AUTUMN/WINTER 2025

myeloma Matters

Spotlight on Support Groups

MyelomaUK

Contents

DEAR READER

Nicola Lamb
Myeloma Matters Editor

Welcome to the Autumn/Winter 2025 edition of Myeloma Matters.

2025 has been a year of celebration here at Myeloma UK. It has been a time to reflect on the progress we have made and the incredible people who have worked to make it happen.

In our last edition, we marked a decade of our Clinical Service Excellence Programme (CSEP), which has helped to transform myeloma care across the UK. In this issue, we celebrate another major milestone: 10 years of our Patient and Carer Research Panel (PCRP) bringing the voices of people affected by myeloma directly into the heart of research. We are proud to celebrate the contributions of this dedicated group.

We also share the story of Maria Watson and her wife Anne. Their story is one of mutual support, resilience, and love, and a reminder of the importance of having people to lean on.

Support is a running theme throughout this edition. Support Groups can be life changing – offering comfort, community, and shared understanding. We hear directly from Support Group members about what their group means to them. Mark and Stuart share why they chose to become Support Group Leaders.

If you are considering joining a Support Group, or even starting one, you can read more on pages 13 to 17.

This year has also brought moments of sadness and reflection. We are saddened by the loss of our friend and colleague, Sarah Henshaw, who was a much-loved part of the myeloma community. We celebrate her life and the legacy she leaves behind.

As the nights draw in and the colder months approach, we know this time of year can bring unique challenges. Our Hot Topic feature on Food and Festivities includes practical tips for enjoying meals and gatherings, even when treatment side effects can make things more difficult. Our Myeloma Information Specialists answer a common seasonal question: 'why do I need a flu jab again this year?'.

All of this is made possible by you: the Myeloma UK community. Together we continue to support one another and drive change. On behalf of Myeloma UK, we wish you all the very best this festive period and 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: Maria Watson

LIVES: Gillingham, Kent

AGE: 52

When Maria Watson's partner, Anne, fell seriously ill, she nursed her back to health and the pair planned to tie the knot. But within months their roles were reversed when Maria was diagnosed with myeloma. After a very difficult year, Maria is thankfully in remission and finally got to say 'I do' to the love of her life.

Watching my partner Anne fighting for her life in hospital was the most terrifying experience of my life. It was April 2023, and there she was at Medway Maritime Hospital in Kent, covered in a jumble of wires with a thick breathing tube snaking out of her mouth.

Through the whir and beep of machines, I vowed to myself that if Anne got through this, we needed to make the love we had for each other official and tie the knot after eleven years together.

> **She was really unwell, but I was at her bedside every day.**

Anne had been diagnosed with an extremely rare form of vasculitis which affects as few as 10 people in every million.

She'd had a range of symptoms over the past 8 months: pain in her wrist, trouble with her grip, muscle cramps, fatigue and weight loss.

In April, when she started vomiting and went to A&E, blood tests revealed her kidneys weren't functioning and she was admitted to hospital and kept in for 6 weeks.

During that time, she had a cardiac arrest, and I was told she might have brain damage. She was put into an induced coma, had multiple blood and plasma transfusions and was on dialysis.

She was really unwell, but I was at her bedside every day. Thankfully as the treatments worked and she was well enough to come home, I was by her side helping her get dressed, getting her dinner and offering her emotional support that she would get better.

In October 2023, on a much-needed break away to Suffolk with our dogs, Anne popped the question and I didn't hesitate to say yes. I was so excited about sharing our love with the world. It felt so meaningful after everything we'd been through.

"We realised something was seriously wrong."

By January 2024, we'd found the perfect wedding venue, a beautiful barn in Kent and even had plans for our dogs to be the ring bearers.

But then I started getting agonising back pain. I'd had issues on and off for over a year but thought it was an old hip fracture playing up or that I'd simply been overdoing it. Working as a postie, I was often lifting heavy loads and jumping in and out of the van. I also worked as a massage therapist twice a week and I was active, taking my dog Dotty to perform in agility trials.

I'd booked to have a scan to get to the bottom of my back pain but cancelled it when it seemed to get better on its own.

But in May 2024, the pain was in my back and ribs was causing me to gasp in pain. I was struggling to breathe at night and I could hardly walk, resorting to using walking poles.

I could hardly shower or put my socks on and was in so much pain that I couldn't eat and lost half a stone. I had no choice but to go on sick leave from work.

I slept in the spare room where the bed is lower, so I could roll out onto all fours and gradually climb up to my feet and get to the bathroom. On one occasion I struggled to get up from the bed and experienced such excruciating spasms that I had to call 101 for an ambulance as I did not know what to do.

My GP took blood tests but couldn't find anything wrong and prescribed heavy-duty painkillers. I was referred to see a specialist but the wait list was 20 weeks long so I paid for a private MRI scan and to see a private rheumatologist. The scans showed fractures in my spine and we realised something was seriously wrong. My specialist called me in August and urgently referred me to my GP for CT scanning.

The scans revealed multiple lesions on my spine and pelvis and a consultant said I probably had myeloma, which was then confirmed by a bone marrow biopsy.

I dread to think what would have happened if I had not sought a private doctor. I cannot however fault the NHS in any way since my diagnosis. I have been well looked after, listened to and very carefully monitored.

I had no idea what myeloma was but when I asked if my symptoms would improve, I was initially told they wouldn't. I was devastated.

Back home, I typed 'myeloma' into Google. To discover it was a type of incurable cancer was scary but I was determined to focus on the positives. Myeloma was highly treatable and I read stories of people living up to 30 years after diagnosis.

"Anne was by my side through it all."

"It's my turn to support you," Anne promised as I started 16 weeks of chemotherapy and immunotherapy treatment.

Less than a year earlier, Anne had to fight for her life. Now it was my turn. We took the same approach as we did with her illness, focusing on each hurdle as it came and not looking too far ahead.

I had great support from Anne, my parents and my twin brother Adrian, who came over from Australia, where he lives, which really boosted me. I also focused on arming myself with as much practical and reliable information as I could using the Myeloma UK website and downloading their booklets on what to expect from the stem cell transplant.

Thankfully, I had minimal side effects from the treatment, just insomnia, so we decided to keep our wedding date of 6 November 2024.

