In time, you will discover who is better at giving you the practical and emotional support you need. See the people you want to see and talk about what you feel comfortable with.

Some are better listeners than others. It is fine to change the subject if you don't want to talk about something. You could say that you are giving yourself a break and having a day without talking about your illness. Asking others about themselves and what they are doing can steer the conversation away from the illness.

Going through AML is an enormous challenge and you and those close to you are likely to feel stressed at times. It is often those closest to us who may feel the brunt of these strong emotions.

We often take out our feelings on those close to us. This can put a strain on relationships. The more open and honest we can be during these times, the easier it is to work through any difficulties or misunderstandings.

## **Telling children or vulnerable people**

Our instinct is to protect children from upset and you may be tempted to put off telling them about your diagnosis. You may worry about how they will cope and how you will support them, especially when you have so much to deal with yourself. Involving the children in your life in what is happening and being open is often the best way, even though you may want to protect them from news that may upset them. Generally, children realise when something is wrong and they may worry it is something they have done. It is important for them to realise that they are not responsible for your illness.

Telling the children in your life means that you can be more open about what you say at home and not have to worry about them hearing something at school or from someone else. It gives them

# Telling others about AML (cont.)

the opportunity to ask questions and to say how they are feeling. It can help you all to feel closer and to work through things together.

If you are planning to tell your children with your spouse or partner, you may find it helpful to discuss how you are going to approach it. If possible, it is better to tell all your children at the same time to avoid one carrying the burden of knowing, or wondering why they were told last.

Asking the children how much they know about the situation to start with can often be helpful. You can fill in anything they don't know. This approach allows them to ask questions so that they can fully understand what is happening. You may want to consider any questions they may ask so you can have the answers ready. However, if you can't answer all of their questions, it is fine to say you don't know but you can try to find out.

There is no general advice on what to tell your child depending on their age. It depends very much on the child and how mature they are. You know your child and what they are capable of taking in better than anyone.

If your children are very young, they may well not understand the situation fully, but as long as they understand that you are ill and that they should be gentle, that is a good start. They will only be able to take in simple explanations and you might need to repeat it several times.

Children can understand more as they get older. You will know the most suitable way to talk to the children in your life. Being honest can help them make sense of the situation and share their worries and fears. Try not to stop yourself getting upset as it will allow the children to know that showing their feelings of sadness is fine.

Teenagers are likely to want more information but will also need time to work through their feelings. They might be reluctant to talk about it with you and may want to spend time alone or will seek support from their friends or other family members. Letting your child's school know will mean that they can also offer support.

As time goes on, help them to be prepared for any changes in your appearance such as hair loss or weight changes. Explain

that fatigue may make it harder for you to do the same activities with them. If they are able to visit you in hospital, explain what they can expect to see. Playing with hospital toy sets, books and imaginary games can help younger children express themselves and to feel connected to what is happening.

Reassure them that their routine and activities will stay the same as much as possible. Explain that family and friends may be more involved in activities such as picking them up from school and be clear about what the plan for them is. Maintaining boundaries and limits for all ages will allow them to feel contained and more able to know where they stand. There is a lot of information about cancer on the television and the internet, including leukaemia, which children are probably aware of. In addition, there are numerous books about cancer and its treatment that your children can read, or that you can read with younger children.

As leukaemia is a blood cancer, this information can be very relevant and may be useful. If you are unsure, please ask your clinical nurse specialist to help

you access this information and other support for the child.

You may have vulnerable people in your life, perhaps a frail parent or relative or friend who is unwell that you would like to tell. Again, plan how you will tell them as appropriate to their circumstances and explain that you may not be able to visit them as frequently whilst you are going through treatment. They may want to feel that they too are able to support you by thinking of you.

Our easy read document, *All About Leukaemia*, may be a useful resource to help tell your loved ones about your diagnosis. To order a copy, call the helpline on **08088 010 444**.

# Diet

## Nutrition and wellbeing

With a diagnosis of AML, many aspects of your day to day life will change during the duration of your treatment. When you are undergoing treatment for any kind of leukaemia, your immune system can be affected, lowering your ability to fight any potential infections. Therefore, it is important to have the information that will help you, or, if possible, someone you care for to stay with you and help you throughout your treatment.

## What is a healthy diet?

To help ensure your treatment is as effective as possible, a well-balanced nutritional intake is a good starting point. This can be difficult if you are not feeling well and some ideas to cope with these particular difficulties will be covered in this chapter.

Diet and nutritional intake is an area where there is a huge amount of information available to the public, and unfortunately not all of it is based on scientific evidence. It is advised that sensible health advice is followed for all patients and that no 'special' diets are used unless this is recommended by your

consultant or a qualified dietitian, and forms part of your clinical treatment.

The Government's Eatwell Guide recommends that you should try to eat a variety of nutrient-dense foods across all the food groups, every day. This guide is available from [www.gov.uk/government/publications/the-eatwell-guide](http://www.gov.uk/government/publications/the-eatwell-guide).

## Carbohydrates

These foods are often considered unhealthy. This is untrue and carbohydrates should make up at least a third of what you eat. You should include carbohydrates at each main meal like porridge, cereals, potato, pasta, rice or couscous. Wholemeal and wholegrain varieties will increase your fibre intake but white ones are also healthy foods. Nutritionally, all these foods are very similar and will provide you with a supply of energy throughout the day.

## Fruit and vegetables

Make sure you have your five portions of fruit and vegetables a day. This can be all kinds of fruit or vegetables, including fresh, frozen, canned, dried or as juice or smoothies; however,

some hospitals are known to recommend avoiding anything uncooked, or fruits that can't be peeled. Smoothies, made with frozen fruit and added milk, can make a high-energy drink and are particularly helpful if your appetite is poor. Fruit and vegetables will also provide dietary fibre which helps to regulate your bowels and prevent constipation which can be a side effect with AML treatment.

### Dairy foods (and dairy alternatives)

Milk, cheese and yoghurt are good sources of protein and calcium, but it must be ensured that these are pasteurised. If you have lost weight or your appetite is poor, these foods are very helpful as they tend to be relatively high in energy and can help to boost your overall calorie intake.

### Other protein foods (meat, poultry, eggs, pulses, peas, beans and lentils, nuts and meat alternatives such as Quorn or tofu)

Protein is an important nutrient as it helps to maintain your muscle strength and enables you to go about your normal daily activities and reduces fatigue. It

is recommended that you have at least two portions of protein foods from this group every day, but you may need to increase this if you have lost weight to enable you to replace lost muscle tissue.

### Oils and spreads

This group includes fats and spreads which are used in cooking. General healthy eating advice is to use less fat, and that the fat you do use comes from healthier unsaturated fats such as olive, sunflower, rapeseed or soya oils. If you need to gain weight it is okay to use a little more of these fats to increase overall energy intake, but remember that the best nutritious way to regain lost weight through illness is by increasing protein and overall energy intake.

Not included in the Eatwell Guide are treat foods such as cake, biscuits, crisps or sweets and chocolate. These foods are not essential to health. However, they can make an important contribution to your total energy intake and can help boost your appetite. A drink of ice-cold milk and a small slice of sponge cake makes a good high-energy snack between meals.

# Diet (cont.)

In summary, the nutrients each food group provides are:

- **Carbohydrates:** energy, B-vitamins, iron, folic acid and dietary fibre.
- **Fruit and vegetables:** vitamins A, C and E, folic acid, dietary fibre and potassium.
- **Dairy foods:** protein, calcium, vitamin B2 (riboflavin) and B12.
- **Other protein foods:** protein, iron, vitamin B1 (thiamine), vitamin B12 (folate) and zinc.
- **Fats, oils and spreads:** energy, essential fatty acids and fat-soluble vitamins A, D, E and K.

## What is neutropenia?

Neutropenia is a condition where the number of neutrophils (white blood cells involved in fighting disease) in the blood are decreased to less than  $1.5 \times 10^9/L$  of blood (normal range:  $1.5 \times 10^9/L$  to  $4.5 \times 10^9/L$ ). The neutropenia is a result of both your AML and side effects of treatment. Neutropenia reduces the body's ability to fight off infections making you at greater risk of infection, including foodborne infections and food poisoning. One of the measures to help with this is to ensure

scrupulous food hygiene.

As well as reducing the levels of neutrophils causing neutropenia, the treatment for your AML can affect your food intake. Common side effects include:

- Nausea and/or vomiting
- Diarrhoea
- Weight changes
- Sore mouth
- Loss of appetite
- Swallowing difficulties

## What you need to be careful of

Treatment for most types of leukaemia will result in lower levels of white blood cells, specifically neutrophils, that would usually fight food-poisoning bacteria. Also, the lining of the gut acts as a barrier preventing bacteria from reaching the bloodstream, but, during chemotherapy and radiotherapy, this can become damaged, increasing the risk of infection.

In the context of this advice, the following guidelines should always be considered when choosing and preparing food:

## Water

Freshly drawn tap water and fizzy bottled water is safe to use as a drink and in cooking. This can also be used to make ice at home.

## Milk, cheese and ice cream

Milk must be pasteurised or UHT. This applies to all kinds of cow milk, sheep and goat milk, and milk alternatives such as soya milk. Similarly, all cheese must be made with pasteurised milk. This includes fresh and vacuum-packed cheese as well as processed cheese spreads. You should avoid blue and veined cheeses, soft mould ripened cheese like camembert and feta cheese.

All commercially available ice cream maintained at the appropriate temperature is fine, so long as it is not allowed to thaw and refreeze. Do not use soft scoop ice cream or ice cream from open ice cream counters.

## Yoghurt

Live yoghurt is not harmful and can be safely included in your diet. However, it is advised to avoid yoghurts and drinks containing prebiotics and probiotics.

