
Living Well with Acute Myeloid Leukaemia (AML)

Leukaemia Care

YOUR Blood Cancer Charity

Please note that this booklet has surpassed its review date.

However, during this unprecedented time, we think it is important to still offer you the information you need. We will have the updated version of this booklet made available as soon as possible.

If you have any medical queries, please call our helpline on 08088 010 444.

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 never have heard of it. This booklet covers a range of topics to help you cope a little better.

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You may experience all of the emotions featured in this booklet, some of them, or maybe none at all. Experiences vary from person to person. 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.

If you would like any information on the sources used for this booklet, please email communications@leukaemiacare.org.uk for a list of references.

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About Leukaemia Care

Leukaemia Care is a national charity dedicated to ensuring that people affected by blood cancer have access to the right information, advice and support.

Our services

Helpline

Our helpline is available 9.00am - 10.00pm on weekdays and 9.30am - 12.30pm on Saturdays. If you need someone to talk to, call **08088 010 444**

Nurse service

We have two trained nurses on hand to answer your questions and offer advice and support, whether it be through emailing **nurse@leukaemicare.org.uk**, over the phone on **08088 010 444** or via LiveChat.

Patient Information Booklets

We have a number of patient information booklets like this available to anyone who has been affected by a blood cancer. A full list of titles – both disease specific and general information titles – can be

found on our website at **www.leukaemicare.org.uk/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**, as well as speak to one of our advisers on our online support

service, LiveChat (9am-5pm weekdays).

Campaigning and Advocacy

Leukaemia Care is involved in campaigning for patient well-being, NHS funding and drug and treatment availability. If you would like an update on any of the work we are currently doing or want to know how to get involved, email **advocacy@leukaemiacare.org.uk**

Patient magazine

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

Changes to appearance and body image

There can be many changes to your body and appearance when you are going through your blood cancer 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 cancer and hair follicles. Hair loss may begin a few days to weeks after starting treatment. Hair loss 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 thinning of hair 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, 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 and ensure your needs and management plans are met in a timely and appropriate way.

The NHS has a provision for wig supply for those who may need them. There are several options available for wigs, which include human hair wigs or synthetic wigs.

You are entitled to a free wig if you a hospital inpatient. For more information, go to the NHS website: www.nhs.uk/NHSEngland/Healthcosts/Pages/Wigsandfabricsupports.aspx



Changes to appearance and body image (cont.)

Alternatively, you may choose to shave off your hair before it starts to fall out rather than waiting for it to fall out on its own, or you may choose to wear head scarves or nothing at all.

Holistic Needs Assessments (HNA):

The Holistic Needs Assessment is seen as a key tool between healthcare professionals. Your clinical nurse specialist will aim to offer you a HNA at different times within the treatment. Each centre has agreed internally when they think it is most appropriate to be carried out. Some departments will offer you a 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 anytime, not only when it is offered to you.

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 of nausea, vomiting or diarrhoea or treatment-related mucositis (sore mouth) and loss of appetite. It is estimated that up to 70% of people receiving high-dose chemotherapy can experience chemotherapy induced nausea and vomiting. Changes in taste sensations can also affect the ability to maintain weight during treatment. These are all factors that can result in eating less and affect your weight. You can expect a fluctuation in weight and can lose an average of 6% of your original weight before starting treatment but will usually find that you recover around the six-month post-treatment mark.

Treatment will always be tailored to your weight. The dose of chemotherapy given to you will be calculated based on your weight. Before starting treatment,

during and after you will always have access to a specialised dietitian that will work with you to improve your eating/drinking and your overall weight. Anybody starting treatment for leukaemia is weighed prior to starting treatment as a matter of protocol. Baseline weight is important because it helps to calculate baseline body mass index (BMI) and because, traditionally, chemotherapy dosages are based according to your body surface area (BSA) or body mass index (BMI). There are some guidelines for approximate dosing for obese adult patients with cancer, however, some studies in AML have found no differences in treatment-related toxicities or outcomes in people with varying body weight. 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 baseline or good weight throughout. These include screening and assessing your weight and nutrition status at

presentation of AML. Daily and/or weekly screenings of you depending on severity of any gastrointestinal symptoms is recommended. If you experience extreme weight loss, you should be referred to a specialist dietician, where appropriate.

Dietary advice also plays an important part in maintaining a good weight. You should be advised on a neutropenic diet (more of which can be read about on page 36), including high calorie and high protein drinks and food. You can also be encouraged to eat whatever you want as and when you can.

Memory and concentration changes

Difficulty in concentration and changes in memory have been reported in people with leukaemia. These cognitive changes have been acknowledged as having a limiting effect on quality of life. There are several factors that can contribute to memory and concentration changes.

Changes to appearance and body image (cont.)

Pain, lack of sleep or difficulty in sleeping, worrying and sadness, have been mentioned as some of the physical and psychological factors that affect concentration and memory changes. Your environment like 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 with changes in memory and concentration during this time. Information on disease, treatment and management as well as a holistic needs assessment (HNA) from the beginning is important. Having this type of routine distress screening at diagnosis can help identify you with 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.

Alternative therapies and psychological interventions like mind-body practice including meditation and mindfulness, have been found to be beneficial for some people. Meditation is said to help with focus, controlled regulation of breathing and control of thoughts over feelings and has been proposed to increase your ability to focus (also known as attentional exercise).

For more information on the benefits of complimentary therapies and mindfulness when living with AML, there are designated chapters later on in the booklet, starting on page 87.

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. Toes and nails may become brittle, change colour, crack or cause 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 treatment is an injection site reaction. An injection site reaction can be anything from a bruise to a large, painful, red welt. Injection site reactions usually go away after several days but it is important to manage them before they cause serious problems like necrosis of the skin.

There are some ways to help

maintain good skin and nail care. Your nurse will do a holistic needs assessment (HNA) from the beginning, 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 and cover up when going in the sun.
- Use gloves when washing dishes.

Physical pain

Pain is multidimensional, but

Changes to appearance and body image (cont.)

physical pain is one of the most commonly reported symptoms in cancer 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 some 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 lack of appetite, fatigue, nausea and psychological distress, as well as chemotherapy related toxicities, such as mucositis and gum disease.

There are different approaches to managing pain. If you experience pain, it can be treated with painkillers.

Other approaches include complementary therapies, psychological interventions like mindfulness, meditation, nerve blocks and TENS (transcutaneous electrical nerve stimulation) used for blocking pain signals from the nerves to the brain. For more information on complementary therapies, go to page 87.

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

If you need any help in dealing with pain, speak to your medical team.

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 60 years of age are known to be at a higher risk of experiencing neuropathy.

Neuropathy is known not to always respond to opioids, however there are other drugs that can be specifically used for neuropathy including gabapentin and other similar formulations.

Mouth care

Sore mouth or mucositis is a common symptom often associated with high dose chemotherapy in patients receiving treatment for AML.

It is recommended to maintain good basic mouth care. This helps promote oral cleanliness, help reduce the risk of infections as well as maintain oral comfort.

Evidence shows that alcohol-based mouthwashes efficacy is similar to a neutral saline mouthwash. If your mouth does not have any sores and you are using a mouthwash to prevent the development of mucositis, a alcohol-based mouthwash can be used. It is worth to note that they can cause your mouth to dry more, but they help maintaining a clean environment.

It is fundamental to keep a good oral hygiene and ensure you brush your teeth after every meal if possible using a soft toothbrush. A saline mouthwash is recommended, is cheap and consists of dissolving one teaspoon of salt in a pint of boiled water. Leave it to cool down, store in the fridge and use during the day after brushing your teeth after every meal.

Patients report that this tends to offer some relief if they have severe mucositis (extensive painful mouth sores). At this stage, we would recommend stopping the alcohol-based mouthwashes as they can cause more pain than relief.

Different hospitals have different mouth-care 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:

Changes to appearance and body image (cont.)

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

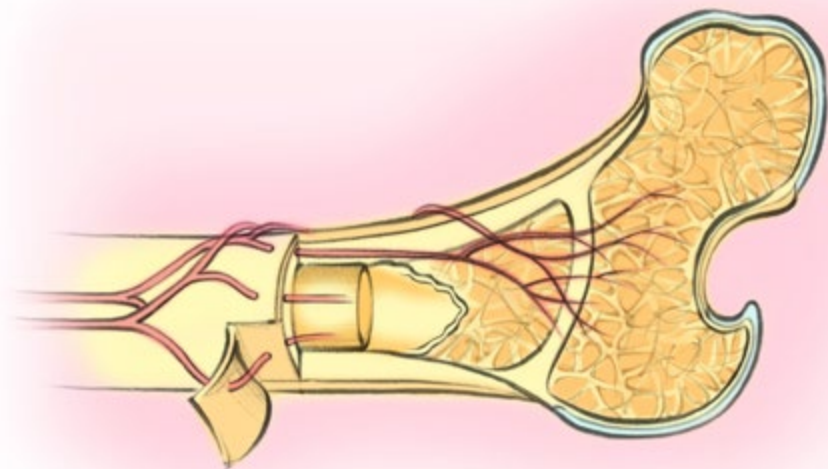
It is important that these two work together to create a balance in your bones. If there are too many osteoclasts your bones become too soft, but if there are too many osteoblasts then your bones may become brittle.

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 AML therapy as there is no standard guidance on it. However, it is something that gets monitored in the aftermath of bone marrow transplantation.

For more information on stem cell transplants, you can order our booklets on autologous and allogeneic stem cell transplants but emailing support@leukaemicare.org.uk or by calling **08088 010 444**.

Alternatively, you can find out more through Anthony Nolan's website: www.anthonynolan.org



Relationships, fertility and sex

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.

Not only hormones interfere in sex life and libido. There are many other factors that influence and interfere in sex life and libido in a permanent or temporary way, including cancer diagnosis and treatment.

At diagnosis

The news of cancer may impact your well-being and create anxiety and fear which may lead to loss of interest in sex and reduced libido. It is important that you communicate your feelings and emotions with your doctor, nurse and partner and not to isolate yourself.

During treatment

Some surgeries and treatments may put you off of having sex and reduce your libido and desire for

sex. If you are feeling this at the moment, that's perfectly normal and a common side effect. There are many ways to express your emotions and feelings.

Remember that your first priority is your health at this particular time, so you may find alternatives to sexual intercourse and ways to express your emotions which are as valuable as sex. It is important to involve your partner along the way.

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 case as they will be able to provide further support.

Contraception

After you start your cancer treatments, your nurse/doctor may advise you to abstain from unprotected sexual relationships. Chemotherapy and radiotherapy affect the cells that produce sperm and eggs and also are toxic for the human body. Avoiding a pregnancy while on treatment is important and you should seek medical advice on this matter before you decide to naturally conceive.

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.

As previously mentioned, there are no contraindications on having sex while on treatment. It is important to use contraception during and up to 2 weeks after treatment as chemotherapy can be excreted through any body fluids. There isn't a right time after completing treatment to have a baby. This will be much dependent on the type of treatment that you had.

Unfortunately after receiving high-dose chemotherapy it is common for patients to struggle to conceive. Overall, we would recommend to wait 6 months to a year after stopping all medications. If you are likely to remain on life-long medication, please talk to your doctor/nurse specialist when you start planning a family.

Pregnancy and breastfeeding

Research studies show that cancer during pregnancy is relatively rare. Depending on the stage of the pregnancy when the diagnosis is disclosed, the way a pregnant woman with a diagnosis of acute leukaemia is treated will vary. Every case is different and the whole team is involved as well as you and your partner. It is important that you seek information and ask all the questions you want. Decisions may need to be made so it is important that you and your partner are comfortable with the explanation obtained as well as feeling confident enough to make

Relationships, fertility and sex (cont.)

the decisions leading up to the due date.