My immune system was low because of the treatment so we kept the ceremony low-key. Wearing matching sheer black shirts and the widest of smiles, we said our vows at Rochester Corn Exchange with our siblings and a few close friends in attendance with plans for a bigger bash once I was better.

I had my stem cells harvested in January this year and in March I had a stem cell transplant at King's College Hospital in London. It was an endurance, especially being isolated for 3 weeks.

I lost my hair and had horrid inflammation in my throat but Anne was by my side through it all.

It's now been a few months and I am in really good remission, which is brilliant news – especially as I have a high-risk form of the disease.

I currently have my bloods taken and checked every month and take maintenance medication to help keep me in remission.

While I am not back at work, I'm so happy to be back walking well again and my pain is gone apart from some stiffness in my lower back. I didn't think my symptoms would improve so I am overjoyed that my quality of life is so much better since treatment.

> **Being diagnosed with myeloma has sent me a message about what's important in life and has made me more appreciative of the people I love.**

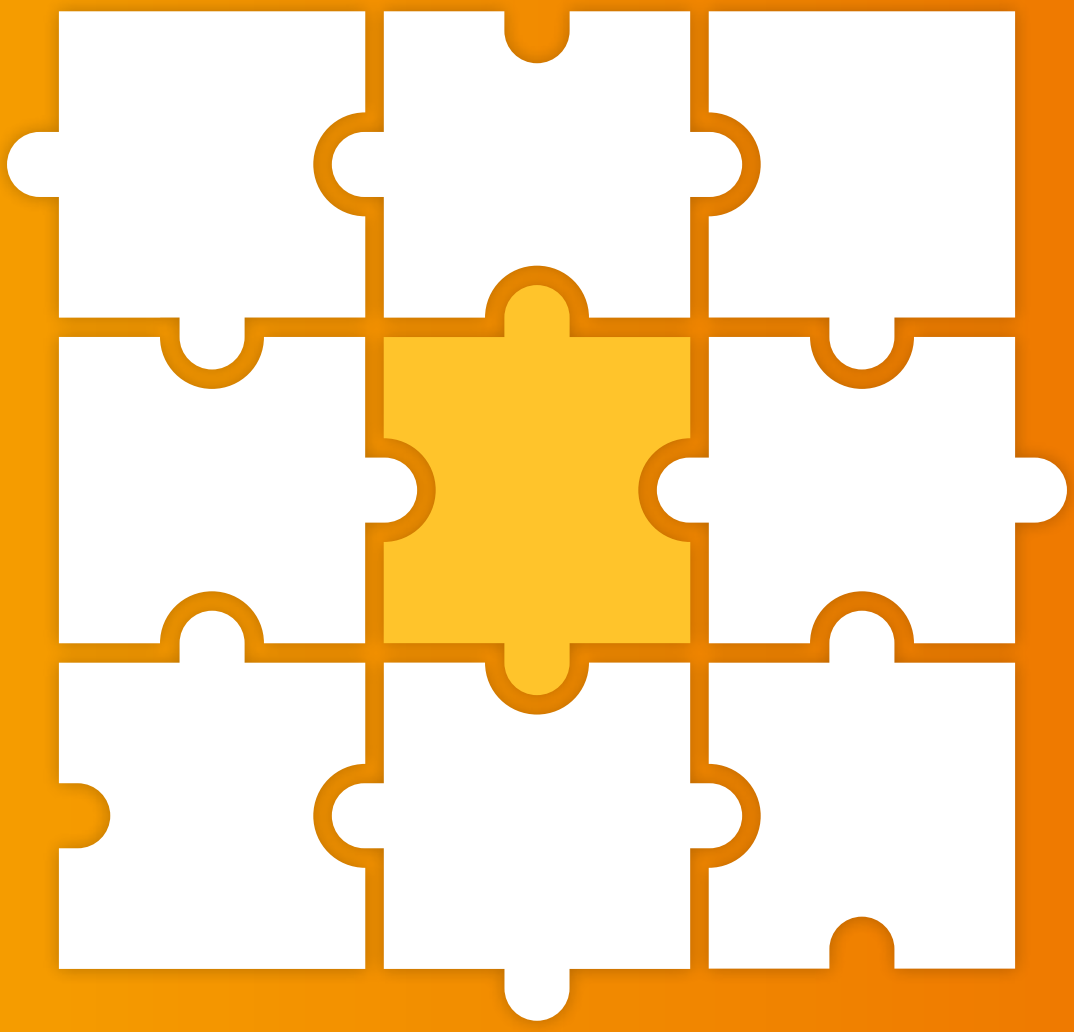
My dog has been my soulmate and really helped me through everything, and sometimes I wonder if she was trying to tell me something was wrong. She licked me more and lay on me in a certain way, like she wanted to be closer to me.

Being diagnosed with myeloma has sent me a message about what's important in life and has made me more appreciative of the people I love. Anne and I have been through a real rollercoaster, and we have tested our vows, supporting each other in sickness and in health.

We are stronger than ever. We had a proper wedding ceremony in July, which was a colourful affair with rainbows, blinged-up trainers, camping and our dogs Dotty, Freddie and Bertie coming down the aisle. We celebrated our love and our second chances at life.

RESEARCH FOCUS

A decade of patient power: shaping research, changing lives



A decade of patient power: shaping research, changing lives

This year marks 10 years of incredible impact, insight and inspiration from the members of our Patient and Carer Research Panel (PCRP).

Collectively, they are shaping myeloma research in the UK. Their voices, ideas and lived experience are ensuring the latest research meets the needs of people affected by myeloma.

What is the PCRP?

The PCRP was first developed in 2015 to ensure that voices of patient and carers are heard in research, and to help make a positive change in the patient journey and experience.

The panel, made up of volunteers affected by myeloma, help Myeloma UK to ensure our research and funding is directed where patients need it most, and to support researchers with their first-hand insight.

This means clinical trials, projects and grant applications can best reflect what is important to people affected by myeloma.

Who are the PCRP?

The panel aims to capture a wide range of diverse lived experience and includes people with:

- Newly diagnosed myeloma
- Relapsed and refractory myeloma
- MGUS
- Smouldering myeloma
- Plasma cell leukaemia
- Experience as carers or family of people with these conditions

What does patient involvement look like in practice?