## Honey

Honey naturally contains yeast and spore-forming bacteria. Despite its antibacterial properties, it is recommended that honey from the following sources is avoided during treatment: raw honey, fresh honeycomb, unpasteurised honey or strained honey. Pasteurised or filtered honey removes fine particles of dust, pollen or nectar and is fine to use. Where possible, use small jars and individual portions.

## Nuts and dried fruit

As long as these have undergone heat treatment to kill off any potential bacteria, they are considered safe to use. Therefore, roasted nuts, nut butters, cooked dried fruit in tray bakes, flapjacks, cereal bars or scones are good sources of snacks.

## Smoothies and fruit juice

If you purchase these, make sure they have been pasteurised. It is not recommended to have smoothies at home with fresh fruit as it cannot be guaranteed that the bacteria has gone.

## Cooking

Generally, all food should be well

# Diet (cont.)

cooked. This includes all meat, poultry, fish and eggs. Avoid any undercooked foods or anything traditionally served uncooked ingredients such as sushi, fresh mayonnaise, homemade ice cream, dressings containing egg or any fresh pâté.

Do not reheat foods where possible. In particular, the one food you must not reheat is boiled rice. Cook, serve hot and eat immediately. Always follow standard food hygiene to store any leftovers in a refrigerator by covering with cling film or foil and using within 24 hours. Defrost frozen food in the fridge and, once defrosted, use at once following cooking instructions.

Good food hygiene is important for everyone and simple things like washing your hands thoroughly before and after food preparation, before eating or after visiting the bathroom should always be followed.

**Remember:** Mealtimes are a key time of day so try to eat with friends and family to help you maintain as normal a routine as possible. This is an enjoyable social activity and may help take your mind off your treatment for a short while, benefiting your overall health and recovery.

## Food safety advice where neutrophil counts less than $2.0 \times 10^9$ /litre\*

Avoid	Alternatives
<ul style="list-style-type: none"> <li>All unpasteurised dairy products e.g. milk sold on local farms</li> </ul>	<ul style="list-style-type: none"> <li>Any pasteurised milk, soya milk, Jersey milk or UHT milk</li> </ul>
<ul style="list-style-type: none"> <li>Soft cheeses made with unpasteurised milk e.g. feta, parmesan</li> <li>Homemade/deli paneer and labnah</li> <li>Mould-ripened cheeses e.g. Camembert, Brie, goat's cheese</li> <li>Blue veined cheeses e.g. Stilton</li> </ul>	<ul style="list-style-type: none"> <li>Cheeses made with pasteurised milk, processed cheese</li> <li>Pasteurised parmesan, pasteurised mozzarella. Paneer made with pasteurised milk</li> <li>Vacuum-packed pasteurised and hard cheeses e.g. cheddar and Edam</li> </ul>
<ul style="list-style-type: none"> <li>Raw/undercooked meat, poultry or fish e.g. meat which is still pink, sushi, caviar and oysters</li> <li>Smoked meats e.g. salami</li> <li>Avoid smoked salmon unless eaten directly from a freshly opened packet</li> </ul>	<ul style="list-style-type: none"> <li>Well-cooked meat, poultry and fish; tinned meat and fish</li> <li>Vacuum-packed cold meats such as turkey and ham stored below 3°C and eaten following the manufacturer's instructions</li> <li>Vacuum packed fish eaten straight from a new packet. This includes smoked salmon.</li> </ul>
<ul style="list-style-type: none"> <li>Raw eggs or undercooked eggs e.g. homemade mayonnaise, homemade ice cream, mousse, egg-nog, meringue, Hollandaise sauce and Béarnaise.</li> <li>Any dressing containing raw eggs e.g. home/restaurant-made Caesar salad dressing</li> </ul>	<ul style="list-style-type: none"> <li>Hard boiled eggs; shop-bought mayonnaise and other products made with pasteurised egg</li> </ul>
<ul style="list-style-type: none"> <li>Prebiotic and probiotic or bio foods, drinks or supplements</li> <li>Yoghurt which is described on the label as bio or probiotic</li> </ul>	<ul style="list-style-type: none"> <li>Any yoghurt that does not describe itself as bio or probiotic including live, plain, Greek and fruit yoghurts</li> </ul>
<ul style="list-style-type: none"> <li>Meat pâté, vegetable pâté</li> </ul>	<ul style="list-style-type: none"> <li>Pasteurised pâté and paste in tins or jars that do not need to be refrigerated</li> </ul>

\*British Dietetic Association 2016

## Further food safety advice where neutrophil counts are less than $0.5 \times 10^9$ /litre\*

Avoid	Alternatives
<ul style="list-style-type: none"> <li>Raw unpeeled fruit or vegetables including salad items, stuffed vine leaves, fatoosh and taboulleh</li> <li>Raw dried fruit, products containing these</li> <li>Damaged or over-ripe fruit or vegetables</li> <li>Unpasteurised or freshly squeezed fruit or vegetable juice or smoothies</li> </ul>	<ul style="list-style-type: none"> <li>Good quality fruit and vegetables that are well-cooked or peeled</li> <li>UHT or long-life fruit juices – in cartons or jars</li> <li>Pasteurised smoothies, canned fruit</li> <li>Cooked dried fruit e.g. in fruitcake, flapjacks or cereal bars</li> </ul>
<ul style="list-style-type: none"> <li>Fresh nuts, nuts in shells</li> </ul>	<ul style="list-style-type: none"> <li>Cooked nuts, nuts in cans, peanut butter, roasted nuts</li> </ul>
<ul style="list-style-type: none"> <li>Raw/undercooked meat, poultry or fish e.g. meat which is still pink, sushi, caviar and oysters</li> <li>Smoked meats e.g. salami</li> <li>Avoid smoked salmon unless eaten directly from a freshly opened packet</li> </ul>	<ul style="list-style-type: none"> <li>Well-cooked meat, poultry and fish; tinned meat and fish</li> <li>Vacuum-packed cold meats such as turkey and ham stored below 3°C and eaten following the manufacturer's instructions</li> <li>Vacuum packed fish eaten straight from a new packet. This includes smoked salmon.</li> </ul>
<ul style="list-style-type: none"> <li>Uncooked herbs, spices and pepper</li> </ul>	<ul style="list-style-type: none"> <li>Cooked herbs, spices and pepper</li> </ul>
<ul style="list-style-type: none"> <li>Cold cooked salmon</li> </ul>	<ul style="list-style-type: none"> <li>Cooked dishes containing smoked salmon</li> </ul>
<ul style="list-style-type: none"> <li>Non-drinking water, bottled mineral or spring water, water from wells, water from coolers, domestic water filters and water fountains</li> </ul>	<ul style="list-style-type: none"> <li>Freshly run tap, carbonated water</li> <li>Please check with your hospital for any local guidance</li> </ul>
<ul style="list-style-type: none"> <li>Ice when away from home e.g. in a restaurant</li> </ul>	<ul style="list-style-type: none"> <li>Ice made from appropriate water sources</li> </ul>
<ul style="list-style-type: none"> <li>Ice cream from ice cream vans</li> </ul>	<ul style="list-style-type: none"> <li>Ice cream from reputable sources, individual portions, wrapped, small pots</li> </ul>
<ul style="list-style-type: none"> <li>Unpasteurised or 'farm fresh' honey and honeycomb</li> </ul>	<ul style="list-style-type: none"> <li>Pasteurised or heat-treated honey</li> <li>Ideally, try to use individual sachets or portions</li> </ul>
<ul style="list-style-type: none"> <li>Unnecessarily large packets of food items from pick and mix, universal jars</li> <li>Deli counter foods e.g. olives, houmous, shawarma and baklava</li> </ul>	<ul style="list-style-type: none"> <li>Ideally, packets should be individual portions</li> </ul>

\*British Dietetic Association 2016

# Diet (cont.)

## Side effects and their impact on diet

### Nausea

If you can avoid preparing and cooking food, let someone else do it for you. The smell of food cooking can make you feel worse so try to stay away from the kitchen if possible. Also, fried, highly flavoured foods can make this seem worse, so simple, chilled or cold meals are often tolerated better.

Sometimes sucking a boiled sweet, trying ginger flavoured chilled drinks or teas, nibbling a plain biscuit or drinking fizzy water can help.

If your nausea is so bad that it prevents you from eating and you are losing weight, anti-sickness medication can be prescribed alongside your treatment to enable you to eat and feel better.

### Sore mouth

A sore and/or very dry mouth can be a side effect of medication or treatments such as radiotherapy. Simple measures that can help include choosing foods that have mild flavours and a relatively soft texture. Highly spiced and high fibre foods like crusty bread, vegetables, fruit or sharp flavours in juices can irritate the lining of

the mouth.

Sucking homemade ice cubes made with fresh tap water or weak squash can help keep your mouth moist and the coldness can help with discomfort. If your mouth is extremely sore or becomes more inflamed, you may need to use a mouthwash or be advised to use pain relief to allow you to eat comfortably. More information about mouthwashes is given in the changes to appearance and body image section of this booklet, starting on page 6.

### Poor appetite

If you have a poor appetite the thought of preparing and eating a meal can be difficult. Often the sight of a large amount of food is off-putting. Allow others to help if they offer. Someone else taking the decision of what to prepare and cooking it means you may find that you can manage a small amount after all. Small frequent meals are much better than three main meals a day so have little and often when possible. Don't worry too much about healthy eating as it is better to have two puddings than nothing at all. In addition, to get the most out of what you can eat do not routinely use low fat, low sugar foods and add extra spread, grated cheese, cream or preserves to help you

# Diet (cont.)

increase calorie value of foods.

Viewing food as fuel can sometimes encourage your intake. We need fuel for energy and to help us cope with the chemotherapy regimens and the side effects experienced. Managing even small amounts of food regularly keeps the gut active which is really beneficial for recovery. Big meals can be over-facing, so little and often is more manageable.

