

Infopack for planning ahead in myeloma

Supporting you with planning ahead
for the terminal stages of myeloma
and the end of life



in partnership
with Marie Curie

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Introduction

This Infopack provides information about the later stages of myeloma when active treatment is no longer an option. This is also called the terminal stage of myeloma. The Infopack includes information and support to enable you to plan ahead, including putting your affairs in order and palliative care. It also discusses the end of life, helping patients and people close to them to understand what to expect.

For many people, death is a difficult subject to discuss or think about. The thought of death nearing can be frightening and it's natural to worry about what will happen.

Learning about what may happen towards the end of life can help you plan ahead, make decisions and begin to take back control in a situation that can often feel overwhelming. This can help you focus on doing the things you enjoy with the people you love and care about.

Our research has shown that there is a need for better and more meaningful information for myeloma patients about the end of life. Myeloma patients and people close to them are seeking full, clear and honest answers to their questions.

This Infopack is for myeloma patients who are looking for answers to questions about the end of life. It is our aim to deliver honest and open information in response to these questions.

We are grateful to everyone who has contributed to this pack: myeloma patients and their families and friends who have shared their personal experiences and reviewed this Infopack; healthcare professional reviewers; and Marie Curie colleagues. You have all helped to make a difference for those affected by myeloma.

“ There are answers in here to questions I did not want to ask but wanted to know the answers. Not only do I now know the answers but I also feel empowered to ask more. ”

About this Infopack

Myeloma UK has produced this pack with support from Marie Curie, a charity that provides care and support to people living with a **terminal** illness and people close to them.

Myeloma is a relapsing and remitting cancer, in which patients may experience a number of periods of **active treatment** (treatment targeting the myeloma cells) followed by **remission**. This means that many myeloma patients have a number of years before active treatment is no longer an option and **supportive treatment** (treatment of symptoms and complications) is the priority. At this later stage the patient's myeloma may be described as terminal, and this is the focus of this Infopack.

This Infopack covers the key questions and topics that myeloma patients have told us they want to know more about when considering the end of life.

It includes information about:

- Why planning ahead can be beneficial
- Getting your affairs in order
- What to expect when myeloma treatment is no longer an option
- What is likely to happen as the end of life draws near
- Choosing where to be looked after

Planning ahead can help you get on with living now. Thinking about the end of life does not bring it closer, and it may bring peace of mind. Making plans can be reassuring, allowing choice and control. Planning ahead for the future can free your mind to focus on the present, on doing the things you enjoy with the people you love and care about. This is discussed further in Section 2.

Who is this Infopack for?

This Infopack is written for myeloma patients. However, we recommend sharing it with those close to you as well. It is a good idea to talk about your wishes and preferences at the end of life with those close to you so that they can support you and each other. Talking to them in advance can also help to ensure your wishes are respected by your healthcare team.

When and how should I read this Infopack?

This Infopack can be read at any time following a myeloma diagnosis. You may find it most helpful at an early stage when you want to explore and prepare for what may happen at the end of life; or you might want to read it at a later stage of your myeloma.

You may find some of the issues in the Infopack difficult or distressing to read, but we hope we have provided this information with sensitivity. You do not have to read the entire Infopack in one sitting; you may wish to read the pack in stages or use it to find answers to specific questions. There is no right or wrong time to start

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thinking about and preparing for the end of life. Read what feels relevant to you at the time, or as much as you wish, and return to the Infopack whenever you need to.

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The Infopack has a contents page and is split into numbered sections to make specific information easy to find. We have also highlighted some key terms in bold throughout the Infopack and you can find the definitions in the **Medical terms explained** section (Section 6).

The quotes in this Infopack are from myeloma patients and their family members, and we are grateful to them for sharing their thoughts.

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Further information and support

The Myeloma Infoline provides information and emotional support to people affected by myeloma at any stage. You can call the Infoline on 0800 980 3332. If you have questions about the terminal stage of illness, need support or just want to talk, you can also call the Marie Curie Support Line on 0800 090 2309.

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We have also listed some useful organisations at the end of the pack in Section 7 that you may want to contact for help, information or to talk about how you feel.

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What do end of life care and palliative care mean?

What do end of life care and palliative care mean?

This section describes and explains the difference between palliative care and end of life care.

When making decisions about your care towards the end of life, you will often hear the terms **palliative care** and **end of life care**. We have also used these terms throughout this Infopack. This section explains what they mean.

Palliative care

Palliative care is part of the ongoing **supportive care** you can receive at any stage of your myeloma, to help control and reduce the symptoms and complications caused by myeloma and its treatment.

It aims to manage pain and other symptoms and also includes psychological, emotional, social and spiritual support. The goal of palliative care is to achieve the best quality of life for patients and those close to them.

End of life care

End of life care is a part of palliative care. It concentrates on identifying your needs and wishes as you near the end of life, and those of your family or others close to you. This timeframe can be difficult to predict but it usually refers to the last year of life. The main focus of end of life care is to help you live as well as possible until

you die. This care can help you die with dignity, in the place of your choice and with as little distress as possible.

There is a misconception that the palliative care team only provides end of life care. This is one aspect of their role but they also provide specialist care in pain management, symptom control and psychological support for patients at all stages of their myeloma. You can be referred at any time to a palliative care team by your doctor, and they can give advice, either in hospital, hospice, care home or your home.

It can be very difficult for you and those around you to hear that you are approaching the end of your life. You may be aware that your myeloma has relapsed and there are no longer any treatment options available to you, however, the news can still come as a shock. Spending as much time as possible with the people you love can be a good focus. Try to talk as openly and honestly as possible to your family, friends and doctor or nurse. This may help you and those around you to better understand what is likely to happen as you approach end of life and what your wishes and preferences are at this time.

There are many organisations that can help and talk to you about end of life if you don't feel you can talk to friends and family, or would prefer not to. See Section 7 for further information.

