

Myeloma

Your guide to diagnosis,
treatment and living
well with myeloma

**Blood
cancer
UK**

Need to talk?

Contact the Blood Cancer UK Support Service with questions or worries about your diagnosis, family, work, mental health, the future.



Call free on **0808 2080 888**

(Monday: 10am to 7pm, Tuesday to Friday: 10am to 4pm
and Saturday and Sunday: 10am to 1pm)

Email **support@bloodcancer.org.uk**

Visit **bloodcancer.org.uk**

Talk to others **bloodcancer.org.uk/our-forum**

We're the UK's specialist blood cancer charity, supporting anyone affected by any blood cancer. Family and friends can contact us for support too.

My diagnosis and care

Ask your doctor or nurse to help you fill in this page about you, your diagnosis and key contacts:

My diagnosis is:

.....

My hospital number is:

My NHS number is:

My main point of contact (key worker) is:

Name:

Role:

Phone no:

Email:

You should be given a key worker. Ask if you're not sure who this is, or call us.

My consultant's name is:

.....

Haematology ward/clinic:

Phone no:

If I need medical help outside normal hours, I can call:

Name of service:

Phone no:

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Finding out you have myeloma



If you have a diagnosis of myeloma, whether it's smouldering or active myeloma, this booklet is for you.

For most people, getting a diagnosis of myeloma will come as a shock. And if you've just been diagnosed with it, you're probably feeling there's a lot to take in.

We have written this booklet with people who know what it's like to live with myeloma. It aims to give you the basics, so you understand a bit more about what having myeloma might mean for you.

Don't feel you have to read it all at once. Keep it handy so you can come back to it when you're ready or show others to help them understand.

You can order more free copies for your family and friends from [bloodcancer.org.uk/our-booklets](https://www.bloodcancer.org.uk/our-booklets)

People hear the word cancer, and they panic. But there are so many different treatments for myeloma, and there's so much research going on. That's what you need to know.

Cecelia, living with myeloma since 2020



Is it normal to feel how I'm feeling?

People have different experiences of diagnosis. Some people are diagnosed with myeloma after a routine blood test, so they may not have known there was anything wrong. Others may have had health problems for some time and struggled to get answers.

Either way, being diagnosed with cancer is life-changing and it's a lot to get used to. People talk about feeling stunned, sad, angry, scared, numb...and it can change from minute to minute. So whatever you're feeling now is normal in these difficult circumstances. And you're not alone.

Over 21,000 people in the UK are living with myeloma. So there are other people who will completely understand. You might find it helpful to connect with some of them on our online forum at bloodcancer.org.uk/our-forum

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The Blood Cancer UK forum has been a blessing. I wanted to say hello, this is me, and start putting the word cancer down on paper and owning it. It's been therapeutic.

Linda, living with myeloma since 2021



The next steps

It's useful to know what will happen next after you've been diagnosed, but it can be hard to take in what your doctor or nurse has told you. Don't be afraid to ask questions and ask them to go over things again. In the meantime:

- 1. You should be given contact details of a key worker,** your main point of contact in the hospital team. Usually, this is a clinical nurse specialist (CNS). Ask who your keyworker is so you can contact them if you have questions.
- 2. You may have more tests** to find out more about the myeloma, whether you need treatment straight away, and what treatment will work best for you. Ask your hospital team what the tests are for and if you're likely to have them again.
- 3. Your hospital team will explain your treatment plan** or how you will be monitored if you don't need treatment yet. Ask any questions you like, including how the treatment or your symptoms will affect everyday things like driving, working, housework and gardening. It's also OK to ask for another appointment. Most people need more than one to take it all in.

Some people don't feel confident about talking to their hospital team at first. If you find this difficult, contact our Support Service who can give you tips on how to build a relationship with your team.

Checklist of things you can do

Here are some practical things you can do to make life a bit easier in these early days:

- Contact our Support Service to talk through your diagnosis and what comes next.
- Try not to google – the information can be out of date, misleading and unnecessarily worrying.
- Put all your appointments in a diary or calendar so you know what's coming up.
- Decide how you will get to face-to-face appointments and consider taking someone with you if you can.
- Get a folder so you can keep medical letters and health information in one place.
- Keep a list of questions to ask at your next appointment or to email to your CNS (see page 13 for suggestions).
- Choose books, magazines, podcasts or videos to give you something to do if you have to go to hospital.
- If you need to, think about who could help you with things like shopping, cooking, gardening, housework, childcare or caring for someone else.
- Follow general advice on healthy eating and ask your hospital team about ways to stay active.

If you need to talk

If you want to talk about what your diagnosis means, how you're feeling or what to do next, contact our Support Service free on **0808 2080 888** or **support@bloodcancer.org.uk** and tell us that you've just been diagnosed with myeloma.

Or talk to people who've been where you are now on our online community forum:
bloodcancer.org.uk/our-forum

Telling people about your diagnosis

When they hear your news, most people will be supportive and offer help. But here are some tips if you have to handle some more difficult reactions:

- **If people get upset** – Explain that myeloma is treatable, and that you can live with it and have a good quality of life. If you end up having a cry together, that's fine!
- **If people don't know what to say or say nothing** – Next time you see them, bring up the subject so they know it isn't something they need to avoid. Then move the conversation on to other things.
- **If people say unhelpful things** – Point them to the Blood Cancer UK website or give them a copy of this booklet so they'll understand more about what it's like living with myeloma.

Don't be afraid to tell people how you want to be treated. Most people just want others to behave as normal.

It's perfectly OK to let people know when you want to talk about your health, and when you would rather talk about other things.

Telling children

The first thing is to decide whether you want to say anything. You may decide that the children you're close to don't need to know right away. Or you may think it's better to explain what's happening. That may depend on their age, the relationship you have with them, how you're feeling and whether your diagnosis is likely to affect their routine.

Many people say it's best to be as honest as you can. Children of different ages can react in different ways, but our Support Service can recommend some age-appropriate resources to help you.

Other people with blood cancer will share their experiences with you at [bloodcancer.org.uk/our-forum](https://www.bloodcancer.org.uk/our-forum)

I said to my family, right, this is what I've got. This is the treatment I'm going to have. You can cry once and that is it. Because I will fight this.

Sandra, living with myeloma since 2008



Telling your workplace

You don't have to tell your employer about your diagnosis, but you might want to, even if you don't need treatment.

Telling them means you can discuss adjustments to help you deal with myeloma symptoms such as tiredness (fatigue) and bone pain. See page 72 for some examples of adjustments that might help you carry on working, and information about your rights as someone with cancer.

You might also benefit from a workplace risk assessment, as you're likely to be at risk from infections like covid-19 or flu.

If you want other people at work to know about your diagnosis, you can ask your line manager or HR team to tell work colleagues. Or tell them yourself, it's your choice. Your employer can't tell anyone without your permission.

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When you tell people, don't just drop it on them. I didn't realise how much it affects people - you need to warn them you've got something quite big to tell them.

Kerry, living with myeloma since 2021



Questions to ask after your diagnosis:

It can be hard in the early days to know what questions to ask your hospital team, so here are some suggestions. There's also space to write your own on page 81.