## Constipation and Diarrhoea

Both of these bowel problems can be the result of oral medication, chemotherapy and also radiotherapy. You may be prescribed medication to help you deal with either condition alongside your AML treatment. However, remember that regular meals as part of a well-balanced diet, a sensible amount of fruit and vegetables and fluids are key to managing both diarrhoea and constipation.

Regular physical activity, even a short walk for 10 minutes in the fresh air, will help regulate your bowels and make you feel better by being more active.

## What about 'special' diets?

Despite evidence that there are links between certain types of diet and the incidence of some diseases, it is important that you do not follow any unnecessarily restrictive diets that cut out entire food groups – such as no dairy or no foods containing carbohydrates, foods that are gluten free or suddenly swapping to vegetarian or vegan diets if you previously ate animal products.

There is no evidence that diet alone causes any type of cancer or that elimination of food stuffs from your diet will improve or cure a cancer over conventional medical care.

There is also no evidence that the use of dietary supplements in the form of over the counter vitamins or minerals will convey any additional benefit in the treatment of leukaemias. You may be given transfusions of red blood cells or prescriptions of iron tablets with some B vitamins such as folic acid and these must be taken as advised.

If you are considering taking any supplements please consult with your Healthcare team to assess that they are safe to take with your current medications.



# Infection control

Patients with AML are at high risk of developing infections. This is because AML itself and the chemotherapy used to treat it both suppress the bone marrow's ability to produce mature white blood cells normally responsible for fighting off infection. Patients who have received intensive chemotherapy or have had stem cell transplants are at a particularly high risk.

## Where do infections come from?

AML patients are at risk of infections from bacteria, viruses and fungi. These may come from other people, from the environment or from the patient's own body, such as from microbes living on the skin or in the gut. Chemotherapy causes damage to the lining of the gut, allowing bacteria that normally lives there harmlessly to get across into the bloodstream and cause severe infections. Viruses, such as herpes and chicken pox, which remain in the body in an inactive state, can be reactivated when the immune system is suppressed.

## How will I know I have an infection?

Patients with AML can develop symptoms and signs of infection similar to the general population such as a runny nose, a cough, stinging on passing urine, diarrhoea and vomiting which can indicate an infection. However, because the immune system of patients with AML is weakened due to low white cell counts, the only indication that they have an infection is a fever. A fever may be defined either as a temperature greater than 37.5°C or greater than 38°C. Fevers may be associated with feeling either very hot or very cold, and sometimes with shivering.

Infections may progress very rapidly in AML patients. Symptoms such as dizziness, confusion, shortness of breath, high pulse rate, low blood pressure or not passing much urine are an indication for urgent medical assessment and treatment.

If you are experiencing any of these, you should speak to your medical team as soon as possible. It is important to measure your temperature on a regular basis

and seek medical attention if you have a fever.

## How are infections treated?

Antibiotics are an effective treatment for the bacterial infections which could otherwise be fatal. For AML patients with suspected sepsis, where the infection has entered the blood, intravenous or oral antibiotics should be administered within 60 minutes of being assessed (this is called door-to-needle time). For patients with confirmed sepsis, intravenous antibiotics should be administered immediately or as soon as possible. This is why it is so important to measure your temperature on a regular basis and seek medical attention immediately if you have a fever. Having a thermometer at home is very important to assess your temperature when staying at home in between treatments.

## How will doctors work out which treatments to give me?

You will receive the following investigations to locate the source of the infection:

- Looking for bacteria in the bloodstream
- Chest x-rays
- Blood culture tests
- Urine culture tests
- A stool culture
- Swabs of any open wounds
- A full medical review to assess any clinical changes

If you have a Hickman, peripherally inserted central catheter (PICC) line or Portacath, blood cultures will also be taken from this. Depending on the results of these tests, antibiotics for the specific bacteria isolated can be given. If no abnormalities are found on these investigations, you will be given broad spectrum antibiotics which cover a wide range of different types of bacteria, since you clinically have an infection which can't be isolated.

Guidelines vary between hospitals as to which are the most appropriate antibiotics to give, depending on the local pattern of infections and also patterns of antibiotic resistance. The Haematology doctors will consult

# Infection control (cont.)

with the Microbiology team at your hospital to ensure you are receiving the correct antibiotics in relation to the infection you have.

## What will happen if the initial antibiotics do not make me better?

It can take several doses of antibiotics to bring your temperature under control and to make you feel better. However, if there are indications that the antibiotics are not working, it may be necessary to change the antibiotics or to add other treatments in. There are a number of reasons why the antibiotics may not work, these can include:

- Antibiotic resistance
- Infection caused by a more unusual type of bacteria that requires an additional antibiotic
- Infection caused by a virus or fungi, which do not respond to antibiotics

If it is suspected that the infection may be coming from a line, it may be necessary to remove this as it can act as a reservoir of infection that the antibiotics cannot clear.

## What about fungal infections?

Fungal infections are extremely rare in healthy individuals but much more common in people who have a weakened immune system. AML patients are now given anti-fungal prophylaxis (preventative treatment) as standard. This greatly reduces the incidence of fungal infections; although, breakthrough infections, particularly by moulds, can still occur.

These infections often affect the lungs and therefore a computerised tomography (CT) scan of the chest, which shows more detail than a chest x-ray, is often helpful in diagnosing them. There are a number of oral and intravenous antifungal drugs that are effective. Long courses of treatment are often required to eradicate a fungal infection.

## What about viral chest infections?

In contrast to fungal infections, viral chest infections and colds are common both in the general population as well as in AML patients. However, in AML patients they often cause more severe

infections. Viral infections in AML patients occur at the same time as in the general population. Some viruses, such as respiratory syncytial virus (RSV) and parainfluenza virus, are spread through direct contact while other viruses, like influenza and adenoviruses, are spread through air-borne droplets when we sneeze or cough.

Some viral infections may be diagnosed by a throat swab. There are no specific effective treatments for most common viral infections, with the exception of influenza and RSV, for which antiviral drugs can be given, if necessary.

It will also become commonplace to test patients for COVID-19 and to appropriately isolate those who are experiencing any symptoms.

### **What about herpes and chicken pox/shingles?**

The herpes simplex virus (HSV), which causes cold sores, and the varicella zoster virus (VZV), which causes chicken pox and shingles, may be reactivated in AML patients who have previously had these infections and in whom the viruses have remained in the body in an inactive state.

VZV can also be caught from other people. To reduce this risk, all chemotherapy patients should avoid exposure to people with chicken pox or shingles or people who develop a rash within 48 hours of vaccination against the virus until all lesions have crusted over. If patients with AML are accidentally exposed to someone with VZV, an AML patient's immunity to this virus should be checked through a blood test.

### **What will my doctor do to prevent me from getting an infection?**

AML patients will receive supportive medications to try and reduce the risk of infection. These include the anti-viral drug acyclovir to reduce the risk of HSV and VZV infections, and anti-fungal medications. Preventative antibiotics may also be given, although this practice is of uncertain benefit. The potential reduction in the risk of infection needs to be balanced against the risk of causing antibiotic-resistant infections.

All caregivers and visitors should follow strict hand hygiene, sanitising or washing their hands each time they visit you. This is

# Infection control (cont.)

very important as it has been shown to significantly reduce the transmission of infection. While you are in hospital, you will be advised to try and limit skin-to-skin contact through the use of aprons and gloves. If you are known to have a respiratory virus that is spread through air-borne droplets, caregivers and visitors may need to also wear masks.

You may also be in an isolation room, with an air filter or positive pressure to minimise the risk of getting an infection from other patients on the ward.

## How can I reduce the risk of getting an infection?

Most AML patients do get an infection while they are undergoing intensive induction chemotherapy. This is because many infections come from organisms that normally live harmlessly in our bodies. However, a number of precautions may reduce the risk including:

- Following a neutropenic diet (more of which can be read about in the diet chapter of this booklet, starting on page 38).
- Plants and dried or fresh flowers

should not be brought into hospital rooms.

- AML patients should try and minimise contact with relatives who have a suspected infection. For example, there should be no contact with relatives or visitors until their symptoms have ceased for 48 hours.
- AML patients should avoid crowded spaces, such as hospital canteens, GP surgeries, supermarkets and shopping malls. While in hospital, AML patients are advised to stay in their own room as much as possible.

## What about immunisations/ vaccinations?

Vaccinations are designed to protect people against infections by priming the immune system. Some vaccinations are live (they are capable of causing a milder version of the infection) while some are inactive (they contain dead particles of the infection and therefore are incapable of causing an infection).

Live vaccines should not be given while patients are undergoing chemotherapy. Live vaccines, such

as measles, mumps and rubella (MMR), and varicella zoster may be given six months after the patient has made a complete recovery from chemotherapy and is in remission.

In contrast, inactive vaccines are safe but unlikely to be effective in patients undergoing chemotherapy because they cannot mount an immune response to them. Vaccinations are therefore recommended after an AML patient has made a full recovery from chemotherapy. Vaccination of family members and close contacts against the influenza virus is strongly recommended to try and reduce the risk of them becoming infected and spreading the infection to a patient.

AML patients who receive chemotherapy alone generally do not need to be revaccinated against infections they have been previously vaccinated against, as they retain their immunity. The exception to this is the influenza vaccine as this changes each year to cover new strains of the virus.

# Bleeding risk in AML patients

AML patients are at an increased risk of bleeding. The most common reason for bleeding in AML patients is a low platelet count. Platelets are blood cells produced in the bone marrow which help to stop bleeding by clumping together to form a clot. Both AML and chemotherapy can reduce the number of platelets by suppressing the bone marrow.

Excess bleeding does not normally occur until the platelet count is really very low. For bleeding in patients with AML, platelet transfusions are usually given when the platelet count falls below 10,000 or 20,000 per microlitre of blood (normal range is between 150,000 and 450,000 platelets per microlitre).

