MyelomaUK

# Planning ahead for the end of life

## Infopack for people with myeloma

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

In partnership with Marie Curie

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# Disclaimer

The information in this Infopack is provided for the benefit and personal use of myeloma patients and their carers, family, and friends.

This information is provided as general guidance for information purposes only. It should not be considered as medical or clinical advice, or used as a substitute for personalised or specific advice from a qualified healthcare professional. In respect of legal, financial, or other matters covered by this information, you should also consider seeking specific professional advice about your personal circumstances.

Whilst we try to ensure that this information is accurate, we do not accept any liability arising from its use.

This publication is intended for a UK audience. It therefore may not provide relevant or accurate information for a non-UK setting.

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# Introduction

This Infopack is for people with myeloma and those close to them. It contains information about the later stages of myeloma, when treatment to kill the myeloma cells is no longer an option. This may also be called the **terminal stage of myeloma**. At this point, **supportive treatment**, that focuses on the management of symptoms becomes the priority. This is also called **palliative care**.

Thinking about dying and discussing it with those close to us can be frightening. It is natural to worry about what will happen and what decisions need to be made. There is no right or wrong way to think or feel.

Learning about what may happen at the end of life can offer many people a sense of control and choice. Some people may also involve those close to them in the decision making process. Planning ahead can also allow you time to focus on the present and enjoying time with loved ones.

> “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.”

## What topics are covered by this Infopack?

This Infopack discusses the key questions myeloma patients have told us they have about the end of life. This Infopack offers clear and honest information in response to these questions including:

- Why you may want to plan ahead
- How to get your affairs in order
- What to expect when myeloma treatment is no longer an option
- What to expect at the end of life
- Choosing where to have end of life care

## Who is this Infopack for?

This Infopack is for people with myeloma and those close to them. Talking about your care and wishes for the end of life can be difficult. However, it can ensure your choices are respected by your healthcare team and those close to you.

## When and how should I read this Infopack?

This Infopack can be read at any time following a myeloma diagnosis. There is no right or wrong time to prepare for the end of life, only what time feels right for you.

Reading about the end of life can be difficult or distressing for many people. You may find it helpful to use our **Sections list** on page 3 to help you pick the sections you want to read.

Here are some tips for reading this Infopack:

- Read the Infopack at your own pace. There are some things you will want to know now, but some things can be left for another time
- You may find it easiest to read the Infopack in small chunks. It has been split into sections to help you find the information as and when you need or want it
- Each section has a 'Key points' list. You may find it helps to read that before the rest of the section
- Words highlighted in **bold** in the text are explained in the Medical terms list in Section 6
- Throughout the Infopack, 'healthcare team' is used to refer to your hospital doctors, palliative care team, and clinical nurse specialist (CNS)

## How has this Infopack been developed?

Myeloma UK has produced this Infopack in collaboration with Marie Curie. This charity provides care and support to people living with a terminal illness and the people close to them.

The information in this Infopack has been gathered together from patients, their families, and carers who have had similar experiences. The information has also been reviewed by healthcare professionals before publication.

The quotes throughout this Infopack are from myeloma patients, their families, and friends. Many of them are taken from **The small things that make a difference** book, which has hints and tips written by – and for – people affected by myeloma. You can download or order a copy from Myeloma UK via the website or the Myeloma Infoline.

## Further information and support

Myeloma UK is here to support you with everything a myeloma diagnosis brings. Whether you need more information, someone to listen to you, or to connect with a community of other patients and family members, we are here to provide the information and support you need. Our **Myeloma Infoline** and **Ask the Nurse** email service provide information, practical advice, and emotional support to people affected by myeloma. See Section 7 to find out more about how Myeloma UK can support you.

You can call the Infoline on **0800 980 3332** or **1800 937 773** from Ireland, or email **AskTheNurse@myeloma.org.uk**

If you have questions about the terminal stage of myeloma, need support, or just want to talk, you can also call the free Marie Curie Support Line on **0800 090 2309** or visit their website at **mariecurie.org.uk**.

## Section 1

# Palliative care and end of life care

# Palliative care and end of life care

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

## Key points

- Palliative care is not just end of life care
- Palliative care is the emotional, physical, practical, and spiritual care that may be offered to someone with myeloma at any time following their diagnosis
- Palliative care helps to control pain and other symptoms that may occur after a myeloma diagnosis. It can also help with advice on planning ahead
- End of life care is a type of palliative care. It focuses on care given in the last 12 months of someone's life
- End of life care helps someone to live as well and as comfortably as possible until the end of their life

## Palliative care

Many people think that **palliative care** is just end of life care. However, there is much more to this specialist service.

Palliative care is the emotional, physical, practical, and social care that may be offered to someone with myeloma at anytime following their diagnosis.

Some people are referred to a specialist palliative care team while they are actively receiving treatment for myeloma. This specialist team can help to manage complex symptoms that may happen because of myeloma or the treatment for it.

Palliative care aims to offer the best quality of life for people with myeloma and those close to them. It can include:

- Pain control and management of other symptoms caused by myeloma and its treatment
- Emotional and spiritual support
- Advice on getting your affairs in order, such as making a will
- Support for those close to you

Palliative care usually includes different professionals that can help meet your needs. This may include your GP, district nurses, social workers, chaplains, counsellors, occupational therapists, and physical therapists. Your GP or healthcare team may also refer you to a community palliative care team. This team involves specialist nurses and doctors who are experts at managing complex symptoms. They are usually based in local hospitals or hospices and can often arrange to meet you at home.

## End of life care

End of life care is a part of palliative care. It focuses on the care and support of people in the last year of life. End of life care supports you to live as well and as comfortably as you can, until the end of your life.

