AUTUMN/WINTER 2026

myeloma Matters



Spotlight on CAR-T

Introducing FLOW
Shaping support today and tomorrow

Closer to a Cure
Our roadmap to faster and fairer treatment access

Hot Topic
Hints and tips for hospital stays

MyelomaUK

Contents

04
My Life with Myeloma
Anthony Taylor shares his story and why he decided to become a community connector.



07
Research Focus
How MyeTRIAL is delivering research that matters.

10
Myelomascope
Myeloma research news from around the world.

12
Ask the Nurse
The Myeloma Information Specialist team at Myeloma UK answer your frequently asked questions.

13
Spotlight
We delve into how CAR-T cell therapy works and why it could transform myeloma treatment.

18
Hot Topics
From preparing for a hospital stay to talking to friends and family about myeloma, we have you covered.

22
Introducing FLOW
Giving you the right support at the right time, whatever your circumstances.

25
Supporter Stories
How Julie and Karen's Christmas wreath-making event is putting the fun in fundraising.



26
Myeloma Advocacy
Closer to a Cure: our roadmap to unlock faster and fairer access to treatments.



DEAR READER

Marion Sauvebois
Senior Media and Brand Officer

It is an honour to take over as editor of Myeloma Matters and to welcome you all to our Autumn/Winter 2026 edition.

As Senior Media and Brand Officer at Myeloma UK, I've spent the last five years speaking to many of you about your experience of living with myeloma, sharing your stories, your struggles to get the right diagnosis, and the challenges you've faced to access the latest treatments. Through it all, I've been in awe of your resilience and your determination to rewrite the future for patients and their families. You'll never know how much your openness, thoughtfulness and patience meant to me when a family member was recently diagnosed with smouldering myeloma. The myeloma community is an unstoppable force and I can absolutely vouch for it.

The festive season is a time to take stock of how far we've come, and this issue we're turning a much-deserved spotlight on the incredible milestones we have achieved together in 2026.

Thanks to your invaluable insights we've released the Closer to a Cure report, our roadmap to faster and fairer access to treatment (page 26). This work would not have been possible without you. Our team has now shared our key recommendations with decision-makers and anyone involved in rolling out drugs on the NHS. Together we can build a system that delivers for people with myeloma – but we must act now.

In another win for the community, two CAR-T cell therapies are set to be considered for approval over the next few months. This has been a long time coming and could transform treatment as we know it. As we get a meaningful step closer to making CAR-T available on the NHS, this issue we delve into how the treatment works and hear from people whose lives have been radically changed by it (page 13).

And because good news comes in threes, we're delighted to introduce FLOW, our new approach to making sure you get the right support at the right time, no matter your circumstances. We've listened to you and your feedback will shape how we develop our support services going forward. You can read more about our exciting plans on page 22. While there is a lot to celebrate, we know that for many the holiday period can bring up a range of complex emotions, from fear and uncertainty to the pressure of planning the 'perfect' day with loved ones. This is why we've compiled useful tips and advice on speaking to your family and friends about myeloma (page 18) and managing your mental health during the festive season (page 12).

Wishing you comfort, joy, and peace this holiday season and a Happy New Year.

Myeloma UK is the only UK charity focused on myeloma and its related conditions. Together, we make it possible to live longer and better lives with myeloma. Together, we are the cure.

myeloma.org.uk

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MY LIFE WITH MYELOMA

NAME: Anthony Taylor

LIVES IN: London

AGE: 65

I found out I had smouldering myeloma in December 2015 and it's been an emotional journey since. From being told I had smouldering myeloma to the myeloma becoming active in 2019 to now, I'm in a completely different place and it's taken me a while to get to where I am now.

You can live well with myeloma, but it's a process. As a psychotherapist, talking about it as a process has helped me to understand what I've been through and what I'm still going through. Hopefully, it can also help other people.

My diagnosis was a shock. In December 2015, I had septic arthritis (a serious type of joint infection) in my right knee and spent three weeks in hospital. During that time, they did blood tests and found a discrepancy within the bloods. When the doctor said I had smouldering myeloma I was just in a daze. I didn't know what myeloma was. It was only down the line, after the bone marrow biopsy, that they actually told me that it was incurable. I didn't know what to do, so I just went to the chapel on the same floor as my room. I was 55 and cancer was the last thing I was expecting. I couldn't sleep for weeks, thinking that I may not ever wake up. Mentally, it really got to me.

At the beginning of 2019, I started getting a lot of pain. It was unreal. I couldn't move my neck or lie down on my back so I had to sleep sitting up. I had a compression fracture in my back, which I did not know at the time. The GP gave me codeine, but it didn't work. I eventually took myself to A&E and that's when they told me the myeloma was active.

I was admitted and I was put on the CARDAMON Trial. Because of the compression fracture I had to wear a back brace for six weeks. I lost about an inch in height. Initially, I thought maybe I was imagining it, but I felt like I was shrinking. Now I know it can happen with myeloma. A lot of people get broken bones and problems with their backs.



Unfortunately, the doctors realised the trial wasn't working so they scheduled a stem cell transplant at King's College in December 2019. It was gruelling and the prep was exhausting. I stayed with my dad after the transplant. He lives near the hospital and I needed a place where I felt safe after everything that had happened. I couldn't help feeling that I was on my own and anything could happen. Sometimes I end up feeling institutionalised spending so much time in hospital. And, at the same time, it feels scary not being in the hospital in case something goes wrong.

"I felt angry: that I had myeloma, that I'd lost part of my life."

When I was first diagnosed I felt angry: that I had myeloma, that I'd lost part of my life. Now, with the support which I've had from psychotherapy, I realise I was grieving for the life I had before. It was a loss.

I had a private practice, but it came to a point where it felt best that I give it up because it was unfair to my clients and the students I was training. I didn't want to let people down. I was also letting myself down by not saying, 'I need to take a break from this'.

In March 2020, the doctor called me to say I was in stringent remission. I remember the word so vividly: stringent. And then in April, after just a month, the pain in my spine came back and they told me the myeloma was activate again. It felt like whiplash. I've relapsed another four times since then. Every time they tell you it has come back, it feels like the very first time.

It's been very painful at times. I've not actually been off any medication for years now, so I wouldn't know what it's like not to be on treatment.



Telling my wife and two children was hard. You're trying to explain something which you don't fully understand yourself. The first time the myeloma came back, telling them was one of the hardest things I've done. I didn't want to hide it. They knew I was in pain. We all just cried.

"Having therapy through all of it has been very important to me. And having my family and friends has given me much comfort."

At the end of 2023, I had a massive seizure and I ended up in a coma. This was on New Year's Eve. I woke up on 6 January 2024.

I relapsed again in 2025 and I am now on selinexor. I'm still in remission at the moment, but there's always that fear that it will come back. Having therapy through all of it has been very important to me. And having my family and friends has given me much comfort. Without them sometimes I feel that I could just wither away.