Bleeding may occur from mucosal membranes. For example, nose bleeds, gums bleeding or mouth blisters, or bleeding into the skin which often causes small purple spots on the legs. Women of child-bearing age may get heavy or prolonged periods. More rarely, bleeding can be more serious such as coughing up blood, bleeding from the gut, or a bleeding on the brain, which may occur spontaneously or as a result of trauma.

Very rarely, in a subtype of AML called acute promyelocytic leukaemia (APL), which accounts for 10% of AML patients, bleeding may occur not only as a result of a low platelet count, but also due to a condition known as Disseminated Intravascular Coagulation (DIC). DIC affects about four out of five patients with APL. DIC happens when the body forms clots. This uses up the clotting factors in the blood and leads to severe, even life-threatening, bleeding.

Fortunately, modern treatments are very effective in resolving DIC. Patients may need to receive fresh or frozen plasma and cryoprecipitate to try and compensate for abnormalities. Menstruating women can be given hormonal treatment to try and stop their period while their platelet counts are low.



# Exercise

## What are the benefits of exercise?

Despite the well-established benefits of exercising, many patients with AML still feel unsure if this will help them, especially when they are going through treatment and feeling unwell and tired. However, everyone is different and as treatment is specifically tailored to each individual, so should their exercise regimen. Side effects, coping mechanisms and general wellbeing effects are not the same for everyone and what works for one person is not necessarily going to work for you.

Exercise is beneficial for our physical and emotional health. An appropriate exercise regimen can help to improve many cancer symptoms or treatment-related side effects. It can be carried out before, during and after treatment, but you need to be mindful of how you are feeling. It is unclear if exercise directly lowers the risk of cancer relapse; however, remaining fit after treatment can reduce longer term risks such as heart disease which may be associated with some anti-cancer treatments, including

daunorubicin.

When thinking about exercising, it is best to speak to your medical team so they can advise you of any precautions you need to take. What you are able to do will be determined by your treatment as you may be in hospital for a few weeks and some treatments may put you at a high risk of infection. Some side effects are more common than others but, in general, if you are able to exercise at a level that is tailored to your physical needs, these side effects should not be made any worse and, in some cases, may actually improve.

Contrary to belief, exercise can help with tiredness and does not make it worse. An overemphasis on energy conservation can result in treatment-related losses of fitness and muscle strength. Exercise can help to decrease bone pain and improve sleep and appetite. If your weight has increased, gentle exercise can help in reducing the amount gained. During treatment, there can be some muscle wastage. However, exercising can help to reduce this muscle wastage. If the amount of lean muscle mass lost has been very significant, it's

best to begin with strengthening exercises first. For more information on suitable exercises, your doctor can refer you to seek advice from an exercise specialist or physiotherapist.

Exercise can also have significant improvement on your wellbeing and quality of life, helping to relieve stress related to the disease and treatment. Please refer to the exercise-based complementary therapies of yoga, tai chi and Tripudio movement.

To summarise, exercise can have the following benefits:

- Moving more, more often can help to lower those long periods of inactivity. Long periods of sitting or lying down are associated with heightened fatigue, muscle tightness and depletion, a build-up of lymphatic fluids, and weakened bones.
- Strength training, including using body weight, consisting of simple exercises that can be done at home, in a chair or your bed can improve functional capacity.
- Core and posture exercises can really help people feel strong

again and are super important for breathing efficiently, spinal health and wellbeing.

- Exercise can positively influence our brains in terms of cognition, confidence, self-image, self-esteem and boosting our mood.

## Active Daily Living

Active Daily Living (ADL) is a great way to increase your fitness. This refers to the jobs or tasks you do naturally during the day, whether at home or work, and building on them. They are ideal if you have a low fitness level or if you struggle for time as they can be incorporated into your daily routine. You can gradually increase them as you feel up to it.

Any tasks which get your heart rate up all count. These can include:

- Getting off the bus or tube a stop earlier and walking the rest of the journey
- Taking the stairs instead of the lift
- Parking at the back of the supermarket car park
- Gardening

The benefit of ADL is to get you

# Exercise (cont.)

thinking about little changes which can then lead gradually to bigger ones. Progressing slowly ensures you are being realistic and allows you to plan achievable goals. If you have never done exercise before, it is a good idea to try and do some gentle activity. Walking or a home programme is usually the most appropriate way to start.

Walking enables you to go at your own pace and distance. The key is to keep it gentle and easy so you can do it little and often, even if it's only a walk to the end of the garden. Gaining strength can also reduce the chance of injury and empower you both physically and mentally. Cancer charities and some centres often run classes specifically for those on or off treatment. This environment can feel safe and supportive for patients and far less daunting.

## Further exercise goals

Despite being on treatment, it is good to try and exercise. If you are used to regular exercise, you should not look to increase your fitness level, particularly if you are still on treatment. Just try and maintain the level of fitness you have. Your fitness may have

dropped but don't be discouraged because simply managing to still exercise is a great achievement.

A lot will depend on your type of treatment and your current fitness level. It is advisable that the exercise you choose is enjoyable so that you are motivated to do it.

For example, some things to consider include:

- If your fatigue levels are high, start small and build up gradually, perhaps with exercises from your bed or a chair.
- If you're experiencing neuropathy, seated exercise may also be suitable for you. Don't use dumbbells to reduce the risk of injury but use resistance bands to gain strength. You can walk with poles for support or have a buddy to exercise with you.
- If you would like to focus on bone strengthening, keep it low impact if your joints are sore before building up slowly. When exercising, it is useful to know the difference between muscle soreness and other pain, so try to listen to your body.

- If you are neutropenic, it may be useful to think about your exercise environments. You may want to avoid gyms where there can be a lot of bacteria through sweat, and they can also sometimes become quite crowded.
- If your blood counts are low, keep your exercise gentle to avoid causing any bruising or bleeding.
- If you have a PICC line fitted, avoid strenuous activity and exercises that involve heavy lifting or risk of overstretching.
- If you think you may not be up to physical exercise, daily deep breathing exercises can still be beneficial. They can help to regulate the nervous system and help people to keep calm and connect (which can be invaluable during treatment and between hospital appointments). They also help to strengthen the diaphragm and encourage better lung function as well as stimulating the lymphatic system.

If you would like tailored advice on which stretches and exercises to do or how to do them, speak to a physiotherapist or fitness advisor.

Always ensure you are sensible and listen to your body.

Before embarking on strenuous activities, you should have an adequate warm up to slowly build up your heart rate. For the cool down, bring the heart rate down slowly by gradually decreasing the intensity of your activity, and not stopping immediately. It is also really important to remember to stretch your muscles after exercise by way of a cool down. If you have any specific areas of reduced flexibility, it can be helpful to work on these regularly. However, it is important to ensure you are gentle and work slowly without overstretching.

There are many variables that can determine which exercises or activities are effective and safe for your particular situation. Every day can bring new challenges and new accomplishments, so it is important to be able to modify your physical activity to suit your needs at any given time.

Other tips include:

- Exercise when your energy levels are at their best.
- Think about how you can schedule your exercise routine

# Exercise (cont.)

into your day, rather than squeezing it in.

- Customise your exercise each day to allow for any physical or psychological side effects you may be experiencing.
- A walking programme is a great way to start physical activity. If fatigue levels are high, start small and build up gradually. This could be as little as five minutes to begin with, adding on a few minutes each time.
- Check in each day: pace, plan, prioritise.
- Keep a diary noting side effects as well as how you felt before, during and after exercise.
- Track progress and performance.



# Fatigue

Fatigue is one of the most common consequences of AML and its treatments. Its cause, however, is not yet fully understood. Significant fatigue is thought to affect the majority of people with AML and may be defined as: *"A distressing, persistent, subjective sense of tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning."*

## What does AML-related fatigue feel like?

Given the subjective nature of fatigue, it may feel different from one person to the next. Most people, however, will experience a degree of fatigue which feels overwhelming in that it affects them physically, emotionally and cognitively. Fatigue is different to the tiredness you might usually have experienced prior to becoming ill or after physical exercise.

It is often described as a tiredness and weakness which may render the patient unable to work or perform usual activities.

## How long does it last?

There are no hard and fast rules

for how long AML-related fatigue will last. Some people report feeling increasingly fatigued in the months leading up to being diagnosed with AML. Patients with AML may experience significant fatigue which interferes with day to day life for several months. However, over time, AML-related fatigue may subside and many people get back to their normal energy levels within six months to a year after finishing active treatments.

## How can fatigue affect your daily life?

AML-related fatigue can negatively impact on all aspects of your day to day life. This may include disruption to your usual activities such as personal care, including showering and dressing; leisure and social activities (keeping fit or going out with family and friends); work and educational attendance and performance. For people who are working and trying to manage with compromised energy levels, there may be a tendency to use most of their available energy for work. By the end of your working week, you may find there is little left in your 'battery' for leisure activities and socialising.

Being unable to perform your normal activities can prevent you from being in contact with other people as much as you would like. This can understandably lead to feelings of social isolation and sadness. Additionally, people may experience a sense of 'loss of former self', akin to feelings of bereavement, and might grieve for the normal life they seem to have left behind.

Some patients also worry about the cognitive impact of AML-related fatigue which may lead to what some people describe as 'brain fog' or 'chemo brain'. This commonly includes reduced concentration, memory issues and communication difficulties, all of which can be scary. Other patients may worry about their own expectations and those of others in terms of their pre-illness roles, responsibilities and involvement in day to day activities and events.

As AML-related fatigue is not always obvious to others, it might be that friends, family, or employers do not seem to understand the impact of fatigue on a person's life or how best to support them. It is often in your best interest to take time to

explain the effects of AML and its treatment to those around you. This will prevent you from feeling frustrated and educate those around you.

Relationships of an intimate nature may also be affected by AML-related fatigue and you may feel too tired for sexual intercourse. Additionally, your partner may worry that they might make your fatigue symptoms worse. If you would like some more information about the impact an AML diagnosis can have on relationships, go to page 14 of this booklet.