Key points

- Palliative care can help myeloma patients at any stage in their myeloma
- It aims to manage pain and other symptoms and complications
- Palliative care is holistic and includes other forms of support such as psychological and social
- End of life care is a specific part of palliative care
- It concentrates on care towards the end of life, usually referring to the last year of a patient's life
- The main focus is to help you live as well as possible until the end of your life

Planning ahead and discussing the future

Planning ahead and discussing the future

This section describes why it can help to plan ahead for the end of life.

It also provides information about discussing your wishes with your family, friends, doctor or nurse, and seeking emotional or psychological support.

Everyone responds in their own way when they are diagnosed with an incurable cancer such as myeloma. Many people feel shock and disbelief and find their hopes and plans for the future are suddenly in question and have to be reassessed. These feelings extend to people close to them too.

You may have questions that have no definite answers. You might wonder how your health will change, the effect your myeloma will have on your independence, relationships and work, and exactly how much time you have left.

Why plan ahead?

After the initial shock of diagnosis it can be helpful to plan ahead because making plans for the future can actually help you get on with living now. Thinking about the end of life does not bring it closer, and it may bring peace of mind. Making plans can be reassuring, allowing choice and control over what happens in the future, as far as is possible.

There is no right time to do this. However, planning ahead for the future can free your mind to focus on the present, on doing the things you enjoy with the people you love and care about.

By planning ahead, you begin to take control and you may find any fears or concerns easier to cope with as you find out about end of life care and the options available. It can also be a relief for those close to you to be made aware of any choices you make so they can try to respect your wishes.

Examples of how you can plan ahead include:

- Identifying priorities for your life when living with myeloma
- Identifying the choices and decisions that you can make (about care, living and dying)
- Deciding where you want to be at the end of your life
- Creating an Advance Care Plan in which you leave written instructions about the future care you want to receive, and discussing it with those close to you (we explain what this is in Section 3)
- Making decisions about particular treatments you would or would not like in the event of you needing them including any Advance Decisions to Refuse Treatment (ADRT) that are important to you (we explain what this is in Section 3)
- Writing a Will, if you don't already have one
- Setting up a Power of Attorney (we explain this further in Section 3)

This Infopack will help you start planning ahead, if this is what you want to do.

Discussing your wishes with your doctor or nurse

Most of us find death or dying a difficult subject to talk about. Your doctor and nurse may not raise issues early on about planning ahead, death and dying, unless they think you want them to do so.

You can bring this subject up at any time. If you want to start a conversation, you can begin by asking direct questions. By opening the conversation, you are giving your doctor and/or nurse 'permission' to explore this subject with you.

You can ask any question you need to ask. It is your right to have your preferences and wishes considered and respected, and talking with your doctor and/or nurse can help you determine what you want to happen at the end of your life.

You will have your own idea of what quality of life would be acceptable for you at the end of your life, and what you would not want to happen. For example, you may want your healthcare professional team to do everything they can to help you, or you may only want treatment if it is very likely to extend your life for a number of additional weeks or months. You may prefer your doctor and/or nurse to focus on making sure you are as comfortable as possible. Talking to your doctor and/or nurse about these preferences will help them to support you and provide you with suitable care.

Ask your doctor and/or nurse to be open and honest in their responses if that is what you would like.

Your doctor and/or nurse may use words that are not familiar to you, so ask them to use plain language or explain anything you don't understand. If you feel the conversation is going too fast, or becomes too abrupt, you can ask them to slow down. It is important that you understand what may or may not happen so you can make clear decisions and ones that are right for you – ask further questions until you get the level of detail that feels right for you.

When to talk to your doctor or nurse

End of life discussions with your doctor and/or nurse do not need to be one-off occasions. It's important you feel that talking about the future is never off-limits.

It is natural for people to decide that they want to talk about the future when their myeloma is deteriorating or when things are becoming more difficult or uncertain. However, it is not always possible to discuss things or put plans in place when you are feeling very unwell.

Speaking to your doctor and/or nurse at an earlier stage may give you and those close to you time to think and take control over decisions.

Emotional and psychological support

Hearing the news that you are reaching the end of your life can be very difficult.

You may have been aware that treatment options were becoming more limited, but you still might find it hard to take in what you're hearing.

Reaching the end of life may bring about a lot of different emotions such as fear, anxiety, isolation, guilt, panic, anger, resentment, sadness, loss of role or control, depression or perhaps a sense of relief or acceptance. You may feel the decline in your health, and worry about the loss of your role in your family or with others close to you.

Some of the emotions you will face are likely to feel uncomfortable, yet everyone's experience, fears and worries will be different.

Questions you have may include:

- How will I die?
- When will I die?
- Will it be frightening for me and those who care about me?
- Will I be in pain?

- What are my choices regarding where I will die?
- Who will be present?

All of these questions can have an impact on your emotions and wellbeing. Difficult emotions usually become more manageable over time as you adapt and

find ways to cope. For example, talking about how you're feeling with friends, your family or your doctor and/or nurse can help. You might find that once you've shared your concerns you feel relieved, especially if you've been worrying about something specific. You may feel that professional emotional support may be helpful. There is more about this in the next section.

“ Talk about your feelings. It's okay to feel sad, angry, or just feel numb. ”

Getting additional support

Some people prefer to talk to a person they don't know, such as a trained counsellor or psychotherapist. If you'd like to see a trained counsellor, your GP or consultant may be able to refer you or you may be able to access a counsellor through your **palliative care** team, although there is often a waiting list. If you would like to find your own counsellor, the British Association for Counselling and Psychotherapy can help (see Section 7 for contact details). You may want to focus your search on one that has particular experience of patients with cancer.

Many support organisations such as Myeloma UK and Marie Curie (see Section 7) have freephone helplines where you can speak to a trained specialist about how you're feeling.

If you are being looked after by a palliative care team they are skilled in communicating and assessing your emotional and psychological needs at the end of life.