I do believe there are great things ahead with research and I do believe that you can live well and have a relatively good quality of life, whatever that looks like individually. But, at the same time, if you don't have support, if you don't feel emotionally well, you're not going to be physically well.

When my consultant mentioned the work Myeloma UK has been doing to raise awareness of myeloma in the Black community and that they were looking for community connectors, he encouraged me to get involved. I didn't jump into it though, I really thought long and hard about applying to be a community connector. I didn't know if I wanted my story out there. It's not about ego, I wanted to be factual in the way I talked about my experience, but also to bring in the emotions. I wanted to do it in a way that felt grounded as well as being transparent.

I decided to apply for a few reasons. As a Black male, finding out you have myeloma is one thing, but finding out it affects the Afro-Caribbean community more was a double whammy. I felt angry it wasn't out there more. When people hear about myeloma, they think you're talking about the skin cancer melanoma.

For me, becoming a community connector is about empowerment.

There's not enough awareness. It's also personal because my older brother was diagnosed with myeloma in 2025 after having pain in his kidney. For me, becoming a community connector is about empowerment.

I want people to be empowered and well informed; to take charge of their own life, so they can make decisions for themselves. I want them to hear my experience and feel like they can challenge health professionals if something doesn't feel right. They shouldn't be afraid to say, 'This is what's going on with my body'. They know their body better and they know their needs.

If just one person can get something out of my experience it is better than none as far as I'm concerned. Having myeloma can be lonely and it's so important to feel that you're not alone, that you can relate to others. Everybody is different and what they're going through is different, but you can still relate, demonstrate empathy and say, 'You know what, I felt that way too', as this is an ongoing process physically and mentally.





I'm on my sixth treatment and the chances are it will come back again but, at the end of the day, I just try to function the best way I can. It will come when it comes. I'm still tired and I do walk with a stick for support but the bottom line is, most people wouldn't realise that I've got cancer.

I go day by day, and I make the most of each day. I don't plan a holiday six months ahead because I don't know where I'll be in six months. If I'm going to do something, I do it on the spur of the moment.

I'm grateful for all the treatments I've had up until this point. I would like to give a special shoutout to my family and friends.

My son is in his 30s and finishing his PhD which is great, and my daughter is in her 20s and has a masters. All I want is to see them happy in their lives and settled.

I'm grateful for all the treatments I've had up until this point. I would like to give a special shoutout to my family, friends and all the haematology team who have been part of my myeloma journey. I trust that my story will give hope to somebody else.

RESEARCH FOCUS



From idea to impact: **How MyeTRIAL is delivering research that matters**

When people think about clinical trials, they often assume it means testing pioneering medicines. While these types of trials are incredibly important, people living with myeloma tell us that improving quality of life is equally vital.

This is what the MyeTRIAL partnership was created to address, by designing studies that unlock a path to living better with myeloma. Funded by Myeloma UK and in partnership with the University of Leeds Clinical Trials Research Unit, MyeTRIAL brings together leading researchers, healthcare professionals and people affected by myeloma to develop innovative clinical trials focused on the issues that matter most to patients. Importantly, MyeTRIAL is not a single research project. It is a long-term investment in the infrastructure, expertise and partnerships needed to develop a pipeline of impactful clinical trials that can improve care and quality of life for people living with myeloma.

We are already beginning to see the value of this approach.

One of the first studies to emerge from the partnership is BACBONE, a national clinical trial designed to improve the lives of people whose myeloma affects their spine. BACBONE is an exciting example of the kind of patient-centred, practice-changing research that MyeTRIAL was created to deliver.

Bone damage can cause vertebral fractures, leading to significant pain and making the spine bend forwards. Even after successful treatment for the myeloma itself, these changes can have a lasting impact on physical function, mobility and quality of life.

BACBONE aims to tackle this problem by answering the question: can a custom-made spinal brace worn during the first 12 weeks after diagnosis help improve long-term outcomes for people with myeloma-related spinal disease?

Although spinal braces are already used in some hospitals, there is currently little evidence to show whether they genuinely improve outcomes. As a result, access varies across the UK.

Some patients may be offered a brace, while others are not. BACBONE has been designed to provide the robust evidence needed to determine whether bracing should become part of standard care.

The study plans to recruit 260 newly-diagnosed patients from hospitals across the UK. Participants will either receive usual care alone or usual care plus a custom-fitted spinal brace. Researchers will then compare outcomes including physical function, pain, quality of life and changes in spinal shape over the following year.

What makes BACBONE particularly exciting is that it was shaped by patients from the very beginning.

The BACBONE and MyeTRIAL teams worked closely with people living with myeloma and carers throughout the development of the study. During these discussions, patients consistently highlighted that their biggest challenge was not simply pain. It was the loss of independence and the inability to do the things they used to enjoy. As a result, BACBONE's main measure of success is long-term function, reflecting what patients told researchers mattered most to them. This patient-led approach sits at the heart of MyeTRIAL.



NIHR | HealthTech Research Centre

Developing a high-quality clinical trial requires substantial work before the first patient is ever recruited. Researchers need support to engage with patients, build collaborations, develop study designs and secure major funding from organisations such as the National Institute for Health and Care Research (NIHR), who have funded BACBONE (NIHR reference number: NIHR175280).

Without this investment, many promising ideas will never reach the stage of becoming a clinical trial. BACBONE demonstrates the value of investing in trial development. It addresses a question that people with myeloma have told us is important, focuses on quality of life, and has the potential to influence care for people with myeloma both in the UK and internationally. If successful, the findings could support changes to clinical practice and help ensure that all patients have access to evidence-based care for myeloma-related spinal disease.

Ultimately, BACBONE is about more than a spinal brace. It is about helping people with myeloma live better lives. It is a powerful reminder of why Myeloma UK's investment in MyeTRIAL matters.

BACBONE is an exciting milestone, but it is only the beginning. By supporting the development of innovative, patient-centred research, MyeTRIAL is helping to build a future pipeline of studies that address the questions people with myeloma most want answered. In doing so, we are creating opportunities to improve care today while building the evidence that will benefit future generations.

Uncovering the side effects **of generic lenalidomide**

In 2021, lenalidomide (Revlimid®) maintenance treatment was made available on the NHS for people newly diagnosed with myeloma following a stem cell transplant.

Maintenance treatment in myeloma is medicine given long-term, after the main treatment has finished. It is intended to lengthen time in remission.

All treatment approvals in myeloma are important, but lenalidomide maintenance stands apart, both in the number of people who benefit and the improved effectiveness it delivers. Around 1,500 myeloma patients have a stem cell transplant every year, and lenalidomide maintenance offers the potential to double remission times and improve overall survival for every one of those patients.

