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# End of Life and Leukaemia: A patient's perspective

A Guide for  
Patients

**Leukaemia Care**  
YOUR Blood Cancer Charity

# Introduction

**When a person is reaching the end of their life, it is normal to have lots of thoughts running through their mind. You may be experiencing a wide range of emotions and thinking about lots of different things. For example, what the future looks like and the many unknowns may concern you. You may also be thinking about all the practical implications.**

Through this time, there is a lot of support available. This booklet will detail some of the organisations that are out there. It will also introduce you to some of the issues that you may face or may already be facing. This includes the kind of choices you can make, dealing with the emotional impact and telling loved ones that you are reaching the end of your life.

You may find all the things in this booklet applicable to you, some of them, or maybe none of them at all. Experiences vary from person to person. Remember, you can

find tailored advice by talking to your GP or your healthcare team.

This booklet was written by our Patient Information Writer, Isabelle Leach. It has been peer reviewed by Prem Mahendra, Consultant Haematologist at Queen Elizabeth Hospital in Birmingham, as well as Anna Stevenson and David Samson at Turn2us, and Jennifer Noel from Compassion in Dying. We are also grateful to Rachel Powell, Jill Weaver and cancer blogger Katharine for their contributions as patient reviewers.

If you would like any information on the sources used for this booklet, please email [communications@leukaemicare.org.uk](mailto:communications@leukaemicare.org.uk) for a list of references.

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# About Leukaemia Care

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

## Our services

### Helpline

Our helpline is available 8:30am – 5:00pm Monday - Friday and 7:00pm – 10:00pm on Thursdays and Fridays. If you need someone to talk to, call **08088 010 444**.

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

### Nurse service

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

### Patient Information Booklets

We have a number of patient information booklets like this available to anyone who

has been affected by a blood cancer. A full list of titles – both disease specific and general information titles – can be found on our website at **www.leukaemicare.org.uk/support-and-information/help-and-resources/information-booklets/**

### Support Groups

Our nationwide support groups are a chance to meet and talk to other people who are going through a similar experience. For more information about a support group local to your area, go to **www.leukaemicare.org.uk/support-and-information/support-for-you/find-a-support-group/**

### Buddy Support

We offer one-to-one phone support with volunteers who have had blood cancer themselves or been affected by it in some

way. You can speak to someone who knows what you are going through. For more information on how to get a buddy call **08088 010 444** or email **support@leukaemiacare.org.uk**

### Online Forum

Our online forum, **www.healthunlocked.com/leukaemia-care**, is a place for people to ask questions anonymously or to join in the discussion with other people in a similar situation.

### Patient and carer conferences

Our nationwide conferences provide an opportunity to ask questions and listen to patient speakers and medical professionals who can provide valuable information and support.

### Website

You can access up-to-date information on our website, **www.leukaemiacare.org.uk**.

### Campaigning and Advocacy

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

### Patient magazine

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

# Finding out your leukaemia is terminal

The end of life stage begins when a leukaemia patient is likely to die in the next 12 months. This might be the case if your leukaemia is advancing and there are no other treatments that you can try.

When you are at the end of life stage, your doctors may say that your leukaemia is terminal. This means that it is likely to result in death within a limited period of time.

## Receiving palliative care

Palliative care is not only for those who are in the last weeks of their life. Nor is it just for those who have stopped active treatment. They are here for you to provide ongoing support. It is also sometimes called supportive care.

A multidisciplinary team (MDT) provides palliative care. The team is made up of different health and social care professionals who will coordinate the care. These include:

- Your GP
- Hospital doctors and nurses

- Community nurses
- Hospice staff
- Counsellors
- Social care staff
- Physiotherapists
- Occupational therapists
- Complementary therapists
- Religious leaders, if you would like this

The purpose of palliative care is to improve your quality of life. This helps with any symptoms (including the emotional impact of your leukaemia). Palliative care will not contribute to curing your leukaemia.

Examples of palliative care include:

- Pain relief
- Antibiotics for any infections you may get
- Medications for nausea or to help you sleep
- Steroids to help improve your appetite

- Emotional support for you, and those closest to you
- Practical coping strategies for dealing with symptoms, side effects and living with leukaemia

For more information about palliative care, go to the Marie Curie website at: [www.mariecurie.org.uk](http://www.mariecurie.org.uk)

## Deciding when to stop active treatment

Your decision to end active treatment can be emotional and difficult. To help make your decision, it is important to discuss it. You can talk to the people closest to you, or anyone else involved in your personal care, such as your medical team, palliative care team or any other professionals you might currently have involved in your care (e.g. a counsellor).

There are factors you need to think about to help you decide if you want to continue with active

treatment. These include:

- Your type of leukaemia
- Its progression and number of relapses
- The effect on your organs
- The results of genetic tests that may determine your prognosis
- Your age
- Any other medical conditions you have

To help you make a decision, your doctor will be able to tell you:

- The benefits and side effects of any treatments
- The consequences of stopping treatment
- The effect of quality of life versus quantity of life

Although it is ultimately your choice, it is important to know that you do not have to make this decision on your own. Your final decision will be made with the support of your doctor. If you have any questions, or are unsure of what to do, your doctor will be

# Finding out your leukaemia is terminal (cont.)

happy to discuss your options.

You may decide to stop active treatment because you feel it is not helping, or you are not well enough to continue. Regardless, you will still receive palliative care.

If you have people close to you, it is important to tell them that you have decided to stop active treatment. They may not want you to do this, but you need to help them understand how you have reached your decision. Your doctor or clinical nurse specialist can help you to explain the situation. Talking about it might not be easy, but it can help them to understand why you made this decision.

It is important to remember that stopping active treatment is not giving up. It may be a way to live as content as possible and remain as well as you can as you approach the end of your life.

## Clinical trials

Clinical trials look at new treatments in specific groups so

you may not always be suitable. If a clinical trial is recruiting, then you might be able to join it. For example, if they are looking for people whose leukaemia has returned or at improving quality of life. You can always speak to your doctor or healthcare team about this.

For more information about potential clinical trials that you might be suitable for, you can speak to our Patient Advocacy team. You can email [advocacy@leukaemicare.org.uk](mailto:advocacy@leukaemicare.org.uk) or call the helpline on **0808 010 444**.

## Knowing how long I have left to live

It is difficult to predict how much time you have left. Your healthcare team may be able to give you an idea if it is likely to be weeks, months or years. They base their estimate on the type of leukaemia

you have, how aggressive it is and the effect on your organs.

Your doctors are only giving you an estimate and they cannot say for certain how long you have left to live. Many people try to put their affairs in order and then try to live in the present, taking one day at a time. This way they can enjoy the time they have left with the people close to them as much as possible.

# Signs and symptoms to expect when reaching the end of life

Several changes will happen to your body from the effect of the leukaemia on your organs. As you reach the end of your life, your body functions will slow down. The complications you experience depend on how the leukaemia has affected your body.

## Effects on the bone marrow

Leukaemia has a huge effect on the bone marrow. The bone marrow makes the red blood cells, white blood cells and platelets. A high number of leukaemia cells can prevent the bone marrow from making new blood cells. This can lead to many complications, including:

- **Anaemia:** A low level of red blood cells, which transport oxygen to body cells. This can prevent your organs from getting enough oxygen and working properly. This causes symptoms of weakness, fatigue or shortness of breath. Fatigue is tiredness and weakness that isn't improved with sleep. This means you have trouble performing your usual daily tasks.
- **Bleeding:** A low level of platelets

can lead to bruising and bleeding. This includes both inside and outside of your body.