End of life care can be provided in the home, hospital, care home or a hospice. The professionals involved in end of life care will always try to support your chosen place of care where possible and ensure any needs are met. You can read more about this in Section 5.

## Section 2

# Your thoughts and feelings about the future

# Your thoughts and feelings about the future

**This section provides information about your emotions and how to access support for you and those close to you. It also discusses how it can help to think about your preferences for the end of life before you become too unwell.**

## Key points

- Hearing the news that you are reaching the end of your life can come with many complex emotions. Allow yourself time and space to process these emotions and to talk about the end of life
- If you do feel overwhelmed, find someone to talk to. You may prefer to speak to someone you are close to or to join a support group. Others may prefer **counselling**, speaking to a healthcare professional or a specialist at a local cancer support service, Myeloma UK, or Marie Curie
- Having conversations about the end of life may give you time to think and offer some control over decisions. It can help to ensure your wishes are respected
- Take a prepared list of questions about end of life to your healthcare team; it is also useful to write down their answers

- Talking with children and teenagers about the end of life can be difficult and upsetting. There is guidance and support to help you and them
- Some people choose to leave behind memories and there are many different ways you can do this

## Your feelings

Everyone responds in their own way when they are told they are approaching the end of life. Some of these emotions are likely to feel uncomfortable, and everyone's experience, fears, and worries will be different.

Hearing the news that you are reaching the end of your life can be very distressing. Even if you were aware that treatment options were limited, the news may still come as a shock. You may experience many complex emotions such as:

- Fear
- Anxiety
- Isolation
- Guilt
- Anger
- Panic
- Resentment
- Sadness
- Relief
- Acceptance

You may also have questions that have no definite answers. Many people wonder how this news will impact their relationships and if future plans need to be reassessed. Other people may have questions about the end of life itself such as, 'how will I die?' and 'how much time do I have?'.

There is no right or wrong way to feel about the end of life. It is likely that your feelings will change over time and you may experience conflicting emotions. Difficult emotions often become more manageable over time as you adapt and find new ways to cope. Allow yourself time and space to process your emotions and seek help when you need it.

## Emotional and psychological support

Talking about how you are feeling with those you are close to can help you process your emotions. The feelings you experience are often shared by those you are close to. Even if you are not sure what to talk about, often just sitting with someone can offer comfort.

It is important to acknowledge that some people may find it too difficult to talk to you about the end of life. They may feel they are not able to support you in the best way, or they are unsure what to say.

Some people find that a support group or online forum allows them the opportunity to share experiences and seek support from someone who is in a similar situation.

> “ Don’t be afraid to talk to someone. ”

Your healthcare team or **palliative care** team can also offer emotional support. They are familiar with your situation and may be able to answer some of your questions about the end of life. They could also refer you for **counselling** if you want to speak to a counsellor or psychotherapist who can help you process your emotions.

If you would prefer to find your own counsellor or psychotherapist, the British Association for Counselling and Psychotherapy can help (see Section 7 for contact details). You may want to focus your search on someone that has experience of patients with cancer.

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You may enjoy **complementary therapies** such as massage or meditation. Although not directly addressing your emotions, they may help with relaxation and stress. Similarly, art and music therapy can help with relaxation and can allow some people to express their emotions if they struggle to do so with words. Local hospices and cancer centres may offer these therapies for free. Speak to your healthcare team to find out what is available in your area.

Charitable organisations such as Myeloma UK and Marie Curie have freephone helplines. You and those close to you can speak to a trained specialist about your myeloma and the end of life, and get information on what support may be available.

☎ You can call the Myeloma UK infoline on **0800 980 3332** or the Marie Curie Support Line on **0800 090 2309**.

## Spiritual or religious support

Spirituality can mean different things to different people. Some people have religious beliefs as part of their spirituality. For others, it is how they relate to the world.

As you approach the end of life, you may have religious beliefs that influence how you are cared for. You may also seek answers to spiritual questions such as the meaning of life and 'why me'. Your local hospital may have a chaplaincy service or can help contact religious leaders. These professionals are familiar with spiritual uncertainty and can help work through any questions with you.

## How others may react

Everyone will respond to news that you are approaching the end of life in a different way. Some people may want to talk about it all the time or try to be overly cheerful. Others may try to avoid you as they worry about saying the wrong thing.

Your interactions with them may also change. You may want to prevent them knowing how you are feeling, or you may be worried about being a burden on them. You may also notice a shift in the relationship dynamic as they take on responsibilities you previously held. This can bring complex emotions for you and those you are close to.

Some people find that the end of life can strengthen their relationships with others. Having conversations about your life, values, and shared memories can bring you closer together and bring you both comfort.

Talking with those you are close to can help everyone with the changes to your relationship. If you are struggling to discuss your thoughts with them, you could try writing a letter to share with those you are close to. You could also suggest practical tasks that can help you such as: preparing meals, getting shopping, or doing housework.

## Thinking about the future

At some point after diagnosis, many people start to think about planning ahead and getting their affairs in order. Some people choose to start planning ahead soon after their diagnosis, rather than waiting until they are too unwell. This can allow more time to think about their wishes and preferences.

Planning ahead for times you may be more unwell can allow you to enjoy the days that you feel well. There is more information about getting your affairs in order and planning ahead in Section 3. Some of the things you may want to think about include:

- Making a will
- Benefits and financial planning
- Assigning a Power of Attorney
- Making an Advance Decision to Refuse Treatment (ADRT) also called a Living Will or Advance Directive
- Funeral planning
- Leaving behind memories for loved ones
- Communicating your preferences to your healthcare team and those you are close to

## Discussing the future with your healthcare team

After your diagnosis, your healthcare team will generally not raise issues about planning ahead or death and dying, unless they think you want them to. 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. However, it is not always possible to discuss things or make plans when you are feeling very unwell. Speaking to your healthcare team at an earlier stage may give you and those close to you time to think and take control over decisions.