- Will I need more tests?
- What kind of tests will I need?
- What are the tests for?
- Do I need treatment?
- If I need treatment, when is that likely to start?
- What kind of treatment will I have?
- If I don't need treatment, what happens next?
- You mentioned [any medical term]. What does that mean?

Understanding myeloma



Many people find it helps them feel more in control to learn about what myeloma is and how it can affect them.

People often talk about having to learn a whole new language when they're diagnosed with myeloma. Different people have different feelings about how much they want to research and read up on their condition, and that's a personal choice. But most would agree there are some things it's good to know from the start.

Knowing more about myeloma can also make you feel more confident about asking questions so you can get more out of your appointments.

This chapter gives you a very brief summary of what myeloma is and the effects it can have on the body.

I've always been curious. I've always felt if it's affecting me, I want to know as much as humanly possible, within reason. I want to know what to expect.

Kerry, living with myeloma since 2021



What is myeloma?

Myeloma is a blood cancer that affects white blood cells called plasma cells. Plasma cells are normally found in your bone marrow – the spongy material inside some of your bones, where blood cells are made.

Plasma cells make proteins called antibodies. These are part of your immune system and protect you by killing germs such as viruses and bacteria.

In myeloma, some plasma cells stop working properly.

- These abnormal myeloma cells make faulty antibodies called paraproteins which can't kill germs effectively.
- They grow more quickly than normal, crowding out your bone marrow so it can't make enough healthy blood cells.
- They may stop your bones growing new tissue, causing holes called lytic lesions which make your bones weaker.
- Small pieces of paraprotein (called light chains) may block the small tubes in your kidneys. This can damage your kidneys and make them work less efficiently.

The things we've listed here can cause a range of different symptoms, although some people have no symptoms when they're diagnosed.

We have more information about the symptoms of myeloma at [bloodcancer.org.uk/myeloma-symptoms](https://www.bloodcancer.org.uk/myeloma-symptoms)

Different types of myeloma

Most people with a diagnosis of myeloma have paraprotein in their blood. But in some types of myeloma, the myeloma cells don't produce paraprotein:

- **Light chain myeloma** – The myeloma cells only produce small pieces of paraprotein called light chains. One in five people with myeloma (20%) have this type.
- **Non-secretory myeloma** – In rare cases, the myeloma cells don't produce (secrete) any paraprotein at all, or very little. Around three people in a hundred with myeloma (3%) have this type.

The treatments for all types of active myeloma are the same.

Smouldering myeloma

People with smouldering myeloma don't have any symptoms of myeloma, or signs of kidney or bone damage. They are often diagnosed by chance following a blood test for something else.

Smouldering myeloma doesn't need treatment straight away. Some people never need treatment. You will be monitored regularly and will only start treatment if your doctor thinks you need it.

You can read more about smouldering myeloma from page 27.

Myeloma key terms

Paraprotein – abnormal antibodies produced by myeloma cells and found in the blood of most people with myeloma

Light chain – small fragments of paraprotein, found in the blood of most people with myeloma

Plasma cells – white blood cells in the bone marrow that normally make antibodies, and are the cells affected by myeloma

Bone marrow – the spongy material inside some of your larger bones where blood cells are made

Lytic lesions – holes in the bones which make the bones weaker

Multiple myeloma – another name for myeloma, because myeloma affects more than one place in the body

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Don't feel you have to learn all the terminology on day one - it's natural to feel confused at first but you will get the hang of it.

Ian, living with myeloma since 2019





How do you cope with a blood cancer that's treatable but not curable?

Louise, Cecelia, Craig, Ian, and Joan talk about living with the uncertainty of myeloma, the adjustments they've made and what works for them when it comes to managing their feelings.

Read their stories at bloodcancer.org.uk/coping-myeloma or call us and we'll send you a printed copy.

What does the future look like?

When you've been diagnosed with myeloma, you may want to know more about your prognosis (what could happen in the future).

Thanks to research, new treatments for myeloma have been introduced in recent years and overall, people with myeloma have a much better prognosis these days.

Myeloma isn't a type of blood cancer that can be cured, but it can be managed so you can get on with your life. Managing myeloma might mean having treatment whenever you need it, with periods of remission where there's little or no sign of the myeloma left. Or, it might mean no treatment, just regular appointments to check what's happening in your blood.

Everyone is different and your prognosis is personal to you.

If you want to know more

The best people to ask about your prognosis are your hospital team. They know you and your individual situation.

Tell them about any concerns you have for the future. It's helpful for them to know what you're thinking and feeling so they can give you the care that's right for you.

If you want to talk about your prognosis but find it difficult to start the conversation, contact our Support Service to talk through how you could approach it.

You'll find information in this booklet about monitoring (see page 27) and treatment (see page 37). Information about living with myeloma starts on page 59.

You may also be interested in our research to improve treatments. Go to bloodcancer.org.uk/researching

Myeloma has changed my life really. It's fair to say it's turned my whole world upside down. But I still have a world.

Louise, living with myeloma since 2017



Your risk of infection

Having active myeloma makes it more likely you'll get infections, because your immune system won't be working well. Infections can get worse quickly and develop into sepsis, a dangerous condition. But if you act fast, they can be treated before they become serious.

Here are three key things to do:

- **Find out who you can contact urgently** (and out of hours) if you think you have an infection. Write the number at the front of this booklet or somewhere you can easily find it.
- **Make sure you know the symptoms of infection** (see the next page) and call your emergency contact number straight away if you have any of these symptoms.
- **Share this information with your family and friends** so they know what to look out for too.

You should also follow general advice about lowering your risk of infection, like washing your hands frequently, staying away from anyone who is unwell, avoiding crowds and wearing a face mask when you go out.

Even if you are in remission, or have smouldering myeloma (see page 27), your risk of getting an infection may be higher than normal.

Check with your hospital team about your own level of risk and what you should do to protect yourself.

Symptoms of an infection

These are common symptoms of an infection, but tell your hospital team straight away if you just don't feel right:

- fever (temperature of 37.5°C or above)
- low temperature (less than 36°C)
- shivering and sweating
- feeling confused
- sore throat or cough
- rashes or swelling
- frequent watery poos (diarrhoea)
- a burning or stinging sensation when weeing
- unusual stiffness of the neck
- achy, flu-like symptoms.

Find out more at bloodcancer.org.uk/infection or call us to ask for printed information.

We have information about blood cancer and covid-19 at bloodcancer.org.uk/coronavirus

Infections can come on really quickly. One minute I was really good, the next minute I could barely get out of bed. I had antibiotics and was feeling better 48 hours later.

Ian, living with myeloma since 2019



Vaccinations that are safe for you

Depending on your treatment plan (see page 39), your doctor will usually recommend you have a flu jab and possibly a pneumonia jab. You will also be on the priority list for any covid-19 vaccinations.

With myeloma, you shouldn't have live vaccines, but the flu, pneumonia and covid-19 vaccines aren't live, so they're safe.

Your risk of shingles

Shingles is an infection of a nerve and the skin around it. You can get it if you've had chickenpox in the past, even if it was a long time ago. It tends to affect people with weak immune systems.