Spiritual or religious support

Seeking out religious or spiritual support may also help. You may have religious requirements that you want to be observed during or following your death. You can also ask to speak to the chaplain in your hospital or hospice for spiritual support or counselling even if you do not have strong religious beliefs.

As you approach end of life, you may also seek answers to spiritual questions such as the meaning of life and 'why me'. Speaking to a spiritual leader or chaplain, who is used to dealing with uncertainty, may help you to answer such questions and provide comfort.

How others may react

People close to you may react in different ways when they find out you are nearing the end of life. Some people may try to be overly cheerful, others may try to avoid you rather than risk saying the wrong thing. Your family or close friends may try to protect each other from the reality of the situation by avoiding certain topics.

It's important to keep your relationships as normal as possible. If you've always been close and talked a lot, try to continue to do this. When words fail you, a hug or holding hands can be comforting.

Starting conversations with those close to you

Even when you know you want to discuss planning ahead and the end of life with family or close friends, starting the conversation can be challenging. How and

when you do this will be individual to you, and will also depend on who you are talking to, but these suggestions may help:

- Think in advance about what you would like to say to your family member or friend
- Choose a time and space when both of you are comfortable and will have enough time to talk without interruptions
- Start by saying you have something important to you that you'd like to discuss
- Then you might want to open the conversation with something like "I've been thinking about what might happen towards the end of my life, and I'd like to talk about this with you" or "I want to make plans for my care in the future, is now a good time to talk about this?"
- Try to be clear and straightforward so they understand what you are saying
- You may find it gets easier to talk further once the discussion has been started
- Be prepared for their reactions which may not be as you expect
- The person may not feel ready to talk about the things you want to. They may be ready later on to discuss the future with you. In the meantime you can think who else might be able to help you think through your plans for the future

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“ We talked about so many things: deaths and funerals of close friends and family, ceremonies and rituals, childhood memories, key life experiences, fears and the future, treasured moments that we had shared. There were many tears, of course, but talking about death and dying led to some of the most profound and meaningful conversations of my life. ”

Key points

- Being open about the future can help you enjoy a better quality of life. You may:
 - Feel less anxious and have an idea of what to expect
 - Access better care and support
 - Make informed choices
 - Be as prepared as you can be for now and the future
 - Make things easier for those left behind by putting your affairs in order
- Even if it feels hard to talk about end of life, having these conversations early may give you time to think and take control over decisions
- You cannot change your diagnosis or prevent what will happen, but you can help to ensure your wishes are respected
- Planning for the end of life can be the most positive action you can take, so that when the time comes, your wishes can be respected and you can die with as little distress as possible
- If you do feel overwhelmed, find someone to talk to. It can be a family member, a friend, a counsellor, a healthcare professional or a specialist at Myeloma UK or Marie Curie
- Take a prepared list of questions about end of life to your doctor and/or nurse; it's also useful to write down their answers

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Putting your affairs in order

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Putting your affairs in order

This section provides an overview of some of the financial, legal and other matters you may need to put in place to ensure your affairs are in order.

Advance Care Planning

You can use Advance Care Planning to guide people involved in your care about your preferences for your future care, including at the end of life. In Scotland, Advance Care Planning is called Anticipatory Care Planning.

Advance Care Planning allows you to set out your wishes for your future care. This helps other people to fulfil your choices and wishes should you become too unwell to communicate them for yourself.

An Advance Care Plan (also called an Advance Statement, or an Anticipatory Care Plan in Scotland) is a written document and can cover almost any aspect of your care. Your preferences might include:

- Your choices about where you want to be cared for at the end of life (e.g. at home, in hospital, in a nursing home or a hospice – see Section 5)
- How your religious and/or spiritual beliefs should be respected
- Any practical information about your daily routine such as who helps care for your pets
- Who you want to spend time with

Your Advance Care Plan can also name who you would like to be consulted about your care, such as your partner. It is not a legal document, but healthcare professionals and others involved in your care must take it into account. It is important to remember that you can change your Advance Care Plan any time, if your feelings about what you want change.

Some parts of the UK are now using standard forms for Advance Care Planning. Ask your GP for guidance about making an Advance Care Plan, and read more at www.mariecurie.org.uk/planningahead

Advance Decision to Refuse Treatment

An Advance Decision to Refuse Treatment (ADRT) is a written instruction that you can use to record specific decisions about the refusal or withdrawal of treatments, if you become unable to make or communicate decisions for yourself. For example, you may wish not to be fed through a tube, or receive a blood transfusion. Your advance decisions can then be used to guide your healthcare team and those close to you, should you become unable to communicate for any reason. An ADRT is sometimes referred to as a 'Living Will'. In Scotland it is an 'Advance Directive'. An ADRT will only be used if you lose the ability to make your own decisions about your treatment. Your doctor or nurse has to follow your ADRT as long as it was made correctly and applies to your current situation. You'll need the signature of a witness if you want to refuse life-sustaining treatment.

An ADRT may bring a sense of personal control, but it needs to be very precise about what you want to happen

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and when, and it must be written correctly and signed for it to be a legal document. It is important to know that you can cancel or alter your ADRT at any time, as long as you still have the capacity to do so. You can cancel it either verbally or in writing, but you should try to tell everyone who knows about your ADRT that you have changed or cancelled it.

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Your GP will be able to help you draw up an ADRT if you want one. Ideally, they then should hold a copy of the document, as well as your main carer and hospital doctor. Your GP may suggest using a process called ReSPECT, if this has been adopted in your area. ReSPECT stands for Recommended Summary Plan

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for Emergency Care and Treatment. The ReSPECT process is designed to develop a personalised plan that records what types of care you would or would not want to receive in an emergency. There is more about ReSPECT on the Resuscitation Council UK website (www.resus.org.uk/respect).

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Do Not Attempt CPR decision

Cardiopulmonary resuscitation (CPR) is a treatment that aims to restart breathing and heart function in people whose breathing or heart have stopped. The chance of CPR being successful is likely to be very low in people with terminal illness and approaching the end of their lives.