However last year, Myeloma UK started hearing feedback from people who were experiencing debilitating side effects linked to switching from the branded form of lenalidomide, Revlimid®, to generic forms of the drug. We decided to explore what your experiences are so that, together, we can work towards a solution.

What is generic lenalidomide?

When a medicine is first licensed for use, it is usually protected by a patent and sold as a branded medicine. This prevents other pharmaceutical companies from making and selling the same medicine for a set period of time. Branded medicines are generally more expensive because the manufacturer must cover the high costs of researching, development and marketing the medicine. Revlimid® is the name for the patented version of lenalidomide.

Once a patent expires, other companies can produce generic versions of the medicine. Generic medicines contain the same active ingredients as the branded version but can be sold at a much lower price as the manufacturer no longer needs to cover the costs of developing the medicine from scratch.

What's different?

Although the active ingredients are the same and the medicine should work in the same way, generic medicines often use different inactive ingredients, such as dyes, fillers or binders. Normally most people don't notice any difference, but in some cases these ingredients may affect how well a medicine is tolerated.

What you told us

In October 2025, a Myeloma UK support group leader raised concerns about the side effects many of the group were experiencing from generic forms of lenalidomide.

The Myeloma UK Patient Advocacy team explored this concern, collecting similar testimonials and evidence from the Myeloma UK Advocacy Partner Panel.

"I didn't want to leave the house anymore."

Qualitative data was collected from 17 people across the panel and the support group.

"Every time we leave the house I always go somewhere where I know there is a toilet."

Analysis of this data gave us insight into things like:

- Types of side effect
- How bad the side effect was
- How long the side effect lasted
- The impact of the side effect on quality of life
- How people tried to resolve the side effect

The most debilitating side effect was gastrointestinal (GI) problems, particularly diarrhoea so extreme that it stopped some people leaving their home. Skin rashes and fatigue were also reported frequently. People expressed that the side effects really impacted their quality of life, preventing them from doing things they enjoy like going for walks, swimming or travelling.

What's next?

By sharing your experiences, you have helped us to identify an issue that is likely to affect other people living with myeloma across the UK. Uncovering the challenges some people taking generic lenalidomide face is an important first step in understanding where more support is needed.

Whilst experiences vary and some people manage well on generic lenalidomide, this feedback shows that side effects can have a significant impact on quality of life and shouldn't be overlooked.

Myeloma UK has already begun conversations with doctors, nurses and pharmacists about these findings.

We know there are mixed experiences – it's clear that we need to reach a shared understanding of the challenges patients face and the best ways to help. Together we can use this evidence to drive positive change.

This means:

- Empowering people with myeloma to speak to their healthcare teams about side effects and how they impact quality of life.
- Improving awareness among healthcare professionals of the experiences some people report after switching to generic lenalidomide.
- Ensuring patients have access to the support they need to inform future discussions about treatment choice and patient care.

"It is difficult to go out for a whole day, to pursue my lifelong love of walking or visiting a new place."

Most importantly, we want you to know that your voice matters. You told us about your experiences and we listened. Your evidence will continue to help us advocate for improved understanding, more support and better outcomes for everybody affected by myeloma.

How do I get involved?

If you are interested in sharing your experience of taking generic lenalidomide, please get in touch at policy@myeloma.org.uk



MYELOMA RESEARCH NEWS FROM AROUND THE WORLD

Linvoseltamab shows benefits beyond myeloma control

Recent results from the LINKER-MM1 clinical trial suggest that linvoseltamab could be an effective option for treating heavily pre-treated relapsed and refractory myeloma – and may also improve health-related quality of life for patients.

Linvoseltamab is a new bispecific antibody, a type of immunotherapy that helps the immune system recognise and kill cancer cells.The phase 1/2 clinical trial included people whose myeloma had returned or stopped responding to treatment after several previous treatments. All participants had previously received the three main classes of treatment.

It can be more challenging for this group to find effective treatments, adding to the importance of these promising results which showed that almost two thirds (63%) of participants achieved a very good partial response or better. Linvoseltamab was generally well tolerated, with manageable side effects.

Patients completed regular quality-of-life questionnaires which showed improvements in pain, fatigue and functioning. These improvements were maintained throughout the study, suggesting linvoseltamab may help maintain or improve quality of life for many patients while controlling myeloma.

Why this matters

Whilst new treatments have improved survival over time, people experience multiple relapses and their myeloma can become resistant to some treatments. When this happens, myeloma symptoms and the cumulative effect of side effects can impact quality of life.

The LINKER-MM1 results offer hope for another effective option for people whose myeloma has stopped responding to existing treatments. People living with myeloma need a 'next' treatment that works for them, which means we need more and better options. Studies such as LINKER-MM1 bring us one step closer to keeping myeloma under control for longer, while maintaining or improving quality of life – and ultimately one step closer to a functional cure.

Is a longer maintenance treatment always better?

Lenalidomide (Revlimid®) maintenance has radically transformed myeloma treatment, helping to keep myeloma under control for longer after initial treatment. Maintenance is given over an extended period of time, after the main treatment has finished, to prolong remission while minimising side effects.

Currently, patients whose myeloma has responded to initial treatment may be offered lenalidomide maintenance until it is no longer tolerated, or their myeloma returns. However, long-term treatment often comes with compromises; side effects take their toll on quality of life.

Now, a phase 3 clinical trial has explored whether a shorter maintenance treatment duration could offer the same benefits with less impact on quality of life.

The ENDURANCE maintenance study included people with standard-risk, newly-diagnosed myeloma who did not have a stem cell transplant.

Following initial treatment, 516 participants began lenalidomide maintenance. Around half received treatment for two years, whilst half continued it indefinitely, in line with standard care.

After seven years, there was no significant difference in long-term outcomes for people who received two-year limited duration treatment compared with those who continued treatment indefinitely. However, people on indefinite treatment were more likely to experience severe side effects.

Why this matters

Many effective myeloma treatments, including long-term treatment with few or no breaks, come with side effects that impact people's everyday quality of life. Although myeloma is currently incurable, recent treatment advances mean that many people are now living longer – so we must ensure that treatment also helps people to live well.

These results suggest that, for some patient groups, a shorter period of maintenance treatment may offer similar long-term benefits whilst reducing the burden of ongoing side effects. Research like this helps doctors understand not only which treatments are most effective, but also how best to use them to support people to live longer and better lives with myeloma.

ASK THE NURSE

Ellen Watters, Rebecca Huntley, Fern Pallister **Myeloma Information Specialists**

How can I make the most out of the festive season while looking after my own wellbeing?

As well as being a time of comfort and joy, the festive period can be challenging for people living with myeloma. Some patients might be worried about socialising – and the increased risk of infection this can bring – during the holiday season. It is okay to turn down invitations if you don't feel comfortable and to enjoy quieter celebrations with loved ones.