Doctors may prescribe an antiviral medicine such as aciclovir to stop you getting shingles, or you may be offered a vaccine called Shingrix, which is not live.

If you're feeling overwhelmed

There's a lot to take in if you've just been diagnosed with myeloma. It's completely understandable if you feel overwhelmed by all this information.

It might help to ask someone you know to read this booklet, or order another one so you can talk things through together. Go to **[bloodcancer.org.uk/our-booklets](https://www.bloodcancer.org.uk/our-booklets)**

You can also talk to us about any worries you have. Call free on **0808 2080 888** or email **support@bloodcancer.org.uk**



Sandra

How did counselling help you through a bad time?

“Counselling helped me to be honest with myself and speak my truth always. I was able to open up and discuss all my fears and worries, without fear of judgement, of being told I was silly or to pull myself together and get over it.”

Read Sandra’s story at bloodcancer.org.uk/sandra or call us and we’ll send you a printed copy.

If you have smouldering myeloma



If you have smouldering myeloma, you will be monitored by your hospital team but won't need treatment.

People with smouldering myeloma have signs of myeloma in their blood, but no signs of damage caused by the myeloma. They may not have any symptoms at all.

Smouldering myeloma doesn't usually need treatment straight away and some people never need treatment.

If you are told you have smouldering myeloma, you will have regular tests. Your hospital team will monitor the results for signs that you need to start treatment. This approach is called watch and wait, active monitoring or expectant management.

It can be hard to know you have blood cancer but won't be treated. This chapter aims to help you manage your physical and emotional health while you're on watch and wait.

Everybody's an individual. You may hear a story about somebody else with myeloma but it doesn't have to be your story. Your story will be different.

Linda, living with myeloma since 2021



Why am I not having treatment?

Doctors won't start treatment if you have no symptoms of myeloma, and no signs of damage to your bones or kidneys.

Watch and wait is the safe and recommended route for smouldering myeloma, because:

- the myeloma may never progress to active myeloma
- it's not affecting your overall health
- it avoids possible side effects of treatment for as long as possible.

Also, myeloma can become resistant to a particular treatment over time. So it's best to delay the process for as long as possible.

Rest assured, you will have treatment as soon as you need it. So if tests show that the smouldering myeloma is at high risk of becoming active, or there are signs it's causing damage to your organs (or will do soon), treatment will start.

The emotional effects of watch and wait

Many people find watch and wait tough emotionally. It's a strange situation to be told you have blood cancer but don't need treatment. People often find their anxiety level rises as their next check-up gets closer.

There's more information about coping with waiting for test results on page 31.

What's the risk of it becoming active?

If you want to find out more about your individual level of risk of the myeloma becoming active, your hospital team are the best people to speak to. They know about your general health, and they regularly monitor your test results. So don't be afraid to ask.

One general thing we can say is that if the smouldering myeloma is stable for five years, the chance of it becoming active drops significantly, and then gets lower over time.

We have information to help you understand watch and wait and explain it to others. You can order or download our free fact sheets from bloodcancer.org.uk/watch-wait-booklets or by calling **0808 2080 888**.

Some people are reluctant to speak to the consultant because they feel a bit intimidated. But they do want to hear from you. So tell them how you feel and ask questions.

Joan, living with myeloma since 2006



What happens at my check-ups?

Your check-ups will involve blood tests, and you may also have an MRI or PET-CT scan. Your doctor or nurse will also ask if you've noticed any changes since your last appointment. These may not be symptoms of myeloma, but do tell your hospital team about anything that feels different.

Your team will tell you how often you will need a check-up. If your test results stay the same over time and you don't develop symptoms, then you may have appointments less often. If you don't need a scan, some appointments may be by phone or video call.

You'll find information about typical symptoms of myeloma at **bloodcancer.org.uk/myeloma-symptoms**

Make sure you and your loved ones are also aware of the symptoms of an infection – see page 23.

If you're feeling very tired

Although people with smouldering myeloma generally have no symptoms, some experience fatigue (extreme tiredness) from time to time. It doesn't necessarily mean the myeloma is becoming active but do tell your hospital team if you are feeling more tired than usual.

You'll find more information about fatigue and how to manage it on page 56.

Waiting for your test results

It's natural to think or worry about test results before you get them. Here are some tips for managing this:

- **Distract yourself** – Get engrossed in an activity you enjoy, something that's achievable but needs a bit of mental or physical effort, or both. This might be a DIY or craft project, an exercise programme, gardening or reading.
- **Unwind and relax** – If you find it difficult to concentrate, something that needs less effort might work better, like watching TV shows or films, reading magazines or chatting to friends about other things. Anything that will take your mind off your worries for a period of time will help.
- **Say your worries out loud** – you might prefer the more direct approach of talking through the possible outcomes of your test results and your feelings about them. Expressing your worries out loud can often help you manage them.
- **Techniques for managing anxiety** – If you've experienced anxiety in the past, you may already know some self-help techniques you can use. If not, or you need a reminder about different things to try, you'll find a range of ideas at [bloodcancer.org.uk/mind-emotions](https://www.bloodcancer.org.uk/mind-emotions)

Anxiety around waiting for test results is a common topic of conversation for people who call our Support Service. Contact us if you want to talk things through.

Coping with your feelings

You may have mixed feelings about being on watch and wait. On the one hand, it's good that you don't need treatment. You should be able to carry on with life pretty much as normal.

On the other hand, it's hard to take in, and explain to others, that you have cancer but aren't being treated for it. And waiting for test results or being on the look-out for symptoms can cause a rollercoaster of anxiety.

Managing difficult feelings

Some people talk about feeling like a "fake" cancer patient. Others say they feel they're not in control, because they don't know if and when they'll need treatment.

There are things you can do to manage these feelings:

- **Talk to your doctor or nurse.** They may be able to put your mind at rest about some of your concerns. They can also refer you for counselling or other professional support, which many people find helpful.
- **Read our checklist of simple things to do** to protect your mental health on pages 61 to 64. There are more things to try at [bloodcancer.org.uk/mind-emotions](https://www.bloodcancer.org.uk/mind-emotions)
- **Visit [bloodcancer.org.uk/our-forum](https://www.bloodcancer.org.uk/our-forum)** and search "watch and wait" to see what's helped others adjust to their new situation.

Questions to ask about watch and wait

Many people make a list of written questions for their hospital team as their mind sometimes goes blank when they're in an appointment.

Here are some suggestions for questions to ask about watch and wait, or you can write your own on page 81:

- Why don't I need treatment?
- When will I need treatment?
- How often will I have check-ups?
- What are the check-ups for?
- What tests will I have?
- How long will it take to get the results?
- What symptoms should I look out for?
- Who can I contact if I'm anxious or feel ill?

Finding out about treatment

If you're on watch and wait, you may not want to find out about treatments for myeloma just yet.

For now, the most important thing is to be aware that if the time comes, there's a range of effective treatments for myeloma and more are being developed.

If you do want to know more about what's involved in treating myeloma, the next chapter will give you a general overview.

If you don't want to know more about treatment at this stage, skip to the chapter on living well with myeloma, starting on page 59.