Despite the influence of fatigue on our day-to-day activities/occupations, identity, roles and responsibilities, there are strategies that you can employ to help you better manage these and feel more in control.

## **Strategies to combat fatigue**

The first step in self-managing your fatigue symptoms is acknowledging that you have AML-related fatigue. Secondly, not being hard on yourself or expecting yourself to perform all the activities you did before

# Fatigue (cont.)

you became ill will help. Be self-compassionate.

Congratulate yourself on what you do achieve rather than punishing yourself for what you don't, regardless of how little it seems, and do not compare yourself with others or past performance. If you accept that your current energy levels are not what they used to be, you can begin to think about how much energy you have available, how you are using it and whether you would like to use it differently. This self-management process will hopefully help you to regain some control over your daily activities, roles and responsibilities.

Activity management and energy conservation have been shown to help.

Here are some useful tips for regaining control of your day to day life:

- Identify activities, both physical and cognitive, that drain your energy the most.
- Identify activities that make you feel you have increased your energy levels, or plugged in your personal battery. These may include a physical activity,

such as a paced walk, and do not necessarily mean resting or sleep.

- Use a diary or calendar as a reminder and to note down the activities mentioned above.
- Schedule the most draining activities appropriately to help you get through to the end of the day easier.
- Prioritise activities and decide whether they really all need to be done on the same day. Avoid overdoing things, even when you are having a good day.
- Plan activities in a diary across the week to manage your energy expenditure.
- Getting back to, or slowly introducing, physical activity into your daily routines may help to reduce AML-related fatigue. This may also help you return to your previous levels of sexual activity. It may be through attending a gym or yoga class, or dancing. For more information, go to the exercise chapter of this booklet on page 56.
- Communicate the impact of fatigue on patients with AML,

as your family, friends and colleagues may be unfamiliar with this. For more information about telling others about AML, go to page 32.

- Eat a well-balanced diet and have nutritious snacks throughout the day to increase your energy levels.
- Adopt a relaxing ‘wind down’ regime an hour or two before you go to bed at night in order to promote relaxation and aid restful sleep. Sleep hygiene strategies may be helpful and enjoyable as sleep is commonly disrupted and may be unrefreshing for some.
- If you are a student, discuss the impact of AML-related fatigue with your student disability services and request support from your organisation, such as extensions on assignment deadlines if needed.

Remember the fatigue you are currently experiencing may well go away over time. In the meantime, self-managing your fatigue will help you feel more in control and add to your sense of wellbeing.

# Work and finances

There is no legal requirement for you to inform your employer of your AML diagnosis; however, if they are not aware of your diagnosis, they cannot assist you during your treatment and recovery. Regular absences or low performance when completing your tasks because of your AML could be seen as performance-related issues and not be attributed to your illness.

## Telling work about your diagnosis

Being diagnosed with AML will probably mean that you need to start treatment straightaway. You, or someone else, could maybe let your employer know about your situation so you can receive the time off you need for your treatment and recovery. You may also need to negotiate a reduction in working hours if you are unwell, or make an arrangement with your employer for times when you are in hospital.

Your medical team will be able to advise you about timescales for treatment and recovery. Your consultant or your GP can provide you with a letter to your employer confirming your diagnosis and the effects it may have on your work

life. It is often worth taking time to explain AML to your employer, as it is likely they will never have heard of the disease. Fitness for work certificates will be provided for your employers to help explain the implication of your AML. They can provide evidence every three months of your current clinical state.

With regard to telling your colleagues, you may want to keep your diagnosis to yourself or you may want to tell only those that you are closest to, so they can support you. Alternatively, you might want to ask your manager to inform your colleagues, so that it is easier when you go back into work. Your colleagues will then also be aware that you are at risk of infection or why fatigue and poor concentration might be a problem.

You may be apprehensive about how your colleagues will react. Some will want to talk about your AML and others won't at all. If people avoid you, it is usually because they don't know what to say or are worried about saying the wrong thing. It can help if you or a trusted colleague let people know if you do or don't want to talk about it. Plan beforehand

what you might say if someone asks how you are.

Sometimes, it can seem that people have forgotten you have AML and you need to gently remind them that you are still coping with side effects and that your recovery will take time. As with all of your conversations about AML, being honest saying what you need to say is generally the most helpful approach, making things easier for all.

## What are my rights at work?

An AML diagnosis at any stage of your life is difficult to deal with and how you approach your diagnosis and treatment is very personal. If the diagnosis occurs while you are working, it can feel very daunting and scary. Some of the questions you may be concerned about are:

- Will the treatment affect my ability to complete tasks at work?
- How much time will I need off for medical appointments, treatment and recovery?
- How will I come back to work after treatment and cope with

treatment and work?

- What if I feel I cannot come back to work after treatment?
- Will I be discriminated against or looked over for promotions?

This is by no means an exhaustive list of questions and will depend on your job.

## Returning to work

Deciding to continue working during your treatment is your decision and should be discussed with your family, as well as your manager or the Human Resources (HR) department, so they can best assist you at work. You can also discuss this with your Clinical Team who will advise you in accordance to your clinical wellbeing. Once you are back at work, your manager or HR should keep in touch with you regularly to determine if you require any assistance with either your job, workload or if there is any other way that they can support you.

AML treatments and their side effects can be very different for each patient. Some patients can have little or no side effects and find that continuing with work is the best way for them, while

# Work and finances (cont.)

others have severe side effects and can only continue with flexible working arrangements, or cannot work at all. The decision to continue working can really only be made once you have started treatment.

If you have decided to continue working, you are still entitled to change your mind later and request more flexible working arrangements as a reasonable adjustment. Employers are legally required to assist you with reasonable adjustments while you are undergoing treatment and thereafter. Hopefully, your employer will be supportive. You may worry that your employment will be terminated or that you are made redundant if you cannot work. However, this is unlawful as all patients with cancer are protected by the Equality Act 2010.

Within the Equality Act 2010, cancer is legally classified as a disability. Cancer patients are also included if they have had cancer in the past or are at any stage of treatment, recovery or remission.

The Equality Act 2020 requires your employer to make reasonable adjustments for illness. However,

if your employer has not been told that you have cancer, or they could not have reasonably known that you have cancer, then they are not required to make reasonable adjustments. This is why it is usually advisable to inform your manager or HR department of your diagnosis on returning to work.

Being required to make reasonable adjustments means that your employer is to assist you in managing your work by either changing how your employment is structured, removing physical barriers, or providing additional support. There is no definitive description of what a reasonable adjustment is but the following will be taken into consideration:

- The size of your employer
- How much will the adjustment cost
- How much will the adjustment benefit you
- Whether making the adjustment will affect the employer's business service or financial situation

Here are some examples of reasonable adjustments:

- Having time off for treatment, recovery and to go to medical appointments.
- Allowing you to tailor your hours to suit your needs. This is called a phased return to work and is very often used to ease employees back into work, after a period off sick.
- Allowing you to undertake light duties, during or after treatment, or allowing you more periods of rest.
- Changing your job description to remove tasks that could prove physically difficult or stressful. This would be done with your full cooperation and agreement.
- Sharing some of your tasks with another employee.
- Making sure your access to work and workstation are suitable (adding a ramp, changing workstation location or set up, enabling homeworking).

Reasonable adjustments are not easily defined as they are usually quite specific to each employee. Let your employer know what reasonable adjustments (either

temporary or permanent) you require, and your employer should endeavour to implement them, and not merely refuse. It is more difficult for an employer to refuse a temporary adjustment and it is a good starting point when asking your employer to implement reasonable adjustments.

If you encounter difficulties having your reasonable adjustments met, it is important to consider seeking legal assistance. There are also a number of free services that can assist you, including Disability Law Service or Working with Cancer.

## Discrimination

In England, Scotland and Wales, the Equality Act 2010 and the Disability Discrimination Act 1995 protect employees. In Northern Ireland, the Disability Discrimination Order of 2006, strengthens the 1995 Disability Discrimination Act. Under these acts, it is unlawful to treat an employee less favourably because of their disability. If your employer does begin to treat you less favourably as a result of your cancer in the present or in the past, that is discrimination.

# Work and finances (cont.)

Not all employers are aware of their responsibilities and rights under the Equality Act. If you encounter difficulties at work, it is advisable to speak to your manager or HR team first, in order to see if a solution can be achieved. It is important that you are aware of your rights, both according to the Equality Act 2010 and your company's procedures. If you are still not satisfied with the outcome, consider seeking legal assistance from either a voluntary organisation such as the Citizen's Advice Bureau or an employment solicitor.

The Equality Act 2010 and Disability Discrimination Act 1995 cover all areas of employment from recruitment, employee's terms and conditions, benefits and bonuses, opportunities for promotion and training. The acts will even protect an employee when they no longer work for the employer.

In order for you to benefit from the protection of these acts, your employer must be aware of your diagnosis, except in the case of Indirect Discrimination. This is why it is usually advisable to inform your manager or HR department of your diagnosis.

The Equality Act 2010 protects employees against Direct Discrimination, Indirect Discrimination, Harassment and Victimisation.

## Direct Discrimination

Direct Discrimination is when you are treated less favourably than someone who does not have cancer. Examples of discrimination by your employer might include:

- Suggesting that you resign or retire because you have cancer
- Selecting you for redundancy or for reduced working hours because of your cancer
- Not making the reasonable adjustments you have requested
- Giving you a warning for persistent sick leave, despite knowing about your diagnosis
- Suggesting you do a different role, which is a demotion, because you have cancer
- Not giving you a promotion or the same opportunities as others because of not taking your cancer into consideration

## Indirect Discrimination

Indirect Discrimination is the existence of a rule, policy or practice that applies to everyone which puts you at a disadvantage compared to other employees who do not have cancer. You can only challenge a practice, policy or role which you think is indirectly discriminatory if it affects you personally.