There are many ways members of the panel can get involved in shaping research. Our panel members have co-developed research protocols, been co-applicants for research projects, taken part in project advisory or steering groups, helped to develop and feedback on patient information and other research materials, and much more.

PCRP achievements and impact

Members of the PCRP have played a vital role across a wide range of research projects. In the last 10 years we have:

Recruited 16 PCRP members to the UK Myeloma Research Alliance (UKMRA). This is the largest collaboration of myeloma researchers in the UK, and all working groups of the UKMRA have representation from PCRP members

Become co-applicants on research projects, supporting teams to secure research funding and deliver projects

Helped to shape the Myeloma UK Research Strategy

Been pivotal in shaping our current Chapman-Livanos research project investigating the source of heart and circulatory disease in myeloma

Why does patient involvement matter?

Patient involvement in research is an active partnership between patients, carers, friends and family, and researchers. By working together, we ensure that research meets the needs of those who will be impacted by the results.

Patient involvement:

- Ensures research is **done with participants**, not for or about them
- Makes sure **real needs** are addressed
- Delivers research that is **relevant and impactful** for the people it intends to serve
- Improves **quality and design**
- Helps with **recruitment and retention** of participants to studies

What's next for the PCRP?

Every year, the panel support 25 to 35 research requests. Individual members choose if they wish to volunteer each time. After the panel take part, the researchers provide written feedback.

Myeloma UK are committed to understanding what living longer with myeloma means for patients, and what support patients need to live well after diagnosis – the panel will continue to be an essential part of shaping this.

1

PCRP gives patients a voice in research, clinical trials, grant applications and more

2

The members experiences and ideas help to shape research

3

This allows research to be conducted with the needs and priorities of patients/carers in the forefront

4

Improving patient experience, research quality, recruitment and retention

Here's how the PCRP is making a difference in myeloma research – in the words of researchers and PCRP members themselves:

HELPS US UNDERSTAND THE INFORMATION WE WISH TO COLLECT...

"The contributions of patients and carers within the space of heart and circulatory issues were invaluable and have significantly impacted the scope of the information we wish to collect, ensuring we capture experiences of patients that we were not aware of. I would like to thank the panel members for doing this work and continuing to contribute."

Romi Carriere, Chapman-Livanos Research Fellow

HELPS TRANSLATE AND SHARE FINDINGS...

"Together we were able to have fruitful conversations, identify a set of priorities and use them to shape our research proposals. The plan will be to continue this group throughout the study, to help us translate these findings, and share them with the wider community. In addition, we were compelled by questions that we were not yet addressing and are now actively working on ways to address them in the future. Overall, we are grateful for the time and expertise provided by this tremendous group of patients and carers and would like to thank Myeloma UK for making it possible."

Dr Eileen Boyle

MAKES OUR THOUGHTS AND FEELINGS KNOWN...

"It's vitally important for people with Myeloma and their care partners to make their thoughts and feelings known. Participation in the PCRP provides just such an opportunity. Whether it's filling in a questionnaire, reviewing a plain-English summary or influencing the design of a research trial to make it more patient-friendly, there are lots of ways I have been able to contribute to research even without being on a clinical trial. It's very satisfying to be involved and help to make a difference."

Peter, PCRP Member

HAS A POSITIVE IMPACT ON THE WAY TRIALS ARE DESIGNED...

"Representatives join the main UKMRA meetings when research projects, planned trials and trials in progress are discussed. All the researchers, clinicians and scientists who attend the meeting understand how vital it is for the patient voice to be heard at the meetings. The reps are strongly encouraged to contribute to these meetings by putting forward the patient and carer perspective and this has had a positive impact on the way trials are designed. The support of the PCRP has been crucial in the development of patient and care representation in research into Myeloma in the UK."

Dr Rakesh Popat, UKMRA researcher

ENABLES ME TO USE MY EXPERIENCE...

"I have been part of the PCRP for many years and have both learned and benefited from being part of the panel. I have appreciated being able to give input, review documents and be part of Zoom meetings with healthcare professionals who have been researching and working extensively to assist those with Myeloma. Being part of the PCRP has enabled me to use my experience of caring for my late husband, having trod the pathways that must be navigated when someone is diagnosed with myeloma."

Karen, PCRP Member

MYELOMA RESEARCH NEWS FROM AROUND THE WORLD

Long-term remission from cilta-cel CAR-T cell therapy

With some of the longest follow-up periods for CAR-T cell treatment in myeloma, the CARTITUDE-1 clinical trial has explored the long-term effectiveness of cilta-cel for people with relapsed and refractory myeloma. 97 patients, most who had received several previous treatments, were given an initial pre-treatment followed by a single infusion of cilta-cel.

Five years later, around 1 in 3 patients were still in remission, including some with high-risk (more difficult to treat) myeloma. Additional testing in 12 patients showed no detectable cancer in any of them at that time. These encouraging results highlight the potential for redefining long-term remission, and perhaps one day, a cure.

Ongoing clinical trials are exploring the best way to use cilta-cel.

Refining risk assessment: A step towards more personalised care

New research exploring why some patients do not respond well to treatment has shown that it is possible to improve detection of those most likely to relapse early. By combining traditional genetic testing with cutting-edge gene expression profiling (GEP), they can identify people who are less likely to respond to standard treatments.

135 transplant-eligible patients were involved in the retrospective study, with 25 patients experiencing early relapse. Out of these, 14 patients were identified as high-risk at diagnosis using current methods. One additional patient was identified through a genetic test called next-generation sequencing (NGS). However, the addition of GEP improved risk identification. The combined approach successfully detected more than 8 out of 10 patients who would go on to relapse early.

Improving diagnostic testing to understand who is most at risk of not responding to treatments opens possibilities of new approaches to targeted, personalised treatments for people living with myeloma in the future – moving towards better outcomes for everyone.

Could a blood test replace bone marrow biopsies?

A new blood test called SWIFT-seq could provide a less-invasive alternative to traditional bone marrow biopsies.

This test can detect myeloma cells circulating in the blood and identify important genetic changes, helping researchers to better understand myeloma and its precursor conditions.