Find out more

When you're ready, you'll find detailed information about the latest treatments for myeloma at **bloodcancer.org.uk/myeloma-treatment**

You may also like to find out more about the myeloma research we're funding. Visit **bloodcancer.org.uk/researching**

Having treatment for active myeloma



There are many treatment options for people with myeloma, and new ones are being developed all the time.

If you have active myeloma, you'll probably need treatment straight away. The aim of treatment is to bring you into remission, where there are few or no myeloma cells left. It's likely you'll then have more treatment to keep you in remission for as long as possible.

Myeloma can be treated, but it can't be cured yet. It almost always comes back (relapses) at some point in the future, but when that happens, there are many more treatment options available.

With a few adjustments, people who are in remission from myeloma can generally get on with their lives.

Because I can't see it and I can't feel it, I've always felt strange about having myeloma. I'm taking things to keep it at bay, but in myself I feel the same as before it happened.

Mart, living with myeloma since 2020



The aims of your treatment

Treatment for myeloma has two main aims:

- to bring you into remission (also known as a stable or plateau phase) where there are few or no myeloma cells left in your body
- to manage the effects of myeloma such as bone and kidney damage and improve your quality of life.

As more and more treatments for myeloma are approved, printed information about treatment is bound to go out of date very quickly. So this chapter just gives an overview of the types of treatment available for myeloma. It also outlines some of the tests you may need.

For up-to-date information about myeloma treatments, please visit [bloodcancer.org.uk/myeloma-treatment](https://www.bloodcancer.org.uk/myeloma-treatment) or call us and we will print the information out for you.

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It looks like a giant mountain in front of you that you've got to climb. But you've got to just take it one step at a time. That's what helped me get through it.

Cecelia, living with myeloma since 2020



Types of treatment

There are many drugs approved to treat myeloma. You will normally have a combination of drugs that work in different ways to kill the myeloma cells:

- **Inhibitors** (cancer growth blockers) are targeted drugs which block the signals that make cancer cells grow.
- **Monoclonal antibodies** (immunotherapy) are targeted drugs which bind to specific cells and then kill them.
- **Immunomodulatory drugs** are targeted drugs which stop myeloma cells growing and help your own immune system to attack them.
- **Chemotherapy drugs** are anti-cancer drugs that work by stopping myeloma cells dividing and growing.
- **Steroids** help to kill myeloma cells and work together with other drugs. They also reduce swelling (inflammation).

You may have drugs through a drip (intravenous infusion), as an injection under the skin (subcutaneous injection), or as tablets or capsules. If you have a drip you will go to hospital as a day patient. Injections can be done in hospital or you can learn how to inject yourself – it's your choice. Tablets and capsules are taken at home.

Stem cell transplants

If you are generally fit and have few other health issues, your doctor may recommend a stem cell transplant as part of your treatment.

Stem cells are undeveloped cells that can turn into different types of blood cell. People with myeloma will usually have a transplant using their own healthy stem cells. This is known as an autologous or auto stem cell transplant.

The treatment involves intensive chemotherapy and can be tough, but people who have been through it say it is doable. You will need to spend a few weeks in hospital so the staff can take good care of you.

If you have a stem cell transplant, it's likely to happen several months after you are diagnosed. When you are ready, you can order our free booklet about blood stem cell transplants from bloodcancer.org.uk/our-booklets

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The consultant said I'd had a particularly rough time with the stem cell transplant, but it's worked because I've not had any treatments specifically for the myeloma in 16 years.

Joan, living with myeloma since 2006



Treatment options

There are many treatment options for people with active myeloma. These are often called lines of treatment.

First-line treatment

Your first line of treatment aims to bring you into remission and keep you there for as long as possible. When the myeloma comes back, you will have a second line of treatment. And then a third, and so on.

There are three possible stages to your first treatment:

- 1. Induction** – This aims to kill as many myeloma cells as possible and get you into remission. It usually involves a combination of different drugs given over the course of several weeks or months.
- 2. Consolidation** – This aims to keep you in remission. This may involve further treatment with a combination of drugs, or if your doctor thinks you are fit enough, you may have a stem cell transplant.
- 3. Maintenance** – It's common now to have maintenance therapy which helps you stay in remission for longer. This is usually a tablet you can take at home.

Treatment for relapsed myeloma

There are lots more treatment options for people whose myeloma relapses (comes back), even if it relapses multiple times. Whatever treatment your doctor recommends, you will have it over the course of several weeks or months with the aim of getting back into remission.

Go to [bloodcancer.org.uk/myeloma-treatment](https://www.bloodcancer.org.uk/myeloma-treatment) or call us for more information.

Treatment decisions

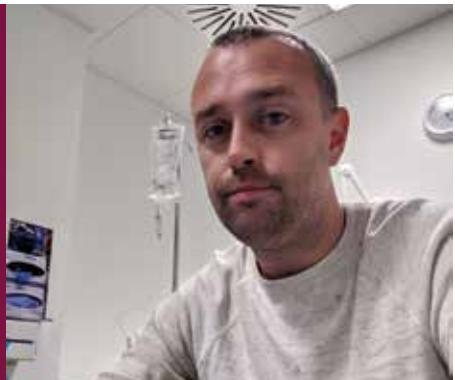
There are several things your doctor will consider when deciding which treatments to recommend:

- your overall health and fitness
- the results of genetic tests
- how long you stayed in remission after your last treatment
- whether you had significant side effects
- your personal circumstances and preferences.

“

It does play on my mind that it will come back. But I know that if I'm the healthiest and the fittest that I can be, it's not going to be as bad.

Scott, living with myeloma since 2019



Refractory myeloma

Sometimes, myeloma stops responding to treatment. This is called refractory myeloma.

If this happens, your consultant might suggest you take part in a clinical trial which gives you the chance of trying a new treatment.

If you don't want to take part in a trial, your consultant will discuss other treatment options based on which drugs you've already tried, your general health, and your wishes.

Clinical trials

A clinical trial is a research study involving people. If there is one available, your consultant might suggest you join it. Clinical trials are done for several reasons, including developing new treatments and improving existing ones.

Taking part in a clinical trial has advantages, such as the opportunity to have a new treatment which might not be available otherwise. You'll be very closely monitored and have detailed follow-up. But it does come with uncertainties, so it's up to you whether you take part.

If you don't want to be in a trial, or there isn't a suitable trial running, you'll be given the best standard treatment that's right for you.

Clinical trials

We have more information about clinical trials on our website. We also have a clinical trials support service which offers individual support to find suitable clinical trials and explain what's involved.

Find out more at
bloodcancer.org.uk/clinical-trials

Questions to ask about your treatment

It can help to jot things down in between appointments, as new questions occur to you. There's space to write down your own questions on page 81.

- What tests will I have during treatment?
- How long will it take to get the results?
- What are the tests for?
- What treatment will I have?
- What's the aim of my treatment?
- Is there a clinical trial I can join?
- How and where will I be given the treatment?
- How long will the treatment take?
- What might the side effects be?
- How can I manage these side effects?
- How will treatment affect my daily life?
- What's the best outcome I can hope for?
- Who do I contact if I don't feel well?
- Who do I contact out of hours?