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A DNACPR decision means that if your heart or breathing stops, your healthcare team will not try to restart them.

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Some patients decide that they don't want to have CPR, and a DNACPR decision can be recorded. Your doctor or nurse may decide that a CPR will not work or will not benefit you. In this case, they should discuss this decision with you. If your healthcare team know that CPR would not work, you can't ask to have CPR, and those close to you can't request CPR for you either. However, if CPR is a realistic option, the healthcare team will make a shared decision with you about what's best. A DNACPR decision is always made on an individual (person by person) basis.

The DNACPR decision is recorded by your doctor on a special form so that healthcare workers involved in your care know what to do in an emergency. A DNACPR decision only covers CPR and does not provide instruction for other treatments. However, it may be recorded as part of an Advance Decision to Refuse Treatment process (see section before this one).

There is more information about DNACPR on the NHS website (www.nhs.uk).

Sharing information about your wishes

It can be very distressing for those close to you to learn that you do not want to be resuscitated or decide to refuse treatment as they may naturally want to do everything they can to spend more time with you. You may want to discuss with your them if you choose to write an ADRT or make a DNACPR decision so they are prepared and it will come as less of a shock at the time.

Power of Attorney

England and Wales

In England and Wales, a Lasting Power of Attorney (LPA) is a legal document. It allows you to put in writing the name of someone you trust to make decisions or manage your financial, legal or health affairs on your behalf in the future if you can no longer do so.

This requires a legal document to be registered with the Office of the Public Guardian, for which you will be charged a fee.

There are two types of LPA:

- For property and finance
- For health and personal welfare

It is important to note that, in certain circumstances, an LPA for health and personal welfare – which gives someone authority to make decisions about your care and treatment – might overrule an existing ADRT. The Office of the Public Guardian will be able to clarify in specific cases.

Scotland and Northern Ireland

In Scotland, a Welfare Power of Attorney (WPA) is the legal document that appoints one or more people to make decisions on your behalf about your treatment and care, should you become incapable. A Continuing Power of Attorney assigns to someone the power to deal with your financial affairs. Both types of Power of Attorney have to be registered with the Office of the Public Guardian Scotland and there may be a fee to do this.

In Northern Ireland, Power of Attorney is known as an Enduring Power of Attorney (EPA) and is registered through the Office of Care and Protection. This only enables decisions on your behalf concerning property and finance, not personal welfare or care related matters. As a result, any ADRT cannot be overruled by EPA.

Choosing your attorney

Choose someone to be your attorney whom you trust completely and who understands you well. They'll have a duty to act in your best interests. Talk to them about what it would mean and make sure they understand what you would want. Many people choose a family member or friend to be their attorney. Check that they're happy to take on this role. You'll also need to tell any other family and friends who might be affected by your decision. You can appoint more than one attorney if you want to.

How to set up a Power of Attorney

It is best to seek legal advice when setting up a Power of Attorney, to make sure nothing is missed. You can get financial help with the costs in some cases.

Find out more about Powers of Attorney at:

- www.gov.uk/power-of-attorney (England and Wales)
- www.mygov.scot/power-of-attorney (Scotland)
- www.nidirect.gov.uk (Northern Ireland)

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Making or updating your Will

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A Will lets you leave instructions about what will happen to your money, property and possessions (known as your estate) when you die. A simple Will is not usually expensive and could save your family costs in legal fees.

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If you don't have a Will, part or all of your estate may go to people who you never intended to benefit. If you create a homemade Will you may forget to include some important details, and it might not be valid. Therefore it is a good idea to contact a solicitor who will be able to help you write your Will and ensure that nothing is omitted.

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Some of the things you need to think about are who you would like to pass your estate on to, specific funeral arrangements and appointing legal guardians if you have children under 18. One other significant matter is identifying executors who will deal with your estate when you die.

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Myeloma UK have partnered with Accord Legal Services Ltd to offer the chance to have your Will written or reviewed for free. For more information go to myeloma.org.uk/wills

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Once your Will has been written it is important that it is kept in a safe place and that you review it regularly in case any of your circumstances change. You should also give your executors a copy or let them know where to find it.

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Funeral planning

For family or close friends who are left behind, arranging a funeral can be stressful if they don't know exactly what type of funeral service you want. Your funeral is much more likely to reflect your wishes if you tell people close to you what you want.

Here are some suggestions of what you might want to include in your funeral plan:

- Whether you want a burial or cremation
- Whether you want to have a religious service or not
- Whether you want specific songs or readings
- Whether you want flowers
- Whether you want donations given to specific charities
- What clothes you want to wear

Funerals can be expensive so you may want to pay for your funeral in advance by taking out a funeral pre-payment plan. You can find out more about this from your local funeral director. Read more about planning funerals at www.mariecurie.org.uk/funeral

Organ, tissue and body donation

Many people think that because they have myeloma they won't be able to donate their organs or tissue to another person when they die.

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Although it may not be possible for you to donate your organs, you can usually donate tissue, such as the corneas of your eyes. Your corneas could help to restore a person's sight. You can ask your doctor or nurse for more information about organ donation.

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In England, Wales and Scotland, the law on organ and tissue donation has changed to an 'opt out system'. This means that you are considered to have consented to organ and tissue donation unless you have said otherwise. However, you can still opt out, or choose to donate some types of organs or tissues but not others. In Northern Ireland, the system is 'opt in' – you need to register if you do wish to donate your organs or tissues. Read more about organ donation at www.organdonation.nhs.uk

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The NHS Blood and Transplant website (www.nhsbt.nhs.uk) also has information about donations and keeps a register of people who wish to donate their body tissues.

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Some people may want to donate their body for medical research. If you're thinking about doing this, it's important to discuss it with your GP, healthcare professional team and your family or friends closest to you. As part of the donation process, you and your next of kin will be asked to sign a consent form. You can find out more about donating your body by contacting the Human Tissue Authority (www.hta.gov.uk).