The research involved 101 participants including healthy individuals and people living with monoclonal gammopathy of undetermined significance (MGUS), smouldering myeloma and newly diagnosed myeloma. Results showed that SWIFT-seq successfully detected circulating myeloma cells in 9 out of 10 patients.

While more research is needed, these early results suggest that SWIFT-seq could reduce the frequency of bone marrow biopsies. It may offer a simpler, more comfortable way to diagnose and monitor myeloma and its precursor conditions and help guide treatment decisions in the future.

CELMoDs: A promising new type of myeloma treatments

Despite the increasing number and effectiveness of myeloma treatments over recent years, patients still face relapse and treatment resistance.

A recent international review exploring the role of a new group of medicines called CELMoDs (known as cereblon E3 ligase modulatory drugs) in myeloma offers fresh hope.

CELMoDs work by targeting and breaking down specific proteins that myeloma cells need to survive.

A recent review focused on two specific CELMoDs currently in clinical trials – iberdomide and mezigdomide – and highlights that the treatments could be effective options for patients who no longer respond to immunomodulatory drugs like lenalidomide (Revlimid®) and pomalidomide (Imnovid®).

Mezigdomide shows promise for patients who have relapsed multiple times, whilst iberdomide may offer versatility, suitable for earlier stages of treatment and as maintenance. Both treatments can be taken orally (by mouth).

Whilst clinical trials are ongoing, this could mean more flexible, less intensive treatment options for people living with myeloma in the future – particularly for those people whose myeloma is resistant to other standard treatments.

SPOTLIGHT ON SUPPORT GROUPS

“It gives you comfort, speaking to others and listening to everything they are going through”

SUPPORT GROUPS

When facing a new diagnosis or relapse, having a support network to help navigate the journey and the unexpected challenges it brings can make a world of difference. Support Groups can be the bridge between feeling isolated and feeling understood.

Myeloma UK runs a Support Group programme which provides the opportunity for patients, families and friends to connect with a welcoming community. Group members truly understand what it is like to live with a myeloma diagnosis. These groups provide an informal and supportive space to learn more about living with myeloma, hear different experiences, and discuss challenges.

Support Group members become part of a community that can offer reassurance and encouragement when it's needed, meaning no one feels isolated in their diagnosis. Support Group members also often form lifelong friendships which extend beyond group meetings.

> **"The room just gets it. It's a wee check-in with others who face similar challenges, some further along the path than others, so a great place to share stories and solutions. You feel less alone when you connect with the group."**
>
> **Anon,** Support Group member

> **"We have made a lovely group of friends through the Support Group, who we refer to as our 'myeloma mates'!"**
>
> **Andrew and Helen,**
> Perth Support Group members

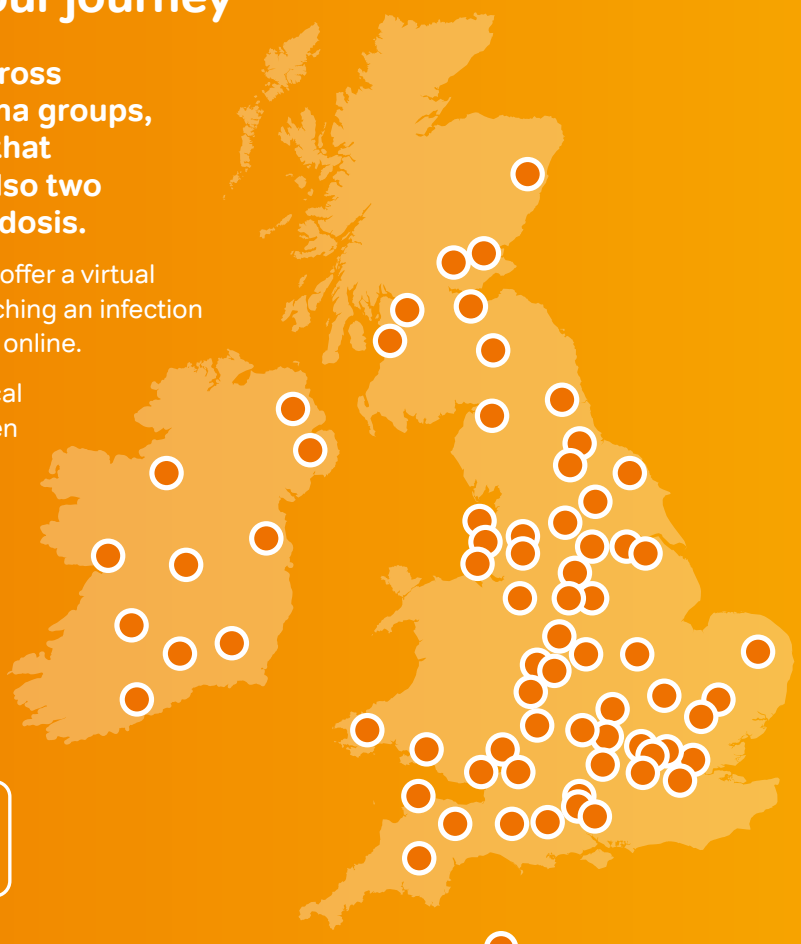
Finding a group of people that understand, and can help you navigate your journey

Currently, there are 82 Support Groups across the UK and Ireland: 61 of these are myeloma groups, and 19 are haematology Support Groups that include people with myeloma. There are also two Support Groups for people with AL amyloidosis.

Around 9 out of 10 groups meet in person, but some offer a virtual option, particularly during winter when the risk of catching an infection is higher. About 1 in 10 Support Groups always meet online.

Normally, Support Groups cater for people in their local area; however, some groups that meet online are open to members anywhere in the UK and Ireland.

All Support Groups welcome people with myeloma and related conditions, as well as their family members and carers. The exception to this are ones designed to support specific groups of people, such as the **Friends and Family myeloma Support Group**, and the **50s and Under myeloma Support Group**.



For a list of all our Support Groups, go to: **myeloma.org.uk/support-groups**.

Why join a Support Group?

You may worry that a Support Group will be all doom and gloom. However, the opposite is true – people often leave a meeting feeling hopeful, inspired and empowered.

The benefits to emotional and mental wellbeing that joining a Support Group can bring are apparent from the feedback that group members have provided about their experiences.