Experts tell us that starting treatment with chemotherapy during the first trimester of pregnancy is avoided due to the high levels of toxicity of chemotherapy agents and the potential to cause high genetic anomalies to the baby.

Following this period, and after 14 weeks of pregnancy, experts have said that chemotherapy can be given to women with acute leukaemia. Doctors will explain the treatment and its side effects. Pregnancy and chemotherapy can be exhausting so it is important that you also rest and take time for yourself.

If you are diagnosed with acute leukaemia and you are in the last weeks of pregnancy, your doctors will discuss your treatment with you. This period of pregnancy and the decision to start treatment before or after the delivery has to be considered. Seek advice from your consultant and medical

team.

Breastfeeding

Milk is produced in the woman's breast, released through the mammary ducts and expelled by the nipples. Whether or not you can breastfeed your baby will depend on the treatment regime you are on. Other clinical situations may impose a challenge in the decision to breastfeed, so seek medical opinion from your nurses, midwives and your doctors.

Regardless of your chemotherapy treatment, once the baby is born, milk will be produced and if it's not expressed, may cause complications. Regardless of the decision to breastfeed, consider expressing, even if you cannot use it to feed your baby to try and alleviate any pain you may be experiencing.

Breastfeeding is also a personal experience, and sometimes can be painful or, in some situations, if there is not enough milk in the breast, anxiety takes over. Discuss

with your midwife and seek help if you are finding breastfeeding difficult.

In the case of acute leukaemia diagnosis and chemotherapy treatment:

- If your chemotherapy has ceased weeks before your baby is born, there will be no problem in breastfeeding.
- If you still need to have chemotherapy after your baby was born you will be advised not to breastfeed. There is a risk that your milk can be contaminated with chemotherapy. This imposes a risk to the baby, and you shouldn't breastfeed.
- If your chemotherapy treatment finishes in the meantime, you can re-initiate breastfeeding again.

Fertility after AML

When facing a diagnosis of leukaemia the priority is survivorship.

As a part of treatment, 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 is the case of testicular cells (responsible for producing sperm) and ovarian cells (that produce eggs). As a result, both men and women are at risk of permanent or temporary infertility when they undergo this type of treatment. Other types of treatment, like pelvic radiotherapy and pelvic surgery may affect fertility directly.

In the UK, there are some restrictions to all types of fertility treatments. Funding for fertility treatments, under the NHS, has several rules so it is important to seek guidance. As soon as possible, you should seek information from both your oncologist and fertility specialists in order to make informed decisions about fertility and the next steps you should take.

Relationships, fertility and sex (cont.)

One of the options is to cryopreserve (freeze) your gametes (eggs and sperm) before you undergo cancer treatment. This will put your mind at ease, and give you an opportunity to have biological children, in case your fertility hasn't recovered after treatment. However, sometimes you need to speed up your cancer treatment, meaning that it may not be possible to get fertility preservation beforehand.

Due to AML being acute, treatment normally starts relatively quickly after diagnosis, so speak to your medical team about timeframes if you are wanting to freeze your sperm or eggs.

You should take all opportunities to discuss treatment and make a shared decision with your doctor and your partner about cancer treatment, chances about fertility in the future and fertility preservation.

Women and infertility

Women are born with all the eggs they will ever have. After puberty, one egg is released which then

travels from the ovary through fallopian tubes until it reaches the uterus. If this egg is not fertilised by a sperm, the pregnancy will not occur. Ovarian reserve is the term used to describe the remaining egg supply of the ovaries.

When you are diagnosed with leukaemia, your fertility may be at risk, due to cancer treatments, but there are options available that can still allow you to have children.

Egg freezing

Due to a technique called vitrification, eggs can now be frozen in liquid nitrogen in order to be used later. It is important to note that there is a reduction in the success of egg freezing in women above the age of 35. For any questions about this procedure, you should seek advice from your doctor.

If you are able to freeze your eggs before starting treatment, you will follow the standard form of fertility preservation for women.

On the day of the procedure, you will go to theatre and be put under

light sedation, and with the help of a scanner and a fine needle, your eggs will be extracted from the ovary, treated in the laboratory and then will be frozen. Before egg collection, some injections of hormones may be given (to stimulate your ovary to mature more eggs than usual) as well as blood tests and ovary scans.

There are alternatives, but some are still in early stages, so seek information from your doctor about what your other options might be.

Men and infertility

Chemotherapy directly affects the cells responsible for producing sperm. Therefore, before undergoing cancer treatment, you should freeze your sperm as this gives you the option of fathering a biological child in the future. Depending on age, strengths of chemotherapy etc, you may, or may not recover your fertility after treatment.

You should seek referral to an Andrology Department in order to freeze your sperm.

On your arrival, you will need some blood count results and a referral from your oncologist. You will be asked to produce a fresh sample that will then be analysed and frozen (cryopreserved) in liquid nitrogen. You will also be asked to fill in some consent forms that are a legal requirement. You can store your samples up to a maximum of 55 years.

In the event that you haven't recovered your fertility, but you are planning to start your family, you can then transfer your frozen sperm to an IVF clinic for your partner.

For more information about sperm storage go to the HFEA (Human Fertilisation and Embryology Act) website at www.hfea.gov.uk

How to cope with infertility post treatment

The uncertainty about your fertility status may be daunting and concern you. Different people will react in different ways and cope differently to infertility.

Relationships, fertility and sex (cont.)

You should check your fertility status as soon as possible. This will empower you to make decisions in the future regarding starting a family, and to make the necessary arrangements.

Before you think of which options to take into consideration, you can 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 and help you to make informed decisions about the future. 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 expose their concerns, bring them to your consultations. This way you and your partner could go through the difficulties together with the support of a medical professional.

If you are infertile and you have frozen eggs or sperm before chemotherapy treatment, you may seek referral to an IVF clinic.

Some fertility clinics offer couples dealing with fertility issues to have a baby through different means. The techniques are:

- **IVF (In-vitro fertilization)**
- when sperm and eggs are placed close to one another, allowing the sperm to swim and fertilise the egg.
- **ICSI (Intra cytoplasmic injection)** - where under the microscope, the embryologist manually inserts the sperm into the egg fertilising it.

The techniques are done in a laboratory environment and they aim to create embryos outside of the human body. The embryo now created can be implanted into the woman's womb in order to start a pregnancy.

If you were looking to try and obtain some NHS funding for the procedure, the first step is to find out what your Clinical Commission Group's (CCG) fertility policy is before getting a referral from your GP to a fertility clinic. The policies for each CCG can be found on the Fertility Fairness website at:

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 any fertility treatment and, generally speaking, egg and sperm donation is not available on the NHS.

If you haven't frozen your gametes (sperm or eggs), you could be refused treatment, or you may be told that you have to cover the costs of the gamete donation part but hopefully secure funding for the procedure.

For leukaemia patients they would need to appeal or submit an Individual Funding Request supported by their GP and any oncology specialists. Sometimes, if there is no funding for fertility treatment in the area, cancer patients can secure money from Oncology Commissioning for fertility treatment.

If you have any questions about NHS funding for fertility treatment or would like some advice or emotional support, information can be found at

fertilitynetworkuk.org

Adoption is also an alternative when all the above options are not possible.

Changes in relationships

Following the news of a cancer diagnosis, the impact can vary from person to person as well as in their partners and family. You should seek as much information as possible about your treatment as well as other factors. This will empower you to make the best decisions regarding your future.

Depending on the cancer, treatment and duration of chemotherapy, there will be a period when you will suffer from some physical symptoms. Cancer and treatment can make you feel physically ill, cause you pain, make you tired, decrease your libido, and cause all sorts of emotional stages. You may feel weak, unattractive, afraid, and that your body is different because of the side effects of chemotherapy or based on the fact that you are losing weight.

Relationships, fertility and sex (cont.)

Changes in your body can affect your self-esteem and your sense of feeling desired. Sex can become the thing that you don't want to do, or something that you don't want to talk about.

There will be some changes in your life, when you are attending the hospital/clinics for your treatments, so it is important that you include close family and your partner in the process to help them understand what you are going through. This will give them the opportunity to be involved and be aware of the decisions that are being made.

An honest and frontal discussion is important. You may have loads of thoughts coming through your head about the disease, future and relationships. It is okay to feel confused and sometimes to feel 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 to have surgery for

any reason, this also may have an impact in your body and this may also affect you, as well as potentially affect your sexual life. You should discuss it with your clinician about the impact the surgery may have on you. Bring your partner to the consultation so they can ask questions. The more information you gather, the better you can make decisions and/or inform your partner.

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



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 way 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 as feeling like being on an emotional rollercoaster ride because of the range of emotions at different times. From the shock of being told about the diagnosis, facing the challenges of going through treatment and to 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 very 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 feel 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 are struggling with physical weakness and fatigue.

Anger makes us feel uncomfortable. Some of us shout and stomp around 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 on to 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 loud music, doing something physical or put 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 of

things. 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.

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 '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. But when your counts

Emotional impact of AML

(cont.)

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. It can feel disconcerting to be on your own and not to have the same reassurance and support on hand after treatment finishes. 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 pine for the life that you had before the illness, and for the hopes and plans that have been put on hold for now, due to the loss of control over your life you feel going through treatment. 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.

Feeling low from time to time is normal and these feelings 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, 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
- Difficulty getting to sleep or waking up very early
- Having thoughts of 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. 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

Emotional impact of AML

(cont.)

thoughts or feelings, you can call the Samaritan 24-hour helpline on **116 123**

www.mind.org.uk and www.nhs.uk have further information and links to support.

Anxiety and worrying about your health

AML brings with it the challenge of living with uncertainty. What will happen to me? Will the treatment work? Will the AML 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 uses adrenaline to tell the body to run away from or to fight a danger and this is called the 'fight-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 like illness in the same way. Because we can't physically run away (although we may feel like it), those same fight-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 focused on the threat, and with it comes a racing heart, tight chest and tense muscles. When we feel constantly stressed 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, perhaps to try and prepare ourselves if the worst happens. Worry can be useful when it helps us to take action to sort out a difficult problem. But more often, these 'What if ...' thoughts or images focus on things that could go wrong in the future. All that worry does is keep our

attention focused on the threat and this keeps the anxiety going. It's helpful to remember that our brain is responding to the threat of something that may happen in the future. It hasn't happened yet and it may never happen.

When we are faced with a threat like AML, our alarm system can become a bit too sensitive and lots of things can trigger our anxiety and keep it going. We are always on the look-out for threats. Each pain, niggle, clinic appointment or wait for test results can set off fearful thoughts about your health. This is normal and gradually eases as you get further from treatment. Your consultant and specialist nurse will be able to guide you about any physical symptoms that you need to watch out for.

If you notice that you are constantly checking, seeking reassurance or you avoid doing things, it may be a sign that 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/Conditions/stress-anxiety-depression/Pages/low-mood-stress-anxiety.aspx

Managing Stress

You cannot remove the stress of AML completely but there are some things that 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 54.
- Relaxation and breathing exercises can help to calm the mind and release muscle

Emotional impact of AML

(cont.)

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 or thoughts down on paper can make them feel less overwhelming. When we hear ourselves out loud, we are more able to rationalise and put worries into perspective. We can ask: "Is this a problem that I can do something about or is this an uncertainty that may never happen? Am I concentrating on negative fears for the future at the expense of hope and enjoying life again today?"
- 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. We are observers of our thoughts and feelings, allowing them to come and go without getting caught up in them. When we bring our attention into the present moment rather than our imagined future, we realise that we are coping, and getting on with life the best we can. If you have experienced trauma in the past, mindfulness may not be helpful and so seek advice. For more information go to the mindfulness chapter of this booklet on page 98.