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You should bear in mind that not everyone who wishes to donate their body will be able to do so.

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Other financial arrangements

You may have many concerns about changes to your loved ones' finances after you have died. This may cause particular anxiety if you generally dealt with the finances for the family in the past. The following may help:

- Make sure important documents such as life policies, pension information and savings accounts and investment details are easy to find
- If you have a terminal illness and are not expected to live for longer than a certain time, you may be able to claim benefits under special rules, meaning you can receive payments at the highest level and more quickly than normal
- Your surviving partner/spouse may be able to claim benefits including bereavement support and funeral expenses payment after your death
- There is more advice about benefits in terminal illness, and about finances when someone dies, at www.mariecurie.org.uk/benefits

Digital arrangements

More and more of what we do is becoming digital (such as photos, email accounts, etc.), so it is a good idea to think about this.

- You may want to make a digital will. It's not legally binding but is an expression of your wishes. Read more at www.digitallegacyassociation.org

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- Let your family or those close to you know what email and social media accounts you have and where your photos are stored
- Ensure those you would want to be able to access your accounts know how to do so

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Key points

- Getting your affairs in order (such as making a Will and planning your funeral) will make practical tasks much simpler for those close to you at a difficult and emotional time
- Even if you feel unsure about what you may want, it is still useful to discuss and write down general preferences about your future care. This may not be specific, but it can still help to guide others involved in your care if decisions need to be made on your behalf
- Ask your GP about Advance Care Planning and Advance Decisions (called Anticipatory Care Planning and Advance Directives in Scotland)
- A Lasting Power of Attorney (or equivalent) enables you to assign to someone you trust the power to manage your affairs in the future if you can no longer do so

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What to expect at the end of life

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What to expect at the end of life

This section explores what to expect when your myeloma can no longer be kept under control and you approach the end of your life.

Please be aware that the following pages contain information about what may happen at the end of life. Read this information when you feel ready to do so – you can always return to this section later.



Myeloma patients generally have a number of lines of **active treatment** of their myeloma followed each time by remission.

Unfortunately, there does come a time when myeloma progresses to a point where active treatment is no longer an option, and the myeloma can no longer be kept under control. **Supportive care** only (management of symptoms and complications of the myeloma) will then be the most appropriate option.

This stage may be reached because:

- The myeloma is no longer responding to any treatment prescribed by your doctor
- Your general health deteriorates to an extent where you cannot tolerate the side effects of treatment
- The gains in the time you have left from further treatment are not enough to justify the side effects

- There are no more treatment options
- You decide you no longer want any treatment

At this point, the focus of your treatment will be to manage your symptoms to ensure the best possible quality of life. If you haven't already, you are likely now to be referred to the **palliative care** team by your doctor (remember that you can also ask to be referred to the palliative care team at any time). In addition to treating symptoms, the palliative care team can help with spiritual or psychological concerns, or decisions about **end of life care**.

The end of treatment for your myeloma may come as a relief. You may feel the decision is right and is very much made in partnership with your doctor, nurse and people close to you. For others, it may feel like a severe blow.

Planning ahead by having early discussions with your family doctor and/or nurse, and your team at the hospital, can help to reduce the chances of decisions being made without your participation.

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How long might I have in the terminal phase of my myeloma?

Myeloma is a very complex and individual cancer and everyone is different. It is very difficult to give a timeframe for the later stages of myeloma, but a number of factors can influence this. For example:

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- How quickly the myeloma is progressing (this would be reflected in an increasing **paraprotein** or **light chain** level and a reduction in the number of healthy blood cells)
- What damage/complications the myeloma is causing
- The impact of any other medical conditions you may have

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Some patients experience a slower progression but others have myeloma that progresses more rapidly and causes more problems and complications. Your doctor will be best placed to be able to talk to you about the likely timeframe for progression of your myeloma, but even they will only be able to give you an estimate.

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How will I die?

This is a question that many myeloma patients ask. Being prepared for what may happen can make the situation a little easier to cope with.

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Ultimately, it is one or more of the complications of myeloma that is the cause of death. The most common complications are infection and **kidney failure**.

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For most patients dying is calm, pain-free and peaceful.

Kidney failure

Myeloma kidney disease is caused by the abnormal protein produced by the myeloma cells, which can damage the kidneys by blocking their ability to filter the blood properly. Other complications of myeloma, such as dehydration and a high calcium level in the blood (**hypercalcaemia**), as well as some of the drugs used in the treatment of myeloma, can also cause kidney damage or aggravate any existing kidney damage.

At the advanced stages of myeloma, these factors can combine to put a great deal of stress and strain on the kidneys. The kidneys can therefore be overwhelmed and they may stop working. This can quickly lead to a build-up of toxins in the blood which leads to organ failure. Death usually follows in anywhere from a few days to a few weeks.

Sometimes excess toxins in the blood can affect the way the heart beats and this may lead to cardiac arrest (heart attack) in some patients. Patients may decide that they do not want intervention at this stage if their heart stops or they stop breathing. There is more information about this on page 28.

Infection

Myeloma affects the production of all types of blood cells, including the cells of the **immune system** – the **white blood cells**. White blood cells protect the body against infection, however, many myeloma patients have a lower than normal number of white blood cells, increasing the risk of infection. This is usually kept under control through treating the underlying myeloma.

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Towards the end of life, myeloma can overwhelm the immune system and significantly affect the production of healthy white blood cells. This causes an increased risk of infection. The various treatments you will have had over the course of your myeloma can further increase the risk of infection by increasingly suppressing your immune system over time.

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Pneumonia is one of the most common infections seen in myeloma patients at the end of life. Pneumonia is an inflammatory infection of one or both lungs, generally caused by bacteria or a virus. The inflammation causes the tiny air sacs inside the lungs to fill with fluid. This makes it harder for the lungs to work properly. Typical signs and symptoms of pneumonia include a cough, chest pain, fever and difficulty breathing.