Support when you are newly diagnosed

Hearing the words "you have an incurable cancer" can stick in your mind and make it difficult to process any other information. Having the time to unpack a diagnosis in a safe space can provide reassurance and hope.

Support at different stages of your journey

Whether you have newly diagnosed myeloma, have smouldering myeloma or MGUS, you are welcome to attend a Support Group, as you will often find others that have walked a similar path to you.

Having people on hand to guide you

Each person gains something different from a Support Group. For some, the group provides a community. For others, it provides a forum for questions they may not yet know how to ask their healthcare team. Knowing that you have other people in your corner who understand the unique challenges that myeloma brings can be transformative.

"The support is invaluable and there is a genuine intention to help and listen to one another. There may be times when we might not have fully understood a comment by a consultant but are reluctant to ask them again, or we may have a question that seems too trivial. There is a good chance that a Support Group member has been in a similar position but if there is any doubt, we will not hesitate to steer them back to their haematology team. I am so glad that I came to the Cambridge Support Group many years ago, and I will continue to come."

Lynn, Cambridge Support Group member

"My husband and I joined the group immediately after I was diagnosed with myeloma. Not knowing what to expect, it was a time of fear and anxiety. Meeting a welcoming group of patients who were navigating myeloma while living active and rewarding lives was reassuring. Learning about side effects and how to minimise them helped when plunged into treatment. Hearing how members have holidays, do activities, and take part in hobbies, gave us hope for our future."

Jane, Cambridge Support Group member

"Our Support Group Leader always knows the right thing to say, even when it's not good news. He provides information on navigating our local health service. I remember first being diagnosed and just how overwhelming this can be, so for newly diagnosed patients, this information can be extremely helpful."

Anon, Reading Support Group member

Signposting to relevant services

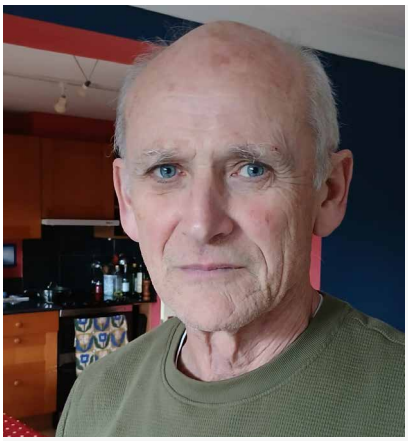
As well as providing a listening ear, a Support Group can be a source of knowledge. Many groups provide their members with **Myeloma UK information booklets** and group newsletters.

Many value the guidance they receive on navigating local health services and recommendations on where to find reliable information.

Meet the Leaders
Winchester Myeloma Support Group

The Winchester Myeloma Support Group was set up in 2013, by myeloma patient Brian Orange. Brian sadly passed away in 2017, after which the group was taken over by Mary Mitchell, who ran the group for 7 years before stepping down in 2024.

New Leaders **Mark Frank** and **Stuart Goldsmith** have been running the group for just over a year. Below, they provide reflections on their myeloma journeys, and in running and attending their Support Group.



Mark Frank

Mark, 74, is a retired IT professional, and was diagnosed with myeloma in 2020. When asked why he decided to take over the group, Mark said:

> **The myeloma department at RHCH have done wonders for me, and have added years to my life, so I wanted to give something back and help others that are in a similar situation to myself.**

In addition to being a Myeloma UK Partnered Support Group, the Winchester Support Group is supported by the clinicians at the Royal Hampshire County Hospital (RHCH) who often attend meetings. In turn, the Support Group were instrumental in helping the hospital to achieve its Clinical Service Excellence status in 2022.

Mark says that being able to input into the programme is just one of the benefits that having (and running) a Support Group brings.

Stuart Goldsmith

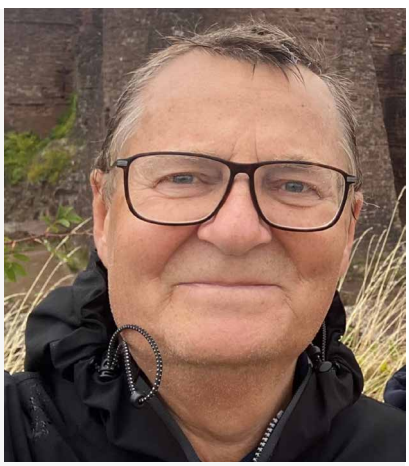
Stuart, 63, is a retired Buyer, spending most of his career working in the retail, food, and beverage sectors.

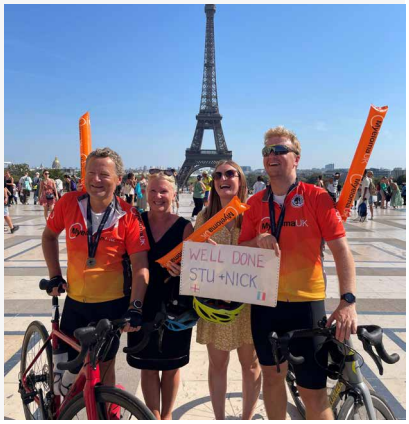
When he was diagnosed in 2022, he heard the words “metastatic cancer” and had no idea what it meant. Reading Myeloma UK information booklets and finding the Winchester Support Group put things into perspective for him, and as a result, he was determined to live well with myeloma.

Despite the physical challenges that he endured from myeloma, Stuart did not let that stop him. Only 6 months after his diagnosis, Stuart completed the London to Paris bike ride with his son on behalf of Myeloma UK. Stuart also gave a talk at the London Infoday in September 2025 about his myeloma journey.

Stuart’s motivation for volunteering for Myeloma UK in various guises, including taking over the running of the Winchester Support Group with Mark, comes from his mantra of taking one step at a time.

> **Myeloma is the elephant in the room, and you can’t eat it all at once. You have to break it down into bite-sized chunks, and that is how I view my various roles with Myeloma UK. I want to try and help people navigate their way through the good times and the bad times.**





What makes your Support Group successful?

Mark and Stuart agree that having input from the clinical team is an asset to the group. Newly diagnosed patients are given the Support Group leaflet at diagnosis and are reassured that there is a reliable network of people they can speak to, when they are ready.

Additionally, having advice and support from Myeloma UK and the information shared by other Leaders on the Partnership Hub has proved invaluable, as each group operates differently.