- 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 87.
- Talking therapies such as 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 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 79.

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 to you. You may have gone through treatment with the goal of getting your life 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 an extraordinary experience and it may seem hard to imagine life ever feeling

Emotional impact of AML (cont.)

ordinary again. You might miss the support from the doctors and nurses at the hospital. Some people say they feel a bit abandoned as they see their hospital team less frequently than before. If you have had a transplant, your recovery may be taking much longer than you hoped and this can be disheartening. It helps to set small and achievable goals.

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. The impact of AML is not something that can be forgotten or left behind but needs to be incorporated into your life story. This is a process that takes as long as it takes and can't be rushed, no matter how impatient you feel to leave the illness behind.

Some of your relationships may feel stronger whereas other relationships have changed.

Perhaps you have discovered that you or those around you are more resilient than you ever imagined.

Your life may have a very different outlook 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 because of AML into your new view of yourself and your life.



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 blood cancer your immune system can be affected, lowering your ability to fight any potential infections. It is therefore important that you have information that will help you, or someone you care for, to stay as well as possible throughout their treatment.

What is neutropenia?

Treatment for all types of cancer acts to 'kill off' the harmful tumour cells in the body, and in doing so the treatment can also destroy healthy cells. When this happens with blood cancers, the protective white cells in our body (called neutrophils) which naturally fight infection, are reduced by both the disease and by the treatments.

Neutropenia occurs when the level of neutrophils falls below a certain level as a result of your illness. As your neutrophils are much lower than normal you

are at greater risk of infection, including foodborne infections and food poisoning, and so one of the measures to prevent this is to ensure scrupulous food hygiene.

As well as reducing the levels of neutrophils causing neutropenia, cancer treatments can affect your food intake. Common side effects include nausea and/or vomiting, diarrhoea, weight changes, sore mouth, loss of appetite and swallowing difficulties.

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 healthy eating 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.

However, just knowing what makes up a well-balanced diet can lead to confusion. The Government's Eatwell Guide shows that you should try to eat foods from all food groups every day and in the following proportions.

Try to have as many different food stuffs from all food groups as this will ensure you get all your necessary nutrients for good health.

Carbohydrates

These foods are often considered unhealthy. This is not true and you should try to have some starchy carbohydrate at each main meal like porridge, cereals, potato, pasta, rice or couscous. These foods should make up at least a third of what you eat. 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 vegetable a day. This can be all kinds of fruit or vegetables: fresh, frozen, canned, dried or as juice or smoothies. Smoothies made with frozen fruit and added milk can make a high energy drink and particularly helpful if your appetite is poor. Fruit and vegetables will also provide dietary fibre which helps regulate your bowels and prevent constipation which can be a side effect with your treatment.

Dairy foods

Milk, cheese and yoghurt are good sources of protein and calcium in the diet. 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.

Diet (cont.)

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

The last very small group is for 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 most important nutrient way to regain lost weight through illness is by

increasing protein and overall energy intake.

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

In summary, the nutrients each food group provides are:

- **Bread and cereals** - provide energy, B-vitamins, iron and folic acid and dietary fibre.
- **Fruit and vegetables** - provide vitamins A, C and E, folic acid dietary fibre and potassium.
- **Fish, eggs, Quorn, nuts, soya** - provide protein, iron, B vitamin thiamine and B12, zinc.
- **Milk and dairy products** - provide protein, Calcium, B vitamins riboflavin and B12.
- **Fats, oils and spreads** - provide energy, essential fatty acids and

fat-soluble vitamins ADE and K.

What you need to be careful of

Treatment for most types of blood cancers 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, and 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 cows' milk, sheep and goats 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 yogurts and drinks containing prebiotics and probiotics.

Honey

Honey naturally contains yeasts and spore-forming bacteria. Despite its antibacterial properties, it is recommended that honey from the following sources is avoided during your treatment: raw honey, fresh honey comb, unpasteurised honey or strained honey. Pasteurised

Diet (cont.)

or filtered honey removes fine particles of dust, pollen or nectar and is fine to use. Where possible, use small jars or 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 made at home with fresh fruit as it cannot be guaranteed that the bacteria has gone.

Cooking

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

Do not reheat foods where possible and 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.

The one food you must not reheat is boiled rice. Cook, serve hot and eat immediately.

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 < 2.0 x 10⁹/litre*

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

*British Dietetic Association 2016

Further food safety advice where neutrophil counts $< 0.5 \times 10^9$ /litre*

Avoid	Alternatives
<ul style="list-style-type: none"> Raw unpeeled fruit or vegetables including salad items, stuffed vine leaves, fetoosh and taboulleh Raw dried fruit, products containing these Damaged or over-ripe fruit or vegetables Unpasteurised or freshly squeezed fruit or vegetable juice or smoothies 	<ul style="list-style-type: none"> Good quality fruit and vegetables that are well cooked or peeled UHT or long-life fruit juices - in cartons or jars Pasteurised smoothies, canned fruit Cooked dried fruit e.g. in fruitcake, flapjacks or cereal bars
<ul style="list-style-type: none"> Fresh nuts, nuts in shells 	<ul style="list-style-type: none"> Cooked nuts, nuts in cans, peanut butter, roasted nuts
<ul style="list-style-type: none"> Uncooked herbs, spices and pepper 	<ul style="list-style-type: none"> Cooked herbs, spices and pepper
<ul style="list-style-type: none"> Cold smoked salmon 	<ul style="list-style-type: none"> Cooked dishes containing smoked salmon
<ul style="list-style-type: none"> Non-drinking water, bottled mineral or spring water, water from wells, water from coolers, domestic water filters and water fountains 	<ul style="list-style-type: none"> Freshly run tap, carbonated water Please check with your hospital for any local guidance
<ul style="list-style-type: none"> Ice when away from home e.g. in a restaurant 	<ul style="list-style-type: none"> Ice made from appropriate water sources
<ul style="list-style-type: none"> Ice cream from ice cream vans 	<ul style="list-style-type: none"> Ice cream from reputable sources, individual portions, wrapped, small pots
<ul style="list-style-type: none"> Unpasteurised or 'farm fresh' honey and honeycomb 	<ul style="list-style-type: none"> Pasteurised or heat-treated honey Ideally try to use individual sachets or portions
<ul style="list-style-type: none"> Unnecessarily large packets of food items from pick and mix, universal jars Deli counter foods e.g. olives, houmous, shawarma and baklava 	<ul style="list-style-type: none"> Ideally, packets should be individual portions

*British Dietetic Association 2016

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 and stay away from the kitchen if possible. Also fried, highly flavoured or fatty 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 nausea is so bad that it prevents you from eating and you are losing weight, anti-sickness medication can be prescribed alongside your treatment drugs to enable you to eat and feel better.

Sore Mouth

A sore and/or very dry mouth can be the side effect of medication or treatment 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 home-made 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 special mouth wash or be advised to use pain relief to allow you to eat comfortably.

Poor Appetite

If you have a poor appetite the thought of preparing and then eating a meal or snack can be difficult. Often the sight of a large amount of food is off-putting and so you can quickly find yourself in a situation where you are eating less and less every day. First of all, allow others to help if they offer. Someone else taking the decision of what to prepare means you do not have to think of it and when you get the meal you may find that you can manage a small amount after all. Also, 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

Diet (cont.)

to have two puddings than no lunch at all. Also, to make sure every mouthful counts do not routinely use low fat, low sugar foods and add extra spread, grated cheese, cream or preserves to help you increase calorie value of foods.

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, plenty of fruit and vegetables (but do not overdo) and fluids are key to managing both diarrhoea and constipation.

Also, 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?

On a large population basis if scientists look at disease and dietary intake, there are links

between dietary patterns in population and disease incidence. However, it is important that you do not follow any unnecessarily restrictive and limiting 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.

Another dietary consideration often asked about is the use of dietary supplements in the form of over the counter vitamins or minerals. There is no evidence that these components, that are normally required in very small amounts, will convey any additional benefit in the treatment of blood cancers. 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.



Infection control

Patients with acute myeloid leukaemia (AML) are at high risk of developing infections. This is because both the disease itself and the chemotherapy used to treat it suppress the bone marrow's ability to produce immune cells normally responsible for fighting off infection. Most importantly, leukaemia and chemotherapy can cause long periods of neutropenia. This is when there is a low level of neutrophils, the white blood cell primarily responsible for fighting off bacterial infections. Patients who have received intensive chemotherapy or have had bone marrow transplants are at 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 bugs 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 blood stream and cause

severe infections. Viruses, such as herpes virus and the chicken pox virus, which remain in the body in an inactive state, can be re-activated when the immune system is suppressed.

How will I know I have an infection?

Sometimes patients with AML develop similar warning signs to healthy patients such as runny nose, cough, stinging on passing urine, diarrhoea and vomiting which can indicate an infection. Sometimes, however, because patients with AML do not mount the same inflammatory reaction of their immune system to infection, the only indication that they have an infection is a fever. A fever may be defined in slightly different ways in different hospitals, 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, 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 often an effective treatment for the majority of these infections which could otherwise be fatal. Receiving antibiotics quickly in this scenario has been shown to improve survival. The time it takes to be receiving antibiotics is sometimes called the door-to-needle time and government targets say that this should be less than 60 minutes. 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.

How will doctors work out which treatments to give me?

You will receive a number of

investigations to try and work out where the infection is coming from as this can help guide which antibiotics to give, these can include:

- Blood culture tests
- Looking for bacteria in the blood stream
- Chest X-rays
- Urine culture test
- A stool culture
- Swabs of any open wounds

If you have a Hickman, PICC line or Portacath, blood cultures will also be taken from this.

If no abnormalities are found on these investigations, it does not necessarily mean that you don't have an infection. This just means that it can't be proved where it is coming from. In this case, you will be given broad spectrum antibiotics which cover a wide range of different types of bacteria. 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.

Infection control (cont.)

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 antibiotics or to add other treatments in. There are a number of reasons why 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 viruses 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 had prolonged neutropenia. AML patients are now standardly given anti-fungal prophylaxis (preventative treatment). 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 CT scan of the chest, which shows more detail than a chest x-ray (CXR), is often helpful in diagnosing them. There are a number of anti-fungal drugs, both oral and intravenous, that are effective in treating such infections. 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 show the same seasonal peak as in the general population. Some viruses, respiratory

syncytial virus (RSV) and para-influenza virus for example, are spread through direct contact while other viruses, like influenza and adenoviruses, are spread through air-born 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 treatment can be given to shorten the duration and severity of symptoms. Sometimes these treatments can also be given if a family member or close contact is known to have been infected to try and prevent the infection from developing.

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 virus has 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 people with VZV infection, an AML patient's immunity to this virus should be checked through a blood test. Previous infection does not guarantee immunity as chemotherapy can cause this to be lost.

What will my doctor do to try and prevent me from getting an infection?

AML patients will receive a number of 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 to reduce the risk of anti-fungal infections. Preventative antibiotics may also be given, although this practice varies between hospitals as it is of uncertain benefit. The potential reduction in the risk of infection

Infection control (cont.)

needs to be balanced against the risk of causing antibiotic resistant infections.

All care-givers and visitors should follow strict hand hygiene, sanitising or washing their hands each time they enter the patient's bed-space. This is very important as it has been shown to significantly reduce the transmission of infection. While you are neutropenic, many hospitals will advise precautions that 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 care-givers and visitors may need to wear masks.

While you are in hospital you will be in an isolation room, often with an ante-chamber, and sometimes with an air filter or positive pressure to minimise the risk of getting an infection from other patients on the ward.

What precautions can I take to reduce the risk of getting an infection?