You can start the conversation with your healthcare team at any time. Having these conversations can help them to support you and provide you with suitable care. You will have your own idea about what is acceptable for you at the end of life. For example, you may want your healthcare team to do everything possible to help you prolong your life or, you may prefer them to focus on keeping you in your preferred place of care.

You may find it helpful to bring a list of questions to the conversation with your healthcare team. Writing down their responses or having someone do this for you can help you remember things later.

You may want to contact your healthcare team before your appointment to let them know you want to make plans for the end of life. This may allow for more time to explore your options. These are challenging conversations to have. You can ask your healthcare team to stop at any time. Ask as many questions as you need to help you make the right decisions for you.

## Talking about the end of life with those close to you

Many people wonder what the best time is to start talking about the end of life with those they are close to. How and when you do this will be a personal choice, but these suggestions may help:

- Think in advance about what you would like to say to the person you are speaking to
- Choose a time and space when both of you are comfortable and will have enough time to talk without interruptions
- 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 reaction as it may not be as you expect. The person may not feel ready to talk about the things you want to. You may need to consider who else can help you think through your plans for the future such as your healthcare team or GP
- If talking still feels too difficult, it may be easier to write your thoughts in a letter to share with those you are close to

> “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.”

## Talking to children and teenagers

It is natural to want to protect your children or grandchildren from difficult news. Talking to a child or teenager about the end of life can be a daunting and difficult task. What you tell them will depend on their age and understanding. While you cannot control their feelings, you can be there to support them.

Marie Curie and Child Bereavement UK have developed resources to support adults in having these difficult conversations. They include suggestions of how to start the conversation, what to say depending on their age, and suggestions for how to best support them moving forward.

For more information on talking to children and teenagers see **mariecurie.org.uk/supporting-children** or **childbereavementuk.org**

## Leaving behind memories

Leaving behind messages or memories can be an opportunity to recall happy moments and may bring comfort to those you are close to. It can also be a difficult and emotional thing to do, so not everyone chooses to do this.

Your healthcare team can support you with whatever you choose. There is no right or wrong thing to do. You should do what feels right for you and those close to you.

Some examples of leaving memories include:

- Create a memory box. You could fill this box with photographs, notes and trinkets
- Write cards or record video messages for birthdays or significant life events such as weddings
- Write letters. Some people prefer to write their thoughts and feelings down as they find them hard to say aloud
- Make a list of activities you would like to do with those you are close to. Alternatively, leave a list of things you would like them to do

## Section 3

# Planning ahead and putting your affairs in order

# Planning ahead and putting your affairs in order

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**This section explains why you may want to plan ahead and some of the different financial, legal, and practical steps you can take.**

## Key points

- There is no right time to plan ahead. However, making plans in plenty of time allows time and space to consider the different options and make preparations. Planning for the end of life can be one of the most beneficial actions you take, so that when the time comes, your wishes can be respected
- Certain benefits may be available to you and those you are close to which can help with some financial concerns at the end of life
- Getting your affairs in order, such as making a will and planning your funeral, may 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
- Speak with your healthcare team or GP about an Advance Decision to Refuse Treatment (ADRT), sometimes called a Living Will or Advance Directive

- A Lasting Power of Attorney (or equivalent) enables you to assign someone you trust the power to manage your affairs if you can no longer do so
- Regularly review and update any legal documents
- The Planning Ahead checklist on page 65 may be a useful guide of things you want to consider

## Why plan ahead?

While there is no right time to plan ahead, many people find that making plans for the future can be a beneficial step. Planning ahead with plenty of time can allow you to consider the different options and make preparations. It can also help people with living in the present day, focusing on doing what they enjoy with loved ones. Making plans can also be reassuring, allowing some choice and control over what happens in the future. For those you are close to, understanding your choices and preferences for care can make things a little easier at an already emotional time.

There are many things you can do to plan ahead which we discuss in this section.

## Benefits and financial arrangements

You may have many concerns about changes to your finances, particularly if you or your partner have had to give up work. You may also be concerned about 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:

- A Lasting Power of Attorney (or equivalent) enables you to assign to someone you trust the power to manage your affairs. We discuss this in more detail on page 33
- Make sure important documents such as National Insurance number, birth certificate, life policies, pension information, bank accounts, and investment details are easy to find. Marie Curie have more information at **mariecurie.org.uk/bank-accounts**

- 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 may be able to claim benefits including bereavement support and funeral expenses payment after your death
- Macmillan Cancer Support offer a money advisor service. They can support you with paperwork and check what benefits you are entitled to. Citizens Advice may also be able to offer support

For more information about benefits in terminal illness see **mariecurie.org.uk/benefits**

## Advance Care Planning

An Advance Care Plan, also called a Future Care Plan in Scotland and Wales, is a written document that allows you to specify how you would like to be cared for. If you are unable to communicate your wishes, an Advance Care Plan can be used by your healthcare team and those you are close to, to help guide decisions about your care.

Although not a legally binding document, your healthcare team must give consideration to an Advance Care Plan when making decisions about your care. You may want to include information such as:

- Practical details about your daily routine and how to care for any pets you may have

- Your favourite things, such as time outdoors or music
- Who you want to spend time with
- Any religious or spiritual beliefs that should be respected
- Where you want to be cared for at the end of life. For example, at home, hospital, a hospice, or care home. For more information see Section 5

There are some Advance Care Plan template forms available that can help with the often overwhelming task of knowing what to include. Your healthcare team, GP, or palliative care team can offer further guidance on completing these. For more information and templates see **mariecurie.org.uk/advance-care-plan**

It is a personal decision who you share your Advance Care Plan with. Your healthcare team can also keep an electronic record of your plan. You may also want to keep it somewhere safe and tell those close to you where they can access it should they need it.