While food and drink play a big part in the festive season, myeloma and its treatments can cause side effects that may affect your digestive system. But little changes can make a difference. For example, if you have lost your appetite, rather than attempting a full three-course meal, why not try to eat small portions instead? If you are experiencing other digestive symptoms, you can discuss these with your medical team. There are a range of supportive care treatments that could help. Some services are reduced over the festive period, so check with your healthcare team ahead of time who you should contact if you need to.

The festive period can come with a lot of expectations and pressure for things to be 'perfect' and can bring up complex emotions. There is no right or wrong way to feel and, sometimes, talking things through can help. Here's to a relaxing and peaceful festive season.

What are supportive treatments and how can they help?

Some patients receiving treatment for myeloma may experience symptoms caused by the disease itself, side effects from treatment, or both. Many of these can be managed with supportive care, so it is important to tell your medical team about any new or increasing symptoms. They will want to know and may be able to recommend ways to help improve your quality of life and wellbeing.

A wide range of supportive treatments are available. For example, there are many different anti-sickness medications (anti-emetics); if one is not effective, another may work better. Gastrointestinal side effects can also be managed with treatments for constipation or diarrhoea.

Pain management is another important aspect of supportive care. Depending on the type and severity of pain, treatments may include medications for nerve pain, such as gabapentin, or stronger opioid-based painkillers such as morphine. Myeloma patients should avoid non-steroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen and diclofenac, even in gels/creams, as these can damage the kidneys. Radiotherapy, bisphosphonates such as zoledronic acid (Zometa®), and occasionally surgery may help manage bone pain caused by myeloma bone disease.

Other supportive treatments may include blood or platelet transfusions and intravenous immunoglobulins (IVIg), when patients are deficient in these. Blood thinners may also be prescribed, as myeloma and its treatments can cause patients to have a higher risk of blood clots. Treatments for infection, nutritional support, and supplements are other common supportive treatments. Always check with your medical team before taking any supplements, vitamins, or herbal remedies.

What are the signs of infection and how difficult are they to spot?

People with myeloma are at higher risk of infection than the general population, both due to the myeloma itself and as a result of some of its treatments. The signs and symptoms of infection can differ depending on the area affected. For instance, a chest infection often causes a cough that brings up green sputum (or phlegm), a raised temperature (above 37.5 or 38 degrees), shortness of breath and pain while breathing.

A urinary tract (water) infection (UTI) can cause pain on passing urine, blood in the urine, a raised temperature, abdominal pain and lead to generally feeling unwell.

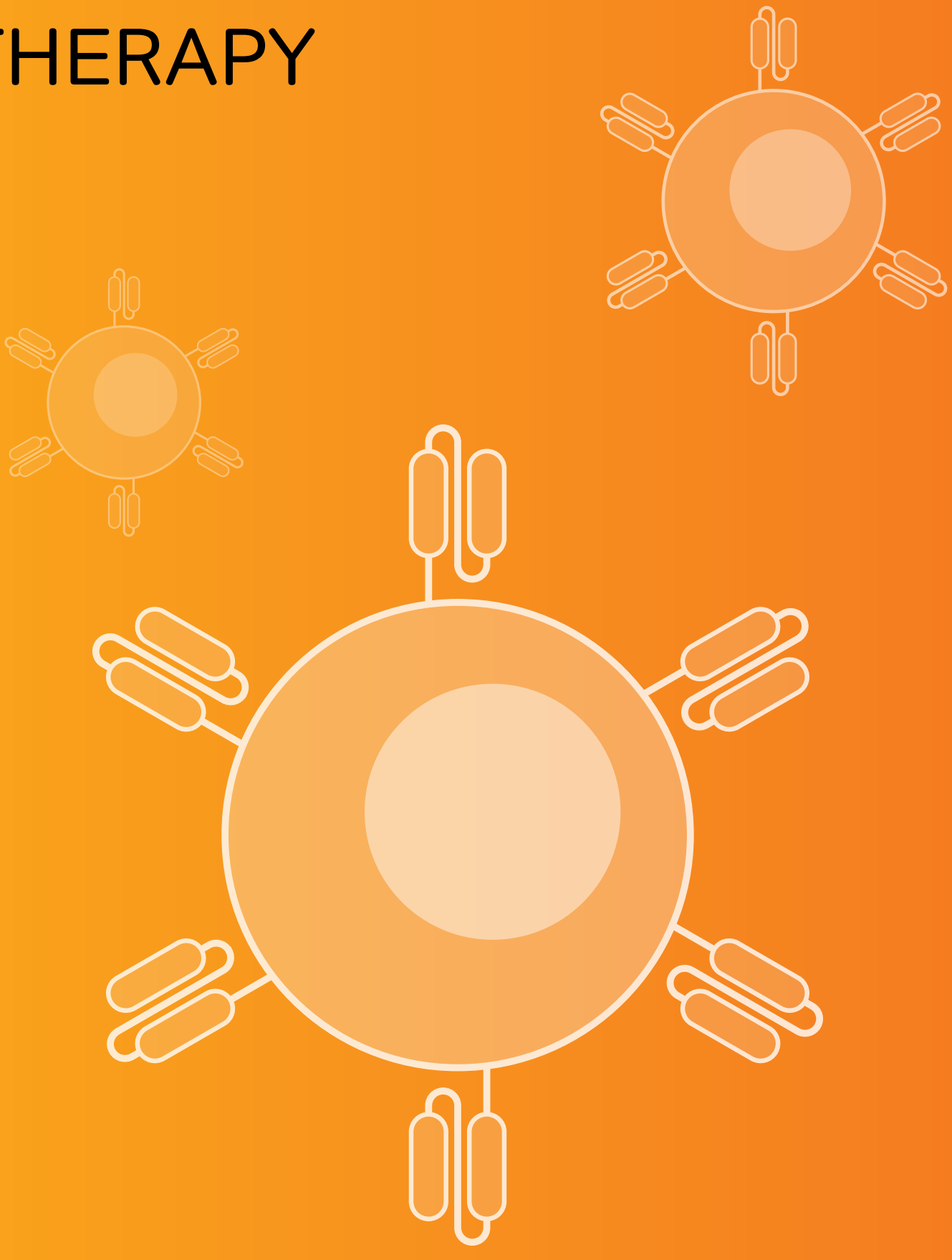
Infection at the site of a central venous catheter (a PICC or Hickman line) or a cut or sore can cause discharge, redness, swelling or pain around the site, a high temperature or shivering.

Stomach or bowel (gastrointestinal) infections can cause sudden watery diarrhoea, nausea, vomiting, and painful stomach cramps, as well as a high temperature and lead to generally feeling unwell.

If something doesn't feel right and you spot any of the signs of infection listed above, get yourself checked quickly so you can be treated with antibiotics and any other supportive treatments necessary.