- **Risk of infection:** A low level of white blood cells means that your body isn't as good at fighting off infection. Maintaining a good level of hygiene to help combat this is important.

Generally, you may receive blood transfusions to replace missing blood cells. This is a temporary measure and you may need further transfusions. Still, you will continue to receive follow up care. This will include checking your blood levels to help identify any problems. Your healthcare team's aim is to respond to these and keep you as comfortable as possible.

## Pain

The pain you experience will depend on the areas of your body affected by the leukaemia. For example, joint pain or swelling in the hips and shoulders may develop after several weeks. Also, bone pain tends to occur in the long bones of the arms and legs and in the ribs. This pain is due to your bone marrow becoming

crowded with leukaemia cells.

There is a lot of pain relief that your healthcare team can prescribe to help you. Codeine or morphine are the most common drugs used depending on the severity of your pain.

It is important that you let your healthcare team know if your pain relief medication is not working. They may be able to increase your dosage or offer you alternatives which may work better for you. There is no reason why you should be in pain.

## Lung problems and changes in breathing

Sometimes people can experience shortness of breath or find breathing difficult. This may be due to anaemia, leukaemia cells getting into your lungs or a chest infection. Your immune system may find this difficult to deal with.

Although rarely prescribed, your healthcare team may be able to give you oxygen. Steroids may also be helpful if you have bronchospasm or partial obstruction. Bronchospasm is

a condition where the muscles that line the airways of the lungs tighten.

Practical strategies can be implemented to help improve your breathing. This can include physiotherapy, breathing exercises, relaxation exercises, gym sessions or group support. If you feel like these may benefit you, speak to your nurse or healthcare team who will be able to organise this.

When you are very near the final days of your life, your breathing may become irregular or louder. Your throat muscles relax as you become weaker and a build-up of fluid or phlegm develops in your throat. Your healthcare team will give you medication to minimise this build-up. If you receive morphine for pain relief, this may also help if you have any breathing troubles. If shortness of breath is causing you distress, you may be given an anxiolytic sedative. This is a drug given to reduce anxiety by providing a calming effect.

# Signs and symptoms to expect when reaching the end of life (cont.)

## Effects on the liver

When leukaemia affects your liver, it becomes less efficient in producing bile. Bile helps to:

- Digest food
- Remove toxins from your blood
- Make the proteins needed to help your blood clot
- Regulate your blood sugar levels

If your liver is not working properly, this can lead to the following symptoms:

- Nausea, decreased appetite and possible weight loss
- Swelling and discomfort of the abdomen
- Fluctuating blood sugar levels
- Jaundice: yellow colouring of the eyes and skin
- Increased risk of bleeding
- Lower level of consciousness

## Effects on the lymphatic system

The lymphatic system is part of

the immune system and consists of a network of fine vessels. These vessels drain the body of toxins, waste material and dead cells.

They drain into:

- The lymph nodes (small glands in the neck, armpits and groin)
- The tonsils
- The thymus (small gland under the chest bone)
- The spleen (large organ under the ribs on the left side of the body)

These lymphatic organs consist of white blood cells. These are called lymphocytes and fight infection in the body. The lymphatic vessels carry waste products from the body. It then drains into large blood vessels in the neck. The kidneys filter your blood before waste products pass through your urine.

The organs of the lymphatic system become full of the abnormal leukaemia cells. They can then increase in size and press against your blood vessels and organs. As a result, you can

experience blockages and pain.

Treatments your healthcare team use to reduce the amount of leukaemia cells include:

- Antimetabolite drugs, such as hydroxycarbamide. These prevent any new leukaemia cells being created by interfering with their DNA.
- Apheresis, where a machine filters out the existing leukaemia cells from your blood. During this process, a tube is inserted into a vein in each of your arms. Blood is then removed from one arm and passed through the machine to filter out the leukaemia cells. The remaining blood is then returned back into your body through the other arm. However, this is rarely done as part of end of life care.
- Steroids are also helpful as they reduce the activity of the immune system.
- Staying hydrated. By drinking lots of water or receiving fluids via a drip, this can help to flush out cell waste.

Common symptoms due to disorders of the lymphatic system include:

### Difficulty in eating and weight loss

As you approach the end of your life, your body becomes less able to absorb food and turn it into energy. Also, the leukaemia cells will be burning up your energy supplies. As you get weaker, you may become less interested in food and drink. You may not want to eat or drink especially if swallowing becomes painful. Swelling can also block your food pipe and prevent the intake of food.

However, it must be noted that it is perfectly normal if you notice a loss of appetite as you are less active. Your body no longer needs as much energy. Your healthcare team can provide you with formulated feeds and drinks. Do not feel like you have to eat or drink anything.

If your mouth becomes dry, you will be encouraged to take sips of water or have ice to moisten

# Signs and symptoms to expect when reaching the end of life (cont.)

your mouth. Prevention of dry lips can be achieved by applying a lip balm.

## Urinary retention

The kidneys may become infiltrated with lymphatic tissue and block the ureters. These are the ducts urine passes through from the kidney to the bladder. The increased lymphatic tissue, which is blocking your ureters cannot be removed. Palliative care is able to reduce the number of leukaemia cells in the body to help.

## Swelling and itching of the skin

This is caused by a build-up of lymph fluid in the affected area. It is thought that high levels of cytokines cause irritation of nerve endings. Cytokines are chemicals released into the blood by the body's immune system.

Swelling and itching of the skin will improve by reducing the number of leukaemia cells in the body. This can also reduce the build-up of lymph fluid in the affected areas. Your healthcare team can also provide you with creams to ease the itching.

## Feeling cold all the time

This can start to happen as your blood circulation decreases. You become more sensitive to cold temperatures and your hands and feet might feel cold. Your skin might become pale, blue and blotchy. The nurses or your relatives caring for you can provide extra bedding or heat pads to keep you warm.

## Fatigue and drowsiness

As leukaemia uses more and more of your body's energy, you will become more tired and need to rest more. As your energy levels become lower, you might lose interest in what is going on around you. At times you may be less eager to see people and prefer to see them one person at a time.

Your healthcare team may see if any drowsiness is being caused by the medication you are on. If possible, they will use alternatives.

Towards the end of your life, your drowsiness may start to increase. As a result, you may spend greater

periods of time asleep. It may be harder to waken you; but you will still continue to hear people around you and feel their touch.

## Bladder and bowel incontinence

Losing control of your bladder and bowel function is not uncommon in the last stages of life. Your nurse can provide you with incontinence pads. They will help to make sure you are comfortable, and your bed linen and clothes are not soiled. This can also prevent your skin becoming irritated and infected.

You may be fitted with a urinary catheter. This is a soft tube inserted into your bladder to drain urine away.

As you tend to eat and drink less, incontinence can become less of a problem as your body produces less waste. Towards the last hours of your life, your kidneys may shut down and stop producing urine.

## Hyperleukocytosis

Seen in CML and AML, but usually quite rare, this is when the blood becomes too thick because of the

leukaemia cells. This can make the passage of the blood through small blood vessels very slow and difficult.

It is important to note that drinking fluids can help to make your blood thinner.