## Advance Decision to Refuse Treatment

An Advance Decision to Refuse Treatment (ADRT) is a written statement to refuse specific medical treatments. This may also be called a ‘Living Will’ or an ‘Advance Directive.’

You can complete an ADRT at anytime following your diagnosis. It clearly states what treatments you do not want to have and in what situations these decisions apply. It is only used when you cannot communicate your decisions. Some people choose to include decisions about refusal of treatments that may prolong life, such as mechanical ventilation. When these decisions are included, the ADRT must be written and signed by yourself and a witness.

You can review your ADRT and change decisions at any time to reflect your current situation. It is important to ensure that any changes are accurately recorded and shared with your healthcare team and those you want to share it with.

You may find it helpful to talk with your healthcare team before making any decisions. They can explain what would happen if you refuse certain treatments and explain what information should be included. You may wish to include decisions such as:

- Receiving blood and platelet transfusions towards the end of life and the circumstances under which you would refuse these
- Having antibiotics if you become very unwell with an infection
- Being fed through a tube or drip
- Mechanical ventilation to help you breathe

You can write your own ADRT or use a template form to create it. In certain areas of the UK, a process called Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) is being used. This is a personalised record of what care and treatment you would want in an emergency. For more information see **resus.org.uk/respect**

## Do Not Attempt CPR decision (DNACPR)

Cardiopulmonary resuscitation (CPR) is an emergency treatment that aims to restart someone's heart and breathing if they have stopped. Although difficult, having conversations about CPR ensures it is only performed when it will benefit someone and be in their best interests.

Some people decide they do not want to have CPR. Their healthcare team would then complete a 'Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)' decision form. This means if your heart or breathing were to stop, your healthcare team would not attempt to restart them.

If you have not made a DNACPR decision, your healthcare team will look at your personal situation and decide if CPR is appropriate. CPR is very rarely successful at restarting the heart and breathing at the end of life. Decisions about CPR are made on a case-by-case basis and your healthcare team should involve you in these discussions. If they know CPR would not work, you and those close to you cannot insist you have CPR. You can however, ask for a second opinion.

There is more information about DNACPR on the NHS website **nhs.uk**

## Sharing information about your wishes

For those close to you, it can be upsetting to learn that you want to refuse treatment or do not want to be resuscitated. You may want to discuss your decisions with those close to you so they can be prepared and it will be less of a shock.

## Power of Attorney

A Power of Attorney is a legal document that allows you to name a trusted person to make decisions on your behalf. This person is called your attorney. Each UK nation has different rules which are discussed below.

For more information on Power of Attorney see **mariecurie.org.uk/power-of-attorney**

### England and Wales

In England and Wales, a Power of Attorney is called a Lasting Power of Attorney (LPA). There are 2 types of LPA:

- Property and financial affairs. Your attorney can make decisions about your finances and help with a house sale for example
- Health and welfare. Your attorney can make decisions about your treatment and care and have access to your medical notes

For an LPA to be valid, it must be registered with the Office of the Public Guardian, for which there is a fee. In certain circumstances, an LPA for health and personal welfare might overrule an existing Advance Decision to Refuse Treatment. Where possible try to ensure the two documents match your wishes. For more information see **gov.uk/power-of-attorney**

### Scotland

In Scotland, there are 2 types of Power of Attorney:

- Continuing Power of Attorney. Your attorney can make decisions about financial and property matters immediately. You can choose to have it to start only if you are unable to make decisions
- Welfare Power of Attorney. Your attorney can make decisions about your treatment and care, and can have access to your medical notes if you become unable to make decisions

These Power of Attorney documents need to be registered with the Office of the Public Guardian Scotland, for which there is a fee. For more information see **mygov.scot/power-of-attorney**

### Northern Ireland

In Northern Ireland, there is 1 type of Power of Attorney called an Enduring Power of Attorney (EPA). This allows your attorney to make decisions regarding property and finance. The EPA is valid once signed by your attorney. If you lose capacity, your attorney needs to register the EPA with the Office of Care and Protection for it to be valid. There is a fee for this.

Currently, there is no health or welfare Power of Attorney in Northern Ireland. For more information see **nidirect.gov.uk**

### Choosing your attorney

You should choose someone that knows you well and that you trust completely. You can appoint more than one person if you prefer. Before appointing your attorney, you should:

- Ensure they are happy to be your attorney
- Help them understand what you would want, as they have a duty to act in your best interests
- Be over the age of 18, or over 16 in Scotland

### 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. For those receiving certain benefits or on a lower income there is some financial help or exemptions available. This can help with the cost of setting up and registering a Power of Attorney.

## Making or updating your will

A will lets you leave instructions about what will happen to your money, property and possessions after you die. This is also called your estate. If you do not have a will, your estate is divided according to the law and may go to people you did not intend.

Things you may want to include in your will are:

- Who you want to manage your estate. Also known as the executors
- Who you want to inherit your estate and what you want them to receive

- Who are the legal guardians of any children under 18 (16 in Scotland)
- Arrangements for any pets

Once your will is written you should store it in a safe place and let your executors know where to access it. You should also regularly review your will in case of any change to your circumstances.

Before writing a will, it is advisable to seek advice from a legal professional. There are many free will writing services or will writing experts in the UK. Myeloma UK offers a free will writing service through their partnership with the National Free Wills Network. You can write or review your simple or mirror wills for free. For more information see **myeloma.org.uk/wills**. Marie Curie also have further information about making a will at **mariecurie.org.uk/wills**

## Online accounts

Much of what we do is now online including various accounts, social media, email, and photos. It can be useful to think about what you would like to do with each of your accounts. You may want to:

- Make a digital will. It's not legally binding but is an expression of your wishes. Read more at **digitallegacyassociation.org**
- Contact social media companies directly and explore your options. These could include: Downloading and storing photos and messages on a secure device, preserving your account so it can still be viewed by others, or deleting your account

- Make a list of online accounts, streaming services, emails and photo storage that you want those close to you to have access to. Ensure you note any information needed to access these accounts

## 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. Although it may not be possible for you to donate your organs, you can usually donate tissue. Your healthcare team can provide more information about organ donation.