If you have questions for our Myeloma Information Specialists, call the **Myeloma Infoline** on **0800 980 3332**, use our online form at **myeloma.org.uk/AskTheNurse** or email **AskTheNurse@myeloma.org.uk**

SPOTLIGHT ON CAR-T CELL THERAPY



PAVING THE WAY FOR CAR-T ON THE NHS

As two CAR-T cell therapies are being considered for approval on the NHS, we take a look at how the treatment works and why it could radically change the lives of people with myeloma.

Over the coming months, both cilta-cel and anito-cel are set to go through the NICE appraisal process for use in England and Wales. Myeloma UK has been making the case for CAR-T to be available on the NHS for years and we're well and truly at a crossroads, one that could transform treatment as we know it. At each stage of the appraisal process, we will play a vital part in bringing forward evidence and ensuring patient voice is heard loud and clear. We believe that everyone should be able to access the treatments they need to keep their cancer at bay regardless of where they live or their ability to pay.

What is CAR-T and is it the next frontier in myeloma treatment?

CAR-T is a newer type of treatment that uses the body's own immune system to help find and destroy myeloma cells. It has shown promising results in clinical trials for some people whose myeloma has come back or stopped responding to other treatments.

T cells are part of the immune system and normally help protect the body from infection and disease. In CAR-T, some of these T cells are collected from the blood and genetically modified in a laboratory so that they have special receptors, called chimeric antigen receptors (CAR). This allows them to identify specific proteins found on myeloma cells.

Once modified, they are infused back into the body where they can seek out and attack myeloma cells. Unlike treatments that need to be given regularly over months or years, CAR-T is usually given as a one-off treatment, although patients continue to be monitored closely afterwards.

Why is CAR-T different from other myeloma treatments?

Most standard myeloma treatments work by directly killing myeloma cells or slowing their growth. CAR-T works differently because it trains the immune system to recognise and attack the cancer itself.

Some key differences include:

- **Personalised treatment**
  The therapy is made using the patient's own immune cells.
- **Targeted approach**
  CAR-T cells are designed to recognise proteins found on myeloma cells.
- **Potential for long remissions and long periods off treatment**
  Some people respond very well to treatment.
- **One-time treatment process**
  Unlike ongoing cycles of treatment, CAR-T is generally given once.

CAR-T is not currently considered a cure for myeloma, and not everyone will respond in the same way.

The CAR-T treatment journey

The CAR-T process usually involves several stages over a number of weeks.

1

Assessment and testing

Before treatment begins, patients will have tests to check whether CAR-T is suitable for them. This may include blood tests, scans, and heart or lung assessments. If CAR-T is not suitable, your healthcare team will work with you to find the most suitable treatment option.

Collecting T cells

2

T cells are collected from the blood using a process called leukapheresis. Blood is taken through a machine that separates out the T cells before the remaining blood is returned to your body.

3

Manufacturing the CAR-T cells

The T cells are sent to a specialist laboratory where they are genetically modified and multiplied. This process can take several weeks.

Bridging treatment

4

Some patients may need additional treatment while waiting for their CAR-T cells to be prepared. This helps to keep the myeloma under control and is known as bridging treatment.

5

Chemotherapy before infusion

Shortly before the CAR-T infusion, patients usually receive low-dose chemotherapy. This helps prepare the immune system for the CAR-T cells.

CAR-T infusion

6

The CAR-T cells are given back into the bloodstream through a drip (intravenously).

7

Monitoring and recovery

Patients are monitored carefully afterwards because side effects can develop quickly, especially during the first few weeks after treatment. Some people need to stay in hospital during this time. Your healthcare team will talk to you about the most suitable care for you, before starting treatment.

MY LIFE **AFTER CAR-T**

David Williams was the first patient in Bristol to enrol in a CAR-T trial at first line.

I hadn't appreciated that CAR-T was a one-hit treatment. Then it's behind you and you receive no further cancer treatment. I wasn't quite prepared for that. It was a bit of a shock. CAR-T has been extraordinary. Back in January 2023, it was extremely painful just to lie on my bed. I could feel the damage to my spine, in my ribs.

I never imagined that, 10 months later, I would be in full remission and pain-free. It seems such a fantastic treatment and I would want as many people to benefit from it as possible.



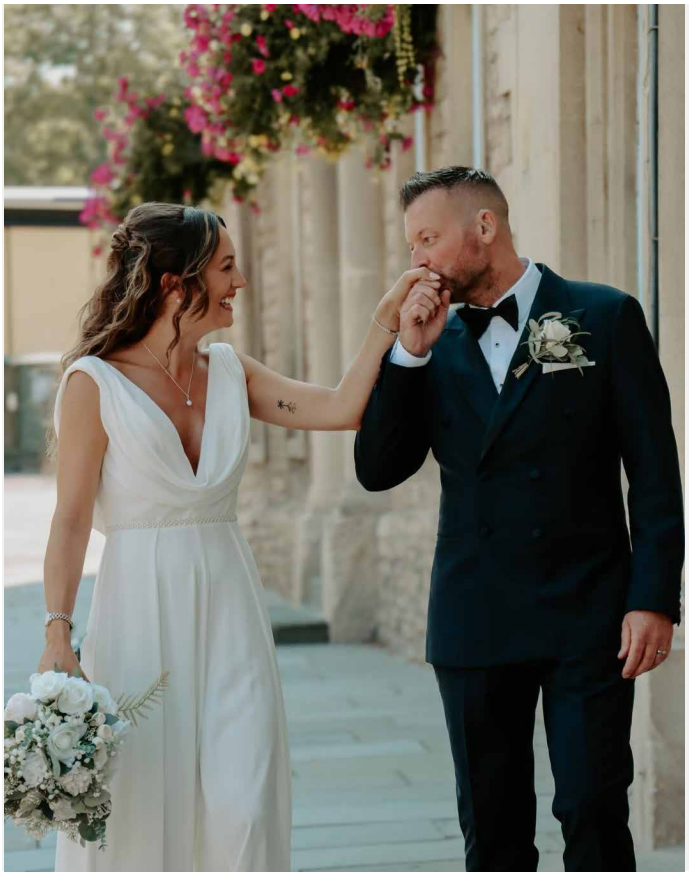


Meera Shah received CAR-T privately after her first relapse.

I did not expect to feel this well. Mostly because I had been on lenalidomide maintenance for years before this and I really hadn't got on with it. We kept lowering the dose and reducing the time that I was on it for. I had such fatigue and brain fog and that feeling of 'You're not yourself' the whole time I was on it. I'd had discussions about whether to stop maintenance or not, but I was too frightened to stop it in case I'd relapse. So, you persevere.

Now I'm not on any chemotherapy or maintenance drug, I'm just on supportive medication. I very quickly saw that chemo fog lift. I just felt a lightness, life [felt] easier after years of persevering and just carrying on.