I went from girlfriend to carer overnight. Mart had two A4 sheets of medication and I was worried I'd give him the wrong dose. But you get into your own routines.

Kayleigh, partner of Mart, living with myeloma since 2020



”

Monitoring your treatment

When it's time to start treatment, you will need tests to monitor your paraprotein and light chain levels and check how the treatment is working. You will also have tests to check how well your kidneys are working, and to monitor any bone damage caused by the myeloma.

If you haven't already, you may have genetic tests to see what changes have taken place in the myeloma cells as this may help doctors decide on your treatment.

These tests will be done on a sample of your blood or bone marrow (see page 48 for information about bone marrow biopsies).

You may also have scans to check for damage to your bones, especially if you have non-secretory myeloma, which can't be monitored effectively by blood tests.

Waiting for test results can be hard, but there are some ideas on page 31 about how you can reduce the stress of it.

We have more information about tests for myeloma at **bloodcancer.org.uk/myeloma-tests**



Linda

Did you find it hard to talk about your myeloma diagnosis?

“I’m quite a communicative, confident, assertive person, but I found it difficult to share what was happening and attach the word ‘cancer’ to it. Instead, I would refer to my ‘poorly bones’ as a way of letting people know that my whole bone structure was affected, but without telling them too much.”

Read Linda’s story at bloodcancer.org.uk/linda or call us and we’ll post you a printed copy.

Bone marrow biopsies

You may have a bone marrow biopsy before or after treatment. This isn't a test in itself, rather a way of collecting samples to test.

Bone marrow is the soft tissue found inside your larger bones. It is where blood cells are made and where normal plasma cells – and myeloma cells – are found.

A bone marrow biopsy means taking a sample of bone marrow so that your doctor can look at it in a laboratory. When you are having treatment, it will give your doctor more information about how the treatment is working and whether you are in remission.

What happens in a bone marrow biopsy?

A doctor or nurse will normally take two samples from the back of your pelvis (the ring of bones between your waist and your legs). You'll be asked to curl up on your side to make this easier. You might need to change into a hospital gown. It's certainly best to wear loose clothing on the day.

They will give you a local anaesthetic to numb the area where the needle goes in. Then they will insert one needle to draw some cells out of the bone marrow and a second needle to take a sample of bone marrow tissue (a core).

The procedure can take up to half an hour but removing the bone marrow samples only takes a few minutes. Your samples are sent to a laboratory and the results usually come back in one to two weeks.

A bone marrow biopsy is done as a day patient, so you can go home afterwards.

Does it hurt?

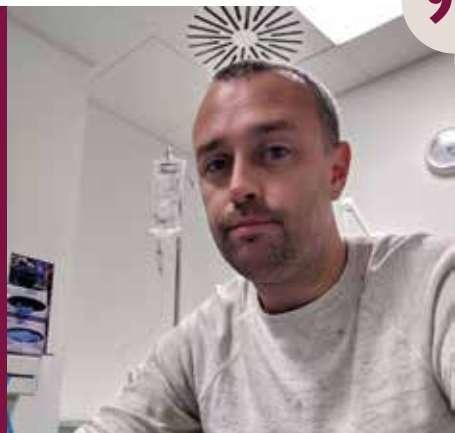
People's experiences of having a bone marrow biopsy seem to vary. Some people feel a pulling or pushing sensation or find it uncomfortable. Others find it painful, even with a local anaesthetic.

Taking paracetamol before and after can help. You can also ask whether you can take something to make you feel sleepy or have gas and air. Different hospitals have different policies, so ask what pain relief is available.

Some people find their back is sore afterwards, so think about how you'll get home after the biopsy.

It made a big difference to me when someone showed me how to breathe properly with gas and air. So if you're offered that, ask how to use it for maximum effect.

Scott, living with myeloma since 2019



”

Protecting your fertility

Myeloma treatments can affect your ability to have children. If you are planning to have a family in the future, or just want to keep your options open, tell your hospital team. It may be possible to freeze eggs, embryos or sperm for use when you're ready.

Talk to us

Being told your fertility is likely to be affected is a hard thing to hear. It may also be a difficult subject to discuss with a partner or close family.

If you would like to talk things through, contact our Support Service. We're here to listen and help you get the support and information you need. Call us free on **0808 2080 888** or email **support@bloodcancer.org.uk**



Kerry

What were you able to do to maximise your chance of having a child?

“I was lucky that I was able to have two cycles of fertility treatment before I started my myeloma treatment. We now have several frozen embryos. It’s good to have that safety net, but we are considering other options too.”

Read Kerry’s story at bloodcancer.org.uk/kerry or call us and we’ll post it to you.

Side effects of myeloma treatment

The drug treatments you will have for myeloma may cause unwanted effects called side effects. Some side effects are more common than others, but everyone reacts differently, even if they are having the same drugs.

The important thing is to tell your hospital team if you notice any change in how you feel. There are medicines and self-help tips that can make a difference. Your doctor may also be able to adjust your treatment to reduce side effects.

It can be helpful to share experiences and tips with other people. You can do this on our online community forum at bloodcancer.org.uk/our-forum

You may also want to read our general information on common side effects of blood cancer treatment at bloodcancer.org.uk/side-effects

“

For me, the anxiety was definitely the worst. I had some therapy but I just knew it was physical. But actually, when the steroids stopped, I came back to normal.

Louise, living with myeloma since 2017



Treating the effects of myeloma

Myeloma can cause a range of health problems. Treating the myeloma should help with these, but in some cases you may need extra support.

Bone damage

Myeloma can cause small holes in your bones called bone or lytic lesions. These can make your bones weak and painful. You will be given bone strengthening medicines called bisphosphonates to treat this.

Your team may also recommend calcium and vitamin D supplements and give you tips about diet and exercise.

For problems affecting your spine or other bones, you may see an orthopaedic surgeon (a doctor who specialises in bones).

Kidney damage

About half of all people with myeloma will have problems with their kidneys. So you'll have regular blood tests to check how well your kidneys are working. If tests show your kidneys are damaged, you will be referred to a nephrologist (a kidney specialist).

Your doctor or nurse will give you general advice about looking after your kidneys such as drinking a lot of water, as this can help to keep your kidneys healthy.

Nerve damage

Myeloma, and some myeloma drugs, can cause nerve damage. The nerves in the legs, feet, arms and hands are most likely to be affected – the medical name for this is peripheral neuropathy.

Tell your hospital team if you have tingling, loss of feeling or pain in any of these areas. They may give you painkillers or adjust your myeloma treatment, or you may be referred to a neurologist (a nerve specialist).

Anaemia

Anaemia is the medical name for a low level of red blood cells. It can make you feel tired and breathless and is a common symptom of myeloma. If you are anaemic, your doctor may suggest injections of a hormone called erythropoietin (EPO) which stimulates your bone marrow to make more red blood cells. Some people may have a blood transfusion.

“

**I'm a tough cookie.
But one day I realised
everything's changed.
I can't just rush to the
shops like I used to. It
has to be planned. It has
to be short. And I wept.
And it's good to cry.**

Linda, living with myeloma
since 2021



Managing pain

If you feel pain anywhere in your body, tell your hospital team. Don't wait for the pain to get worse, because it may be easier to treat it at an earlier stage.