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The main treatment for pneumonia is **antibiotics**. However, when someone has a very weak immune system, pneumonia is more likely to be life-threatening. At the end stages of myeloma the body is often not able to fight infection and withstand it, even with supportive treatment. This means that effective treatment of the infection is not possible. Eventually, the reduced ability of the lungs to move oxygen around the body means that the vital organs begin to shut down and death may follow in a number of days or weeks, when the heart stops beating.

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What symptoms may patients experience in the final weeks and days of life?

When someone with myeloma approaches the last few weeks and days of life, they are likely to experience certain physical symptoms. The body has a normal, natural way to prepare itself to shut down. In most instances, the shut-down is an orderly series of physical changes which may include the following symptoms.

Loss of appetite

When someone nears the end of life their metabolism slows down. The body no longer needs food as it can't digest it well. At this stage it's important not to force yourself to eat and it is fine if you don't. You can try liquid meals such as Build-up® or Complian®. This can be difficult for people around you whose instinct may be to feed you. It is important that you are honest with them if you do not feel like eating.

You may not feel thirsty in the final hours of life but your mouth may become dry and need to be moistened. Those with you can help to moisten your mouth if it becomes dry. Your nurse may be able to provide mouth-care sticks (like big cotton buds) to help, and could also put lip balm on to your lips to stop them getting dry and cracked.

Increasing sleepiness

The final stages of myeloma will usually involve gradual weakening and increasing sleepiness. In the last days of life you may feel very weak and sleepy and may want to spend more time in bed.

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It's not uncommon for people nearing death to become withdrawn. You may not be fully aware of people and events around you. This is generally a natural part of gradually retreating from the world. It helps for you and those close to you to be prepared for this as it may be upsetting for them.

3

Changes in skin colour and temperature

Sometimes the skin changes colour and becomes slightly more blue, grey or white. You may also find that your skin becomes very sensitive to the touch, or feel very cold and possibly moist. Several layers of light, warm clothing and bedding can help keep you at a comfortable temperature.

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Pain

Not everyone with myeloma experiences pain. However, if you have new or increasing pain towards the end of life it is important to let people know as it can usually be very effectively managed.

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Your healthcare team will try to do all they can to ensure that any pain is kept under control. This could involve prescribing pain-relieving drugs and helping you find a comfortable position to sit or lie in.

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Painkillers are usually given as tablets, liquid or patches stuck on to the skin. If you're unable to swallow well or are being sick, your nurse or doctor can give you painkillers such as morphine, fentanyl, diamorphine and oxycodone as an injection or by using a **syringe driver** (sometimes called a pump).

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Changes in breathing/ breathlessness

When your breathing becomes weaker you may feel breathless and this can be distressing for you and those around you. There are various ways this can be eased and managed so it's important to let your doctors and/or nurses know if you're breathless so they can help you as soon as possible.

Shortness of breath can be managed in a number of ways. You can be prescribed treatment such as low-dose morphine, and encouraged to do some very gentle breathing and relaxation exercises to help reduce anxiety and relieve your breathlessness.

As you get closer to death your breathing pattern will probably become even more irregular, with longer gaps between breaths. It may also become noisy, but shouldn't cause you any pain or distress. Shallow breathing usually leads to reduced consciousness, so that death comes peacefully as breathing slowly reduces and eventually stops.

Supportive treatments

The sections above describe the typical course of a person's last days and hours of life, as the body gradually shuts down. Sometimes the pattern may be different, and symptoms such as breathlessness, pain, agitation or nausea may be distressing to the patient or to those around them. It is important to remember that there are supportive treatments to help deal with symptoms such as these, and they will still be provided at the end

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of life. Treatments to help with nausea or sickness, pain, agitation, or excessive secretions in the airways, can all be given through a syringe driver (pump) when needed.

In most cases, the actual end phase of life is calm, pain-free, dignified and peaceful. You'll slip slowly into unconsciousness when your breathing stops and be unaware this has happened.

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For more advice and information about what to expect at the end of life, visit www.mariecurie.org.uk/what-to-expect



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Key points

- There does come a time when treatment for your myeloma is no longer an option or appropriate, and best supportive care becomes the focus
- Infection and kidney failure are the most common causes of death in myeloma
- There is much that can be done to manage symptoms at the end of life and make you as comfortable as possible
- The body has an instinctive way of preparing itself to shut down, which gives rise to some predictable physical changes
- Sometimes excess toxins in the blood can affect the way the heart beats and may lead to cardiac arrest (heart attack) in some patients

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Where can I spend my last days?

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Where can I spend my last days?

This section identifies and explains the types of care available at the end of life and who is involved.

When it is time to think about where you want to be at the end of your life, your choices are likely to be guided by what is important to you as an individual. Wherever you're cared for, you may want to think about:

- Who will be with you
- Being somewhere that is peaceful and private
- Having some of your own and familiar things around you
- If there is a difference in the type of care you will receive depending on where you choose to spend your final days

Wherever you're cared for at the end of life, it's important that you get the care you need and your symptoms are well controlled. This can happen at a variety of places including home, hospital, hospice or nursing or care home.

Home

Many people prefer to remain at home in a familiar environment towards the end of life. Being at home may make you feel more in control of what is happening. You may therefore want all of your end of life care to take place at home.

If home is where you want to be, there are a number of healthcare professionals and voluntary organisations that can help manage any symptoms you may have and support you and your family or those looking after you. For example, your GP and community healthcare team (such as district nurses) and community **palliative care** team are available to help if needed. They may also be able to provide out-of-hours support in the evenings and on weekends. Marie Curie Nurses may also be available to care for you overnight, allowing your carer to take a break. A number of hospices provide 'hospice at home' services. Speak to your district nurse or GP for more information about these options.