It's only now that I can see the contrast of actually how much I struggled in the last few years being on permanent treatment compared to now. It's quite amazing to have that clarity of mind again. And not having to work out which is going to be your worst week on treatment before you book something into your calendar, or you say yes to a social event, or a work event, or when my son wants us to do something as a family. Now I feel like I can plan longer-term and it's exciting to feel well in yourself. I don't really know how to describe that feeling.



Jason Johnson received CAR-T through a trial after relapsing three times.

When I was first diagnosed in 2014, the outcome and the treatments available were not as great as they are now. Until I had CAR-T, I'd never had zero paraprotein and I've managed to achieve that for two and a half years. It may be expensive at the moment, but when you weigh that against the cost of all the initial treatments that other people have, I think this should potentially be used as first-line treatment.

My goal is first and foremost to enjoy the time I have with my family and my wife. We got married in August.

I just want to be able to do things like everybody else. I'm out on my mountain bike now and due to go to Morzine with some friends. I wouldn't have thought I'd ever be able to do that or to hold down a full-time job. CAR-T, and my previous treatments, have been able to provide me with the opportunities that I've had so far and, hopefully, will have in the future.

Side effects of CAR-T

CAR-T can cause significant side effects, although not everyone experiences them in the same way. Patients are closely monitored during and after receiving treatment to help spot and manage side effects quickly.

Cytokine release syndrome (CRS)

CRS is one of the most common side effects. It happens when the immune system becomes highly activated. Symptoms can include fever, low blood pressure, chills, breathing difficulties, and a fast heartbeat.

Neurological side effects

Some people may experience confusion, headaches, difficulty speaking, drowsiness, or tremors. These side effects are caused by immune effector cell-associated neurotoxicity syndrome (ICANS) and are usually temporary but require careful monitoring.

Increased risk of infection

CAR-T can reduce the number of healthy blood cells and weaken the immune system, increasing the risk of infection.

Fatigue and low blood counts

Tiredness, anaemia, bruising, and bleeding can also occur after treatment. Patients are monitored closely so side effects can be treated quickly if they develop.

We hope the Scottish Medicines Consortium (SMC) will also look at the appraisal of CAR-T in due course. In Northern Ireland, the Department of Health can follow guidance issued by either NICE or SMC to make their decisions on which treatments to fund.

The Myeloma Trial Finder

Some patients may be offered CAR-T through a clinical trial. Check out the **Myeloma Trial Finder** on **trials.myeloma.org.uk** for more information.

MYELOMA

HOT TOPICS



HINTS AND TIPS FOR HOSPITAL STAYS

Here are some handy tips to make your upcoming hospital stay more comfortable.

Your hospital stay

- Your room may be small. A fold-up bag that you can stow under the bed may be better than a hard suitcase.
- Your room will be thoroughly cleaned every day, so it helps to have minimal clutter.
- In the early days after high-dose therapy and stem cell transplant, visitors will be restricted. You may also feel too tired to have many visitors.

> **"For me the thing that helped most was having a loved one sitting close by – not speaking, just reading or knitting."**

Clothes

- Hospital wards can be very warm, but side effects of treatment might make you feel cold. Pack clothes you can wear in layers, and hats and scarves.
- Pack plenty of pyjamas, so you can change into fresh ones regularly.
- Pack a dressing gown and non-slip slippers or slipper socks.
- Pack comfortable underwear, such as soft crop tops or wire-free bras that are easy to put on and take off.
- Clothes with loose or elasticated waistbands are helpful if you have a sore stomach.

Toiletries

- A toiletry bag with a drawstring or loop is useful if there is not much space in the bathroom.
- A pillow spray can help to mask 'hospital smells'.
- Flannels can help cool you down on hot days.
- Soft toilet paper and wet wipes are helpful in case of diarrhoea or sickness.
- Your treatment may make your skin dry or sensitive. Sensitive shampoo and soap, moisturisers for face and body, and lip balm can help.

Entertainment and exercise

- If you are recovering from treatment, you may not have much concentration, so pack things that are relaxing and easy to pick up and put down.
- Take a mobile phone, laptop or tablet, and headphones. Don't forget chargers!
- Before you go, download some audiobooks, movies, or shows, or sign up to a streaming service.
- Take reading materials, puzzle books or simple crafts – anything you find relaxing and that does not require too much concentration.
- Doing some regular gentle exercises, stretching or walking can help you relax and can reduce the loss of muscle tone.
- Music playlists are nice to have, including relaxing music and music for exercising or walking around.

> **"Try to keep a routine of getting showered and dressed each day. Even if you can sit up for an hour or two it helps."**

Food and drinks

- Mints and boiled sweets, and cordials or fizzy water, can help with dry mouth and unpleasant tastes.
- Take a variety of individually wrapped sweets and savoury snacks. You won't know what you will feel like eating at any time.
- Ask your healthcare team for ice lollies to eat before and during high-dose melphalan, to reduce the risk of inflammation of the mouth lining.

Other bits and bobs

- An eye mask and ear plugs (or noise-cancelling headphones) will help if the room is too bright and noisy at night.
- A photo or something sentimental can help remind you of home (but nothing too large or fragile).
- A sleep or meditation app can help you relax.
- A small basket or box can be useful, for those small things that can roll off the bedside table.

We are grateful to patients, their families and friends, and our Peer Buddy volunteers, for sharing their experiences to help others.

For more information

HDT-SCT Infoguide

Your healthcare team

The Myeloma Infoline on 0800 980 3332

AskTheNurse @myeloma.org.uk

TALKING TO FRIENDS AND FAMILY ABOUT MYELOMA

Talking to those close to you about your myeloma can be challenging and may feel overwhelming. But open communication can help you to find the right support at home, at work, and from your healthcare team.

There is no perfect way to discuss your myeloma with someone. Everyone deals with cancer differently. People may not always react the way you expect. Some will become closer and others more distant. This may feel upsetting but is not a reflection on you.

Talking to friends and family

- There is no right way to talk about your myeloma and how you feel, so just do what's best for you. This could be having a conversation over the phone, in person, or sharing news in a letter or by email.
- Choose somewhere comfortable and free from interruptions.
- It may be helpful to give people a heads-up before having a conversation, so they can be prepared. For instance, you could say: "I have some difficult news to share".
- Check every now and then that the other person understands what you are saying.
- Repeating the same information over and over can be hard, so do not be afraid to ask for help telling others.
- Create a group chat or email thread where you, or others, can share updates on your treatment with everyone at once.

For more information

Share our Carers of myeloma patients Infopack with family and friends who want more information.

Staying connected with your partner

For most couples, dealing with a myeloma diagnosis on top of the usual stresses of life can be difficult.

The physical and emotional impacts of living with myeloma can affect your relationship. These factors may affect sex and intimacy too. Having quality time with your partner can help things feel more normal. This can be anything you enjoy together and can be adjusted to reflect your energy levels.