There's a range of ways to manage pain, depending on what's causing it:

- painkillers for general pain
- nerve pain blockers for nerve damage
- strengthening medicines for bone pain
- radiotherapy for pain in a specific area of bone
- surgery for spinal problems or fractures.

Your hospital team may also suggest physiotherapy or self-help techniques.

Don't take over-the-counter painkillers unless you check with your hospital team first. They will know what's safe to take if you are having myeloma treatment or have had it in the past.

It's important to know that you shouldn't take anti-inflammatory medicines like ibuprofen – they can damage the kidneys, which are already sensitive because of the myeloma.

Managing fatigue

Fatigue is a feeling of extreme tiredness that can leave you feeling completely drained. It's common in people with myeloma, even in remission, and can be a side effect of treatment. Some people with smouldering myeloma experience fatigue too. There are things that can help:

- **Take light exercise** – It may seem strange, but exercise can help. Check with your hospital team what's right for you, especially if your bones are weak.
- **Balance activity and rest** – Plan time to rest in between activities or days out and learn what's doable for you. If you work, think about adjusting your hours (see page 72).
- **Go easy on yourself** – If you need a rest day, make sure you have one. You're not being lazy.

We have more information at bloodcancer.org.uk/fatigue

“

The fatigue was worst a few weeks after my transplant. I felt as if someone had unplugged me. Walking round the village wiped me out, but I kept going and things gradually got better.

Craig, living with myeloma since 2020



Once you're in remission

When your treatment has finished and you are in remission, your hospital team will still be in charge of your care.

They will monitor you using blood tests and scans where necessary. If you are having maintenance treatment, they will check how this is going. Ask them how often you will need check-ups and whether these will be face-to-face or virtual appointments.

When you're in remission you should be able to get on with life, with a few adjustments. The next chapter about living well with myeloma gives you ideas about how to take care of yourself, physically and mentally.

Remission and your mental health

Being in remission is similar to being on watch and wait. It's good to know the myeloma is at a low level. But at the same time, it's hard not to worry that things will change.

You will find information on pages 31 and 32 about waiting for test results and managing difficult feelings.

Remember that our Support Service is here if you want to talk to someone outside of your circle of family and friends. We can also help you find professional support if that's something you're thinking about.

Living well with myeloma



Having myeloma doesn't have to stop you being you, and living life to the full.

We've talked to people with myeloma to get their thoughts on what has helped them cope with their diagnosis and continue to enjoy life.

This chapter covers:

- What can I do to help myself?
- Checklist: 10 things that can help
- Balanced thinking
- Keeping active
- Eating well
- How to help your family and friends
- Working when you have myeloma
- Help with money
- Places to get support

I've not really stopped doing anything, in fact I probably do more. I've started paddleboarding, and we bought a motorhome. We always said we would but myeloma brought things forward.

Craig, living with myeloma since 2020



What can I do to help myself?

Looking after your physical and mental health is important. When we say mental health, we just mean how you feel about your daily life and what's happening.

Everyone reacts differently to their diagnosis. Some people feel sadness, fear, guilt or anger. Many find themselves asking, "Why me?"

Some people don't have strong emotions or are able to accept the diagnosis quite quickly. Others feel shocked, or like it isn't really happening.

Whatever you're feeling is normal. For now, it's just important to take care of yourself in any way that works for you. The next few pages have some ideas to try.

“

I think you can always learn from other people's stories. The doctors do all that training but they can never tell you about the experience because they don't live it, day in, day out.

Mart, living with myeloma since 2020



Checklist: 10 things that can help

This section is about small, simple things you can do that can make a big difference. These are all things that have helped other people with blood cancer at different times:

- 1. Focus on the here and now** – Focusing on the present moment can help if you feel overwhelmed. Try focusing on your breathing for a minute, or engaging your senses (listen to the sounds around you, feel the texture of something in your hands, or simply look at the objects around you and notice their shapes and colours). Exercises like this can help calm you if you feel stressed, and you can do them anywhere.
- 2. Give yourself time to absorb and ask questions** – You don't have to learn everything at once. Take time to read information, write down all your questions, and then take them to your hospital team, GP or our Support Service.
- 3. Listen to your body** – If you're tired, the housework can wait, and most plans can be changed. You're going through a lot, so it's OK to say no to people and take time out. People will understand. If you're having a good day, going on a walk or doing some exercise can help. Do what feels right for you and take it one day at a time.

4. Keep up your hobbies, or start a new one –

Anything you enjoy and which keeps your mind occupied can give you a break and lift your mood. A hobby can be something you find relaxing, or something that motivates you. Getting engrossed in something that requires some mental or physical effort can help. Gardening, DIY, drawing or crafting can take you out of your head.

5. Have goals or a focus – Goals can keep you going, provide motivation, and help you feel positive. While there is a lot you can't control, try to think about the things you can. Whether it's planning the next place you want to visit as soon as you're able, having mini goals for each day, or simply keeping a photograph of someone special to look at – find something that can motivate you to get through this.

6. Keep a diary or log – Record your goals, things you've achieved, things that have helped you, and how you're feeling each day. It can be helpful and motivating to look back at how far you've come.

7. Try to stay active – Physical activity can help you sleep better, release feel-good hormones and help manage stress, anxiety and depression. Even a five-minute walk can help you feel better. Exercise also helps by giving you something to focus on and brings a sense of achievement. Ask your hospital team what's safe for you.

More ideas

There are more tools on our website to help you try some of these practical tips, including some mindfulness videos to help you relax.

Visit **bloodcancer.org.uk/mind-emotions**

If you don't use the internet, call us free on **0808 2080 888** and we will send you some resources.

- 8. Keep connecting with other people** – While it's OK to say no when you don't feel like seeing people, it's also important not to withdraw too much. Seeing or talking to other people about things that are not related to blood cancer can really help to lift your mood.

- 9. Talk to someone** – Trying to keep things to yourself can add extra pressure and make things harder. Talking about things can make them feel more normal and less scary, even when that thing is blood cancer. Be open with close friends and family if you can – many people say this is their biggest support. Or contact our Support Service and talk to us – we are here to talk about anything that's bothering you.

- 10. Keep doing things that make you smile** – People say it's important to carry on as much as you can with the things you enjoy, and that life should not stop because of myeloma. There might be some things you can't do right now but try to focus on the things you can.



Scott

Is living with myeloma different for people in the LGBT+ community?

“There are very few differences for an LGBT+ person with myeloma. But the more open you can be with your medical team about your life, your circumstances and other health issues, the better they can care for you.”

Read Scott’s story at bloodcancer.org.uk/scott or call us and we’ll send you a printed copy.

Balanced thinking

Balanced thinking is based on the idea that our thoughts affect our feelings. It's a way of changing our thought patterns so we can change how we feel about things. This involves turning unhelpful thoughts into something more constructive.

You can spot unhelpful thoughts because they are often very unbalanced (things are either all good or all bad) or catastrophic (worst-case scenarios). Sometimes these thoughts don't relate to what your doctor or nurse has actually said.