Most AML patients do get an infection while they are

undergoing intensive induction chemotherapy and in the neutropenic period prior to recovery of their blood counts. This is because many infections come from organisms that normally live harmlessly in our bodies. However, a number of precautions may reduce this risk including:

1. Following a neutropenic diet (more of which can be read about in the diet chapter of this booklet, on page 36):
 - People preparing food for an AML patient should observe strict hand hygiene.
 - All meat and fish should be fresh and cooked through. Rare meat should be avoided.
 - Fruit and vegetables should be washed carefully and well cooked. Uncooked fruits and vegetables should be avoided. Fruit that can be peeled, for example oranges and bananas, are an exception.
 - Unpasteurised cheese and tinned meat should be avoided.
 - Prepared food should not be left to cool and then re-heated in a microwave.

2. Plants and dried or fresh flowers should not be brought into the hospital rooms of neutropenic AML patients.
3. AML patients should try and minimise contact with relatives who have a suspected infection.
4. AML patients who are neutropenic should avoid crowded spaces, such as hospital canteens, GP surgeries, supermarkets and shopping centres. 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 incapable of causing an infection).

Live vaccines should not be given while patients are neutropenic or undergoing chemotherapy.

Live vaccines, such as measles, mumps, 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, is in remission and is no longer neutropenic. 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 and do not undergo bone marrow transplant generally do not need to be revaccinated against infections they have previously been 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 increased risk of bleeding. This may present as bleeding from mucosal membranes for example, nose bleeds, gum bleeding or mouth blisters, or as bleeding into the skin, often causing small purple spots on the legs. Women of child-bearing age may get heavy or prolonged periods. More rarely, it can be presented as more serious bleeding, such as a bleed into the brain, which may occur spontaneously or as a result of trauma, coughing up blood or bleeding from the gut.

The most common reason for AML patients to bleed is low platelets. Platelets are small fragments of cells in the blood that prevent uncontrolled bleeding and that are produced in the bone marrow. Both AML and chemotherapy reduce the number of platelets by suppressing the bone marrow. Excess bleeding does not normally occur until the platelet count is really quite low. Based on previous trials of preventing bleeding in AML

patients, platelet transfusions are usually given when the platelet count falls below 10 or below 20 if the patient has a severe infection.

In some cases of AML, most notably a subtype of AML called acute promyelocytic leukemia (APML or APL), bleeding may occur not only as a result of low platelet numbers but also due to a condition known as Disseminated Intravascular Coagulation (DIC). In DIC, clotting factors in the blood are used up. As a result, patients may need to receive fresh frozen plasma and cryoprecipitate to try and compensate for these 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?

There is a huge amount of research and information available on the benefits of exercising with cancer. However, many people still feel unsure how this can help especially when you are going through treatment, feeling very unwell and tired.

You need to remember everyone is different. Treatment is specifically tailored to each individual and this should be the same with exercise. Side effects, coping mechanisms and general wellbeing effects are not the same for everyone and what works for one person isn't necessarily going to work for you.

A good exercise programme can help to improve many cancer or treatment-related side effects.

Exercise is medicine, wonderful for our physical and emotional health. It is one thing you can do for yourself, which is very empowering. It can be carried out before, during and after treatment but you need to be mindful of how

you are feeling.

It is possible that exercise lowers the risk of cancer relapse, although, whether it can prevent the recurrence of leukaemia or any other type of blood cancer is still unknown. Keeping your fitness up after treatment can reduce longer term risks such as heart disease which may be associated with some treatments. It can also increase the likelihood that you are fit enough for optimum treatment in the future, should your cancer return.

When thinking about exercising it is always good to speak to someone from your medical team to keep them informed as they may 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 due to low blood count and some treatments may put you at a higher 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 aerobic fitness and muscle strength. Exercise can help to decrease bone pain, improve sleep and appetite. If your weight has increased, gentle exercise may not stop you putting weight on but it can help in reducing the amount gained.

During treatment, there can be muscle wastage which impacts on your muscle to fat ratio. As your fat increases, your muscle mass depletes. However, by exercising, you can try and reduce this wastage and start to control the weight increase. If the amount of lean muscle mass lost has been very significant, it's best to begin with strengthening exercises first, then build up to some aerobic exercise. For more information on suitable exercises, your doctor can refer you to seek advice from an exercise specialist or physio.

Exercise can also have significant

improvement on your wellbeing and quality of life, helping to relieve stress related to the disease and treatment.

What sort of exercise is recommended?

You need to ensure you choose something you enjoy which is also appropriate for your age and circumstance. There is no point doing something you have no interest in as most people find it hard enough getting motivated to exercise in the first place. If you don't want to do it, without taking into account other factors that could come into the equation, you are likely to struggle.

You need to be aware of any side effects which may affect your choice. For example, if you have trouble with your balance or you have altered sensation in your hands and feet but want to walk, you could take some walking poles or go with a friend. Your physiotherapist or exercise instructor could also provide you with a seated programme and work with any restrictions you may have. Light strength work can include equipment such as therabands. These are cheap, transportable and ideal for use at home.

Exercise (cont.)

If your cancer has affected your bones you need to ensure you choose low impact exercise to avoid putting more pressure on your joints, or risk of fracture if the bones are frail, but at the same time still strengthening your heart and lungs, such as cycling or using a cross trainer. It is best to avoid impact sports and lifting heavy weights and ensure you wear supportive shoes and loose, comfortable clothing.

Going through treatment is a worrying time but it is good to try and exercise gently. A lot will depend on your type of treatment and your current fitness level. You need to be aware of picking up infections so gyms and swimming pools are not always the best options.

Always ensure you are sensible and listen to your body. Those who are already active should not look at increasing your fitness level if still on treatment, but focus on maintaining what you have. Your fitness may drop but don't be discouraged, the fact that you are managing to still exercise is a great achievement. If you have

never done exercise, it is still a good idea to try and do some gentle activity and walking or a home programme is usually the best prescription.

Walking enables you to go at your own pace and distance. The key is to keep it gentle and easy so you can do little and often, even if it's a walk to the end of the garden.

Treatment can be tiring and some days you may struggle to get out of bed and feel completely exhausted. On these days, keep positive, rest and when you feel better try to do a small amount of exercise. People who are exercise driven or determined to make a change need to be cautious. Pushing yourself on the days when you feel better can have a negative effect. Hard exercise could end up being too much and result in you spending the next few days completely exhausted, resulting in no exercise and leading to a negative effect. By being sensible, it means you can exercise the next day or every other day which results in you having more active days. You need to feel energised not wiped out.

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.

Things to consider:

- Exercise when energy levels are at their best.
- 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.

Consult with a nutritionist (your doctor should be able to refer you to one, where appropriate) to address weight loss and focus on gentle strength exercises to improve muscle mass. It is important that you seek out tailored advice on what is appropriate for you as your personal experience can affect what exercises would be best.

Once treatment has finished and you are feeling better, you can start looking at increasing your activity level by basing your starting point on what you have currently been doing. If you were unable to do any activity during treatment now is the time to look at what you can do.

The guidelines for staying healthy are 150 mins of moderate aerobic activity a week plus two or more strength days. Moderate means getting slightly out of breath such as a brisk walk or cycling. You can still have a conversation but you are aware of your increased rate of breathing and are feeling warm. This can be broken down into smaller bouts of exercise to suit you. For example, six lots of five minutes may seem more achievable to begin with, before slowly building up to the 30 minutes for one day.

Strength and resistance days are where you work your main muscle groups: legs, back, chest, hips, abdomen, shoulders and arms. Try to do this two to three times per week, ideally not on consecutive days. Improving muscular strength and stamina can help to improve your quality of life by making day to day activities easier and more enjoyable.

Exercise (cont.)

Gaining strength can also reduce the chance of injury and empower you both physically and mentally.

While diet is often the most critical factor for weight loss, we cannot forget that the loss of lean muscle mass contributes towards this very significantly. When we don't use our muscles, we simply lose them.

For some people, this is far more than they have ever done or are capable of, so keep your goals achievable and realistic. There is no point setting the targets too high, keep them small so you are more likely to succeed and it will be much easier, more positive and you can then look at your next step to take your fitness further.

Lifestyle plays a huge role in what we can do and there are many barriers which may need to be looked at. Not just side effects but motivation, finances, time, lifestyle, risk and fear. Exercising with a friend can help and there are lots of ways to exercise which are free, not just walking and cycling. Some local borough councils have set up exercise groups that are friendly,

convenient and free of charge. Local exercise classes are a great way of meeting new people and can provide the support you need and give you some confidence. If you prefer to exercise at home, there are a number of workout DVDs and home exercise programmes available.

Cancer charities and some centres often run classes specifically for those on and off treatment. This environment can feel safe and supportive for patients and far less daunting.

Exercise can be daunting and walking is a good way to start. You can tailor it specifically to your needs in time, intensity and when it is convenient for you. Pedometers are a great way to increase your daily activity and can be picked up cheaply, or there are numerous phone apps which can help. It doesn't matter how many steps you do a day, whether it's a few hundred or more, you can build on this.

Try and aim to be consistent with your efforts by doing something every day. When energy levels are very low, perform some

stretches or practice deep breathing techniques or balance movements.

Active Daily Living (ADL)

ADL is another great way to increase your fitness, these are jobs or tasks you naturally do 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 built into your daily routine.

Jobs at home which get your heart rate up all count. These can include:

- Getting off the bus or tube a stop earlier
- Taking the stairs instead of the lift
- Iron a couple of items, putting them away, coming back and repeating
- Parking at the back of the supermarket car park
- Gardening

There are lots of things you can do. The aim is to get you thinking about little changes and then these little changes can then lead

onto bigger ones. Progressing slowly ensures you are being realistic and allows you to plan achievable goals which you can build on.

Before embarking on your chosen activity, you need to ensure you have an adequate warm up which can be incorporated into your exercise. It is important to start off gently and gradually increase your range of movement and to get your body warmer and to slowly build up your heart rate. For the cool down, bring the heart rate down slowly by gradually decreasing the intensity/speed of your exercise and not stopping immediately. If you have a slow progressive warm up you may decide not to include stretches. However, it is really important to remember to stretch the muscles you have used after exercise. If you are unsure of which stretches to do or how to do them, speak to a physiotherapist or fitness advisor. Any areas of reduced flexibility should be worked on daily, ensuring you are gentle and work slowly without over stretching. Whilst there is no research to suggest yoga and tai chi can help prevent or treat cancer, some people find it makes them feel emotionally

Exercise (cont.)

and physically better and can help with strength and range of movement.

Once you have established your exercise routine ensure you build on it gradually. Increase the time before intensity until you are doing at least 20-30 minutes of moderate intensity exercise a few times a week before making it harder. Strength work which involves repetitions should be done moderately, working towards three sets of 12-15 repetitions (resting between each set). Ensure you can complete one set before continuing to two and then three sets and only then increase the weight.

Exercise is important for those receiving palliative care. Systematic reviews have shown exercise is feasible with important benefits in physical function, symptoms and quality of life. There can be improvement in fitness, functional ability, emotional wellbeing as well as symptoms such as fatigue, dyspnea and anorexia. Quality of life can be helped by keeping you independent and able to carry out everyday tasks which

are important to you. Depending where you are on your pathway, there are different options available. Keep in mind what would work best for you and speak to the team around you who can give you the help and support needed.

Once you have decided what you would like to do, you need to ensure you stay safe. If you are going through treatment and experience extreme fatigue, have a low blood count or are anaemic, you should not exercise. If you are unsure, your medical team will be able to advise you on this. After treatment, if you are experiencing extreme fatigue, balance problems, aching, heaviness, swelling, dizziness, shortness of breath for no reason, sharp pain in a specific area you should not exercise and seek help from your GP/medical team.