> **"The advice I would give to someone thinking about joining the Partnership Programme, is to just do it. Knowing that Myeloma UK are there to support us, in whatever capacity it might be, and having the support that's there in the background."**
>
> **Stuart Goldsmith**

What if I don't have a local Support Group?

MyelomaUK
Support Groups
Partnership Programme

If you don't have a Support Group in your local area, why not start one? The Myeloma UK Support Groups Partnership Programme is here to help anyone who runs a Support Group or would like to set up a new one.

The programme gives Support Group Leaders exclusive access to the Partnership Hub, a dedicated online platform, and a community of Leaders that they can share ideas with. The platform offers a wealth of information on setting up a new group and how to sustain it, best practice guidelines and templates to use for your Support Group.

> **"The Support Group is very valuable, and I hope other groups start elsewhere where they don't already exist."**
>
> **Anon**,
> Support Group Leader

> **"We have found that the Partnership Programme set up by Myeloma UK is a hugely positive step forward in patient support."**
>
> **Iain**, Milton Keynes
> Support Group Leader

> **"The Leaders Network within the Partnership Hub has been a great source of knowledge and advice for me. It's a comfort knowing they are there if I have any questions or need support."**
>
> **Samantha**, Derby
> Support Group Leader

Setting up a new group starts with someone who is passionate about providing support to others, and Myeloma UK are on hand for support throughout the process.

Over half of Support Group Leaders are patients, carers, or family members. You don't need a medical background to run a group; just a desire to help and support others.

If this sounds like you, please get in touch with **Prabs Parmar** in the Support Groups team at **supportgroups@myeloma.org.uk**.

MYELOMA

HOT TOPICS

ANAEMIA

Whether a side effect of treatment or a result of the myeloma itself, many patients experience anaemia at some point after their myeloma diagnosis. However, anaemia can usually be treated and managed effectively.

What is anaemia?

In the body, red blood cells use a protein called haemoglobin to carry oxygen from the lungs to your tissues and organs.

Anaemia happens when there is a low number of red blood cells or low haemoglobin. When these are low, less oxygen is carried around the body.

What causes anaemia?

There can be many causes of anaemia. For people with myeloma, these can include:

The myeloma itself: Abnormal plasma cells grow quickly and overcrowd the bone marrow (where healthy blood cells are produced). This makes it harder to produce enough red blood cells, causing anaemia.

Kidney damage: A hormone called erythropoietin is produced by the kidneys and tells the body to make more red blood cells. If the kidneys are damaged, they will make less of this hormone.

Myeloma treatments: Anaemia can be a side effect of many treatments.

Low iron levels: Iron helps form haemoglobin. When iron levels are low, haemoglobin levels drop, causing anaemia.

How is anaemia diagnosed?

Anaemia is usually diagnosed with a blood test. The blood tests check the number of red blood cells, haemoglobin and iron levels and your kidney function.

Different people will experience different symptoms, so blood tests are only part of the diagnosis. Your healthcare team will also explore how your symptoms impact you and your medical history.

Common symptoms of anaemia

Fatigue and weakness

Dizziness or light-headedness

Shortness of breath

Looking paler than usual

A more noticeable, fast or irregular heartbeat

How is anaemia treated?

Identifying the cause of anaemia is the first step in treating it. This will allow your healthcare team to offer the most effective treatment. Treatment options may include:

- Iron supplements or infusions
- Changes to your treatment plan, such as a reduced dose or a treatment break
- An injection of erythropoietin
- A blood transfusion

How can I live well with anaemia?

As well as getting treatment for anaemia, here are some tips for managing your symptoms you may find useful:

- **Eat a diet rich in iron, folic acid and vitamin B12**. Foods such as leafy greens, lean meats and fortified cereals can help with red blood cell production. A dietitian can offer specific advice.
- **Have a daily routine**. You may find it helpful to plan your activities around the times you feel less fatigued during the day.
- **Keep a diary**. This may help you identify and keep track of things that may contribute to your fatigue or recognise things that help to relieve it.
- **Try regular, gentle exercise**. This can help to boost your energy and reduce fatigue. Discuss any new exercise routine with your healthcare team first.

Sources of information and support

Fatigue and myeloma Infoguide

Infopack for living well with myeloma

Read our Ask the Nurse blog about Myeloma and anaemia

myeloma.org.uk/library/myeloma-and-anaemia

Watch our Digital Infoday Session on Fatigue

SMOULDERING MYELOMA

Smouldering myeloma is a form of myeloma without symptoms, which is often diagnosed by chance. Read on for more about living with this condition.

What is smouldering myeloma?

Smouldering myeloma is an early form of myeloma. In myeloma, some of the plasma cells (a type of blood cell) in the bone marrow become cancerous. Myeloma is often called 'active' myeloma when it has reached the point where it needs to be treated. With smouldering myeloma, the level of activity of the cancer is lower than for active myeloma, and there are no symptoms.

Smouldering myeloma is often picked up by chance, but the diagnosis will be confirmed by tests.

How will I be monitored and treated?

If you have smouldering myeloma you will not normally be given myeloma treatment. This is because the benefits of starting treatment at this point are not certain. However, you will be regularly monitored to check for any changes in test results, and any symptoms that could indicate you are developing active myeloma (which would then be treated).

You will be given other treatments as needed, such as extra vaccines because your risk of infections will be higher. You may be given a treatment to protect your bones.

Most people with smouldering myeloma will develop active myeloma at some point. However, how long this takes varies. Occasionally, it stays unchanged and never develops into active myeloma.

Tips for living well with smouldering myeloma

Try to stay positive and to continue living normally – don't let constant worry take over

Find ways that help you to relax

There is nothing specific you can do to delay or prevent smouldering myeloma from developing further, but it is good to keep healthy by eating a balanced diet, being physically active and looking after your mental health

Watch out for new symptoms. They may be unrelated to the smouldering myeloma, but you should always get them checked by your healthcare team

Turn to page 22 for advice from our Myeloma Information Specialists about coping with the uncertainty of a smouldering myeloma diagnosis

For a list of travel insurers that specialise in insuring people with pre-existing medical conditions, see the **Travel insurance and myeloma Infosheet** from Myeloma UK.