Thicker blood can lower the supply to organs such as your brain. This can cause the following symptoms:

- Drowsiness or confusion
- Headaches
- Blurred vision
- Dizziness
- Loss of control over movements
- Imbalanced chemical levels

There is a fine balance of salts and chemicals in your blood, which your body regulates so that it can function. Your tissues can produce waste products and disrupt your levels of chemicals.

Your kidneys and liver remove waste products and manage the chemicals in your blood. But, if they are not working, high levels of chemicals in the blood can lead

# Signs and symptoms to expect when reaching the end of life (cont.)

to the following symptoms:

## Confusion and agitation

Confusion and agitation are often experienced by people towards the end of life. Causes of this tend to be blood chemical imbalances, or side effects from medication.

Your healthcare team will identify if any drugs are causing confusion and agitation. They will then be able to provide any support you need or offer you medication to help you feel less agitated.

Confusion and agitation are often a result of high levels of calcium in the blood. Your doctors can set up a drip or an infusion containing bisphosphonates. This is to help move the calcium in your blood back into your bones.

Lengthy periods of vomiting or diarrhoea can make you dehydrated. This can contribute to increasing your calcium levels. It is important to let your healthcare team know if this happens to you. High levels of calcium in your blood will increase your

drowsiness until you are falling asleep. If you are not treated, it is possible that you may go into a coma.

## Night sweats

This can result from chemicals released by the leukaemia cells. They stimulate the brain to increase the body temperature.

Keeping spare pyjamas/bedsheets close to the bed may help if you become drenched. Being able to easily change may prevent your sleep from being as disturbed during the night. Alternatively, you could try sleeping on top of towels.



# Coping with the emotional impact of a terminal diagnosis

If you're not already receiving palliative care, you may be referred to the palliative care team. Generally based in the community, the palliative care team will work with your GP. Their aim is to help you live as high a quality of life as possible. The palliative care team will also be able to offer you emotional support.

Being told that your leukaemia is terminal is a big thing for you to deal with. There is no right or wrong way to feel when receiving this news. It is a personal experience and people react in different ways.

The way you feel will depend on many factors, including:

- Your personality
- If you have family and friends to help you
- How satisfied you are with the life you have led
- If you are a religious or spiritual person

Yet, it will help you to feel more positive if all your needs are addressed towards the end of your life.

It is normal to feel shocked and upset when it is confirmed you are approaching the end of your life. For some there is a sense of disbelief, others may be angry, sad or anxious or afraid.

It is important to give yourself the time to reflect on the news you have received. It is natural for others to get upset or feel numb but letting the people around you know is a major step. Do not feel like you have to talk about it straight away. Although it tends to be a natural reaction, try not to ignore your emotions. It is better to voice your feelings, even if it is hard and difficult to cope with.

You may experience a range of emotions, including:

- Uncertainty
- Isolation
- Anxiety
- Anger
- Sadness and depression
- Acceptance
- Loneliness

Understanding each emotion and developing ways to deal with them

will help you face what is to come. You may experience all, some or none of the feelings mentioned in this booklet. A person's reactions can fluctuate and vary from person to person.

If you speak to your healthcare team, they can offer support. Some people find it helps to talk to a trained counsellor. This is someone who will help you to explore your thoughts and feelings. Alternatively, if you are feeling up to it, you may find it beneficial to join a support group or buddy scheme. It may help you to talk with people who are in a similar situation to you.

## Shock and denial

Finding out your treatments have not worked, and that you will die from your illness can be a shock. You may feel numb or unable to absorb the information. You might be unable to think about your emotions.

Shock is a survival process to protect yourself from pain in the short-term. This goes hand-in-hand with denial. It is a common reaction that stops you from becoming overwhelmed by

difficult news. But it is likely that you are taking in this information at a subconscious level. Your period of denial should not be rushed as you will move beyond it, when you are ready to do so.

## Anger

Feeling angry at your news is a natural and normal response to your anxiety about the end of your life. You may be angry with yourself, the healthcare team or the people closest to you. You may display your anger as impatience, irritability or frustration. You may feel that you have lost control of your life and that you're leaving the people you love behind. Talking about feelings and letting them out may help to stop you lashing out and keep things calm.

## Isolation

Irrespective of whether you have people around you, you can still feel very isolated. Try not to push away the people closest to you. They want the best for you. You will need their help to achieve the end of life you want, which is different for everyone.

You may feel dealing with your situation will allow you to spend

# Coping with the emotional impact of a terminal diagnosis (cont.)

more time with those closest to you. But, being around the people closest to you can be positive and negative.

Let the people closest to you know:

- What you do and don't want to do
- How you do and don't wish to be treated
- What you do and don't feel comfortable talking about

Sometimes, it is difficult for your loved ones to understand what you are feeling. Being clear with them will help create a positive, supportive, and caring environment.

## Uncertainty and anxiety

Being uncertain and fearful of the unknown when we are feeling threatened is normal. You may experience an increased heart rate, rapid breathing, or muscle tension. These things help us to face a danger or run away as part of the 'fight or flight' response. Any feelings of discomfort, pain, or even the prospect of

another appointment, may create such anxiety. This can give you sleepless nights or feelings of worry. This is completely natural.

Your healthcare team can help you with uncertainty so that you have a clear path set out in front of you. They can also provide you with medication if necessary. Help, care, kindness and support will be available to you from your healthcare team. You may have access to counsellors and therapists where appropriate. Cognitive behavioural therapy can help you deal with your worrying thoughts.

## Sadness and depression

Sadness and depression are often associated with end of life. You may feel sad for yourself or your loved ones. You may have a feeling of regret or loss. If these feelings continue for more than several weeks, you feel hopeless and lose interest in life, then you may have depression. Let your healthcare team know. They can prescribe antidepressants to enable you to enjoy the rest of your life. Trying to manage your

depression on your own and cope with your leukaemia as well is difficult. Palliative care nurses are often trained counsellors or can arrange counselling for you. Some counsellors can visit you at home or in a hospice or hospital.

## Acceptance

If you can achieve acceptance as you reach the end of your life, this can give you a feeling of relief and peace. But not everyone can achieve this. The people closest to you might not achieve acceptance until a long time after a loved one has died.

Practicing mindfulness and relaxation techniques can help you to:

- Calm the mind
- Release tension
- Ease any pain

You might also find it helpful to write letters to loved ones or meet friends you haven't seen in a long time. You can even try to resolve any conflicts that you may have.

## Loneliness

If you are facing your diagnosis on your own, or are feeling lonely and isolated, you will still be able to discuss things with your healthcare team.

Leukaemia Care and other organisations such as Macmillan Cancer Support, Cancer Research UK and Maggie's are happy to answer any queries you have on the phone. They also run support groups and training days and have staff who can signpost you to further help.

Leukaemia Care provides a Buddy Support scheme so you can talk with someone going through a similar experience to you. For more information about this service and others that Leukaemia Care provides, you can go to [www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk) or call the helpline on **08088 010 444**.

# Telling children about my terminal diagnosis

## Telling children

If you have children, or there are children close to you, you may want to protect them from news that may upset them. However, involving the children in what is happening and being open is often the best way. Children generally realise when something is wrong. They may worry it is something they have done. It is important for them to realise that they are not responsible for your illness.

If the children are already aware of your leukaemia, then you will be bringing them up to date. If the children do not know about your leukaemia, it can be better to not tell them everything straight away. You could give them small bits of information about your illness over a longer period of time.