Fatigue

Fatigue is one of the most common consequences of cancer and related treatments. Its cause, however, is not yet fully understood. Cancer-related fatigue is thought to affect the majority of people who have had a cancer episode 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 cancer-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 invasive in that it affects them both physically and cognitively. This means that it is different to the tiredness you might usually have experienced prior to becoming ill or as a consequence of doing something pleasurable.

It is common for patients to sometimes find it difficult to

adequately explain how cancer-related fatigue actually feels due to its invasive, fluctuating and troublesome nature.

How long does it last?

There are no hard and fast rules for how long cancer-related fatigue will last. Some people report feeling increasingly fatigued in the months leading up to being diagnosed with cancer. Many patients expect to feel fatigued following diagnosis and during active treatments such as chemotherapy as they can exacerbate fatigue. However, as diagnosis and treatments improve we are beginning to learn that people living with and beyond cancer may experience significant fatigue which interferes with day to day life for several months and, in some instances, for years. The good news is that, over time, cancer-related fatigue may subside and a lot of 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?

Your cancer episode and associated fatigue can negatively

impact on all aspects of your day to day life. This may include disruption to your usual and taken for granted activities such as personal care, including showering and dressing; leisure and social activities, such as keeping fit or going out with family and friends; and others may experience disruption to 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 purposes. 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 do everything you need, want and have to do 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 cancer-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.

You may also have worries over the expectations others may have of you in terms of pre-illness roles, responsibilities and involvement in day to day activities and events. As cancer-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. This may cause you to experience some feelings of frustration, anger or guilt if you are currently unable to do everything you normally do, or what others expect from you. For some, feelings of anxiety and a sense of sadness may lead to distress and low mood which can be difficult to cope with alone.

Relationships of an intimate nature may also be affected by the presence of cancer-related fatigue and you may feel too tired to participate in sexual intercourse.

Fatigue (cont.)

Additionally, your partner may be cautious to do so and worry that they may make your fatigue symptoms worse. If you would like some more information about the impact a cancer diagnosis can have on relationships, go to page 16 of this booklet.

All of these affects are commonly reported by people living with and beyond cancer. However, there are strategies that you can employ to help you better manage these and feel more in control of your day to day activities, roles and responsibilities.

Steps to combat fatigue

The first step in self-managing your fatigue symptoms is acknowledging that you have cancer-related fatigue. Secondly, being self-compassionate and not expecting yourself to perform all the activities you did before you became ill will help if fatigue is an issue.

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 available energy is not currently what it used to be, you can then begin to think about how much energy you have in your battery, how you are using this and whether you would like to use it differently. This self-management approach will hopefully help you to regain some control over your daily activities, roles and responsibilities.

Research evidence demonstrates that activity management and energy conservation may help.

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

- Identify activities, both physical and cognitive, that drain your battery/energy the most and make a note of these.
- Identify activities that make you feel you have topped up your battery/energy levels. These may include physical activity, such as a paced walk, and do not necessarily mean resting or sleep. Make a note of these.
- Use a diary or calendar as a reminder and to note down what drains your energy and what tops you up.

- Pace the most draining activities and use top up activities to replenish your battery in between. This may help you get through to the end of the day easier.
- Prioritise which activities you need, want and have to do and decide whether they really all need to be done on the same day. Avoid overdoing things when you are having a good day.
- Plan activities in a diary and pace them across the week if possible, to spread out energy expenditure. Plan outings and events and incorporate top up points during the day.
- Getting back to, or slowly introducing, some form of physical activity into your daily routines may help to reduce cancer-related fatigue. There is also some research evidence to show this may also help you to return to pre-cancer levels of sexual activity. It doesn't really matter what type of physical activity it is so it is your opportunity to choose something you would enjoy. It may be through attending a gym or yoga class, or pursuing something less traditionally considered as physical activity, such as dancing, which has been shown in some research to reduce cancer-related fatigue. For more information, go to the exercise chapter of this booklet on page 54.
- Communicate your needs and share your knowledge of AML in a calm and articulate way with all those around you including family, friends, employers, colleagues and health professionals. Some people will need to be educated by you about the impact of fatigue on patients with cancer, as they are unfamiliar with this. For more information, go to the tell others about AML chapter of this booklet on page 79.
- If you are struggling emotionally, try learning a relaxation exercise, mindfulness technique and/or seek medical help from your GP to discuss other support. This may be in the form of counselling or 'talking therapies' and/or include temporarily taking medications to raise your mood and reduce anxiety. For more information, go to the emotional impact chapter of this booklet

Fatigue (cont.)

on page 26.

- Eat a well-balanced diet and have nutritious snacks throughout the day to top up 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.
- Contact an organisation such as Relate **www.relate.org.uk** if you are struggling with communicating your needs to your partner, or intimate relationships.
- Access available information and local support groups and online forums see **www.leukaemicare.org.uk** as this may help reduce feelings of social isolation.
- If you have concerns linked to employment issues contact your local Citizens Advice Bureau or access the Advisory, Conciliation and Arbitration Service (ACAS) website **www.acas.org.uk**. Reasonable Adjustments to your workplace

and/or work role under the Equality Act, 2010, can be explored to make things easier for you and your employer. For more information, go to the work and finances chapter of this booklet on page 67.

- If you are a student, discuss the impact of cancer related fatigue with student disability services and request support from your organisation, such as extensions to hand-in dates for assignments 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

I'm still working - what are my rights?

A cancer diagnosis at any stage of your life is hard to digest and how you approach your diagnosis and treatment is very personal. If the diagnosis does occur while you are working, it can feel very daunting and scary. Some of the questions you may be concerned about are:

- How will I cope with treatment and work?
- How will the treatment affect my ability to complete my tasks at work?
- How much time will I need off for treatment and/or recovery time?
- What do I do if I need time off for treatment or medical appointments?
- Will I be assessed differently at work due to my cancer treatment?
- Will I be looked over for promotions because of the length of time I took off work for treatment or recovery from treatment?

- Will my bonus be impacted?
- How will my colleagues react to my cancer diagnosis and treatment?
- How will I come back to work after treatment?
- What if I feel I cannot come back to work after treatment?

This is by no means an exhaustive list of questions and depending on your job, there may be many more.

Deciding to continue working during your treatment is a very personal decision and should be discussed with your manager or Human Resources (HR) department, so they can best assist you during this time.

Treatment plans and the side effects are as unique and complex as the individual undergoing treatment. Some people have little or no side effects and they find that continuing with their normal day to day life is the best way of dealing with their diagnosis.

Other people have severe side effects and can only continue with flexible working arrangements, or cannot work at all. These

Work and finances (cont.)

decisions can only be made once you have started treatment.

Although you may have decided to continue working for the time being, it does not mean that you cannot change your mind later and request more flexible working arrangements from your employer as a reasonable adjustment. You should note that your employer is required to assist you with reasonable adjustments while you are undergoing treatment and thereafter.

You may not be discriminated against for continuing to work but, if your employer does begin to treat you less favourably as a result of you having cancer at present or in the past, that is discrimination and is in contravention of the Equality Act 2010.

During treatment, your employer should allow you as much time off as you require to attend medical appointments, or undergo treatment to aid your recovery.

Your employer should also allow you reasonable sick leave after an operation or invasive medical procedure. The time off required should be specified by

your medical practitioner and communicated to your employer.

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.

Going through cancer treatment can be very challenging but your rights at work are protected under the Equality Act. Try to be open and honest with your employer about your treatment plan and your needs, to enable you to negotiate your treatment and recovery as best as you can.

Not all employers are aware of their responsibilities and your rights under the Equality Act. It is important to make sure you are aware of your rights both as they relate to the Equality Act and your company procedures. If you encounter difficulties at work, speak to your manager and HR team first, in order to see if a solution can be obtained. If you are still not satisfied with the outcome seek legal assistance from either a voluntary organisation, Citizens Advice Bureau (CAB) or an employment

solicitor.

The Equality Act and Cancer Patients

In England, Scotland and Wales, the Equality Act 2010 as well as the Disability Discrimination Act 1995 (DDA) protects employees. In Northern Ireland the extension, the Disability Discrimination Order of 2006, protects employees.

Under these acts, it is unlawful to treat an employee less favourably because of their disability. Cancer is legally classed as a disability and will also include a person who had cancer in the past, has gone through treatment and is now in remission. The employer cannot treat the employee less favourably because of his/her past cancer diagnosis.

The Equality Act and DDA, covers all areas of employment, including but not limited to:

- Recruitment
- The employee's terms and conditions
- Benefits and bonuses
- Opportunities for promotion
- 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 for Indirect Discrimination. It is advisable to discuss your diagnosis with either your Human Resources (HR) Department or your manager, as soon as possible, so that you can determine the best way forward.

There is no legal requirement for you to inform your employer of your diagnosis, but if they are not aware of your diagnosis, they cannot assist you during your treatment and/or recovery period. Regular absences or low performance when completing your tasks could be considered performance-related issues and will not be attributed to your treatment or period of recovery.

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

Discrimination can occur in

Work and finances (cont.)

various ways and may even be well intentioned. Some of the following are examples of discrimination that you may encounter:

- You are not promoted or offered the same opportunities because of your cancer.
- Your employer does not make reasonable adjustments. These are suggested workplace adjustments that could assist you during your treatment and/or recovery.
- Giving you a warning because of persistent sick leave and not taking your cancer into consideration.
- Your employer may suggest that you do another role in the business which is a demotion from your current role, and does so because you have cancer and without your consent.
- Your employer gives you a poor end of year appraisal and does not take your cancer into consideration.
- Your employer may give you a reduced or pro-rated bonus.
- Your employer may suggest

that you resign from your employment or retire because you have cancer.

- Your employer may select you for redundancy or for reduced hours working because of your cancer.
- Not being offered a job because you have or have had cancer in the past.

Direct Discrimination

Direct Discrimination is when, due to your cancer diagnosis, you are treated less favourably than someone who does not have cancer. This can include not being offered a job or not promoted because you have or have had cancer.

Indirect Discrimination

Indirect Discrimination is when there is a "rule, policy or practice which applies to everyone" but it puts you at a disadvantage compared to the other employees who do not have the same disability. You can only challenge a practice, policy or rule which you think is indirectly discriminatory if it affects you personally.

For example, if your employer

wants to make redundancies using the amount of sick leave taken as a selection criterion, that is indirectly discriminatory. An employee with cancer could be discriminated against because he/she has had to take time off work due to treatment and will be at a clear disadvantage compared with a person who has not had cancer. In these circumstances, you would need to make your employer aware that the policy is discriminatory because, although neutral in nature, it disadvantages you and others with cancer. With Indirect Discrimination, an employer may not be deliberately discriminating against anyone but it is still discrimination and not knowing you have cancer is no defense.

It should be noted, Indirect Discrimination may be permitted if the employer can show that the aim of the policy is for a good reason or can be justified, that the aim of the organisation is fair, balanced and reasonable and that reasonable adjustments have been considered.

Reasonable adjustments

The Equality Act 2010 and the DDA, requires your employer to make reasonable adjustments.

Your employer is not required to make reasonable adjustments if they are unaware or have not been told that you have cancer, or they could not have reasonably known that you have cancer. However, "should have reasonably known," will be difficult for your employer to dispute once they start to see physical changes occurring due to your cancer treatment. For example, if your hair is falling out; you are looking ill; you are unable to do tasks that you previously could have done or you are taking extended and/or frequent periods of sick leave.

Being required to make reasonable adjustments means that your employer is required to assist you to manage your work with either a change in how your employment is structured, by removing physical barriers, or by providing additional support.