That's completely understandable after the shock of a myeloma diagnosis, but it is possible to turn these thoughts around. There are some examples of how to do this on the next page. You may want to add your own.

“

There is life after a myeloma diagnosis. It's a case of not thinking about the things you can no longer do but thinking about the things you can still do. And I don't let it hold me back.

Sandra, living with myeloma since 2008



No one should put pressure on themselves to be fine all the time. But many people find that balanced thinking is a tool that helps improve their mood.

Examples of balanced thinking:

It might be hard, but I have coped with challenges in life before, and I can find a way to cope with this.

Life will be different, but there are still things I can enjoy. There are good things in my life, and I can focus on these.

If I feel lonely, I know there are people out there who understand. I can contact Blood Cancer UK.

Rather than dwelling on things I can't change, I'm going to concentrate on what I can control, like keeping active.

Keeping active

Research suggests that being physically active can improve your fitness and strength, reduce fatigue and improve your mood. Many people with blood cancer find that to be true.

- **Walking is good exercise** – If you haven't done much recently, start with 5–10 minutes a day and slowly build up.
- **Goals are motivating** – Set yourself goals and tick them off when they're done. Order a free activity planner from us, or use an app like Habit Tracker or Done.
- **Do something you enjoy** – If you choose an activity you like, you're more likely to keep it up. If you're not sure what to do, ask other people for recommendations but check with your hospital team before you try something new.
- **Make it social** – This usually helps people stick to their plans. Find an exercise buddy (your partner, a friend, a neighbour) and follow a plan together.
- **Get tips from other people with blood cancer** – Join our online community forum and find out how other people with blood cancer are staying active.
- **Don't push yourself too hard** – Your body has been through a lot and may need time to recover. But doing a little more each time will help to build up your stamina.

We have a range of exercise videos for people with blood cancer at [bloodcancer.org.uk/keeping-active](https://www.bloodcancer.org.uk/keeping-active)

Eating well

Eating well is important, as it will give you the nutrients and energy you need to stay healthy. Here are some general tips to bear in mind:

- **No diet, supplement or “super food”** can cure cancer – in fact, cutting out too many foods could mean you’re not getting everything you need.
- **It’s best to follow a healthy, balanced diet** – Ask your hospital team if there’s anything specific you need to eat more or less of.
- **You need carbohydrates** – Wholewheat pasta, wholegrain bread or potatoes with skin on will release energy through the day. Carbs should make up around a third of a meal.
- **Eat lots of fruit and veg** – They’re packed with vitamins, minerals, and are a good source of fibre. Boost your intake by adding extra vegetables into sauces.
- **Protein helps your body grow and repair** – Try beans, peas, lentils, fish, meat, dairy, eggs and vegetarian and vegan alternatives such as Quorn or tofu.
- **Iron is vital for energy** – As well as meat, you can get iron from beans, nuts, dried fruit, wholegrains, and dark-green leafy vegetables.

We have more tips for making cooking and eating easier if you’re tired at [bloodcancer.org.uk/eating-well](https://www.bloodcancer.org.uk/eating-well)

How to help your family and friends

If you've told people about your diagnosis, you might find you're getting asked lots of questions.

If you haven't told people about your diagnosis, you might be worried about how you're going to tell them, and how it might make them feel.

It might be hard to deal with different people's reactions. We have some ideas about how to deal with difficult or unexpected reactions on page 10.

Here are some suggestions about ways you can help your family and friends come to terms with your myeloma diagnosis so you can make sure they're OK, and that life for everyone goes on as normally as possible.

“

My husband had some counselling, which was good because he could talk to somebody who wasn't personally involved. I think we sometimes forget it's just as tough for the carer.

Joan, living with myeloma since 2006



- **Help them get information** – Googling can cause unnecessary worry as not everything on the internet is true or balanced or up to date. So if they want to know more about myeloma, encourage them to use information from trustworthy sources like Blood Cancer UK. You could give them copies of this booklet which you can order for free from bloodcancer.org.uk/our-booklets
- **Tell them where to find a listening ear** – If they are finding it hard to cope with your diagnosis, they are very welcome to call our Support Service to ask questions or just talk things through.
- **Be honest** – Talking openly about myeloma to other people can make you and them feel better. It's not something you have to hide. People often worry more when they don't feel they know what's going on.
- **Let family and friends help you** – It's common to feel that asking for help is a sign of weakness, but this isn't true. Asking for support is a positive way to help yourself, and it also makes family and friends feel better if they have a role to play.
- **Talk to us about it** – We often talk to people about the impact their diagnosis is having on their family or friends. We can also help you prepare to tell people, whether they are family, friends, children or your employer.

We have information and stories for friends and family at bloodcancer.org.uk/friends-family

Working when you have myeloma

If you are working or studying when you are diagnosed with blood cancer, you should know:

- **You're protected** – Even if you're on watch and wait, you are entitled to support.
- **You have rights** – Cancer is classed as a disability in UK law, so you are protected against discrimination.

If you're worried about going to work because of the risk of infection, or you are finding it hard to do your job, your employer has to consider "reasonable adjustments" to help you stay in work. Examples include:

- having time off for medical appointments
- taking more breaks
- changing your duties or hours to help you manage fatigue
- changing your hours so you can travel when it's quieter
- supporting you to work from home.

Contact our Support Service for help talking to your employer about managing at work.

We also have a fact sheet about blood cancer you can share with your employer. You can order or download it for free from **bloodcancer.org.uk/our-booklets**



Kayleigh and Mart

What happened when you told work colleagues about Mart's diagnosis?

"We work at the same shopping centre. Mart was off work for 18 months and I'd tell everyone how he was doing...they were all behind him. We couldn't ask for a better team at work. They've been so supportive."

Read Kayleigh and Mart's story at [bloodcancer.org.uk/kayleigh-mart](https://www.bloodcancer.org.uk/kayleigh-mart) or call us and we'll send you a printed copy.

Help with money

If you're worried about money, make sure you get the financial support you're entitled to.

- **Benefits** – If you're on a low income, you may be able to claim benefits like Universal Credit, Employment and Support Allowance (ESA) or Personal Independence Payment (PIP), or Attendance Allowance if you're state pension age or older.
- **Sick pay** – If you can't work because of the myeloma or another illness, your GP or hospital doctor can give you a fit note (previously called a sick note) which gives you access to your company's sick leave policy and pay, or Statutory Sick Pay (SSP).

Ways to save money on health costs

- **Parking** – At all hospitals in Wales and most hospitals in Scotland parking is free. In England and Northern Ireland, some hospitals offer free parking to people with cancer in certain circumstances – check with the hospital.
- **Prescriptions** – These are free in Scotland, Wales and Northern Ireland. In England, they are free if your prescription is related to cancer. If you live in England, ask your GP for an exemption certificate.
- **Travel to hospital** – If you have a low income, or get certain benefits, you may be able to get refunds for your travel to hospital. Ask your doctor or nurse about this.

Help paying bills

Talk to your suppliers about energy bills, council tax and mortgage payments. There is usually support available for people with cancer. Get help from Citizens Advice at citizensadvice.org.uk

Do you have insurance?

If you have income protection insurance or critical illness cover, contact your provider to see if you can make a claim.