Travelling with smouldering myeloma

It is perfectly possible to enjoy travelling when you have smouldering myeloma. However, it is important to have suitable travel insurance. Keep these tips in mind when looking for travel insurance:

- You must disclose your smouldering myeloma to ensure that your insurance cover is valid
- There are many travel insurers that specialise in insuring people with pre-existing medical conditions, including cancers
- The cost of travel insurance (called the premium) varies widely – it pays to shop around and find the best insurer for you, so allow enough time to do this
- It is essential to check whether the policy covers cancellation of your trip
- Depending on your plans, it may be more cost-effective to buy an annual policy

It is often easier to give your details over the phone to avoid misunderstandings – make sure the insurer is aware that your myeloma is smouldering and that you do not yet need treatment.

Sources of information and advice on smouldering myeloma

Ask your haematologist or Clinical Nurse Specialist (CNS) if you are worried about any aspect of your smouldering myeloma

Read the Smouldering myeloma Infosheet from Myeloma UK for more information

Call the Myeloma Infoline on 0800 980 3332 or AskTheNurse@myeloma.org.uk for information, advice or just a listening ear

FOOD AND FESTIVITIES

For many of us, the winter and holiday season is associated with seeing family and friends, parties, and lots of delicious food. But when you have myeloma, what is usually a time of celebration may feel challenging.

Myeloma and myeloma treatments can affect your appetite and sense of taste. They can also cause symptoms such as nausea and vomiting. These may be particularly difficult to manage when you want to participate in your usual traditions involving food and drink with loved ones.

Here we've put together some useful tips to help you continue to eat, drink, and be merry this holiday season.

There are no specific foods or diets recommended to all people with myeloma. However, as is the case throughout the year, it is important to aim for a healthy, balanced diet. This can help you maintain strength and energy and support your immune system.

You might find maintaining a healthy diet, or dealing with changes to your appetite, difficult when you have fatigue. Try to rest when you need to. The holiday season can be very social, which may be tiring. Try to pace yourself throughout the day and eat when you feel you have the energy to.

Managing nausea or vomiting

Eat little and often. Snacking on plain, cold, or room-temperature food may be easier than hot meals. It you cannot stomach solid food, high calorie drinks, such as smoothies or soups, may help.

Stay hydrated. Sip drinks such as still or sparkling water or fizzy drinks.

Try sitting near an open window while you eat, or outside if the weather allows.

Try not to do too much activity straight after eating but do stay sitting upright if you can.

Having company can help to take your mind off feeling nauseous. Talk to people, watch a film with them, or play music to distract yourself.

Avoid alcohol for a time as this can make nausea worse.

Avoid strong smells if they make you feel sick. Ask others to cook for you or keep the window open while you cook. Try putting light perfume, such as menthol, onto a handkerchief to help mask smells.

Managing changes in taste

If food tastes metallic, avoid metal cutlery and avoid food and drinks from cans. Try sipping a flavoured water, such as water and lemon, afterward to avoid unpleasant metallic aftertastes.

Try different flavours if all your food tastes the same. Try adding garlic, lemon juice, herbs, spices, or sauces.

Have warm and cold foods together, such as a warm mince pie with ice cream.

You might prefer stronger versions of your favourite foods, such as smoked ham, or a stronger cheese.

Managing appetite loss

Ask your friends and family to help you prepare meals if cooking puts you off eating. Or have a stock of convenience foods in the cupboard such as soups and puddings.

Focus on what you have managed to eat or drink, rather than worrying about what you have not.

Try to eat small amounts of high protein and calorie foods every few hours instead of 3 large meals a day.

Try gentle exercise to increase your appetite.

Try to remember...

Everyone's tastes are different, and everyone's experience with myeloma will be different. What works for someone else might not work for you. Be patient and keep trying to find a balanced diet that works for you.

Sources of information on eating well with myeloma

Living well with myeloma Infopack (chapter 6)

The small things that make all the difference book for more hints and tips

wcrf.org and search 'eating well' for recipes, resources and more

ASK THE NURSE

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

I have been diagnosed with smouldering myeloma – how do I keep from worrying about it?

Smouldering myeloma is an early form of myeloma which does not usually cause any symptoms and does not require treatment. It is however monitored regularly as it will at some point progress to active myeloma, although this can take some time.

It is very common to feel anxious, emotional and uncertain when diagnosed with a condition for which there is no treatment except regular monitoring. Many patients find that one of the best ways to manage this is by becoming better informed. Patients often tell us that this helps them take some control, enabling them to be better prepared at appointments and helps to build a collaborative relationship with their medical team.

- Our **Smouldering Myeloma Infosheet** has information about smouldering myeloma, how it is monitored, and what signs to look for which may show your myeloma is becoming active.
- Our **Digital Infoday Session: Smouldering myeloma** features Consultant Haematologist Dr Stern who describes what smouldering myeloma is and discusses the common issues faced by patients.
- Our **Digital Infoday Session: Living with uncertainty** features psychotherapist Surabhi Chaturvedi, who gives some top tips on how to manage the uncertainty of living with myeloma and smouldering myeloma.

Myeloma UK are here to support you in any way we can. The Myeloma Infoline is answered by Myeloma Information Specialists to talk through what you may be experiencing and provide information, practical advice and a listening ear. Calls have no time limit, and you can talk as long as you need.

I have been told that I cannot have a transplant – what are my options now?

Initial treatments for newly diagnosed myeloma patients can broadly be divided into intensive and less intensive. The intensive treatment is offered to patients who are generally younger, fitter and more able to cope with high dose therapy and stem cell transplant (HDT-SCT), though there is not a strict age cut off.

As of the 4 September 2025, there is a new treatment option for patients who are not eligible for HDT-SCT – called IsaVRD. This is a treatment combination made of 4 medicines: Isatuximab (Sarclisa®), bortezomib (Velcade®), lenalidomide (Revlimid®), and dexamethasone.

Patients not eligible for HDT-SCT may also be offered a treatment called 'DRD'. This is a treatment combination made of 3 medicines: Daratumumab (Darzalex®), lenalidomide and dexamethasone. It has been shown in studies to be effective at bringing myeloma under good control.