However, it's important to bear in mind that your care needs may be, or become, too complex to manage in your home. Depending on circumstances in your area, it may not always be possible to provide you with the level of care you need (for example, providing care on call overnight, or providing the care that you need if your condition begins to worsen rapidly). Your doctor or nurse may talk to you about being admitted to hospital or a hospice. Equally, those looking after you may feel anxious about you dying at home – that they don't have the skills to look after you and that you would be better cared for elsewhere.

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If you need to move from home at some point near the end of your life, for whatever reason, you and those looking after you shouldn't see this as a failure. Instead, try to see it as making sure you get the best possible care.

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“ Mum and I had discussed her wishes for the final hours so I had an understanding of what constituted a 'good death' for her. This knowledge helped, in part, to prepare me for the difficult path ahead. ”

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Hospital

You may want to, or have to, go into or remain in hospital when you need more care towards the end of your life.

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If you have an acute infection, such as **pneumonia**, hospital care may be necessary to maintain your quality of life towards the end of life.

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A hospital may not be the most peaceful place to be if the ward is busy. However, hospitals have palliative care teams that include specialist doctors and/or nurses – they can advise you on controlling your symptoms and can give you and those close to you emotional support.

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Hospice

The aim of hospice care is to improve the lives of people who have an incurable disease. People can go into a hospice for different reasons. They may go in for a short time for help with symptom control, or because they are entering the end of life phase.

You may decide that you'd like to die in a hospice rather than at home or elsewhere.

Hospices have staff who are experts in controlling symptoms and providing emotional support. They are very different from hospitals. Hospices are quieter and visiting times are usually less restricted than in a hospital. They offer a wide range of services for patients and those close to them, such as counselling, spiritual care and complementary therapies.

If you're not sure about going into a hospice, you can ask to visit one before making a decision. The staff will be able to show you around and talk through any questions or concerns you have.

Unfortunately, low numbers of hospice beds in some areas of the UK mean this is not always an option – you can find out more about your local hospice options from your GP or your hospital doctor and/or nurse.

Nursing home

If you're likely to need longer-term nursing care, a nursing home may be more appropriate than a hospice.

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Your GP or district nurse can arrange for you to go to a nursing home but it may take some time. The way nursing home fees are paid for varies across the UK. Speak to your district nurse, doctor or social worker for more information.

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Residential care home

In a residential care home, staff members are professional carers. They provide the same kind of care that family members might offer at home, such as help with washing and dressing, help taking medicine and providing meals. But the staff aren't nurses and they don't offer medical or nursing care themselves. Care homes usually offer long-stay care, but they may also offer short-stay care.

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Complementary therapies

Some people find complementary therapies such as relaxation, meditation or gentle massage helpful. They are not designed to replace your medical care but may be helpful with symptoms such as pain and anxiety. Patients may have complementary therapies at any time during their myeloma, but they may be particularly helpful toward the end of life. Ask your hospice or hospital if it provides free complementary therapies. It is important, though, that you tell your doctor before using any complementary therapy so that they can discuss any possible harmful effects with you.

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Key points

- When it is time to think about where you want to be at the end of your life, your choices are likely to be guided by what is important to you as an individual
- It may not always be possible to meet your choice, and if you have a preference about where you want to be cared for at the end of life, ensure you discuss this with those close to you and with your doctor and/or nurse
- Wherever you choose, you should be well cared for by a team of healthcare professionals including your GP, district nurses and the palliative care team
- If your preference is to remain at home, you may need to move from your home at some point if your care needs become too complex to be managed there

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Medical terms explained

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Medical terms explained

Active treatment: In myeloma, active treatment refers to treatment of the myeloma itself, aiming to kill as many as possible of the myeloma cells. This is in contrast with supportive treatment (treatment of symptoms and complications).

Antibiotics: A type of drug used to prevent or treat an infection caused by bacteria.

End of life care: End of life care concentrates on identifying and supporting your needs, and those of people close to you, as you near the end of life. This timeframe can be difficult to predict but it usually refers to the last year of life.

Hypercalcaemia: A higher than normal level of calcium in the blood, which may cause loss of appetite, nausea, thirst, fatigue, muscle weakness, restlessness and confusion. Often associated with reduced kidney function since calcium can be toxic to the kidneys.

Immune system: The complex group of cells, tissues and proteins (including antibodies) that protect the body against infection and disease.

Kidney failure: The inability of the kidneys to function properly and filter waste products from the blood.

Light chain: A protein that makes up part of the paraprotein (see below), but can also exist separately. Measurements of light chains can be used to diagnose and monitor myeloma.

Palliative care: Palliative care is part of the ongoing supportive care you can receive to help control and reduce the symptoms and complications caused by myeloma. It aims to manage pain and other symptoms and also includes psychological, social and spiritual support.

Paraprotein: An abnormal antibody (immunoglobulin) produced in myeloma. Measurements of paraprotein in the blood can be used to diagnose and monitor the disease.

Pneumonia: Inflammation of one or both lungs, which is usually caused by an infection. The inflammation causes the small air sacs inside your lungs to fill with fluid making it more difficult for the lungs to function properly.

Remission: The period following active myeloma treatment, when myeloma cells and paraprotein are no longer detectable, and there are no clinical symptoms of myeloma.

Supportive treatment: Treatment intended to relieve symptoms and complications rather than treating the underlying disease.

Syringe driver: A small battery-powered pump that helps to reduce pain and other symptoms by delivering a steady flow of drugs under the skin (subcutaneously). Syringe drivers can be used at any time, but are often used in the last few weeks and days of life.

Terminal: In cancer, terminal usually means that the cancer can't be cured and is no longer responding to treatment, so the focus is on managing symptoms.

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Patients with myeloma may experience an number of periods of active treatment followed by remission, before the stage is reached where it is considered as terminal.

White blood cells: A type of blood cell involved in the body's immune system, which help to fight infection.