There is no definitive description of what a reasonable adjustment is but the following will be taken

Work and finances (cont.)

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 to go to medical appointments.
- Having time off to recover from treatment.
- 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 lighter 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 co-operation and agreement.

- Sharing some of your tasks with another employee.
- Requesting physical assistance – changing the way your work station is set up.
- Requesting props to assist you at work, like a back rest or a cushion
- Making sure that you can access your place of work – including adding a ramp, lift or hand rails to name a few.
- Requesting that your work location is adjusted – moving to a lower floor or working from home.

Reasonable adjustments are not easily or formally defined. They are usually quite specific to you and the assistance that you require during treatment or thereafter. Whether it is a change in your duties or hours, counselling, coaching or something more physical, always speak to your employer to determine whether they can assist you. Your employer is required to try and implement reasonable adjustments and

cannot merely refuse. Reasonable adjustments can be either temporary or permanent. 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 agreed to, it is important to think about seeking legal assistance. There are also a number of free services available that can assist you, including the Disability Law Service or Working with Cancer.

Victimisation

Victimisation is when you, as a disabled person, are treated less favourably than another employee, for asserting your rights as a disabled person.

An example of this would be if you were to request time off for treatment and your manager does not grant your request. You decide to take the matter up with your HR department. They agree that you are entitled to the time off and instruct your manager to grant the time off. Your manager is now

so annoyed that you went over their head to HR that they do not put you forward for training and you are given a negative appraisal.

The law will also protect your colleagues from Victimisation if they support you in making the complaint.

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 work place. According to the Workplace Bullying Institute, bullying at work means "repeated, health-harming mistreatment of a person by one or more perpetrators. It is abusive conduct that is: threatening, humiliating, or intimidating, or work interference or sabotage which prevents work from getting done, or verbal abuse."

Work and finances (cont.)

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

If you feel that you have been discriminated against at work, speak to your manager or HR Department and see if the issue can be resolved. Quite often issues arise due to miscommunication or the employer not being fully aware of your needs and/or your situation. Try to speak openly and update them about your situation throughout your treatment and after your return to work.

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 like issues are not being addressed, seek assistance from the Citizens Advice Bureau or organisations like Working With Cancer or Macmillan Cancer Support which deal specifically with providing advice about work to cancer patients.

What should I do?

- Have a look at the relevant company procedures and policies. Your manager or HR department should be able to provide you with a copy.
- Approach your employer with solutions and suggestions. This will show that you are committed to your job and invested in resolving the situation.
- Make sure you know and understand your legal rights.

If the matter still stays unresolved despite you approaching your employer and speaking openly about it, you may be required to lodge a formal grievance.

Your employer will have their own grievance procedure, either in their employer handbook or stated in your contract of employment. If you are unable to find this, ask your manager or HR department for a copy.

To raise a formal grievance, you will need to write a letter to your manager detailing the incidents which have led you to believe that you have been discriminated against. It is suggested that you

be specific and detailed when drafting this letter. Your employer will be required to investigate your grievance and deal with it fairly.

If you are not satisfied with how your employer is dealing with your grievance and you believe that it is not being dealt with fairly, or your employer is being unreasonable, 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 sort out disputes 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/employment-tribunals

Alternatively, you should seek advice from an Employment Solicitor.

I'm unable to work: what benefits am I entitled to as a cancer patient?

There may be various benefits available to you, all of which will depend on your individual circumstances - there is no benefit for which you automatically qualify solely based on your cancer diagnosis.

Statutory Sick Pay

If you are an employee taking sick leave, then you are likely to be entitled to Statutory Sick Pay from your employer. You can have 28 weeks (about 6 months) of SSP before it runs out. This is usually straightforward to 'claim' because it is arranged and paid by your employer like your normal pay. If you (and your partner's) income is low then you might be able to top up your income with a benefit called Income Support.

Employment and Support Allowance

If you are not entitled to Statutory Sick Pay or your Statutory Sick Pay has expired then you may be entitled to claim ESA. This is a

Work and finances (cont.)

benefit for people of working age who can't work due to ill health. You will be assessed to see if you have 'limited capability for work'. If you are having chemotherapy or radiotherapy then you should pass this test automatically. Based on your national insurance record, you might be entitled to Contributory ESA. Contributory ESA is non-means tested, meaning that you can claim it even if you have other household income or savings. Alternatively, you could claim the means-tested version of ESA called income-related ESA if your income and capital are low enough.

Tax Credits

Depending on your circumstances, a reduced income might entitle you to Working Tax Credit or Child Tax Credit or both. The eligibility criteria for Tax Credits can be complicated and will look at how many hours you were working, how long you have been on sick leave, whether you are paying for childcare, and much more. Working Tax Credit is paid for people in full-time work and you can be treated as being in full-time work for the first 28 weeks of sickness

if you were working sufficient hours beforehand. You have to be responsible for a child in order to get Child Tax Credit.

Personal Independence Payment

If you have care or mobility needs and you expect these needs to continue for another 9 months or more, then you might be eligible for PIP. There is a fast-track system with guaranteed eligibility for the enhanced daily living component of PIP for claimants with a terminal illness who have a 'DS1500 form' from their doctor or specialist nurse. PIP is not means-tested, so you can claim it regardless of your employment status, income, and savings.

Housing Benefit and Council Tax Support

These two benefits can help with rent and council tax bills. You cannot claim Housing Benefit for mortgage payments. These are both means-tested and will take account of your circumstances to determine how much help you are entitled to, such as non-dependents living with you and how many bedrooms you have.

Housing Benefit is unlikely to cover the full cost of a privately rented property.

Universal Credit

This is a new benefit rolling out across the country which replaces Income-related ESA, Income-based JSA, Income Support, Housing Benefit, and Tax Credits and unifies them into one benefit. In some areas of the country – you must claim Universal Credit instead of the benefits it replaces. For sick or disabled people, Universal Credit will usually mean less weekly income than the benefits it replaces. If you live in an area that only offers and accepts new claims for Universal Credit but you still receive the old benefits, you should seek specialist advice before making any new claims – it could trigger a switch to Universal Credit and leave you worse off.

This is only a brief overview of benefit entitlement for people too ill to work. There are many other benefits available, as well as further eligibility criteria for the benefits that are listed above. It is well worth seeking help from specialist advisors at Citizens Advice, Macmillan, or other

benefits advice agencies locally. More information about benefits can be found at www.gov.uk

Can those caring for me claim any benefits?

If someone is caring for you then they should be able to claim Carer's Allowance as long as:

- They spend at least 35 hours per week caring for you
- They don't earn more than £116 per week
- They are over 16 and not a full-time student

In addition, they have to be caring for someone who receives a disability-related benefit such as Personal Independence Payment or Attendance Allowance. If the person being cared for does not receive such a benefit, then the carer cannot claim Carer's Allowance.

If the carer does meet all the criteria, then they can claim Carer's Allowance of (currently) £62.70 per week. If they have a low income, then they might be able to have their income topped up by another benefit called Income Support.

It is feasible that you could face a situation where your carer has to stop work to care for you, but cannot claim Carer's Allowance because you are not in receipt of Personal Independence Payment.

As a PIP claim can take months to reach an award, and often are unsuccessful, it could mean a long wait without any income for the carer. If your carer is on a low income they could be entitled to Income Support whilst you are waiting for your PIP or Attendance Allowance claim to be decided. However, they will not get paid beyond 26 weeks if your claim takes longer than that to decide. If you are living on your own and receiving a disability-related benefit in addition to other benefits, such as Employment and Support Allowance or Pension Credit, then seek advice before allowing a carer to claim Carer's Allowance. Their claim could reduce your weekly income if you are receiving a severe disability premium.

If the person caring for you already receives state benefits or a State Pension, then they might not be able to receive any Carer's Allowance payments.

This is because other benefits 'overlap' Carer's Allowance. Even if this is the case, the carer should still apply for Carer's Allowance. Although they will not receive any payments directly, they should be awarded an 'underlying entitlement to Carer's Allowance' that can be beneficial to them when calculating other benefits and credits them with National Insurance contributions.

In some circumstances, a carer under 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.

Telling others about AML

Your relationships are unique to you and so there is no one way to tell others about AML. Our relationships can be a great source of support when we are ill and can bring people closer together. Relationships are often complicated and the challenge of illness can open up difficulties as well. It generally helps when communication is as open and honest as possible. Here is some guidance to help you think about what feels right for you.

Should I tell others about the 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 this enormous thing that is happening to you before you decide when and how you 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.

There will be some people that you want to know and others that you would prefer not to. It is up to you who you tell and how much you tell them but going through treatment for AML is not something that 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

Telling others about AML (cont.)

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 also 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 hear the information being given and have the opportunity to ask questions. We often have different needs for information. Perhaps one prefers 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. You may want to try and protect each other from upset or how you feel and this can get in the way of talking to each other when you most need to. Finding ways to manage your different needs can be a challenge throughout your experience of AML.

Some couples describe having to go through 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.

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 some time to catch up and give each other a chance to say how you are. Identify what is helping

each of you get through this time and what is making it difficult. This could be on both an emotional and a practical level. It is also helpful to set aside some time when you can be a couple and 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.

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.

If they have more questions, you may find it easier to direct them to information leaflets or the Leukaemia Care website for more information than to try and explain it all yourself. 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.

It is exhausting to have to keep repeating the same difficult conversation and you could ask someone else to tell people who are not so close to you. It can be easier over the phone or by letter or email as this gives you more control.

People will often want to do what they can 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 to pass on information. This saves you from having to repeat similar conversations. You may not feel up for long conversations when you are feeling unwell but keeping in touch through texts can help you

Telling others about AML (cont.)

feel connected to others.

Some people send out a group email or use social media to pass on news. This can make it quick and easy to contact a lot of people at once. However, do consider who you want to see your posts, check your privacy settings and remember that information stays on the internet unless you remove it.

Coping with other people's emotional reactions

You can be sure that there will be a wide range of reactions from people you talk to about your illness. Hopefully, they will be supportive and open to following your lead about what will be most helpful to you. Some may be upset and distressed by your news and you may find yourself needing to be strong and supportive for them. This is hard when you not feeling well yourself. People who care will want to help you as best they can but they may first need time to adjust.

You may find that not everyone is sensitive to your needs and this

can be upsetting and frustrating. If some people avoid you, it is usually because they don't know what to say or are worried about saying the wrong thing. 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 to look ahead. They may have advice about particular diets or supplements you can take. This may not reflect how you are feeling or be what you want to hear. 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 that you need.

See the people that you want to see and talk about what you feel comfortable with. Ideally, people will give you the opportunity to talk about how you are feeling if that is what you want or respect your wishes if you prefer not to talk about it. Some of us 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 the illness. Asking others about themselves and what they are doing can steer the conversation away from illness.

Going through AML is an enormous challenge and you and those close to you are likely to feel stressed at times. It's natural to feel anxious, angry or frightened when faced with AML and 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. We know from research and the experience of others that children cope better when they are told about an illness. Children are very good at sensing when something is wrong and it can be more distressing for them to not know what this is. Not telling them can leave them feeling frightened when they don't understand what is happening. Talking about the illness with openness and honesty sets the tone for the way ahead.

Telling your children 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 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.

Telling children about the AML in a way that they can understand will vary according to their age. If you have more than one child, telling them together or as closely together as possible will avoid one carrying the burden of knowing or wondering why they were told last.

You know your child best and so

Telling others about AML (cont.)

trust your instincts when it comes to supporting them. You might like to think about what you will say in advance and choose a time to avoid interruptions. Try and not to put pressure on yourself to have the perfect conversation. The aim is to convey enough information to begin an on-going process with many more opportunities to talk about what is going on. You may be surprised by their questions or reactions. It is fine to say if you can't answer all of their questions but can try to find out.