In the UK, the law on organ and tissue donation is 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. Read more about organ donation at **organdonation.nhs.uk** and **nhsbt.nhs.uk**

Some people choose to donate their body for medical research. You and your next of kin will have to sign a consent form as part of the donation process. Unfortunately, not everyone is able to donate their body for research, so your next of kin may need to make other arrangements. For more information about donating your body, contact the Human Tissue Authority at **hta.gov.uk**

## Funeral planning

For those close to you, funerals allow time to share their grief and pay their respects. Those planning a funeral usually want the funeral to reflect your wishes. It can therefore be helpful to write your wishes down or discuss them with those close to you.

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 or charity donations
- Whether you want a wake or gathering
- 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 **mariecurie.org.uk/planning-your-funeral**

## Section 4

# What to expect at the end of life

# What to expect at the end of life

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**This section explores what to expect when you are no longer having treatment for your myeloma and you approach the end of your life.**

⚠ Please be aware this section contains details about what may happen at the end of life. You do not need to read it all at once and can come back to it when you feel ready to.

## Key points

- Eventually, the focus of treatment shifts from treating the myeloma to controlling symptoms
- **Supportive treatment** or **palliative care**, focuses on controlling symptoms and providing emotional, spiritual, and practical support to you and those close to you
- As you approach the last few weeks of life, you may experience certain physical and emotional symptoms and changes
- There are many things that can be done to manage symptoms at the end of life and make you as comfortable as possible

- For many at the end of life, there is a gradual slowing down of the body's natural processes. For others, this process may happen quickly due to unexpected complications, such as an infection

Generally, people with myeloma have a number of **active treatments** to kill the myeloma cells, followed by a period of remission. Unfortunately, myeloma will continue to progress until there are no further treatment options. At this time, **supportive treatment**, also called **palliative care**, becomes the focus of care. It aims to manage any symptoms and provide emotional, spiritual, and practical support to you and those close to you.

A decision to move to supportive treatment may be made because:

- The myeloma is no longer responding to treatment and there are no further treatment options
- Your general health declines and you would not be able to tolerate treatment side effects
- The side effects of treatment and the impact they have on you, outweigh the benefits of having treatment
- You have chosen to no longer have treatment

The end of treatment for your myeloma may come as a relief. You may feel the decision is right and has been made in partnership with your healthcare team and those close to you. For others, it may come as a shock and can cause some complex emotions.

## How long might I live after I stop treatment?

Many people want to know what time they may have to allow them to make plans. Myeloma is a complex and individual cancer and your healthcare team cannot give an exact answer to this question. They may be able to give you an estimate in weeks or months by considering your personal situation and how the myeloma and side effects have impacted you. The time you live for could be shorter or longer than they suggest.

## 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.

**For most patients, dying is calm, pain-free, and peaceful with the right symptom management.**

For many people, there is a gradual slowing down of the body's natural processes and they may experience certain symptoms. For others, this may happen more quickly due to complications. This may include infection or kidney failure. These symptoms are discussed further on page 43.

Many people with myeloma have a weakened **immune system**. Unfortunately, even with antibiotic treatment, infections in the **terminal stage of myeloma** can be life-threatening. For others, the kidneys may struggle to filter blood. This can cause life-threatening organ failure.

You may experience a gradual slowing down of the body's processes or a complication that causes a more sudden change. However, the focus of care will always be to keep you as comfortable as possible until the end of your life.

## Symptoms in the last weeks of life

As you approach the last few weeks of life, you may experience emotional and physical symptoms. Being prepared for what may happen and what can help these symptoms, can make them a little easier to cope with. Common symptoms include:

### Tiredness

It is normal to feel tired and less mobile in the last weeks of life. You may find normal activities exhausting and you may want to spend most of your day resting. Focusing on conversations and activities with those around you can also become challenging.

Allow yourself time to rest and try to save your energy for things that are important to you. When possible, ask others to help with chores, personal care, and cooking.

### Breathlessness

Breathlessness can be upsetting for you and those around you. There are different ways it can be managed, depending on the cause. For example, people with myeloma often have anaemia and a blood transfusion may help to ease breathlessness.

You may be prescribed treatment such as low-dose morphine, and encouraged to do some gentle breathing exercises. These can help reduce anxiety and relieve your breathlessness. Sitting upright with pillows to support your back and having a fan blowing across your face can also help. You may also be referred to an occupational therapist or breathlessness clinic for support.

## Pain

Pain is often one of the primary worries people have about dying. Importantly, there are many ways that pain can be managed effectively and not everyone with myeloma experiences pain.

Pain can impact your physical abilities and your emotions. If you do experience pain, speak to your healthcare team as soon as possible. The earlier they know about pain, the easier it is to control. They may prescribe painkillers and other medicines including:

- Non-opioid painkillers, such as paracetamol, to control mild to moderate pain
- Opioid painkillers, such as codeine and morphine, to control moderate to severe pain
- Medicines such as pregabalin and gabapentin, to control nerve pain
- Steroids such as dexamethasone and antidepressants such as amitriptyline can also be used alongside painkillers to help control pain

You should take your painkillers as prescribed, even if you are not in pain. Regular doses will help prevent high pain levels and make the painkillers more effective.