An example of this would be if your employer selects employees for redundancy using the amount of sick leave recorded. An employee with cancer will be at a clear disadvantage compared to other employees. It is important that you make your employer aware that the policy is discriminatory because, although neutral in nature, it disadvantages you. With Indirect Discrimination, not knowing you have cancer is not a defence for your employer.

Indirect Discrimination may be permitted if the employer can show that the aim of the policy is for a justifiable reason, that the aim of the organisation is fair and balanced, and that your reasonable adjustments have been taken into account.

## Victimisation

Victimisation is when you are treated less favourably than another employee, for asserting your rights as a disabled person. For example, your manager gives you an unfairly negative appraisal because of the following incident: You have requested time off for your treatment and your manager does not grant you it. You approach your HR department who agrees with you and instructs your manager to grant the time off. Your manager is annoyed that you went over their head to HR and victimises you.

## Harassment

Harassment is where certain behaviour is meant to, or has the effect of, either violating your dignity, or creating an intimidating, hostile, degrading, humiliating or offensive environment. Harassment would also include bullying in the workplace which means "*repeated, health-harming mistreatment of a person by one or more perpetrator(s). It refers to conduct that is abusive, threatening and intimidating, or work interference or sabotage which prevents work from getting done.*" More information can be found at [www.workplacebullying.org](http://www.workplacebullying.org).

# Work and finances (cont.)

## What do I do if I encounter discrimination in my workplace?

If you feel that you are being discriminated against, speak to your manager or HR Department and see if the issue can be resolved. Quite often issues arise due to miscommunication or because the employer is not fully aware of your needs and/or situation. Try to speak openly and update them about your situation. Approach them with solutions and suggestions to show that you are committed to your job.

If you are unable to speak to your manager or HR department, speak to your Union if you belong to one, or ask for help from an Occupational Health Adviser, which your employer can arrange for you. If you still feel your issues are not being addressed, seek assistance from the Citizen's Advice Bureau or organisations like Working with Cancer or Macmillan Cancer Support which deal specifically with providing advice about work for cancer patients.

It is important to be fully aware of

the relevant company procedures and policies. If you do not already have a copy, your manager or HR department can provide you with a copy. Make sure you know and understand your legal rights. If the matter still stays unresolved, you may be required to lodge a formal grievance.

Your employer will have their own grievance procedure, either in their employee handbook or in your contract of employment. To raise a formal grievance, you will need to contact your manager in writing, detailing the incidents which have led you to believe that you have been discriminated against. Being specific and detailed in this approach is recommended. Your employer will be required to investigate your grievance and deal with it fairly.

If you are still not satisfied with how your employer is dealing with your grievance, you can bring a complaint to an Employment Tribunal. Before you bring a claim, you will have to notify ACAS (Advisory, Conciliation and Arbitration Service) of your intention to lodge a claim. ACAS will try and resolve the dispute between the parties before the matter goes to an Employment

Tribunal.

More information on how to lodge a claim with an Employment Tribunal can be found here: [www.gov.uk/employmenttribunals](http://www.gov.uk/employmenttribunals). Alternatively, you should seek advice from an Employment Solicitor.

## Not returning to work

If your condition is such that you are unable to work, there are a number of benefits you may be entitled to as a cancer patient. This largely depends on your personal circumstances, because there is no benefit which you automatically qualify for solely based on your cancer diagnosis. However, you may be eligible for the following benefits:

### Employment and Support Allowance

This benefit is for people under State Pension age who have a disability or illness that makes it hard for them to work. You will be assessed to see if you have 'limited capability for work'. However, if you are having chemotherapy or radiotherapy, then you will pass this test automatically.

There are three different types of

ESA, each with different eligibility criteria:

- 1. 'New Style' ESA** - To claim this you will need to have been employed or self-employed and paid National Insurance contributions, usually within the last two to three years, and now have an illness or disability that affects your ability to work.
- 2. Contribution-based ESA** - This follows the same type of criteria as 'new style ESA', but you also have to be in receipt of the severe disability premium or you should have received it within the last month and still be eligible for it.
- 3. Income-based ESA** - This type of ESA is not related to your National Insurance contributions, but you need to have savings of less than £16,000.

For 13 weeks after your claim you will receive the assessment rate and, if you are entitled to ESA, you will be placed in either the work-related activity group or the support group.

Relatively few people can still make new claims for contribution-

# Work and finances (cont.)

based or income-based ESA. For example, only those in receipt of the severe disability premium are able to make a new claim for income-based ESA.

More details of ESA payments can be found at [www.gov.uk/employment-support-allowance](http://www.gov.uk/employment-support-allowance).

## Personal Independence Payment

This benefit is for individuals aged between 16 and State Pension age who require help at home with preparing food, bathing and dressing because of a disability or illness. An extra payment is available for those who have difficulty moving around. The health condition must have been present for at least three months and expected to last for at least nine months. Personal Independence Payment replaces the old Disability Living Allowance.

More details can be found at [www.gov.uk/pip](http://www.gov.uk/pip).

## Attendance Allowance

Individuals of over State Pension age can claim an Attendance Allowance if they have the need for care or supervision because of an illness or disability, for example getting out of bed, having a bath

or getting dressed. These needs must have been present for at least six months.

More details can be found at [www.gov.uk/attendance-allowance](http://www.gov.uk/attendance-allowance).

## Carer's Allowance

This allowance is for individuals aged 16 or older caring for someone for at least 35 hours a week. The carer must not be in full-time education or studying for 21 hours a week or more, and their income must be less than £128 a week after tax, national insurances and expenses.

To be eligible for Carer's allowance, the person cared for and the type of care you provide must meet certain criteria.

The person you care for must already be in receipt of one of these benefits:

- Personal Independence Payment (the daily living component)
- Disability Living Allowance (the middle or highest rate for the care component)
- Attendance Allowance

The type of care provided must include:

- Helping with washing and cooking
- Taking the person cared for to doctor's appointments
- Helping with household tasks, like managing bills and shopping

In some circumstances, a carer under State Pension age can claim Carer's Credit even if they aren't entitled to Carer's Allowance. This won't give the carer any income, but it will credit them with National Insurance credits towards their State Pension.

More details are available at [www.gov.uk/carers-allowance](http://www.gov.uk/carers-allowance).

### Universal Credit

Universal Credit is a monthly payment for people to help with their living costs. It is available for those on a low income or out of work. Universal credit may be relevant for you if you cannot work because of your AML.

Universal Credit is being rolled out across the country and replaces six benefits:

1. Income Support
2. Income-based Jobseeker's

Allowance

3. Income-related ESA
4. Working Tax Credit
5. Housing Benefit
6. Child Tax Credit

If you are not already on Universal Credit, but are already in receipt of any of the benefits above, the Department for Work and Pensions will contact you when you need to move over to Universal Credit.

However, you cannot claim Universal Credit if you either:

- Get the Severe Disability Premium, or are entitled to it
- Have got or were entitled to the Severe Disability Premium in the last month, and you're still eligible for it

You can find out more details about Universal Credit at [www.gov.uk/universal-credit](http://www.gov.uk/universal-credit).

### Disability Premium Allowance

Disability Premium Allowance is a payment which can be added onto Universal Credit (or the equivalent if you haven't moved onto Universal Credit).

# Work and finances (cont.)

These disability premiums are added to your payments automatically and you should not need to apply for them. There are three types:

1. Disability premium
2. Enhanced disability premium
3. Severe disability premium

More details on the eligibility for disability premiums can be found at [www.gov.uk/disability-premiums-income-support/eligibility](https://www.gov.uk/disability-premiums-income-support/eligibility)

## Special rules for end of life allowance

If your doctor estimates that you may have less than six months to live, you can apply for certain benefits using a fast-track process. This is called special rules. This will entitle you to get benefits at the highest rate, avoid any extra assessments and prioritise your claim. Special rules usually apply for up to three years.

Special rules apply to certain benefits. These are:

- **Employment and Support Allowance** – entitlement to this depends on if you have been working and paying National

Insurance contributions previous.

- **Universal Credit** – entitlement to this depends on your household's income and savings. You could use a benefits calculator to work out if you should be entitled to it: <https://www.gov.uk/benefits-calculators>.
- **Personal Independence Payment** – if you are under pension age and have less than six months to live, you will be entitled to this.
- **Attendance Allowance** – if you are over pension age and have less than six months to live, you will be entitled to this.

You will need to fill in the relevant benefit form, together with a form called a DS1500. Your doctor or clinical nurse specialist can fill this out.

For full and up-to-date details of these benefits and how to apply for them, go to:

- For England, Wales and Scotland: [www.gov.uk/browse/benefits](https://www.gov.uk/browse/benefits)
- For Northern Ireland: [www.nidirect.gov.uk/information-](https://www.nidirect.gov.uk/information-)

**and-services/benefits-and-money**

If you are unsure about applying for benefits, or would like some more support and advocacy, organisations such as the Citizen's Advice Bureau are able to help.

# Complementary therapies

Complementary therapies are non-mainstream treatments which are used together with conventional anticancer treatments. They include therapies such as:

- Massage
- Aromatherapy
- Meditation
- Relaxation therapies
- Tai chi
- Yoga
- Acupuncture
- Hypnosis

They are approved by the NHS and charities for enhancing the wellbeing of patients with cancers, including blood cancers such as AML. Aromatherapy, massage, reflexology, reiki and relaxation techniques may be available to you on the NHS.

Patients use complementary therapies with their conventional anticancer treatments to promote general health and help with side effects of treatment.

You may need to seek complementary therapies

privately, but the types of complementary therapies included in this section will guide you in what to seek.

## Complementary therapist

A complementary therapist should only offer supportive therapy alongside standard medical treatment for AML, and it should not be an alternative treatment. When looking for a therapist it is important to ensure your therapist has the appropriate training. The therapist will generally be a member of a representing body and must have the appropriate insurance. The Complementary and Natural Healthcare Council is an accredited representing body and all therapists on their register will have a certain level of qualifications and insurance.