Younger children will respond to small chunks of information at a time and may be keen for reassurance about how it will impact on them. Let them know that they have not caused the AML and that they cannot catch it from you. They may carry on playing as if they haven't understood but they will be processing the information in their own way. They may then surprise you with a very direct question when you least expect it.

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 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 and 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 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 help them to feel contained and more able to know where they stand.

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**

Telling work about the diagnosis

Being diagnosed with AML will mean that you need to start treatment straightaway. You or someone else will need to let your employer know about your situation. Your medical team will be able to advise you about timescales. You may need to

negotiate a reduction in working hours or make an arrangement with your employer for times when you are in hospital or for when you are not well enough to go into work.

Your consultant or your GP can arrange letters to your employer to confirm 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.

Hopefully, your employer will be supportive. You may worry that you could be given the sack or made redundant if you cannot work. This should not happen because people with any form of cancer are covered in law by the Equality Act. This means that legally your employer cannot discriminate against you and must make reasonable arrangements relating to your disease.

You may also be wondering about what you tell your colleagues. You may want to keep your diagnosis to yourself and it is important that your privacy is respected. Telling those you are

closest to gives them a chance to support you and may help you feel connected to work. It can also make it easier when you do go into work if they know that you are at risk of infection or if fatigue or poor concentration is a problem.

Returning to work after your treatment has finished can feel like another big challenge. You may wonder if people will want to talk about it too much or not at all. If some 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 your colleagues 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. It is up to you what you say and in how much

detail. At other times, it can seem that people have forgotten what you have been through and you need to gently remind them that you are still coping with side effects and that your recovery is taking time. As with all of your conversations about AML, being honest and saying what you need to say is generally the most helpful approach and makes it easier for you both.

If you would like advice about telling people of your diagnosis, you can speak to one of our nurses or a trained volunteer on the help line **08088 010 444**

Complementary therapies

Complementary therapies have been used in a supportive capacity both within the NHS and by charities for the enhanced well-being of patients and clients within haematology for over 30 years. Aromatherapy and reflexology are generally the most popular and available within the NHS due to their effectiveness; assisting with overall wellbeing and relaxation as well as addressing pain, nausea and other side effects from treatment and medication as part of a package of care. Consultants have commented that the more relaxed the body and mind is, the better accepting of their treatment it is, even taking bloods.

In the next section, there is some information about a variety of complementary therapies and exercise that may be helpful at different stages; before, during and after your treatment.

The guidance is to enable you to have an overview of the benefits of different therapies also contacts and information to enable you to find an appropriate therapist privately.

During your treatment and hospital visits you may be offered

a choice of treatments from a complementary therapy team, this service would usually be free and provided by experienced therapists who are accustomed to AML and the treatment you are receiving.

Complementary Therapist

A complementary therapist will offer supportive therapy as part of an integrated practice, alongside standard medical treatment for AML, not an alternative treatment.

When looking for a therapist it is important to ensure your therapist has appropriate training for your needs. The therapist will generally be a member of a representing body for their therapies and must have the appropriate insurance.

The Complimentary and Natural Healthcare Council (CNHC) is a representing body for yourself as the client. All therapists on this register will have a certain level of qualifications and insurance. Most NHS therapists will be members. When approaching a therapist do check that they have taken part in some additional training or continued

Complementary therapies (cont.)

professional development (CPD) or have experience with haemato-oncology clients and understand the appropriate guidelines that apply.

When treating patients with AML, all hands-on massage therapists are advised to work with light touch techniques and massage due to the possibility of low platelet counts and the risk of bruising. This doesn't affect the quality of treatment but ensures you receive massage or reflexology with the appropriate lightness of touch, and therefore the best outcomes.

Before starting on a course of treatments the therapist should take a detailed case study on your overall health and well-being, in order to tailor the treatment to you, accommodating your needs.

Types of complementary and supportive therapies

Acupuncture

Acupuncture is a form of Traditional Chinese Medicine (TCM). This treatment uses the application of fine needles in points in the body which have

been identified as helpful for various symptoms and side effects that are present at the time. Many people find acupuncture very relaxing and useful for health problems such as fatigue, sleep problems, nausea and pain. It can also support emotional wellbeing.

Health professionals and doctors also train in a method of acupuncture called Western Medical Acupuncture which is often used as part of an integrated service. NICE guidelines recommend acupuncture for headaches, whilst it has also been reported as beneficial for nausea and vomiting. The WMA approach is different to TCM but they are used for similar concerns.

For more information on the two approaches – including how they differ and which may be more suitable for you – speak to a professional acupuncturist or your medical team.

Aromatherapy

Aromatherapy is the use of essential oils which are aromatic volatile oils extracted from plants. Aromatherapy as

a therapy is most often used with massage but can be used in bath and skin preparations, inhalation, compresses and other methods. The chemical constituents or make-up of each oil assists the aromatherapist in choosing the most appropriate oil or combination of essential oils for their client's needs. These therapeutic properties of essential oils may assist with psychological, emotional and physical concerns and importantly relaxation. Clinical aromatherapists would also choose essential oils to assist with side effects of standard medical treatments which might include nausea, poor sleep and pain.

The use of touch and essential oils are documented with positive results. For example, lavender has been found to be beneficial for stress and anxiety due to the amount of the chemical esters in this oil which are known to be calming and soothing. When buying essential oils for home use, good quality oils should be used especially when they have contact with the skin. Essential oils should always be diluted, the exceptions being lavender

and tea tree which are generally acknowledged as being suitable to apply directly to the skin. However, if you are unsure, a patch test should be carried out with the oils first. Oils used in an aromatherapy fan or ceramic burner are using the olfactory senses and so, the aroma must be pleasurable. Only a few drops are needed, and, if using in the bath, always follow guidelines. If you have nothing to hand, the fat content of a couple of tablespoons of milk will disperse the oil into water. Coconut oil is also suitable.

For a massage, the aromatherapist will blend a dilution of 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 those who are less well. An aromatherapy massage should be light touch and leave you with a feeling of deep relaxation. Relaxation is an important part of recovery. Massage can be full body, or directed to specific areas of discomfort. A hand massage can be extremely relaxing.

Complementary therapies (cont.)

In addition to massage the aromatherapist may make a personal inhaler to assist with specific problems. Inhalers can be useful to carry with you for nausea, using a blend that might include Spearmint. Inhalers can also assist with deepening the breath. Frankincense may be used to help when we are anxious our breathing often becomes shallow. Blends of essential oils can also be diluted for use in a roll-on bottle which can be used like a perfume on pulse points. Suitable blends can be extremely helpful assisting with stress and anxiety, or the feel-good factor. An aromatherapist may give the balance of an oil blend in this way for home use and a lovely reminder of the benefits of the treatment received.

Nourishing blends of carrier oils can feed the body through the skin providing a variety of nutritional benefits when absorbed as well as excellent skin care.

Bowen technique

The Bowen technique is a gentle therapy which aims to rebalance the body's energy flow to assist the body to heal itself.

This treatment utilises a light rolling movement of the thumb and fingers over the skin. This system uses subtle and precise mobilisations called "Bowen moves" which affect the muscles, tendons, nerves and fascia (connective tissue) by application of this gentle treatment with non-invasive pressure. These procedures follow prescribed sequences to affect specific body systems. The therapist will take frequent pauses during the treatment to allow the body to adjust and absorb the treatment.

Energy therapies

Bach flower remedies and flower essences

Flower essences are preparations which utilise flowering plants and the sun's energy. Bach flower remedies were created from British plants. Other examples of essences are made from varieties of rose or other countries indigenous plants such as Australian Bush plant remedies.

Flower essences are considered by some to assist with emotional imbalance often assisting with emotions, mood, mental state, shock and sometimes

trauma. These are often seen as precursors to physical illness. The essence from the flower of the plant is usually stabilised in alcohol although special preparations are available for those who wish to avoid any alcohol content. Just a few drops are added to water or dropped under the tongue.

Each plant has a unique signature addressing different emotions. A blend of essences is common as a rescue remedy, as in Bach flower remedies, and thought to assist with stressful situations such as hospital visits and exams.

Flower essences are available from many chemists and health shops with accompanying information to assist in correct selection.

Therapists who specialise in flower essences will take a case history and then blend a group of essences to address their client's emotional needs.

Energy therapies; healing, reiki, therapeutic touch

These therapies are frequently used in supportive and palliative

care. Although the word healing is used as part of the treatment, this is not referring to cure and likewise spiritual is not associated with any religion. These modalities are often used with the intent to assist with pain relief, promote relaxation, improve sleep, to contribute to a sense of well-being or to reduce side effects of chemotherapy and radiotherapy.

Healing

Healing, sometimes referred to as spiritual healing, is described by The National Federation of Spiritual Healers as "a process that promotes better health, through the channeling of healing energies through healer to receiver". Healing should not be confused with curing cancer.

There is some evidence that suggests this supportive therapy may quicken the body's own healing process. The practitioner will use light touch or no touch as appropriate for the patient who will be clothed.

Reiki

Reiki is a method of healing which promotes the aim of homeostasis through balancing the body's own

Complementary therapies (cont.)

Ki or energy with Rei, or universal energy. This healing modality originated in Japan with its origin in self-healing. Reiki treatments are received in a similar way to healing with the recipient fully-clothed.

Therapeutic Touch

Therapeutic touch is a modern interpretation of some traditional healing approaches. It is described as an exchange of energy between client and practitioner, a healing meditation. During the treatment, the practitioner will place their hands a little way above the client's body and rhythmically move their hands from head towards the feet with the aim of creating a sense of deep relaxation for the client with the potential of reduced anxiety.

Hypnotherapy

Clinical hypnotherapists believe that creating a more positive relaxed state of mind helps the body to repair and heal.

Hypnotherapy is a way of reducing the stress response. During a first hypnotherapy session, the hypnotherapist will take their client through a progressive relaxation, relaxing first the

body and then the mind. The therapist may provide clients with relaxation techniques and recordings to help them relax at home and, after a little practice, these may assist a reduction in stress levels with an improved sense of relaxation, with the aim of feeling much better as a result.

Hypnotherapy aims to create powerful and positive changes. 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 habit behind, often after only two or three sessions.

There is significant evidence for the use of hypnosis within integrative care in reducing different side effects to treatment such as nausea or anxiety or overcoming phobias. Some medical practitioners receive training in these techniques.

Hypnotherapists will often tape record sessions for use at home in the same way as a meditation, with mindfulness techniques often incorporated into it. During a hypnotherapy session, the patient or client will be guided into a trance state, through suggestion

of voice. This trance is a state of awareness where the client is in touch with the practitioner's voice but in a deep sense of relaxation. The therapist will make positive suggestions which may assist in a change in mental attitude towards a problem or life concern, either physical or emotional, according to the desire of the patient. Hypnotherapists also have reported success with addictions.

Massage

This touch therapy is the most well-known, but sometimes met with reluctance. A clinical/professional therapist will have completed extensive training and qualifications in anatomy and physiology in addition to extensive massage techniques. Therapeutic Massage is a combination of different touch techniques manipulating the soft tissue using the hands and perhaps forearms. Each treatment will vary according to the client's requirements and health state. AML patients and others recovering from ill health should receive a lighter touch as they may be at risk of bruising. Pressure will vary dependent on

the sensitivity of the body and will ideally be a gentle rhythmical touch. Oil or sometimes powder is used to ensure a smooth and comfortable treatment. The therapist will offer a full body massage or massage to specific areas of discomfort such as neck and shoulders. In cancer and palliative care, several studies have taken place identifying assistance with anxiety, pain and a variety of reduced physical and emotional symptoms.