Your partner may be adapting to a new role of giving you care and support. Their role in your care is likely to vary at different times as you go through treatment and remissions. We know that many people do not like the term 'carer' but it is important for those supporting you to access support themselves when they need it.

The changes that come from living with myeloma can have a positive impact as well. Focusing on shared priorities can bring you closer as a couple.

Speaking with children or grandchildren

It is natural to want to protect your children and grandchildren from difficult news. Before telling your children or grandchildren, give yourself time to process your own feelings. Give information in small chunks and allow time to ask questions.

Explain how your lives may change and that they can ask questions or share their feelings. Reassure them that they are loved.

It may be helpful to balance any bad news with something positive for them to focus on. For example, at diagnosis you can explain to them your treatment plan or that the doctor will closely monitor you to see how treatment is helping. This can be useful for both younger children and adult children.

For more information

Our illustrated children's book Kelsey and the Yellow Kite can help you explain myeloma to young children.

These organisations can help provide emotional support to parents with cancer and their children

Barnardo's
barnardos.org.uk

Fruitfly Collective
fruitflycollective.com

Hope Support Services
hopesupport.org.uk

The Osborne Trust
theosbornetrust.com

Who to tell

Sharing your diagnosis is a personal decision. People often tell those closest to them first. Talking about what is happening can help you to understand how you feel. If you are employed, telling your employer early helps them to provide any support you may need in the workplace.

There may be times when you feel like talking to someone outside of your close circle of family and friends. Our Myeloma Information Specialists can offer support.

How to handle offers of help

Family and friends may offer support and ask how they can help. It may help to focus on practical things, such as housework, cooking, shopping, or attending appointments. Sometimes just having someone there to talk to or sit with is enough.

You can decline help if you do not feel you need it now, and let people know their support may be welcome in future.

Phone **0800 980 3332** or email **AskTheNurse@myeloma.org.uk**
You can find a local support group near you or access our Peer Buddy service through the Myeloma UK website.

What if I do not want to talk about it?

Sometimes, you may not feel like talking about myeloma, even if others want to. It's okay to let them know that now is not the right time.

You can write in a diary to help you keep track of your experiences. It may help you recognise your successes and achievements as well as any challenges.

Focus on the things that bring joy and purpose to your day-to-day life and share these with the people close to you. This can be as simple as talking about a good show you watched, or meal you cooked. Talking about everyday things is just as important.







INTRODUCING

FLOW

A new foundation for supporting people affected by myeloma

For more than 25 years, Myeloma UK has been providing information, support and a listening ear to people affected by myeloma and its related conditions. During that time, we've learned a great deal from our community about the challenges of living with uncertainty and the support that can make a real difference.

One thing has remained clear:
no two experiences are the same.



As treatments and care continue to improve, more people are living longer with myeloma than ever before. This is something to celebrate, but it also means people's support needs are evolving.

Alongside information about treatment and disease management, many people are looking for support with their emotional wellbeing, day-to-day challenges, relationships, and maintaining a good quality of life. And the nature of myeloma means that the support people need today could be very different to the support they need tomorrow, next week or next year.

To help us respond to these changing needs, we've launched FLOW, a new framework that will guide and shape how we develop our support offer in the years ahead, so that more people affected by myeloma can access the right support at the right time and live as well as possible, whatever their situation.

What is FLOW?

FLOW is a set of four principles rooted in the experiences of our community and informed by psychological approaches to help people live well alongside uncertainty. Providing a framework for how we think about support will enable us to develop resources, services and tools that are more responsive to the realities of living with myeloma.

F

Focus on the present

Living with myeloma can bring a lot of uncertainty. You might find yourself worrying about test results, treatment decisions or what the future holds. Focusing on what is happening right now can help when those worries start to feel overwhelming. It can help you make space for the things you can do today, rather than getting caught up in thoughts about what might happen next.

L

Live what matters most

Myeloma can affect many areas of your life, but it doesn't take away the people, activities and values that make you who you are. Whether it's spending time with family and friends, enjoying a favourite hobby, or planning for the future, staying connected to what matters most can help bring meaning and purpose even in difficult times.

O

Open to change

Living with myeloma often means dealing with change. There may be changes to your health, your routines, your plans or the way you see yourself. While change isn't always easy, finding ways to adapt can help you feel more confident in facing new challenges. Being open to change doesn't mean liking it, it means finding ways to move forward alongside it.

W

Wellbeing through small steps

When you're living with myeloma, even small actions can make a difference to how you feel. Simple things like getting some rest, being physically active when you can, eating well, speaking to someone you trust or doing something you enjoy can all support your wellbeing. Small steps may not remove every challenge, but they can help you feel more supported, connected and in control day to day.



The thinking behind FLOW

The FLOW principles are informed by Acceptance and Commitment Therapy (ACT), an evidence-based psychological approach that helps people develop what is known as psychological flexibility. Psychological flexibility is the ability to respond to difficult thoughts, feelings and situations in ways that support wellbeing and help us stay connected to what matters most.

For people living with myeloma, this way of thinking can be particularly helpful. The realities of diagnosis, treatment, remission and relapse can lead to a wide range of emotions, often changing from one day to the next. Rather than trying to push aside these difficult feelings, ACT focuses on helping people respond to them while being compassionate towards themselves.

FLOW takes inspiration from these ideas and translates them into practical principles that can inform the support Myeloma UK provides.

Through our work with the myeloma community, we've heard how important it is to have support that reflects the changing nature of life. People have told us they need help not only with understanding their condition and treatment, but also with coping with uncertainty, adapting to change, maintaining wellbeing and focusing on being independent.

What does the rollout look like?

Over the coming months and years, you'll see new resources, new tools and new ways to access support, all guided by the FLOW principles.

Some developments will be small, while others will transform how people find information, connect with support and manage the emotional and practical realities of living with myeloma.

We're also committed to reaching more people from a wider range of backgrounds, experiences and circumstances. By broadening the ways people can access support and developing a wider range of resources, we hope to ensure that more people can find the information, guidance and support that feels right for them.

Developing new tools and resources

We are currently developing a set of conversation starter cards to provide support and guidance in having difficult conversations about myeloma and the changes this can bring. We'll also be creating new resources informed by FLOW, including tools to help people manage their physical and emotional wellbeing, navigate uncertainty and adapt to change.

Making support easier to access

We're improving the ways people find information and support. This includes developing better ways of finding information on our website, so people can get what they need more easily. We have already refreshed the ways you can find help and support at **myeloma.org.uk/flow**

Increasing our focus on emotional wellbeing

Living with myeloma or a related condition can have a significant emotional impact. Guided by the FLOW principles, we'll continue to expand support that helps people manage uncertainty, build confidence, and live well alongside the challenges they may experience.