A professional massage therapist will have completed a broad training with qualifications in anatomy and physiology in addition to extensive massage techniques. When approaching a therapist, please make sure they have had additional training or experience with haemato-oncology patients. For example,

they should be aware that light touch techniques and massage are required due to the possibility of low platelet counts and the risk of bruising.

## Types of complementary therapies

The therapies described below include massage-based therapies, relaxation techniques and holistic techniques, which consider the whole person (physically, psychologically, socially, and spiritually).

### Massage-based Therapies

#### Regular Massage

Therapeutic massage is a combination of different massage/touch techniques manipulating the soft tissue where the therapist uses their hands or forearms. Each treatment will vary according to the patient's state of health and personal needs. AML patients will receive a lighter touch as they may be at risk of bruising.

Oil or sometimes powder is used to ensure a smooth and comfortable treatment. The

therapist will offer a full body massage or massage a specific area of discomfort such as the neck and shoulders. In cancer and palliative care, therapeutic massage has been shown to benefit patients with anxiety, pain, various reduced physical symptoms and emotional problems.

#### M Technique

The M technique is a very light touch manual therapy which utilises a formula such that each treatment is given in the same sequence and same level of light touch throughout, making it available to anyone, however unwell. The M technique is extremely relaxing and invaluable to anyone with low energy or high stress levels, or where deeper massage is inappropriate. The results are more similar to a meditative state.

Treatment can be the full body or just specific areas. M technique training is available to health professionals, therapists and anyone who wishes to give M technique therapy to friends and family.

#### Bowen Technique

# Complementary therapies (cont.)

The Bowen technique is a gentle message therapy which is given to rebalance the body's energy flow and assist the body to heal itself. This treatment involves a light rolling movement of the therapist's thumb and fingers over the skin. It uses subtle and precise mobilisations called 'Bowen moves' which affect the muscles, tendons, nerves and connective tissue. These procedures follow prescribed sequences to affect the specific body systems.

## Holistic Therapies

### Reiki

Originating from Japan, Reiki is a technique for relaxing and reducing stress. It is based on the principle that a life force energy flows through all of us, and if it is unbalanced, we are more likely to get sick or feel stressed. Reiki is a holistic treatment which is directed at the body, mind and spirit.

Reiki is carried out by the practitioners who are attuned to the Reiki energy and act as a mirror to help students adjust their energy. Using their hands, Reiki practitioners channel the energy to help balance clients'

energy.

### Aromatherapy

Aromatherapy is a holistic treatment that uses aromatic essential oils extracted from natural plants to improve the health of the body, mind and spirit. It works through the sense of smell and skin absorption of the essential oils. Aromatherapy is most often delivered as a massage but it can also be used in creams, bath preparations, lotions and inhalation devices. Each essential oil has a number of unique properties. For example, lavender is known to relieve stress and anxiety and have a calming effect.

Aromatherapists combine the essential oils according to their properties to create a synergistic blend which will benefit the patient. These properties can assist with psychological, emotional and physical issues. They can also help mitigate the side effects of treatments which might include nausea, poor sleep and pain. Essential oils should always be diluted in oil or lotions, except in the case of lavender and tea tree which are suitable to apply directly onto the skin.

For a massage, the aromatherapist will blend a dilution of an essential oil in a vegetable oil, often known as the carrier oil. A very weak dilution, usually of around one percent, would be made up for those with AML who have undergone treatment, or for those who are less well. Relaxation is an important part of recovery. Massage can be full body, or directed to specific areas of discomfort.

### Hypnotherapy

Hypnotherapy is a form of therapy that uses the power of suggestion to create powerful and positive changes in the mind. Clinical hypnotherapists believe that creating a more positive and relaxed state of mind helps the body to repair and heal.

Hypnotherapy is a way of reducing the stress response.

During your first hypnotherapy session, the hypnotherapist will take you through a progressive relaxation, relaxing first the body and then the mind. You will be guided into a deeply relaxed state, through the suggestion of the hypnotherapist's voice. In this very relaxed state of awareness,

you are still in touch with the hypnotherapist's voice. You will be given positive suggestions to assist in a change in mental attitude towards a problem or life concern, either physical or emotional, according to your request.

The hypnotherapist may provide you with relaxation techniques and recordings to help you relax at home and, after a little practice, these may assist you in reducing your stress levels with an improved sense of relaxation and a general feeling of being. Unlike other therapies that work over a prolonged period, hypnotherapy will help you to move on as quickly as possible leaving unwanted anxiety, stress, fear, phobia or habits behind, often after only two or three sessions.

### Acupuncture

Acupuncture is a form of traditional Chinese medical practice. Many people find acupuncture very relaxing and useful for health problems such as fatigue, sleep problems, worry, nausea and pain. It can also promote emotional wellbeing and is deeply relaxing. Doctors and health professionals in the

# Complementary therapies (cont.)

United Kingdom use a method of acupuncture called Western medical acupuncture, which is an adaptation of traditional Chinese medical acupuncture practised by non-medically qualified acupuncturists. It uses current knowledge of anatomy and the principles of evidence-based medicine. It involves the insertion of fine needles and acts mainly by stimulating the nervous system. For more information on whether acupuncture may be suitable for you, speak with your medical team.

## Reflexology

Reflexology is a form of holistic massage which involves applying intermittent pressure to specific points on the feet and hands which are thought to be connected to certain organs and body systems. A foot chart which relates to areas of the feet to areas of the body is used to guide the reflexologist. Reflexologists use specific thumb, finger, and hand massage techniques with the aim of stimulating energy, releasing blockages, and bringing equilibrium and balance. This treatment of feet or hands is deeply relaxing.

Reflexology is thought to offer deep relaxation and boost the immune system. It has been linked to improvement of anxiety, pain, nausea, sleep and digestive problems.

Reflexology for Lymph Drainage (RLD) is a specialist form of reflexology therapy for those suffering with secondary lymphoedema. It concentrates on lymphatic reflexes of the feet, thereby stimulating the lymphatic system throughout the body. RLD treatment stimulates the lymph flow through the lymphatic system leading to a reduction in swelling and oedema.

## Meditation

Meditation is a technique which you can use to train your attention and awareness in order to help achieve a more emotionally calm and stable mental state. Meditation allows you to become aware and to develop a healthier sense of perspective. It involves observing your present moment experience without judgement. Meditation aims to bring your awareness more fully into the present, being aware of thoughts, physical sensations and emotions, as they arise,

experiencing them as they are without trying to change anything. With regular practice, this move towards acceptance helps reduce stressors of everyday life and builds mental and emotional resilience.

This simple act of bringing attention and awareness to our experience from moment to moment allows us to find better ways of responding to situations in our lives rather than our automatic habitual reactions such as panicking or being distressed. This can lead us to reduce physical and emotional distress and live a happier life no matter what we are facing.

There are a number of meditation techniques, including mindfulness or focusing on a particular object in the present moment, like awareness of sensations in the body or the movement of breath. This is also part of a number of exercise-based disciplines such as tai chi or yoga.

Mindfulness meditation involves paying attention and awareness to the experience of the present moment, your own thoughts and feelings, and therefore being

involved in responding to it in an effective way. This will help improve your mental, emotional and physical wellbeing.

Proven benefits include:

- Reduced stress symptoms
- Improved quality of sleep
- Enhanced quality of life
- Improving mood states
- Improving mental and emotional wellbeing

The next section of this booklet will talk about different mindful approaches in more detail.

## Exercise-based therapies

### Tai Chi

Tai chi is often described as meditation in motion. It uses a sequence of gentle flowing movements that combine breathing, movement and awareness exercises with meditation. Practiced regularly, tai chi can help reduce symptoms or side effects, increase flexibility and balance, reduce stress and anxiety, and improve overall physical and emotional wellbeing.

# Complementary therapies (cont.)

## Yoga

Yoga is a holistic practice which concentrates on a mix of stretching and postures, breathing and some meditation or relaxation. There are many different styles of yoga, some very vigorous, and others slow, gentle and relaxing, which would be more appropriate for patients with AML. Yoga aims to bring balance to the whole mind, body and spirit through an awareness of your breathing and movement. Classes usually last one hour and require loose or comfortable stretch clothing and bare feet.

## Yoga Nidra

Yoga nidra is a form of guided visualisation bringing attention to different parts of the body. This practice requires the participant to lie or sit quietly while their mind is guided through a structured sequence of visualisations. Yoga nidra may be offered as a one to one session or in a class. This practice is deeply relaxing and can also be taught for self-practice.

## Tripudio Movement Systems (TMS)

TMS is a gentle form of exercise, generally performed

to music, which includes gentle mobilisation movements and stretches, to restore the flow of fluid systems of the body, which include the lymphatic and cardiovascular systems. It can be done seated or standing and there is no floor work involved making it suitable for any age or ability. It can also be taught for home practice. Classes are often on offer at cancer centres, hospices or hospital clinics as well as in the community.

## Alternative therapies

As opposed to complementary therapies, alternative therapies are non-mainstream practices used instead of conventional cancer treatments. They include:

- Laetrile (man-made form of the substance amygdalin found in fruit pits, raw nuts and lima beans)
- Shark cartilage
- Energy crystals
- The Gerson's diet (seven to nine kilograms of organic vegetables per day with extremely low levels of sodium, fats and protein)

There is no evidence showing

that alternative therapies can improve or cure cancer. They are used instead of conventional cancer treatment rather than with them because they may interact with conventional anticancer treatment, or create harmful side effects, particularly those based on herbal medicines. Not complying with conventional cancer treatment is known to decrease the survival rate from cancer.