Non-medical pain management can also help to control pain. Regular position changes, use of hot and cold packs, **counselling**, and **complementary therapies** can help to ease pain and distract your focus away from it.

## Weight loss and low appetite

As the body begins to slow down and use less energy, it is normal for you to eat less. Some people may also feel sick or have problems swallowing as they become weaker.

Many people will also lose weight and muscle. This can be difficult for those close to you and they may encourage you to eat. You do not have to eat if you do not want to. If you do want to eat, high calorie, soft foods such as custard or ice cream may be easier to eat than a large meal.

## Restlessness and confusion

Some people feel restless and may appear confused or shout out. There can be a number of causes including: infection, pain, medication side effects and emotional or spiritual worries. The healthcare team will explore the reasons for agitation and confusion and offer support. They may suggest medications to treat underlying causes or to help keep you calm. They may also suggest talking to a counsellor, religious leader, or chaplain to help with any spiritual or emotional causes of agitation.

For those who are close to you, it can be difficult to see you restless or confused. It may be helpful to keep your environment calm and have someone talk to you as a distraction.

### Bladder and gut changes

Some people find it harder to control their bladder and bowels. A commode, bedpans, urine bottles, medical underwear, or pads on the bed can be used if you struggle getting to the bathroom. Some people may have a small tube called a catheter placed in their bladder to drain the urine into a bag.

Constipation is also common as you are moving and drinking less. Some painkillers may also contribute to this. Your healthcare team can prescribe laxatives as needed.

### Nausea and vomiting

If you are feeling sick, your healthcare team can prescribe anti-sickness medicine. These are often in tablet or injection form. Some people find that ginger tea or biscuits can help ease nausea. Travel sickness acupressure bands may also provide some nausea relief.

### Dry mouth

Small sips of water, chewing gum, ice lollies or ice chips can all help with a dry mouth. Lip balm may also be useful in preventing cracked lips.

### Emotional changes

It is normal to experience many different emotions at the end of life such as anxiety, fear, guilt, anger, and depression. Some people may withdraw from those close to them and become much quieter.

Everyone will cope with these emotions in different ways, but it can help to talk. Talking to those you are close to, the healthcare team, a trained counsellor, or a religious or spiritual leader can help you to process these emotions. Section 2 provides information about your emotions and how to access support for you and those close to you.

## Symptoms in the last days and hours of life

In the last days and hours of life, the body will start slowing down its natural processes. Each person's experience and how long this takes will be different. Generally, you get gradually weaker and spend less and less time awake. For others, changes can happen more quickly. Physical changes may happen such as:

- Spending most of the day asleep. You may become unconscious, where you cannot be woken but may still be able to hear those around you or feel touch
- Not drinking or eating. This can often cause those close to you distress and worry, but be assured it is a natural process and forcing you to try could make you uncomfortable
- Cold arms, legs, hands, and feet. Blankets and socks can help keep you comfortable
- Changes to skin colour. Lighter skin tones may appear blue, and darker skin tones may appear purple or darker than normal. It can be easier to see changes on the lips or inside the mouth. Skin may also appear mottled
- Noisy breathing may occur if there is a build-up of saliva or mucus in the chest or throat
- Irregular breathing with long pauses between each breath or breathing very quickly

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7

The final moments of life are usually calm and pain-free. Your breathing becomes more irregular with longer pauses between each breath, until you take a final gentle breath.

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

## When should I seek help with symptoms?

Make sure you know who to contact if you have any worries. It may be a GP, care home staff, or palliative care team. Keep their contact details somewhere safe and ask who to contact out-of-hours.

You should speak to your healthcare team about any new symptom or symptoms that are getting worse. You do not need to manage these alone.

Your healthcare team can also ensure you get your medicines in the most appropriate way. Medicines can often be given in different forms including: tablets, liquids, injections or as patches stuck to the skin. You may also be offered a **syringe driver**. This is a small pump that delivers a continuous dose of medicine through a thin tube under the skin. These pumps can deliver medicines such as painkillers, anti-sickness and other medicines to relieve symptoms. They can be used at any stage of your myeloma and can be useful in helping to control your symptoms.

You can find more information about syringe drivers at **mariecurie.org.uk/syringe-drivers**

## Complementary therapies

Often local hospices and cancer centres offer complementary therapies such as: massage, reflexology, and meditation. These therapies can be very enjoyable and can help manage symptoms such as pain and anxiety. Speak to your healthcare team to find out what is available in your area and ensure they are safe for you.

## Caring for someone in their last days of life

It can be emotionally and physically exhausting to care for someone at the end of life. You will have your own emotions to process and your own needs. Ensure you are taking regular meals and taking some time for yourself if you can. It can also be difficult to see the physical changes and symptoms. It may offer you some comfort to know that changes in the last days of life do not usually cause distress. They are a natural part of the dying process. Your presence with the person, speaking gently to them and holding their hand can provide both you and them with comfort.

If you have any worries, contact the palliative care team, GP, or care home staff. Be sure to keep their contact details somewhere safe. These teams are there to offer you support, as well as the person you are caring for.

You can also contact the Marie Curie Support Line for emotional support and bereavement support on **0800 090 2309**

## Help and support for those caring for someone at the end of life

When helping to care for someone at the end of life, you may have questions or want to talk about your experience. Both Myeloma UK and Marie Curie have dedicated services for those caring for someone with myeloma.

Our specialist team are available on the phone to offer information and emotional support. We also offer online forums where you can speak with people in a similar position to yourself and share your experience. Marie Curie also offer bereavement support from a trained volunteer.

Full details of the services available and some other useful organisations can be found in Section 7.