Continuing to learn from the myeloma community and finding the gaps

As treatments improve and more people live longer with myeloma, there is an exciting opportunity to rethink what support can look like. FLOW was shaped by insights from our community and will continue to evolve through ongoing collaboration with people affected by myeloma or related conditions and healthcare professionals. Part of this will involve us identifying any gaps in support and understanding changing needs. Together, we can build resources, services and tools that help people not just live with myeloma, but live well.

Want to get involved?

We're looking for people affected by myeloma and related conditions to help us develop future resources and support. Whether you'd like to share feedback or take part in user testing, we'd love to hear from you. Sign up to stay in touch **myeloma.org.uk/about-us/sign-up-to-our-newsletter**

SUPPORTER STORIES

Turning a diagnosis into hope: Julie and Karen's fundraising journey

When Julie Jones was diagnosed with myeloma in 2022 at the age of 55, her world changed overnight. Like many people diagnosed with myeloma, she had never even heard of the disease.

For months beforehand, Julie had been experiencing symptoms she put down to the menopause. Fatigue, brain fog, memory problems and recurring infections seemed easy enough to explain. Working in a demanding banking role while juggling family life, she simply carried on. It was only when brain fog began affecting her work that she visited her GP, expecting a conversation about hormone replacement therapy.

Just days later, Julie was told she had myeloma. Hearing the words "blood cancer" was devastating.

Her sister Karen immediately became her treatment partner, accompanying her to consultant appointments, taking her to chemotherapy sessions and visiting every day during the two weeks she spent in hospital recovering from her transplant.





Throughout the ordeal, Myeloma UK was an invaluable source of information for Julie.

In a show of support to her sister and others affected by myeloma, in 2022 Karen completed the Myeloma UK Lost in Lapland virtual walk and raised more than £2,000.

Spurred on to do more for the myeloma community, the following year Julie and Karen launched a Christmas wreath-making event. The festive fundraiser was a hit. Nearly 100 people attended the three sessions and helped the pair collect £6,500 for Myeloma UK. Since then, the event has continued to grow, raising another whopping £6,500 in 2024 and an impressive £7,800 in 2025.

Julie said: "Over the three years we have received donations of Christmas trees from local businesses and friends have allowed us to take suitable foliage from their gardens. A lot of greenery is required! It takes organisation and there is a bit of prep work involved, but our supportive family and friends are always around to lend a hand.

"We would find it difficult to do it without them and all of their help creates a special day and keeps the funds coming in.

"This year's event will take place on the last weekend of November and we will be keeping our fingers crossed that it is just as successful as the prior ones."

Has Julie and Karen's story inspired you to take on your own fundraising challenge? Whether it's a coffee morning, bake sale, sponsored walk, Christmas craft event or something completely unique, every pound raised helps Myeloma UK continue its vital work supporting patients and funding life-changing research.

How do I get involved?

Together, we can bring hope, improve lives and move closer to a cure. To start your fundraising journey, visit **myeloma.org.uk/fundraising**

MYELOMA ADVOCACY

CLOSER TO A CURE: OUR ROADMAP TO UNLOCK FASTER AND FAIRER ACCESS TO TREATMENTS

Over the past 30 years, treatment for myeloma has transformed. More people are living longer, and many are living better because new treatments are now available.

However, myeloma remains incurable and the burden of treatment is too high for too many people. The myeloma community told us that they want fast access to new treatments that keep their cancer under control for longer and have fewer side effects. They also want more personalised care and more flexibility, so each person can get the right treatment at the right time.

Unfortunately, today's health innovation and access system is not keeping pace with the change we urgently need to get closer to a cure. Policy is too fragmented, and ambitions across research, regulation, and assessment are too often disconnected.

The UK is falling behind other countries in approving and using myeloma treatments. Quality of life is often overlooked when new treatments are developed, and the drug-approval process is built on a one-size-fits-all model. But it doesn't have to be this way. This is why we've launched Closer to a Cure, our roadmap to end geographical inequalities, remove the barriers preventing people from receiving the most effective drugs and put treatment in the hands of patients faster. Built on three decades of insight, this report sets out the five urgent steps needed by government, industry and policy-makers to ensure everyone can access the treatments they need, when they need them.

	What's the problem?	What needs to change?
1	The system that approves medicines in the UK is fragmented, long and complex. As a result, the UK is falling behind other countries in approving and adopting new myeloma treatments.	We need research and drug access systems to work in harmony to deliver better access to treatment innovations.
2	Many people with myeloma spend years on continuous treatment and live with serious side effects, repeated hospital visits and constant disruption to daily life. Yet, quality of life is often overlooked when new treatments are being developed.	Innovators must focus on improving as well as extending people's lives.
3	Myeloma affects each person differently, yet the drug-approval process too often relies on a one-size-fits-all model. If we want to find a cure for all patients, we cannot accept this lack of differentiation.	Treatments must be tailored to individual patients.
4	Strict eligibility rules and outdated restrictions often stop clinicians from using the treatment that best fits the patient's needs. As a result, too many patients are excluded from or miss out on new treatments and have to settle for substandard treatments with reduced effectiveness and increased side effects.	Treatment pathways must become more flexible and more patient-led.
5	The approval of a drug by NICE means little if local barriers delay the rollout of a treatment to a particular trust, hospital or region and lead to patients missing out on the most effective treatment.	Approved treatments must reach patients quickly and fairly.

These changes are achievable, but we need to act now. Progress will only come if everyone involved in getting drugs approved works together and prioritises what patients want: longer lives, a better quality of life and more personalised choices.

You can download your copy of the report at **myeloma.org.uk/closer**

The launch of the report is the first stage in our ongoing efforts to improve access to medicines. To find out more or get involved, please contact **policy@myeloma.org.uk**

Order your Myeloma UK Christmas cards today

Every pack of cards you buy helps people affected by myeloma get the support, information and treatments they need.

Help spread a little Christmas cheer, and a **lot** of awareness about myeloma with friends and family.

Visit **charitycardshop.com/myelomauk**

scan me!



Festive fundraising

From Festive Jumper Days to Craft Fayres and Coffee Mornings to Carol Concerts. However you celebrate with friends, family or at your workplace, please consider raising funds for Myeloma UK.

Get in touch at **fundraising@myeloma.org.uk** or **0131 230 0429** to get your fundraising pack and all the support you need.







MyelomaUK

We're here for everything a diagnosis of myeloma brings

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 on **AskTheNurse@myeloma.org.uk**

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

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

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

Visit **myeloma.org.uk**, a one-stop-shop for information on myeloma; from news on the latest research and drug discovery to articles on support, treatment and care.

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

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

Help make myeloma history by **fundraising and donating**. Email **fundraising@myeloma.org.uk** or call **0131 230 0429** to find out ways you can help.

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MyelomaUK

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