Telling a child that an adult close to them has terminal leukaemia is a difficult thing to do. However, you do not have to do it on your own. Support from the people closest to you and healthcare professionals is available. They can step in if you become

emotional.

If you have a partner and want to tell your child with them, it might be helpful to discuss how you are going to approach it. Asking them how much they understand about the situation to start with can often be helpful. You can fill in on anything they don't know and then explain the news of your prognosis. This approach allows the children to ask questions. Asking questions will help them to understand what is happening. You may want to consider any questions they may ask so you can have the answers ready.

If you would like help from your healthcare team, they can join in a meeting with your children. They can be available to help answer their questions. Or you can ask for their advice on how to word things.

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

The main points to convey are:

- Your illness is nothing to do with them and it is not their fault
- They will still be loved and cared for when you are gone

If the children are very young, they may not understand the situation well. There may also be a change in their behaviour as they begin to display their anger, confusion and/or sadness. But, as long as they understand that you are ill and that they should be gentle, that is a good start. They will only be able to take in simple explanations and you might need to repeat these several times.

Children can understand more as they get older. You will know the most suitable way to talk to the children in your life. Being honest with them can help them to make sense of the situation. It also gives them the opportunity to ask questions and share their worries and fears. Try not to stop yourself getting upset. It will allow the children to know that showing their feelings, including sadness, is okay.

A lot of information about leukaemia is out there which children are probably aware of.

There are also lots of books about cancer and its treatment. As leukaemia is a blood cancer, even general information about cancer can be relevant.

Macmillan Cancer Support have a comprehensive section of how to prepare children for the loss of a loved one from cancer on their website, including questions that children may ask and suggestions for answers: [www.macmillan.org.uk/information-and-support/coping/advanced-cancer/relationships/talking-to-children-if-not-going-to-recover.html](http://www.macmillan.org.uk/information-and-support/coping/advanced-cancer/relationships/talking-to-children-if-not-going-to-recover.html).

Marie Curie also have booklets to help with talking to children. These include a booklet for those with a relation who has a terminal illness and a booklet for those with a relation who has died. You can download them from their website at: [www.mariecurie.org.uk](http://www.mariecurie.org.uk)

# Telling children about my terminal diagnosis (cont.)

## Children's reactions to the news of your illness

Children react in different ways to the news that one of their loved ones is likely to die from leukaemia. While some may be very upset, others may become distant or change their behaviour. It is important to understand that this is not a reflection on you, but their way of showing how upset they are.

It is important to keep reassuring children that your illness has nothing to do with them. It is a common misunderstanding by children that they are to blame. It is particularly difficult for teenagers. They are becoming independent but feel like they should be at home to spend time with you. This may add to their feelings of guilt.

Let children know that their worries of what will happen are often greater than the reality. Explaining to them what will actually happen will help reassure them.

It may also be useful to let the children's teacher/school know

of your situation. They will know to be more understanding and be able to let you know if their behaviour changes. It may also help to maintain their normal routine as much as possible if their teacher/school is kept in the loop. You can let them know who you would like to be aware of your illness within the school.



# Practical steps you can take

You may have already attended to your financial affairs, but if not, now is a good time to do it. By doing so, you can arrange for your wishes to be carried out in the future. It may also mean there is one less thing for you and your loved ones to worry about.

Alternatively, you may want to ask someone close to you to help you see to these practical end of life matters. It can be quite a task to sort out your affairs and one that needs strength, energy and courage. It can be easy to put this job off or not do it at all.

Practical steps you can take could include:

- Writing a will
- Planning a funeral
- Registering a Power of Attorney
- Sorting out plans for dependents
- Sorting out social media and other online accounts
- Deciding who you want to be involved in decisions (next of kin)
- Putting together personal documents (and leaving where

they can be found by your next of kin, or Power of Attorney)

- Putting together an Advanced Care Plan

More information about some of these can be found later in this booklet.

For more information on these topics - including planning and paying for a funeral, Lasting Power of Attorney and writing wills - you can read our toolkits on the Leukaemia Care website at [www.leukaemicare.org.uk](http://www.leukaemicare.org.uk).



# Advanced Care Planning

This is a process of discussing preferences and important information such as how you want to be cared for, how you would like your life to be, what and who is important to you as well as any treatment decisions you may want to make in advance.

Documents that may feature in your Advanced Care Plan include:

- An advanced statement (free to create)
- An advanced decision (free to create)
- Lasting Power of Attorney (free to create, but £82 to register)

## Advantages of having an Advanced Care Plan

Taking the time to create an Advanced Care Plan can often act as a good way to start conversations with the people closest to you about the future as you reach the end of your life. It also ensures that everyone involved in your care understands your wishes and what is more important to you well ahead of time.

For more information and support regarding Advanced Care Planning, go to the Compassion in Dying website at [www.compassionindying.org.uk](http://www.compassionindying.org.uk).

## Making an advanced statement

An advanced statement is a written statement that sets out your preferences with regards to any aspect of your future health or social care. As long as you have mental capacity, you are able to put together the document yourself, but you may want some help from your healthcare team.

An advanced statement can include any of the following:

- Any religious or spiritual preferences
- Where you would like to be cared for
- How you like to do things
- Concerns about practical issues

While an advanced statement is not legally binding, it must be

taken into account by anyone who is providing care for you. To ensure it is clear that the statement was made by you, you may want to sign it; however, this is not mandatory.

An advanced statement is not the same as an advanced decision. An example of one can be found on the Compassion in Dying website at: <https://compassionindying.org.uk/library/advance-statement/>.

## Making an advance decision

You may want to consider writing an advance decision. This is also called a living will or an advance directive. The document sets out any future treatments you do not want, in case you aren't able to tell your healthcare team in the future. It must be written down, signed by you and by a witness. The document is legally binding so long as the following criteria can be applied:

- The person making the advance decision has mental capacity
- The advance decision is valid
- The advance decision applies to

the situation

An example of an advanced decision can be found on the Compassion in Dying website at: <https://compassionindying.org.uk/library/advance-decision-pack/>.

For more information about planning ahead for your treatment and care, including advance statements and advance decisions, you can read our toolkit on the Leukaemia Care website at [www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk).

## Power of attorney

A Power of Attorney is a legal document which allows someone to make decisions on your behalf. You should choose someone you trust as your attorney as they are going to act for you when you are no longer able. In the UK, an attorney is a person, often a lawyer, appointed to act for you in business or legal matters. However, the person you choose does not have to be a lawyer and you are allowed to have more

# Advanced Care Planning (cont.)

than one attorney. For example, your power of attorney can be a relative, friend or a spouse.

To set-up a Power of Attorney, you must be able to show mental capacity which is defined as having the ability to:

- Understand information relevant to a decision
- Retain that information
- Evaluate that information as part of the process of making the decision
- Communicate your decision (by talking, using sign language or any other means)

In England and Wales, there are two types of Power of Attorney:

1. Ordinary Power of Attorney - this is temporary
  2. Lasting Power of Attorney - this is permanent
- Property and financial affairs (this includes managing your bank account(s), paying bills, collecting benefits or a pension, selling your home)
  - Health and welfare (this includes your decisions

affecting your daily routine, medical care or life-sustaining treatment, moving into a care home)

A Lasting Power of Attorney is required if you want to allow someone to take over your affairs permanently. Once it is granted, you need to register before it can become effective. This process can be quite lengthy so it may be worth putting it in place as early as possible. If you do this process online, you can complete the application. Also, you can fill in the registration of the Lasting Power of Attorney. More information can be found here: [www.gov.uk/government/publications/make-a-lasting-power-of-attorney](http://www.gov.uk/government/publications/make-a-lasting-power-of-attorney).