M Technique

Touch M has been widely used in hospital and hospice care. This very light touch manual treatment utilises a formula where each treatment will be given in the same sequence and same level of light touch throughout, making it accessible to anyone, however unwell. Treatment can be full body or just to specific areas. Training is available to anyone who wishes to give touch to friends and family, also for health professionals and therapists. M technique is extremely relaxing and invaluable to anyone with low energy or high stress levels or where deeper massage is inappropriate.

Complementary therapies (cont.)

Reflexology

A reflexologist will apply an intermittent pressure using their thumb and fingers to areas of the feet or hands which they believe will access all body systems with the aim of bringing balance, or homeostasis, to their client. A reflexologist does not diagnose but, with reference of a foot chart which relates areas of the feet to areas of the body they can identify potential areas of imbalance through an altered state in the feet in different areas. Clients may also feel areas of discomfort in their feet or sensation in their body. If this is the case, the therapist and client together will identify areas of imbalance in the body. This holistic treatment is found by many clients to offer deep relaxation, boost their immune system and assist with maintaining good health. Some studies and client feedback have suggested that reflexology can assist with anxiety, pain, nausea, sleep and digestive problems.

Reflexology Lymphatic Drainage (RLD)

RLD is additional training available to qualified

reflexologists which focuses specifically on the lymphatic system. Early indications from the founder suggest RLD is useful in reducing volume for lymphoedema and assisting with oedema as well as inflammatory and auto-immune disorders. This treatment of feet or hands is deeply relaxing.

Movement, mindfulness and meditation

Mindfulness and meditation

Meditation, or mindfulness meditation is often offered by yoga teachers as a separate class or as part of a regular yoga class. The aim of meditation is to bring your attention and awareness more fully to the present moment, being aware of thoughts, physical sensations and emotions, as they arise, experiencing them as they are without trying to change anything. 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. This can lead us to reduce physical

and emotional distress and live a happier life no matter what we are facing.

A candle or flower or other object may be used to focus the mind to help build concentration. The instructor or teacher will use the patterns of your breathing and may also use guided meditation as well as other techniques for self-practice.

Mindfulness classes and courses in healthcare have become increasingly popular including the following programmes: Mindfulness-based stress reduction, Mindfulness Based Cognitive Therapy and Mindful Self-Compassion. For more information, go to the mindfulness chapter of this booklet on page 98.

Mindfulness invites you to pay attention to your present moment experience with kindness and curiosity; thus changing your relationship with your experience. Proven benefits include reduced stress symptoms, improved quality of sleep and enhanced quality of life.

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.

Tai Chi

Tai Chi could be described as a moving meditation, using a sequence of gentle flowing movements that combine breathing, movement and awareness exercises with meditation.

There are many forms of Tai chi and, practiced regularly, may help reduce symptoms or side effects including stress and anxiety, increase flexibility and balance and improve overall physical and emotional wellbeing.

Tripudio Movement Systems (TMS)

Tripudio Movement was developed

to provide a short practical sequence of movements that can be taught for home practice encouraging a healthy, flowing lymphatic and circulatory system utilising a mixture of gentle mobilisation and stretches which can be done seated or standing. This Tripudio Flow sequence is also used at the beginning and the end of a one-hour class which uses a mixture of seated and standing gentle stretching, mobilisation, strengthening and low impact aerobic exercise all set to music. There is no floor work involved and TMS is suitable for any age or ability. Classes are often on offer at cancer centres, hospices and hospital clinics as well as in the community.

Yoga

There are many different styles of yoga, some very vigorous and others slow or relaxing. Gentle classes which focus on a mix of stretching/postures, breathing and some meditation or relaxation would be most appropriate. To support your wellbeing, find a class that offers a gentle, relaxing approach or a class that is specifically designed for people who are affected by

cancer.

Yoga aims to bring balance to the whole (mind, body and spirit) through awareness of your breath and movement. Classes usually last between one to one and a half hours and require loose or comfortable stretch clothing and bare feet.



Mindfulness

What is mindfulness?

Mindfulness is a way of living our lives that can help us become more resilient and cope more effectively with whatever we are facing, including living with a diagnosis of leukaemia. Mindfulness is a natural human tendency that we can all develop. Through the practice of mindfulness, we become more aware of the experience of what is happening from moment to moment and therefore engage in an effective way of responding to it. The present moment is the only time that we can change anything, including our automatic reactions and responses to any given situation.

With regular practice, we can cultivate mindfulness; we learn to rest back into the awareness of the moment to moment comings and goings of physical sensations, thoughts, emotions, sounds, sights, smells and tastes. We can bring curiosity to this rather than judgement. This can help us to become less reactive and we can become more effective in our responses to whatever we are experiencing. This helps us become more resilient and cope

much better.

What are the benefits of mindfulness?

Mindfulness can help us learn to respond more effectively to whatever is happening in our lives. Whilst we cannot prevent difficulties from happening, through mindful awareness we can learn to cope better with situations. Increasing our awareness of what is happening from moment to moment enables us to notice our automatic reactions and learn to respond more effectively. We can respond better to our constant stream of thoughts and worries. Research in people affected by cancer has shown this to be helpful with pain, stress, fatigue, anxiety and depression, and generally helpful with general wellbeing. Essentially, mindfulness can help us to live happier and healthier lives, whatever we are facing.

How to be more mindful

We can incorporate mindfulness into our lives in two ways.

One is the formal practice of mindfulness, setting time aside

to bring awareness to sensations occurring during our breathing, when we move, when we are lying down and when we are walking. These practices are often done slowly, giving the attention time to become fully absorbed. These practices can be done for anything from a few minutes to longer practices of up to an hour. Research tells us that it is the regular daily practice of mindfulness which is so beneficial and anything from 10-30 minutes has been effective in its cultivation.

We can also be mindful in the activities of everyday life. We can turn off the phone, TV or music and just pay full attention to sensations when we are, for example, standing and walking, sitting down or lying, chopping up the vegetables, taking a shower or getting dressed. Maybe walking outside in the park and feeling the air and sun or rain on our faces and the ground underneath our feet.

There are eight-week courses available in mindfulness provided by trained teachers called Mindfulness Based Stress Reduction and Mindfulness-Based

Cognitive Therapy. Courses can be found on www.bemindful.co.uk

Mindfulness Practices

These come in various forms including the mindful body scan, mindful walking, mindful movement, and mindful sitting practice. There are podcasts available that can help you and have been especially designed for people affected by blood cancers <http://www.abbvie.co.uk/mindfulness.html>

Mindfulness of the soles of the feet

While you are standing or sitting, gently bringing your attention to the soles of the feet and start to notice the sensations - whatever is happening from moment to moment and remembering that there is no right or wrong way to experience the present moment so whatever is happening is completely fine. Maybe there is heat, coolness, moisture, dryness, tingling or numbness or maybe other sensations. The point 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 the attention

Mindfulness (cont.)

back to the soles of the feet again.

You can practice this for a few seconds or a few minutes. Try it for yourself.

Mindfulness of breathing

Find a comfortable position, sitting up or lying down, allowing your body to settle. Become aware of your body in the position that you have chosen and take a couple of breaths. Let go of any tension in the body as you breathe out. Now bring your attention to the movement of the breath in the body and become aware of where you notice it most. Allow your attention to rest on the movement there as you breathe, gently coming back to that area each time your mind wanders away, as it surely will. You can practice this as long or short a time as you have available.

Is mindfulness helpful for everybody?

Many people find mindfulness helpful and find ways to apply it in their lives which are beneficial especially when facing the uncertainty of a leukaemia diagnosis. Like anything, some

people may find it less helpful than others, but generally speaking, many people find that there is something helpful that they can take from the practices and use to support them in daily life.

If you are suffering from a mental health condition, you should check with your doctor that this is appropriate for you right now.

Glossary

Acute Leukaemia

Leukaemia is cancer of the white blood cells. Acute leukaemia means it progresses rapidly and aggressively, and usually requires immediate treatment.

Acute Myeloid Leukaemia (AML)

Acute myeloid leukaemia (AML) is a type of blood cancer that starts from young white blood cells called granulocytes or monocytes in the bone marrow.

Allopecia

Hair loss.

Alternative therapies

These are treatments used instead of conventional western medicine. For example, acupuncture is a type of alternative therapy.

Antibiotics

These are used to treat or prevent bacterial infections. They work by killing bacteria or preventing them from reproducing and spreading.

Blood cells

Blood cells have many different functions including transporting oxygen and nutrients to the lungs

and tissues, forming blood clots to prevent excess blood loss and carrying cells and antibodies that fight infection.

Cancer

A group of diseases involving abnormal cell growth with the potential to invade or spread to other parts of the body.

Chemotherapy

A form of cancer treatment that uses one or more anticancer drugs as part of a standardised treatment regime.

Complementary therapies

These are treatments used alongside conventional western medicine.

Fatigue

Extreme tiredness, which is not alleviated by sleep or rest. Fatigue can be acute and come on suddenly or chronic and persist.

Full Blood Count (FBC)

A blood test that counts the number of different blood cells,

Holistic Needs Assessment (HNA)

This can help identify some of the

physical and psychological needs of patients and ensure patients' needs and management plans are met in a timely and appropriate way.

Leukaemia

Leukaemia is an excess number of abnormal cells in the bone marrow, usually white blood cells, which stop the bone marrow working properly. Some forms are acute (develop quickly) and others are chronic (develop slowly).

Mindfulness

Mindfulness is a way of approaching life that can help with resilience and coping more effectively in the present moment.

Mucositis

Chemotherapy-induced mucositis causes the mucosal lining of the mouth and gut to waste away and break down forming ulcers, leading to a sore mouth and diarrhoea.

Neuropathy

Also known as parathesia, but more commonly called pins and needles, this is indicated by tingling or numbness on the skin.

Neutropenia

A condition in which the number

of neutrophils (a type of white blood cell) in the bloodstream is decreased.

Neutrophil

A type of white blood cell that helps fight infection.

Red blood cell

The blood cell that carries oxygen. Red cells contain haemoglobin, which permits them to transport oxygen (and carbon dioxide).

Platelet

A disc-shaped element in the blood that assists in blood clotting. During normal blood clotting, the platelets clump together (aggregate).

White blood cell (leukocytes)

One of the cells the body makes to help fight infections. There are several types of white blood cells. The two most common types are the lymphocytes and neutrophils.

If you would like more definitions of terms you may come across during your blood cancer journey, you can order our A - Z of Leukaemia by calling Patient Services on **08088 010 444**

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 helpline for any medical queries relating to your diagnosis.

Helpline: **08088 010 444**
www.leukaemicare.org.uk
support@leukaemicare.org.uk

Bloodwise

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

020 7504 2200
www.bloodwise.org.uk

Cancer Research UK

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

0808 800 4040
www.cancerresearchuk.org

Macmillan

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

0808 808 0000
www.macmillan.org.uk

Maggie's Centres

Maggie's offers free practical, emotional and social support to people with cancer and their families and friends.

0300 123 1801
www.maggiescentres.org

Citizens Advice Bureau (CAB)

Offers advice on benefits and financial assistance.

08444 111 444
www.adviceguide.org.uk

Leukaemia Care is a national charity dedicated to providing information, advice and support to anyone affected by a blood cancer.

Around 34,000 new cases of blood cancer are diagnosed in the UK each year. We are here to support you, whether you're a patient, carer or family member.

Want to talk?

Helpline: **08088 010 444**

(free from landlines and all major mobile networks)

Office Line: **01905 755977**

www.leukaemiacare.org.uk

support@leukaemiacare.org.uk

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One Birch Court,
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Registered charity
259483 and SC039207

Leukaemia Care
YOUR Blood Cancer Charity