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Further support and information

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Help from Marie Curie

Marie Curie provides practical information and emotional support for people living with a terminal illness and the people close to them.

Marie Curie Support Line

0800 090 2309

Open Monday to Friday, 8am to 6pm,
and Saturday, 11am to 5pm.

Check-in and Chat

www.mariecurie.org.uk/help/support/check-in-and-chat

Our free Check-in and Chat service provides ongoing emotional support via telephone calls with the same person each week. You can access up to 12-weekly sessions from a trained volunteer. It is not counselling or psychotherapy and may not be suitable for people who need a higher level of support.

Marie Curie Community

www.community.mariecurie.org.uk

Share experiences and find support from people who understand what you're going through. Available 24 hours a day.

More information and further support

Marie Curie also has an extensive range of information materials available to view online or in print. Visit www.mariecurie.org.uk/support where you can also find film guides, information about services, and links to further support.

Marie Curie Nurses

Marie Curie Nurses work night and day, in people's homes across the UK, providing hands-on care and vital emotional support. If you're living with a terminal illness, they can help you stay surrounded by the people you care about most, in the place where you're most comfortable. Visit www.mariecurie.org.uk/nurses

Marie Curie Hospices

Our hospices offer the reassurance of specialist care and support, in a friendly, welcoming environment, for people living with a terminal illness and their loved ones – whether you're staying in the hospice, or just coming in for the day. Visit www.mariecurie.org.uk/hospices

Marie Curie Helper

We know the little things can make a big difference when you're living with a terminal illness. That's where our trained Helper volunteers come in. They can visit you regularly to have a chat over a cup of tea, help you get to an appointment or just listen when you need a friendly ear. Visit www.mariecurie.org.uk/helper

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Useful organisations

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British Association of Counselling and Psychotherapy
01455 883300 www.bacp.co.uk

Professional Association for members of the counselling professions in the UK.

3

Hospice UK www.hospiceuk.org

Works for the benefit of people affected by death and dying, collaborating with hospices and other partners who work in end of life care.

4

Macmillan Cancer Support www.macmillan.org.uk
0808 808 0000

Provides practical, medical and financial information and support to all cancer patients and their carers.

5

Maggie's www.maggies.org
0300 123 1801

Provides free practical, emotional and social support to people with cancer and their family and friends.

6

Mind www.mind.org.uk
0300 123 3393

Provides advice and support for anyone with mental health problems.

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National Association for Hospice at Home
01489 668333 www.nahh.org.uk

Organisation for Hospice at Home services in the UK.

NHS 111 Servicewww.nhs.uk/111**111**

Call 111 when you need medical advice fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year.

Sue Ryderwww.sueryder.org**0808 164 4572**

Supports people living with a terminal illness, a neurological condition or who have lost someone.

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Myeloma UK – here for everything a diagnosis brings

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Call our **Myeloma Infoline** on **0800 980 3332** for practical advice, emotional support and a listening ear.



Get answers to your questions by emailing **AskTheNurse@myeloma.org.uk**



Learn about myeloma from experts and meet other patients at our in person **Infodays** and online **Digital Infoday Sessions**.



Read our **information booklets**, which cover all aspects of myeloma – call **0800 980 3332** or visit **myeloma.org.uk/publications**



Join your nearest **Myeloma Support Group** to meet other people living with myeloma face to face or online.



Visit **myeloma.org.uk**, a one-stop-shop for information, videos and news about myeloma.



Get matched up with a trained **Peer Buddy** for one-to-one support from someone with direct experience of myeloma.



Chat and share experiences with others affected by myeloma, including our peer volunteers, on the **Discussion Forum**.



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We need your help

Thanks to our generous supporters we are able to provide information and support to patients and their families, as well as fund vital research that will help patients live longer and with a better quality of life.

Myeloma UK receives no core government funding. We rely on fundraising activities and donations.

You can support Myeloma UK by:

- **Making a single donation or setting up a Direct Debit**

Online at myeloma.org.uk/donate

Over the phone **0131 230 0429**

Or by posting a cheque payable to **Myeloma UK** to:

Myeloma UK, 22 Logie Mill, Beaverbank Business Park, Edinburgh, EH7 4HG

- **Fundraising** – fundraising is a positive way of making a difference and every pound raised helps. As myeloma is a rare, relatively unknown cancer, fundraising is also a great way to raise awareness

- **Leaving a gift in your will** – legacies are an important source of income for Myeloma UK and help us to continue providing practical support and advice to myeloma patients and their families. They also help us to undertake research into the causes of myeloma and investigate new treatments

However you decide to raise funds, our Fundraising Team is here to support you. Contact us on **0131 230 0429** or email fundraising@myeloma.org.uk



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“

Nobody ever forgets the moment they are diagnosed with myeloma. Myeloma UK advances the discovery of effective treatments, with the aim of finding a cure. That is what patients want, it's what they deserve and it's what we do.

”

Judy Dewinter – President, Myeloma UK

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We appreciate your feedback. Please fill in a short online survey about our patient information at myeloma.org.uk/pifeedback or email any comments to patientinfo@myeloma.org.uk

For a list of references used to develop our resources, visit myeloma.org.uk/references

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For more information about myeloma and Myeloma UK

Call the Myeloma Infoline on

 **0800 980 3332**

Email Ask the Nurse at

 **AskTheNurse@myeloma.org.uk**

Visit our website at

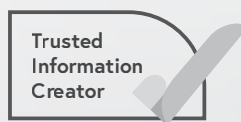
 **myeloma.org.uk**

For more information about Marie Curie and living with a terminal illness contact:

Marie Curie Support Line:

 **0800 090 2309**

 **mariecurie.org.uk**




Patient Information Forum




Patient Information Awards 2016
Highly Commended

Myeloma UK

22 Logie Mill,
Beaverbank Business Park,
Edinburgh EH7 4HG

 0131 557 3332

 myelomauk@myeloma.org.uk

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