As soon as it is registered, a Lasting Power of Attorney remains in place even if you lose mental capacity. An Ordinary Power of Attorney is revoked if the donor loses mental capacity. It gives someone the power to manage your property and financial affairs for a set time.

Power of Attorneys are called different things and work slightly differently in Scotland

and Northern Ireland. For more information about how a Power of Attorney works:

- If you live in Scotland, more information can be found here: <https://www.mygov.scot/power-of-attorney/>
- If you live in Northern Ireland, more information can be found here: <https://www.nidirect.gov.uk/articles/managing-your-affairs-and-enduring-power-attorney>

## My options for where and how I die

### Choosing where I die

For some, choosing where to die is important. For others, the focus is less on the place of their care or death, and more on their needs and what can be achieved in different settings.

In most areas of the UK, the following options of where to die are already available:

- Own home
- Hospital
- Care home (with or without nursing)

- Hospice

Other things that you might find important, include:

- A need for calm and tranquility, having loved ones close by and feeling respected.
- A flexible approach to providing places to die.
- Having the choice of where to die.

The choice of where you want to die may depend on:

- Your health
- What is available in your local area
- What support you can get, particularly if you would like to be cared for at home

It is important to note that, due to certain circumstances, the choice you end up making about where and how you want to die may not be what you initially wanted. But, if your healthcare team and the people closest to you are aware of your wishes, they can do their best to fulfil them. Your healthcare team can give you an idea of what you can expect and what support you will need.

# Advanced Care Planning (cont.)

## Dying at home

Being at home, sleeping in your own room and having your loved ones around you can be very comforting. You might feel that being at home can provide peace and privacy.

You need to discuss with your GP and district nurse what support you might need. It is important to get an accurate assessment of your needs so you can make realistic plans. You might find it easier to do this with the people closest to you present so everyone can understand what will happen. While most pain or other symptoms can be managed at home, some people need specialised care. For this, they will need to be in a hospice or care home with nursing.

It is important to discuss dying at home. If your loved ones will be caring for you, they may also need support as it can be demanding. This can be from relatives or your GP and nurses. If you have children or teenagers at home, they may need help understanding the process and how to cope.

Healthcare professional support

is available, but it is unlikely to be full-time. Your GP or nurse can let you know what they provide. Your GP will manage your medical care. This includes prescribing medication and arranging for other healthcare professionals to visit.

Someone within your healthcare team will be able to take care of nursing needs at home. This includes giving injections and providing bowel and bladder care. They will work to help you with washing, using the toilet, and eating and drinking.

A palliative care nurse may visit on a regular basis. They will help to guide the nursing team on managing pain and other symptoms. Occupational therapists can provide any home equipment or home alterations when required.

Medical care at home tends to be free. You may have to pay for or contribute towards some of the costs of your personal or social care. This will depend on the care you need, where you live and how much savings or income you have. Social workers will be able to tell you how to navigate your way

around the health and social care system.

## Hospitals

Unless your advance decision says otherwise, if you are unwell or need specific tests or treatment, you will be admitted to hospital. Control of any symptoms and care will be provided in the hospital. The majority of hospitals have specialised care teams who are experts in caring for people at the end of their lives.

There may come a time when you will not benefit from further treatment in hospital. In this case, you will need to consider a process known as discharge planning. This will include thinking about what kind of care and support you need and where that can be provided.

Before you leave hospital, the palliative healthcare professionals will assess your care needs. They will then communicate this to the healthcare professionals looking after you. This is often communicated as a discharge plan or letter, which you will also receive a copy of. The hospital palliative care team can explain

what you might expect in the days or weeks ahead. They are also available to answer any questions if you are unsure about anything.

## Hospices

Hospices are very experienced in providing palliative and end of life care. They provide both nursing and some medical care. Hospices are free and you won't need to pay for any aspect of the hospice care.

You may have the option of staying at a hospice for specialist care, and then returning home. Alternatively, you can remain in the hospice if you and your carer can no longer cope at home. Visiting the hospice for care during the day but not staying overnight is another option. Additionally, some hospices will provide care for you in your home.

Hospices can provide care for you and the people closest to you, ran by a team of professionals. These include:

- Nurses
- Specialist nurses and doctors
- Physiotherapists
- Occupational therapists

# Advanced Care Planning (cont.)

- Social workers
- A chaplaincy service

Hospices work in close contact with healthcare professionals to provide the best care.

Hospice UK is the national charity for hospice and palliative care and their website can give you information if hospices are for you and how to find a hospice near you at: [www.hospiceuk.org/about-hospice-care/find-a-hospice](http://www.hospiceuk.org/about-hospice-care/find-a-hospice).

Marie Curie, which is a charity that provides care and support through terminal illness, also have nine hospices throughout the UK: [www.mariecurie.org.uk/help/hospice-care](http://www.mariecurie.org.uk/help/hospice-care).

## Care homes, with or without nursing

Care homes, with or without nursing, provide care day and night, but they are not free. In a care home with nursing, the

carers are registered nurses. This benefits people with a long-term illness or condition requiring medical care. The NHS may provide funding towards a care home for some people.

Marie Curie has an excellent webpage which will help you decide where to be cared for at the end of your life: [www.mariecurie.org.uk/help/support/terminal-illness/preparing/choosing-where#residentialcare](http://www.mariecurie.org.uk/help/support/terminal-illness/preparing/choosing-where#residentialcare).

## Choosing how I die

How you die is often related to where you have chosen to die. Involving the people closest to you in both decisions is sensible. It can be beneficial to make these decisions together.

The most important aspect is that you are able to die in a peaceful and dignified way with your loved ones. Your medical and palliative care teams will be aware of your personalised care plan. They will review and update it as necessary.

Local registers in areas of England can hold peoples' preferences for end of life care. Your GP or healthcare team will help get you placed on these registers.

Authorised staff can access these local registers. This ensures that everyone involved in your care is aware of your preferences.

## **Spiritual and religious considerations**

When you are at the end of your life, it is important to feel that your spiritual needs are also being met. Spiritual support is available to everyone, regardless of whether someone has religious beliefs. Some people have well-established religious beliefs or spiritual practices. Others may only become aware of this when they are nearing the end of their lives. Others might not have any spiritual or religious beliefs to consider.

Let people caring for you know if you have any spiritual or religious needs. For example, you might want a religious or spiritual leader to visit you during your last few weeks of life. Many people find this helpful and comforting. Religious or spiritual advisers are able to visit you if you're at home, in a care home, in a hospice, or in hospital. Whatever your needs are, your healthcare team will add this to your notes.

# Making a will

Writing a will ensures that your estate will go to the people and organisations that you want it to go to. This includes any property, money and possessions that you have. If you do not leave a will when you die, dealing with your estate can be more complicated and take longer.

## Advantages of having a will

If you die intestate (i.e., with no will or an invalid will), the rules of intestacy stipulate how your estate is divided up. In this case, only married or civil partners and some close relatives can inherit. Unmarried partners or stepchildren have no legal right to inherit from your estate. By including them in your will, you can make sure they are looked after.