# Mindfulness

Mindfulness is the state of being aware of the present moment which includes your thoughts and feelings, your body and the world around you. The benefits of mindfulness comprise of enhancing your enjoyment of life, reducing symptoms of stress and improving your mental wellbeing. Mindfulness can also help you to get to know yourself better. It can give you a positive outlook on life and determine how you respond to challenges. It can help you become more resilient and cope more effectively with whatever we are facing, including living with a diagnosis of leukaemia.

Whilst we cannot prevent difficulties from happening, we can learn to cope better with situations through mindful awareness. We can respond better to our constant stream of thoughts and worries.

Because the present moment is the only time in which you can change anything, mindfulness can help you become more aware of the moment, and therefore engage in an effective way of responding to it. If you are in the present being aware, rather than judging previous experiences, you will be less reactive and often

more effective in your response to the present.

There is positive evidence for the use of mindfulness in health, education and the workplace. In people affected by cancer, mindfulness is reported to be of help with pain, stress, fatigue, anxiety and depression.

Mindfulness-based cognitive therapy is recommended by the National Institute for Health and Care Excellence (NICE) for preventing depression in patients with three or more previous episodes and relieving patients with different illnesses, including multiple-sclerosis, tinnitus and dementia.

## How to practice mindfulness

Mindfulness can be incorporated into our lives in two ways: in everyday life and in formal practice sessions.

### Mindfulness in everyday life

This involves bringing a curious and kindly attention to noticing your thoughts, feelings, body sensations and the world around you on a daily basis, particularly being aware of the sights, sounds

and smells in the present. You can have a regular time every day when you decide to be aware of the sensations created by the world around you. Turn off your phone, television or music and just pay full attention to the sensations where you are, whether you are walking, sitting or lying down, chopping up the vegetables or taking a shower.

You should also be aware of your thoughts as well as the present moment. Importantly, mindfulness is not about banning these thoughts, but being aware that they are just thoughts. In time, you can train yourself to notice when your thoughts are taking over and realise they do not control you.

### Formal mindfulness practice

In addition to practicing mindfulness in everyday life, we can practice mindfulness in more formal sessions by setting time aside and bringing awareness to our breathing, our movement or even the soles of our feet (such as heat, coolness, moisture, dryness, numbness or tingling). Whatever the object of our mindfulness practice, it is important to notice what is happening from moment

to moment, and remember that there is no right or wrong way to experience the present moment. Practices can be done for anything from a few minutes to longer practices of up to an hour.

The point of mindfulness is to just notice whatever is there from moment to moment. Each time that you find your mind has wandered away, which all our minds do, just bring your attention back to the present. More information about mindfulness and online practice courses can be found on the Mind website <https://www.mind.org.uk/information-support/drugs-and-treatments/mindfulness/how-to-learn-mindfulness/>.

There are several eight-week training courses in mindfulness provided by trained teachers available called Mindfulness Based Stress Reduction, Mindfulness-based Cognitive Therapy and Mindfulness Self-compassion. Teachers and courses can be found on [www.bamba.org.uk](http://www.bamba.org.uk) or [www.mindfulnessselfcompassionUK.com](http://www.mindfulnessselfcompassionUK.com). These come in various forms including the mindful body scan, mindful walking, mindful movement, and mindful sitting

# Mindfulness (cont.)

practice.

There are also podcasts available that can help you and have been especially designed for people affected by blood cancers at <https://www.abbvie.co.uk/responsibility/improving-health-outcomes/mindfulness-for-blood-cancer-patients.html>. A short mindful breathing exercise video can be seen on YouTube from Every Mind Matters: <https://www.youtube.com/watch?v=wfDTp2GogaQ>.

Many people find mindfulness helpful and find ways to apply it in their lives. Like anything, some people may find it less helpful than others, but most people find a useful aspect they can take from the practices and use in their daily life, even when facing a diagnosis of AML.



# Glossary

## Acute Myeloid Leukaemia (AML)

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

## Acute Promyelocytic Leukaemia (APL)

A rare sub-type of AML in which there is an increased production of immature, abnormal white blood cells called promyelocytes in the bone marrow.

## Alopecia

Hair loss.

## Amino Acids

Organic molecules which are the building blocks for making proteins.

## Antibiotic

A drug used to treat or prevent bacterial infections.

## Blood Cells

The cells present in the blood 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.

## Body Mass Index (BMI)

A calculation which involves using people's height and weight

to check if they have a healthy weight. The calculation is weight (Kg) divided by [height (meters)]<sup>2</sup>. A BMI between 18.5 and 25 kg/m indicates a normal weight.

## Body Surface Area (BSA)

Measured or calculated surface area of a human body. There are tables of average BSAs for men, women and children of different ages. A simple formula which involves the individual's height and weight. BSA is expressed in m<sup>2</sup>, height in cm and weight in kg.

## 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.

## Bone Marrow Biopsy

A bone marrow biopsy involves the collection of a sample of bone marrow from the hip bone, generally under local anaesthesia. A bone marrow surgical instrument with a cylindrical blade, called trephine, is used to remove a 1 or 2 cm core of bone marrow in one piece.

## Brain Fog

Also known as 'chemo brain', this is a general term to describe

having issues with short-term memory, lack of concentration or mental clarity, or the inability to focus on a task.

### 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.

### Clinical Commissioning Group

Clinically-led statutory National Health Service bodies responsible for the planning and commissioning of health care services for their local area.

### Cognitive Behavioural Therapy

A therapy that involves conversation to help patients manage their problems by changing the way they think and behave.

### DNA (Deoxyribonucleic Acid)

A thread-like chain of amino acids found in the nucleus of each cell in the body which carries genetic instructions used in the growth, development and functioning of the individual's cells.

### Eosinophil

A type of white blood cell which has a protective immunity role against parasites and allergens.

### Fatigue

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

### Haematology

The branch of medicine which studies the cause, prognosis, treatment, and prevention of diseases related to blood.

### Haemoglobin

A protein contained within the red blood cells and responsible for transporting oxygen to the tissues of the body.

### Holistic Needs Assessment (HNA)

An assessment of the physical and psychological needs of patients to ensure their needs and management plans are met.

### 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 chronic (develops slowly).

# Glossary (cont.)

## 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.

## Lymphoedema

A condition that causes swelling in the body's tissues affecting any part of the body, but usually develops in the arms or legs. It develops when the lymphatic system is blocked or does not work properly.

## Macrophage

A type of white blood cell that submerges and digests cellular debris, foreign substances, microbes, cancer cells, and anything else that does not have the type of proteins specific to healthy body cells on its surface.

## Microbe

Also called a micro-organism, this is a microscopic organism which is present in almost every habitat on earth. Depending on the

microbe they may be beneficial or harmful to humans. Microbes include bacteria, fungi or viruses.

## Monocyte

A white blood cell that attacks invading organisms and helps combat infections.

## Mucositis

Painful inflammation and ulceration of the mucous membranes lining the digestive tract.

## Mucous Membranes

Mucous membranes protect the inside parts of your body that are exposed to air. Examples of mucous membranes include lips, mouth, nasal passages, and the middle ear. Mucous membranes are rich in mucous glands that secrete mucus to help keep membranes moist.

## Myeloid

Relates to bone marrow.

## Myeloid Cell

A cell originating in the bone marrow which will eventually become the following white blood cells: neutrophils, monocytes (present in the blood), macrophages (present in different tissues), basophils, and eosinophils. Myeloid cells also give to the red blood cells and

platelets.

### Neuropathy

Damage or dysfunction of one or more nerves that can result in numbness, tingling, muscle weakness and pain in the affected area.

### Neutropenia

A low number of neutrophils which are white blood cells involved in fighting disease.

### Neutropenic Diet

The diet recommended for patients who have low neutrophil counts and may be immunocompromised.

### Neutrophils

White blood cells involved in fighting inflammation and infection specifically bacterial infections.

### Oedema

Excess fluid in an area of the body which usually causes swelling of the area.

### 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 long term and/or life-threatening illness and their loved ones.

### Parainfluenza Virus

Viruses which cause upper and lower respiratory illnesses in infants, young children, older adults, and people with weakened immune systems.

### Peripherally Inserted Central Catheter (PICC) Line

A long, thin tube that is inserted through a vein in your arm and passed through to the larger veins near your heart.

### Physiology

A branch of biology that studies the normal functions of living organisms.

### Plasma Cell

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

### Platelets

One of the types of blood cells which help to stop bleeding.

### Portacath

An implanted venous access device for frequent/ administration of chemotherapy.

### Prognosis

An indication of how well a patient is expected to respond

# Glossary (cont.)

to treatment based on their individual characteristics at the time of diagnosis or other timepoint in the disease.

## Prophylaxis

Treatment given, or action taken, to prevent disease.

## Radiation

The release of energy in the form of particles or waves.

## Radiation Therapy

Cancer treatment that uses high doses of radiation to kill cancer cells and shrink tumours.

## Red Blood Cells

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

## Respiratory Syncytial Virus (RSV)

A common respiratory virus which is responsible for mild, cold-like symptoms which last for a week or two.

## Sepsis

An infection in the blood that can cause septic shock.

## 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

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

## Toxicity

Harmful effect.

## White Blood Cells

White blood cells are one of the types of cells found in the blood and bone marrow, along with red blood cells and platelets. 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](http://www.leukaemicare.org.uk)**  
**[support@leukaemicare.org.uk](mailto: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](http://www.bloodcancer.org.uk)**

## Cancer Research UK

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

**0808 800 4040**  
**[www.cancerresearchuk.org](http://www.cancerresearchuk.org)**

## Macmillan

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

**0808 808 0000**  
**[www.macmillan.org.uk](http://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](http://www.maggiescentres.org)**

## Citizens Advice Bureau (CAB)

Offers advice on benefits and financial assistance.

**08444 111 444**  
**[www.adviceguide.org.uk](http://www.adviceguide.org.uk)**

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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](http://www.leukaemicare.org.uk)**

**[support@leukaemicare.org.uk](mailto: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