Help from charities

Many charities offer grants that you don't have to pay back, including Leukaemia UK and Macmillan Cancer Support.

Who else can help?

Ask your GP, doctor or nurse about financial help or ask a family member or friend to research it online. The government website MoneyHelper offers free webchat, WhatsApp and phone advice on all money matters at moneyhelper.org.uk

I didn't know what I could claim and used up all my savings. My dad told me I'd always paid my national insurance, and was only getting back what I'd put in. I'd never looked at it like that.

Sandra, living with myeloma since 2008



Places to get support

Blood Cancer UK Support Service

We will talk to you about anything that's on your mind, whether you want more information or just want a chat.

People contact us about:

- understanding their condition
- blood cancer treatments
- living with blood cancer
- the impact on their family and friends
- work issues
- mental health
- how they're feeling.

Call our confidential support line free on **0808 2080 888** or email **support@bloodcancer.org.uk**

Blood Cancer UK website

Our website has more information about myeloma and blood cancer in general, plus regular news articles and stories from people affected by blood cancer. Explore **bloodcancer.org.uk**

Blood Cancer UK publications

If you prefer your information in printed form, browse our booklets about conditions, watch and wait, treatment and side effects and living with blood cancer. Go to **bloodcancer.org.uk/our-booklets**

Blood Cancer UK online community forum

Talking to other people with blood cancer helps. They understand and will have tips from their own experience. You can ask questions, or just read other people's posts. You don't have to create an account and you can remain anonymous. Visit **[bloodcancer.org.uk/our-forum](https://www.bloodcancer.org.uk/our-forum)**

Local groups

These give you the chance to meet other people affected by blood cancer face to face.

- Ask your hospital what support groups are available in your area.
- Enter your postcode on the NHS website and find support groups near you: **www.nhs.uk/service-search/other-services/cancer-information-and-support/LocationSearch/320**
- Contact Blood Cancer UK on **0808 169 5155** to see if we have a branch in your area. Our branches are for fundraising and volunteering, but you might find that it helps to do things with other people affected by blood cancer.
- Myeloma UK has information about myeloma and general haematology support groups. Some groups are virtual, some meet face to face in local venues. Go to **[myeloma.org.uk/help-and-support/support-groups](https://www.myeloma.org.uk/help-and-support/support-groups)**

Counselling services

Many people find talking to a trained counsellor helps them come to terms with difficult emotions or life changes.

NHS counselling

- Ask your hospital team how you can access counselling. Some hospitals offer counselling themselves.
- Tell your GP you want counselling.
- Refer yourself online. In England, go to **nhs.uk/service-search/find-a-psychological-therapies-service** and in Scotland, **breathingspace.scot/living-life**. In Wales and Northern Ireland, you will need to go through your GP.

Private counselling

Find a qualified counsellor anywhere in the UK at **BACP.co.uk** or call them on **01455 883300**.

Local cancer support centres

Cancer support centres such as Maggie's offer different types of emotional and psychological support for people diagnosed with any type of cancer and their families.

Visit **maggies.org** or ask your hospital team about cancer support centres in your area.

Social media

Some people find support in Facebook groups or other social media platforms.

- Find Blood Cancer UK on Facebook – many people get and give support to each other in comments on our posts. You can also find us on Instagram and Twitter.
- Search online or on Facebook for myeloma support groups.

Travel advice

People often wonder if they can still travel and get travel insurance once they're diagnosed with myeloma.

- You can call our Support Service on **0808 2080 888** to talk through your plans and where to get more information about travel insurance.
- Myeloma UK has information about travel planning and insurance. Search "travel insurance" at **myeloma.org.uk**
- Macmillan Cancer Support offers online information about buying travel insurance at **macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/travel/buying-travel-insurance**
- MoneyHelper has information on travel insurance for people with cancer and other health conditions: **moneyhelper.org.uk/en/everyday-money/insurance/travel-insurance-if-you-have-a-medical-condition**

Useful publications

Printed resources

- **Your blood cancer diagnosis: what happens now?**
- **Watch and wait fact sheets**
- **Watch and wait explained: for employers**
- **Blood stem cell and bone marrow transplants: the 7 steps**
- **Eating well with neutropenia**

Order free copies at bloodcancer.org.uk/our-booklets
or call us free on **0808 2080 888**.

Online resources

- further information about myeloma:
bloodcancer.org.uk/myeloma
- key things to know after your diagnosis:
bloodcancer.org.uk/newly-diagnosed
- living well with blood cancer:
bloodcancer.org.uk/living-well
- blood cancer and infection risk:
bloodcancer.org.uk/infection
- current blood cancer research
bloodcancer.org.uk/researching
- support and advice for friends and family:
bloodcancer.org.uk/friends-family
- ways to get involved with Blood Cancer UK
bloodcancer.org.uk/involved

If you don't have internet access, call our Support Service
free on **0808 2080 888**.

Because we face it together

Finding out you have blood cancer can have a big impact on your life. But we hope it helps to know that there's a community of people out here ready to support you.

Everyone needs help at one time or another. And the most important thing to take away from this booklet is that you can get help from us when you need it, and in a way that suits you.



bloodcancer.org.uk



0808 2080 888 (calls are free and confidential)



support@bloodcancer.org.uk



bloodcancer.org.uk/our-forum



Blood Cancer UK



@bloodcancer_uk



@bloodcancer_uk



Blood Cancer UK

Thank you to our blood cancer community

Blood Cancer UK is the UK's specialist blood cancer charity. But we're much more than that – we're a community of people with blood cancer, friends, family, medical professionals, researchers and everyone who works for the charity.

Many thanks to everyone involved in making this booklet. To Cecelia, Craig, Ian, Joan, Kayleigh, Kerry, Linda, Louise, Mart, Sandra and Scott for their insights into what it's like to be diagnosed with myeloma, and for steering us in the right direction. To Dr Lydia Eccersley and Dr Emma Searle for checking the medical content and to haematology nurse Jenny Jacob for her advice and support.

A list of references used in this booklet is available on request. Please email information@bloodcancer.org.uk

Disclaimer

We make every effort to ensure that the information in this booklet is accurate, but you should always seek advice from your doctor if you have any concerns or questions about your health. As far as applicable by law, Blood Cancer UK cannot accept responsibility for any loss or damage resulting from any inaccuracy in this information, or in external information that we link to.

By law, this disclaimer cannot limit or exclude our liability for death or personal injury resulting from negligence, or any other liabilities that cannot be excluded under applicable law.

Who are Blood Cancer UK?

We're the UK's specialist blood cancer charity, working to beat blood cancer within a generation.

Since 1960, we've invested over £500 million in research, improving treatments for leukaemia, lymphoma, myeloma, MDS and MPNs. Thanks to generous donations from our supporters, we:

- fund ground-breaking research to improve survival and quality of life
- campaign for better access to treatments and services for people with blood cancer
- provide information and support for anyone affected by any blood cancer.

Find out more at bloodcancer.org.uk

Or call us free on **0808 2080 888**

Monday: 10am to 7pm, Tuesday to Friday: 10am to 4pm
and Saturday and Sunday: 10am to 1pm



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