If there are no surviving relatives, your estate will pass to the Crown or government. More details of the rules of intestacy can be found here: [www.citizensadvice.org.uk/family/death-and-wills/who-can-inherit-if-there-is-no-will-the-rules-of-intestacy/](http://www.citizensadvice.org.uk/family/death-and-wills/who-can-inherit-if-there-is-no-will-the-rules-of-intestacy/)

If you have children, you can

leave instructions about who is to look after them. This can include leaving a legal guardian. You can also include instructions for any pets that you have. You may want to send them to an animal shelter or pass them on to someone close to you to look after them.

You can specify the plans for your funeral in your will. This states what you would like to happen such as:

- How you want to be dressed
- What music you would like to be played
- Any other choices you have for your funeral

Writing a will can also help you to minimise any inheritance tax. The law will deal with your inheritance if you do not have a will. Information about this can be found at: [www.gov.uk/inherits-someone-dies-without-will](http://www.gov.uk/inherits-someone-dies-without-will)

## Writing a will

Writing a will is not particularly challenging or costly. But, as it is a legal document, the correct preparation of a will is vital.

If your affairs are very

straightforward, you can write your own will. For example, if you are married and want to leave everything to your spouse, but if they die before you then you want to leave everything to your children. Templates for preparing your own will are not expensive and are available online.

You need to include a responsible person of your choice to carry out the instructions in your will. This is called an executor. You need to have complete trust and confidence in this person. You also need to make sure you sign the will in the presence of two witnesses, who must also sign the will for it to be valid. Your will should be stored in a safe place and you need to make sure your executor knows where it is. You can also register your will with Certainty, the National Will Register. This costs around £30.

If your will is likely to be complicated, see an independent solicitor. They can ensure your will is a valid document, hold the will for you and make sure your wishes are carried out. You should get a quote from several solicitors to make sure you get the best deal. Local will solicitors can be

found on the following web sites depending on where you live:

- [solicitors.lawsociety.org.uk](https://www.solicitors.lawsociety.org.uk) for England and Wales
- [www.lawscot.org.uk/find-a-solicitor](https://www.lawscot.org.uk/find-a-solicitor) for Scotland
- [www.lawsoc-ni.org/solicitors](https://www.lawsoc-ni.org/solicitors) for Northern Ireland

MacMillan Cancer Support and Cancer Research UK provide a free will-writing service. Marie Curie also provides a free will-writing service for people over the age 55.

## Updating your will

You will need to update your will if there are any changes to your situation. You can make them using a supplement to your will called a codicil. You will need to sign the codicil and have witnesses. The witnesses do not need to be the same as for the original will. Although it is possible to add as many codicils as you want, it is better to write a

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# Making a will (cont.)

new will if the changes are major.

Changes which should be added to your will include a marriage or civil partnership. In England, Northern Ireland and Wales, these events will revoke the existing will. In Scotland, this will not revoke a will, but may affect it. If you have children or grandchildren, or have met a new partner, you may need to update your will to now include them.



# Taxes to consider

## Transferable tax-free allowance

Inheritance tax is a tax on the estate of someone who has died. Inheritance tax rate is 40% of the value of the estate. No inheritance tax is applicable when either:

- The value of your estate is below the £325,000 inheritance tax threshold
- You leave everything above the £325,000 threshold to your spouse, civil partner, a charity or a community amateur sports club

If your estate is worth less than £325,000, you may transfer the tax-free allowance to your spouse or civil partner. When they die, they can then leave more money before paying inheritance tax on their estate.

If the value of your estate is more than £325,000, it is worth thinking about putting more of your current savings into a personal pension. When you die, this can pass to whoever you name in your will and no inheritance tax will be due.

If you decide to give your

home to your children or your grandchildren, your threshold will increase from £325,000 to £475,000. This also includes adopted, foster or stepchildren.

If you share a property, your share will count as part of your estate. Unless the person you own the property with is your spouse or civil partner, inheritance tax will be due on your share.

## The Family Home Allowance

This is an extra tax-free allowance for people who own a home. The property must have been your home and left in your will to either children or grandchildren to qualify.

The Family Home Allowance is also transferable between spouses and civil partners.

The Family Home Allowance will only apply if your estate is worth less than £2 million.

## Charitable legacies

A charitable legacy is where you leave a sum of money to a charity of your choice which is deducted from your estate before

inheritance tax is calculated. If you leave 10% or more of your estate to charity, you may be subject to less inheritance tax. Following a deduction of the inheritance tax-free allowance, your estate will be taxed at 36% rather than 40%.

# Other financial considerations

## Bank accounts

Several banks such as Lloyds Bank, Bank of Scotland and Halifax are working with MacMillan Cancer Support to provide personalised support to cancer patients.

Macmillan has developed Cancer Support Teams who understand the financial impact of cancer. They offer support with finance management, including debt management. They also provide practical guidance on personal banking, savings, loans and credit cards. This initiative is to handle any money worries for cancer patients, so they can get back to the things that matter most.

Details of this initiative can be found at: [www.macmillan.org.uk/about-us/working-with-us/corporate-partners/lloyds-bank.html](http://www.macmillan.org.uk/about-us/working-with-us/corporate-partners/lloyds-bank.html).

## Benefits

When you have leukaemia, you might need support with extra costs. Benefits are payments from the government for people who need financial help. If you are not able to work, you might be able to receive some benefits.

It is important to know that special rules exist for people who are terminally ill when it comes to applying for benefits.

## Special rules

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

Special rules apply to certain benefits. These are:

- **Employment and Support Allowance** – entitlement to this depends on if you have been working and paying national insurance contributions previous.
- **Universal Credit** – entitlement to this depends on your household's income and savings. You could use a benefits calculator to work out if you should be entitled to it: <https://www.gov.uk/benefits-calculators>.
- **Personal Independence**

**Payment** – if you are under pension age and have less than six months to live, you will be entitled to this.

- **Attendance Allowance** – if you are over pension age and have less than six months to live, you will be entitled to this.

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

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

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

If you are unsure about applying for benefits, or would like some more support and advocacy, organisations such as the Citizens Advice Bureau and Age UK are able to help. You can also speak to our Patient Advocacy team by calling **08088 010 444** or emailing [advocacy@leukaemiacare.org.uk](mailto:advocacy@leukaemiacare.org.uk)

## [leukaemiacare.org.uk](http://leukaemiacare.org.uk).

Some of the benefits that may be available to you are listed below.

### Statutory Sick Pay

If you work for an employer and have time off work because of your illness, you are entitled to Statutory Sick Pay. Your employer will pay this for up to 28 weeks. This statutory amount can be increased if your employer offers a sick pay scheme. More details can be found at [www.gov.uk/statutory-sick-pay](http://www.gov.uk/statutory-sick-pay).

### Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who have a disability or illness that makes it hard for them to work.

There are three different types of ESA, each with different eligibility criteria:

1. **‘New Style’ ESA** – To claim this you will need to have been employed or self-employed and paid National Insurance contributions, usually within the last two to three years, and now have an illness or disability that affects your

# Other financial considerations (cont.)

ability to work.

## 2. Contribution-based ESA -

This follows the same type of criteria as 'new style ESA', but you also have to be in receipt of the severe disability premium or you should have received it within the last month and still be eligible for it.

## 3. Income-based ESA -

This type of ESA is not related to your National Insurance contributions, but you need to have savings of less than £16,000.

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

Relatively few people can still make new claims for contribution-based or income-based ESA. For example, only those in receipt of the severe disability premium are able to make a new claim for income-based ESA.