For more information on caring for someone and accessing support see the Myeloma UK **Infopack for carers of myeloma patients** and **mariecurie.org.uk/carer**

## Section 5

# Where can I spend my last days?

# Where can I spend my last days?

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

## 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
- 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 your healthcare team
- 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
- It may be that a combination of environments offers you the best support. For example, a stay in hospital or hospice to control symptoms, followed by a discharge home
- There are circumstances where plans may need to change. Complex symptoms can be challenging to manage in the home environment. You may need to move to a hospital or hospice to receive the best symptom control

It can be difficult to think about dying and where you would want to spend your last days. Your care needs and preferences may change and your choices will likely be guided by what is important to you. For many people, it can be helpful to think about choices before becoming too ill. You may want to consider:

- Being somewhere that is peaceful and private
- Being in a familiar environment or having personal possessions nearby
- Who you want to have with you and what support they can provide
- The availability of services in your area
- Any costs involved with care at home or a nursing home. See **mariecurie.org.uk/social-care** for more information

If you have somewhere you would like to spend your last days, speak to your healthcare team and those close to you. They can help to set up the necessary support to honour your wishes. Unfortunately, there are circumstances where the plan needs to change. For example, if you develop a complex symptom that needs specialist support in a hospital or hospice.

It may be that a combination of settings works for you. Such as a short stay in a hospice to provide symptom support or carer respite, followed by a discharge home. Whether at home, hospital, a hospice, or care home the priority will be to control any symptoms and to help you be as comfortable as possible to the end of your life.

## 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 and you can be surrounded by those you are close to.

Some people may worry about the impact on those caring for them or managing symptoms at home. Before deciding to be at home it is important to understand what support is available in your area. It may be that a combination of settings works best for you.

There are a number of healthcare and voluntary organisations that can support you and those caring for you at home including:

- Your GP, district nurses, and social services can help provide personal care and symptom control
- Community palliative care teams or 'Hospice at home' services who can provide symptom control, emotional support and support to those caring for you
- Marie Curie nurses are available in some areas, offering overnight care and allowing those caring for you to rest
- Occupational therapists and physiotherapists can help provide equipment and support to adapt your home as needed. For example, some people choose to adapt a downstairs living area and place a hospital bed in here. This ensures no stairs are involved and you remain close to kitchen facilities when mobile

> “ 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. ”

## Hospital

Some people prefer to be in hospital towards the end of their life. They may have established trust with staff members or feel reassured by the presence of palliative care teams. For others, complex symptom management or infections may result in a hospital stay.

Most hospitals have specialist palliative care teams. They are experts in managing symptoms and providing emotional support. Some hospitals may even have palliative care wards. These wards are generally quieter with more flexible visiting hours. Some people find their stay in hospital more comfortable if they bring personal belongings such as a duvet or photographs.

It can be challenging to quickly arrange care at home after a hospital stay. Your healthcare team may suggest discharging you to a hospice or care home. Talking to your healthcare team about your discharge can allow you to explore your options and share your priorities.

## Hospice

A hospice provides care and support to anyone with a terminal illness. Hospices are very different from hospitals. They usually have a more relaxed environment and much more flexible routines. They also have palliative care teams who are experts in managing symptoms and providing emotional support.

Hospices are often associated with care in the final days of life, however, they offer wide ranging support from the time of diagnosis of an incurable illness. Short term stays to help control symptoms such as pain can be arranged. Services such as **counselling**, spiritual care, and **complementary therapies** are also available. Some hospices may even offer respite care to allow those helping you at home to rest.

Some people feel they want to spend their final days in a hospice. You should speak with your healthcare team, palliative care team, or GP to find out what hospice support is available in your area and if you would be able to stay.

## Nursing home or residential home

If you need more support than is possible at home, a nursing home or residential care home may be more appropriate. A nursing home has trained nurses working to provide specific nursing care. A residential home has staff who are carers and provide care that those close to you might offer at home such as help with personal care and meals.

## Section 6

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# Medical terms explained

# Medical terms explained

**Active treatment:** Treatment of the myeloma itself, aiming to kill as many as possible of the myeloma cells.

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

**Complementary therapies:** A therapy used alongside prescribed treatment, such as reflexology or massage.

**Counselling:** A talking therapy that involves a trained therapist listening to you and helping you find your own ways to deal with emotional issues.

**End of life care:** Care provided in the last year of life to you and those close to you. It focuses on supporting your physical, emotional, and spiritual needs to help you live as comfortably as you can, until the end of your life.

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

**Palliative care:** A type of care or treatment that concentrates on preventing and relieving symptoms and improving quality of life, for patients with an incurable illness.

**Remission:** The period following 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 or the side effects of treatment, rather than treating the underlying disease.

**Syringe driver:** A small battery-powered pump that delivers a continuous flow of medicine under the skin. It can be used at anytime and is often used in the last weeks of life.

**Terminal stage of myeloma:** The final stage of myeloma, where it cannot be treated and is no longer responding to treatment. It is expected to lead to a person's death.

## Section 7

# Further support and information

# Help from Marie Curie

**From medical and physical support to psychological and emotional care, at whatever stage of the myeloma, Marie Curie can help you to live the best life possible – right to the end.**

## Marie Curie Support Line

**0800 090 2309**
**mariecurie.org.uk/support-line**
**support@mariecurie.org.uk**

Marie Curie’s free Support Line is for anyone with an illness they’re likely to die from and those close to them. The team, including nurses and Energy Support Officers, offers practical and emotional support on everything from symptom management and day-to-day care, to financial information and bereavement support. The Support Line is available in over 200 languages, or via webchat.

## Marie Curie Companions

**mariecurie.org.uk/companions**

Companion volunteers focus on what’s important to you and those close to you. It might be accompanying you to appointments, being there to listen to how you’re feeling without judgment, or stepping in so family or carers can take a break. Companions provide the emotional and practical support you want – at home, in hospital, or over the phone.