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

## Personal Independence Payment

This benefit is for individuals aged between 16 and the State Pension age who need help at home with preparing food, bathing and dressing because of a disability or illness. An extra payment is available for those who have difficulties moving around. The health condition must have been present for at least three months and expected to last for at least nine months. The Personal Independence Payment replaces the old Disability Living Allowance. More details can be found at [www.gov.uk/pip](http://www.gov.uk/pip).

## Attendance Allowance

Individuals of over State Pension age with the need for care or supervision because of an illness or disability, for example getting out of bed, having a bath or getting dressed, can claim Attendance Allowance. These needs must have been present for at least six months. More details of Attendance Allowance can be found at [www.gov.uk/attendance-allowance](http://www.gov.uk/attendance-allowance).

## Disability Premium

Disability premiums are payments which can be added to the following benefits:

- Income Support
- Income-based Jobseeker's Allowance
- Income-related ESA
- Housing benefit

You do not need to apply for a disability premium. There are three types of disability premium for adults:

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

The disability premium that you will receive is based on what other benefits you are in receipt of and at what rate. For example, for the severe disability premium, you must get the disability premium or income-related ESA, and one of the following qualifying benefits:

- PIP daily living component
- Armed Forces Independence Payment

- DLA care component at the middle or highest rate
- Attendance Allowance (or Constant Attendance Allowance paid with Industrial Injuries Disablement Benefit or War Pension)

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

## Universal Credit

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

Universal Credit is a replacement for the following benefits:

- Child Tax Credit
- Housing Benefit
- Income Support
- Income-based Jobseeker's Allowance
- Income-related ESA
- Working Tax Credit

# Other financial considerations (cont.)

If you currently receive any of these benefits, it might be a good idea to use a benefits calculator to check if you would be better off staying on your existing benefits or claiming Universal Credit. If you make a claim for Universal Credit, any claim you have for tax credits, housing benefit, income support, income-based Jobseekers Allowance or income-related ESA will be closed.

You cannot claim Universal Credit if you either:

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

However, you can still make new claims for the benefits Universal Credit replaces.

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

## Carer's Allowance

This allowance is for individuals aged 16 or older caring for someone for at least 35 hours a week. There are some rules that

the carer has to comply with:

- The carer must not be in full-time education/studying for 21 hours a week or more
- Their earnings from employment or self-employment must be less than £123 a week after tax, national insurance and expenses

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

## Grants from charities

Several cancer charities provide grants to people with cancer and their families:

- Macmillan Cancer Support offer one-off grants for people with cancer who have a low income and low savings.
- Charis Grants Ltd provide help for people who are finding it difficult to pay for energy and other essential household bills. It works with utility companies and local authorities to offer grants.
- Turn2us offers financial help and support to people who need it, including those with cancer.

## Pensions

### The state pension

Your State Pension age is the earliest age you can start receiving your State Pension. Since December 2018, the State Pension age for men and women has been increasing in stages from 65 to 68 years.

Your State Pension age is currently worked out based on your gender and date of birth. A State Pension age calculator is available on the government website [www.gov.uk/state-pension-age](http://www.gov.uk/state-pension-age).

As it is reviewed on a regular basis, the State Pension age may be subject to further changes in the future.

### Personal pensions

The two most important reasons for reviewing your personal pension are:

1. You may be able to access your pension early
2. You need to find out if your family will benefit from your pension when you die

There are two main types of personal pensions:

1. **Defined-contribution pension:** Money in this type of pension is derived from how much you and your employer have contributed, or yourself in the case of a private pension, together with the tax relief on this money.
2. **Defined-benefit pension:** Often called a final salary pension, the pension money is based on your salary and how long you've worked for your employer. Your employer's scheme pays a guaranteed amount to you rather than into a pension pot on retirement.

It is important to check the details of your personal pension to see what it offers. This includes seeing what payments might be available for your dependents. If this is an option, you will need to inform your pension provider using an expression of wish form. Without this form, the Trustees will decide who it will benefit.

### Special tax rules for people who have a serious illness

Special tax rules are in place for

# Other financial considerations (cont.)

people who have a serious illness, which is defined as expected to live for less than 12 months. You may be able to take your whole pension pot tax-free if all of the following apply to you:

- You are expected to live for less than a year because of a serious illness
- You are under 75 years old (if you're over 75, you pay Income Tax on the lump sum)
- You do not have more than the lifetime allowance of £1,055,000 in pension money

You can find more details on this pension provision at [www.pensionwise.gov.uk/en/ill-health](http://www.pensionwise.gov.uk/en/ill-health).

## Taking money out of your pensions

Before taking any money out of your pension(s), you are advised to consult the Pensions Advisory Service or, book an appointment with Pension Wise if you are over 50 years old.

Both the Pensions Advisory Service and Pension Wise provide expert, independent advice in a language that is

easy to understand. Moreover, the information they provide is completely free. They are keen to point out that they cannot provide advice or guidance on which options you should take. If you are unsure, you could consult an independent financial adviser.

It is important to be aware of firms which try and entice savers to unlock their pension pots early. They will tell you they know of a legal loophole, so you don't pay the tax penalty for these unauthorised payments. There is no legal loophole and these unauthorised transactions will lead to a large tax bill. You can find more details of the implication of unauthorised pension payments on the Government pensions webpage [www.gov.uk/guidance/pension-schemes-and-unauthorised-payments](http://www.gov.uk/guidance/pension-schemes-and-unauthorised-payments).

## Defined-contribution pensions

For defined-contribution

pensions, you can access your pension from 55 years old. You will need to decide how to take your pension money, and if you want to leave money behind for your spouse or partner.

The options available to you include:

- Take all your pension pot as cash in one go – 25% will be tax free and the other 75% will be subject to tax.
- Take out smaller lump sums of cash from your pension pot as and when you need it until it runs out. These amounts are sometimes referred to as Uncrystallised Funds Pension Lump Sums. For each lump sum, 25% is tax free and the rest is taxable.
- Arrange a Flexi-Access Drawdown which allows you to take a tax-free lump sum of up to 25% of your pension and leave the rest invested. Income can then be withdrawn from your pension fund as and when it is needed.
- You can buy an annuity with all or part of your pension pot. This will generate guaranteed

regular income for the rest of your life. It is important to shop around to get the best deal and get advice from an authorised financial adviser. In most cases, annuities stop paying out on your death. Some annuities include the option of providing for a dependent for life after you die. This is in return for a lower income.

- Leave your pension pot untouched i.e. it remains invested.

Aside from the last option, you can arrange for a mix of any of the above, especially if you have several pension pots.

### Defined-benefit pensions

The options above for a defined-contribution pension are not available for defined-benefit pensions. These pensions pay out a secure income for life with annual increases.

These pensions are often offered by large private employers or public funded organisations. These schemes continue to pay a pension to your spouse, civil partner or dependents when you die.

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# Donating my organs

Cancer does not automatically prevent you from donating your organs. However, it can influence what organs you can donate. If you would like to donate your organs, talk to your medical healthcare team. They will be able to determine which of your organs or tissues will be suitable for donation based on your medical history.

Some people want to donate their body for medical research. It is important to discuss this with your healthcare team and the people closest to you. More information about donating your body, organs or tissue is available at the NHS Blood and Transplant website: [www.nhsbt.nhs.uk](http://www.nhsbt.nhs.uk).