## Marie Curie Online Community

**community.mariecurie.org.uk**
Marie Curie's Online Community is a space for you to share thoughts, feelings, and experiences. It's moderated by the Marie Curie Support Line team, who can also help answer your questions.

## Marie Curie Hospice care at home

**mariecurie.org.uk/nurses**
Marie Curie's nurses, healthcare assistants and other healthcare professionals bring the clinical, practical, and emotional help you need to you, in the comfort of your own home. They offer support to the people close to you too – from reassurance and practical information to letting them take a break.

## Marie Curie Hospices

**mariecurie.org.uk/hospices**
Marie Curie's hospices help people with any illness they're likely to die from, and the people close to them, receive the support they need. From medical and physical support to psychological and emotional care, whatever your illness, at whatever stage of the journey, they can help you to live the best life possible, right to the end.

## Marie Curie Telephone Bereavement Service

**mariecurie.org.uk/bereavement**
Get ongoing bereavement support over the phone from the same volunteer. You can access up to six sessions of 45 minutes. Marie Curie can help if your bereavement was expected, happened recently, or was some time ago.

## More information and further support

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

# Planning ahead checklist

Planning ahead for the end of life can be a beneficial step. It can help you focus on doing what you enjoy and allow some choice and control over what happens in the future.

This Infopack explores the different things you may want to consider when planning ahead for the end of life. This list offers a brief summary of the things you might want to consider, including:

## Your estate and finances

- ☐ Making a will
- ☐ Power of Attorney
    - ☐ Lasting Power of Attorney for estate and financial affairs (England)
    - ☐ Continuing Power of Attorney (Scotland)
    - ☐ Enduring Power of Attorney (Northern Ireland)
- ☐ Plans for any children
- ☐ Arrangements for any pets
- ☐ Benefits available to you and those caring for you
- ☐ Making a list of financial documents such as bank accounts, pensions, investments, and insurance policies
- ☐ Keeping important documents such as national insurance number, birth certificate, utility bills in one place and ensure a trusted person knows where these are
- ☐ What you would like to do with online accounts?

## Your health

☐ Do you have an Advance Decision to Refuse Treatment (ADRT) or Living Will?

☐ Have you considered resuscitation?

☐ Power of Attorney

  ☐ Health and Welfare Power of Attorney (England)

  ☐ Welfare Power of Attorney (Scotland)

## End of life care

☐ Preferred place of care for the end of life

☐ Leaving memories for those you care for

☐ Wishes for your funeral or any pre-paid funeral plans you may have

☐ Would you want to donate your body or organs?

For more advice and information about planning ahead for the end of life you can call the Myeloma UK Infoline on **0800 980 3332** or **1800 937 773** from Ireland, or email **AskTheNurse@myeloma.org.uk**

You can also call the Marie Curie Support Line on **0800 090 2309** or visit their website at **mariecurie.org.uk**

# Useful organisations

**British Association of Counselling and Psychotherapy**
**0145 588 3300** **bacp.co.uk**
Professional Association for members of the counselling professions in the UK.

**Child Bereavement UK** **childbereavementuk.org**
**0800 028 8840**
Provides support and information for children, teenagers, and young adults (up to age 25) who are grieving the loss of a loved one.

**Cruse Bereavement Support** **cruse.org.uk**
**0808 808 1677**
Provides support and information to people who are grieving the loss of someone they were close to.

**Hospice UK** **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.

**Macmillan Cancer Support** **macmillan.org.uk**
**0808 808 0000**
Provides emotional, practical, physical, and financial information and support to all cancer patients and their carers.

**Maggie's** maggies.org
**0300 123 1801**
Provides free practical, emotional, and social support to people with cancer and their family and friends.

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**Mind** 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**
**0148 966 8332** nahh.org.uk
Organisation for Hospice at Home services in the UK.

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**NHS 111 Service** nhs.uk/111
**111**
Call 111 when you need medical advice fast but it is not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year.

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**Samaritans** samaritans.org
**116 123**
Listening and support free, 24 hours a day, to anyone who is struggling to cope.

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**Sue Ryder** sueryder.org
**0808 164 4572**
Supports people living with a terminal illness, a neurological condition or who have lost someone.

# We’re here for everything a diagnosis brings

Visit **myeloma.org.uk**, a one-stop-shop for information on myeloma; with videos, news and articles to help you keep up to date and live well with myeloma.

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

Get answers to your questions by emailing our Myeloma Information Specialists at **AskTheNurse@myeloma.org.uk**.

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

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

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

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**.

@MyelomaUK

# We are Myeloma UK

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**Myeloma UK is the only UK charity focused on myeloma and its related conditions. We are here for everyone affected by myeloma. Together we make it possible to live longer and better lives with myeloma. Together, we support, so no-one faces myeloma alone.**

All our charitable activity is funded by fundraising, voluntary donations, and gifts in wills. We couldn't do it without you, our supporters. Together, we are the cure.

## Make a donation

You can donate online at **myeloma.org.uk/donate**, by phone, or by posting a cheque payable to **Myeloma UK**.

## Fundraise

Fundraising is a positive way of making a difference. Whether taking part in or holding your own event it raises vital funds and helps raise awareness.

## Leave a gift in your will

Over a third of all our charitable activities are funded by gifts in wills. That's a third of Infoline calls, a third of drug approval panels and a third of research projects.

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

> **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

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**

MyelomaUK

## Get in touch to find out more about myeloma and how Myeloma UK can support you:

Call the Myeloma Infoline on
☎ **0800 980 3332**

Email Ask the Nurse at
✉ **AskTheNurse@myeloma.org.uk**

Visit our website at
👆 **myeloma.org.uk**

Trusted Information Creator
*Patient Information Forum*

BMA | **Patient Information Awards 2016**
Highly Commended

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