NHS Blood and Transplant keep a register of people wanting to donate organs after death. You can join the register online or by phone. In Wales (and England from 20th May 2020 and Scotland from Autumn 2020), people must opt out if they do not want to be an organ donor.



# Organising a funeral

A funeral is a ceremony held shortly after a person's death, such as a burial or cremation. It is often conducted with the people closest to you present. It helps them to say goodbye and celebrate your life.

Discussing what you would like at your funeral will give your family some comfort. They will know that they are organising a funeral you would like. Also, it makes things a little easier for your loved ones while they are grieving for you.

Suggestions for some of the topics you could discuss include:

- Type of funeral such as burial, cremation, civil/non-religious or memorial service
- Location of the funeral
- Guests
- Type of service such as religious, multi-faith or natural/woodland/green
- Clothes you would like
- Special requests for readings, songs, flowers

Depending on the type of funeral you want, the cost can be quite

expensive. The cheapest option is a direct cremation. Your body will go straight from the mortuary to the crematorium. The cremation is then carried out at the crematorium's convenience. No ceremony happens at the crematorium. Instead, loved ones can hold a memorial service at a time and place that suits them.

If you would like a traditional funeral, the funeral director will be able to organise:

- The visitation (display of the body before burial, either at your home or the funeral parlour)
- A funeral procession led by the hearse
- Transport of the guests to and from the ceremony
- The burial ceremony itself
- The wake, if not held and organised in the family home

As this can be very expensive, you might want to think about setting up a funeral pre-payment plan. You can find out more from the National Association of Funeral Directors. Someone may have recommended a funeral director

to you. It is important to be clear on which services the quote covers as this can vary.

If the person arranging the funeral has a low income, they may qualify for a Funeral Expenses Payment. For more information on this, go to: <https://www.gov.uk/funeral-payments>.

# Glossary

## Acute Leukaemia

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

## Acute Lymphoblastic Leukaemia (ALL)

Acute lymphoblastic leukaemia is a cancer of early white blood cells. Normal white blood cells divide and grow in an orderly and controlled way; however, in leukaemia this process is disrupted. This means signals that stop the body making too many cells are ignored. Cells continue to divide but do not mature into normal lymphoid cells.

## Acute Myeloid Leukaemia (AML)

Acute myeloid leukaemia is a type of blood cancer that starts from the myeloid cells in the bone marrow. Myeloid cells have the ability to develop into any of the blood cells (red, white or platelet cells).

## Advanced Care Planning

A process that allows individuals to make decisions about their future health and social care.

## Advanced Decision

Also called a living will or an advance directive, this legally binding document sets out any future treatments you do not want.

## Advanced Statement

A written statement that sets out your feelings and preferences regarding any future health and social care.

## Blood Cells

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

## Bone Marrow

The soft blood-forming tissue that fills the cavities of bones and contains fat, immature and

mature blood cells, including white blood cells, red blood cells, and platelets.

### Chronic Lymphocytic Leukaemia (CLL)

A cancer that affects the blood and bone marrow derived from lymphocytes.

### Chronic Myeloid Leukaemia (CML)

A type of blood cancer of the myeloid cells in the bone marrow. In CML, it is mainly the white blood cells such as the granulocytes that are most likely to multiply. CML involves the presence of the BCR-ABL fusion gene.

### Clinical Trial

A medical research study involving patients with the aim of improving treatments and their side effects. You will always be informed if your treatment is part of a trial.

### End of Life Care

End of life care is support for people who are in the last few

months or years of their life. The aim is to help patients enjoy a good quality of life until they die, and to die with dignity.

### Lymph Node or Lymph Gland

An oval-shaped component of the lymphatic system that helps to destroy viruses and bacteria. It contains white blood cells that fight infections.

### Multi-Disciplinary Team (MDT)

A meeting of the group of professionals from one or more clinical disciplines who together make decisions regarding recommended treatment of individual patients. MDTs may specialise in certain conditions, such as cancer.

### Palliative Care

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

# Glossary (cont.)

give you and your loved ones the best quality of life possible. Your doctor will discuss the options with you in detail before you decide the next steps.

## Platelets

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

## Power of Attorney

A Power of Attorney is a legal document which allows someone to make decisions on your behalf. This can be temporary (Ordinary Power of Attorney) or permanent (Lasting Power of Attorney).

## Prognosis

Indication of how well a patient is expected to respond to treatment based on their individual characteristics at the time of diagnosis or other timepoint of the disease.

## Red Blood Cells

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

## Refractory Condition

A condition for which treatment does not result in a remission. However, the condition may be stable.

## Relapse

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

## Spleen

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

## Toxicity

Harmful effect.

## White Blood Cells

White blood cells create an immune response against both infectious disease and foreign invaders. Granulocyte white blood cells include the neutrophils (protect against bacterial infections and inflammation), eosinophils

(protect against parasites and allergens) and basophils (create the inflammatory reactions during an immune response). Other white blood cells include the lymphocytes (recognise bacteria, viruses and toxins, to which they produce antibodies) and monocytes (clear infection products from the body).

# Useful contacts and further support

There are a number of helpful sources to support you during your diagnosis, treatment and beyond, including:

- Your haematologist and healthcare team
- Your family and friends
- Your psychologist (ask your haematologist or CNS for a referral)
- Reliable online sources, such as Leukaemia Care
- Charitable organisations

There are a number of organisations, including ourselves, who provide expert advice and information.

## Leukaemia Care

We are a charity dedicated to supporting anyone affected by the diagnosis of any blood cancer. We provide emotional support through a range of support services including a helpline, patient and carer conferences, support group, informative website, one-to-one buddy service and high-quality patient information. We also have a nurse on our help line for any medical queries relating to your diagnosis. Helpline: **08088 010 444**  
[www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk)  
[support@leukaemiacare.org.uk](mailto:support@leukaemiacare.org.uk)

## Blood Cancer UK

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

**0808 2080 888**  
[www.bloodcancer.org.uk](http://www.bloodcancer.org.uk)

## Cancer Research UK

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

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

## Macmillan

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

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

## Maggie's Centres

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

**0300 123 1801**  
[www.maggiescentres.org](http://www.maggiescentres.org)

## Citizens Advice Bureau (CAB)

Offers advice on benefits and financial assistance.

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

### Marie Curie

Marie Curie help you and everyone affected by your diagnosis to achieve the best quality of life, and support you to keep your independence and dignity for as long as possible.

**0800 090 2309**

**[www.mariecurie.org.uk](http://www.mariecurie.org.uk)**

### Turn2us

Turn2us helps people in financial need gain access to welfare benefits, charitable grants and other financial help - online, by phone and face to face through our partner organisations.

**0808 802 2000**

**[www.turn2us.org.uk](http://www.turn2us.org.uk)**

### Compassion in Dying

Compassion in Dying can help you prepare for the end of life. How to talk about it, plan for it, and record your wishes.

**0800 999 2434**

**[www.compassionindying.org.uk](http://www.compassionindying.org.uk)**

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

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

## Want to talk?

Helpline: **08088 010 444**

(free from landlines and all major mobile networks)

Office Line: **01905 755977**

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

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

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

Leukaemia Care is registered as a charity in England and Wales (no.1183890) and Scotland (no. SC049802).  
Company number: 11911752.

Registered office address: One Birch Court, Blackpole East, Worcester, WR3 8SG

**Leukaemia Care**  
YOUR Blood Cancer Charity