Your opinions are very important when treatment decisions are being made. Patients should be fully informed about the options available to them, what side effects they might expect, and what the treatment plan will look like. Your haematologist and clinical nurse specialist can help answer any questions.

I had a flu vaccine last year - why do I need to have one again this year?

Having the flu vaccine every year is recommended for myeloma patients, as it is an effective way to reduce your risk of getting an infection. This is particularly important for people who have a weakened immune system, such as myeloma patients.

No vaccine is 100% effective, but the flu vaccine can make any resulting infection milder and the recovery period quicker.

The flu vaccine should be repeated every year because the strains of flu virus change from one year to the next, and the previous years' vaccine may not be effective at protecting against a new strain.

The effectiveness of vaccines also decreases over time, so it is necessary to repeat every year to give the best protection. The flu vaccine is not a live vaccine and is safe for myeloma patients.

The flu vaccine is free for myeloma patients, and can be given at your GP surgery, local pharmacy or hospital. Your GP, haematologist or clinical nurse specialist can advise on the best time for you to have your vaccine.

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

CELEBRATING THE LIFE OF SARAH HENSHAW

Our dear friend and colleague, Sarah Henshaw sadly passed away earlier this year. Here we would like to remember her and the impact she had across Myeloma UK and the wider myeloma community.

Sarah was a phenomenal person and myeloma Clinical Nurse Specialist who dedicated her life to supporting people living with myeloma, the advancement of treatments and holistic clinical practice. She was a valued member of the Myeloma UK Board of Trustees and served on our Lived Experience Committee and Research and Clinical Access Committee.

"Throughout her long and successful career, Sarah supported Myeloma UK in almost all of our activities. She was a passionate advocate for patients, healthcare professionals and the Myeloma UK community. Sarah was one of the first myeloma Clinical Nurse Specialists and really set about defining how important myeloma nurse specialists are to improving the quality of care for myeloma patients.
I will remember her passion, her dedication and her kindness. I always enjoyed listening to her wisdom. She was a great friend to many in the myeloma community, and I count myself lucky that I was one of them."

Prof Graham Jackson, Myeloma UK Chief Clinical and Scientific Advisor

"Sarah joined the Board of Myeloma UK in 2019. She was a passionate advocate for people living with myeloma and for making sure that everything we do was centred on what matters most to them. Her depth and breadth of experience, together with her compassion and kindness, have left a lasting legacy, both at Myeloma UK and in the wider haematology world. I miss her smile and her enthusiasm."

Dr Sophie Castell, CEO of Myeloma UK

"Sarah welcomed new members to the Nottingham Myeloma Support Group with open arms. She was known as a problem-solver, and patients felt reassured knowing that their problems were listened to and acted upon. Her legacy lives on, with many group members saying to this day how Sarah would always make patients feel at ease."

Prabs Parmar, Support Group Coordinator

"Sarah once kindly allowed me to shadow her for a day. Through this I got to see first-hand how her knowledge, expertise and compassion benefitted the patients and their loved ones that she came into contact with on a daily basis. It was very clear how much Sarah was respected by patients and her colleagues."

Ellen Watters, Myeloma Information Specialist

Lasting Legacies

A lasting impact on people living with myeloma

There is a theme to all tributes we've received about Sarah – she was more than a nurse; she became a significant part of people families and lives. She cared deeply and was authentic, kind and caring in all that she did.

Here are some of the words from her tributes...

Fundraising in Sarah's memory

Sarah's devotion and passion to the Myeloma UK community can be seen in the overwhelming support that Sarah's family and friends have shown since her passing. Nottingham Myeloma Support Group formed the team 'Striving for Sarah' to take part in Challenge 30, whereby each member completed 30 miles in the month of July. In total, our generous supporters have raised over £7,250 in memory of Sarah. One of Sarah's NHS colleagues has also secured a place to run The London Marathon in 2026 to fundraise for Myeloma UK in tribute to her.

Myeloma UK is committed to preventing and treating myeloma, and to supporting people to live well with myeloma. All these gifts that have been given in memory of Sarah will provide information and support to patients and families, help us fight for access to new treatments, and fund myeloma research, pushing us forward on our journey towards a cure.

The Sarah Henshaw Award for Clinical Excellence

Finally, we are delighted to announce the Sarah Henshaw Award for Clinical Excellence, to align with our Clinical Services Excellence Programme (CSEP) 10-year anniversary celebrations. Sarah was a passionate advocate for CSEP and, with the team at Nottingham, achieved re-accreditation last year. This annual award will recognise a CSEP accredited team which stands out for particularly innovative and person-centred myeloma care. We hope this award is a fitting legacy for our much valued, treasured and missed colleague and friend.

"Sarah was a fantastic ambassador for myeloma nursing. Sarah was a clear and passionate communicator and educator and was always seeking to improve practice to ensure patients got the very best care possible."

Monica Morris,
Clinical Services Excellence Programme Lead

"Sarah was a passionate advocate for every person in her care. She had a gift for making people feel truly seen, heard, and valued. To the myeloma nursing community, Sarah was a leader and a mentor. She shared her knowledge with generosity, encouraging others to grow in confidence and skill. Her determination to always put patients first will be remembered with deep respect and gratitude."

Suzanne Renwick,
Head of Clinical Practice

"Sarah was a wonderful human being and always found the time and energy to reach beyond her inner circle to influence peers and patients alike. I was struck by her ability to understand what matters for people living with myeloma."

Prof Karthik Ramasamy,
Former Myeloma UK Board member

COST-EFFECTIVENESS: WHAT IS IT AND HOW IS IT MEASURED?

"Is this new treatment good value for money for taxpayers?"

That is the question that health bodies like NICE (the National Institute for Health and Care Excellence) must ask when deciding if a new treatment should be made available on the NHS.

How 'good value for money' a treatment is, is known as its 'cost-effectiveness'. NICE will recommend a new treatment if it is more cost-effective than treatments currently available.

To determine cost-effectiveness, NICE calculates the new treatment's Incremental Cost-Effectiveness Ratio (ICER).

This is done in 4 steps:

Step 1: Identify the current standard of care

First, the currently used treatment that would be replaced by the new treatment must be identified.

Once identified, this current treatment is known as 'the comparator', as it is what the new medicine will be compared against.

Step 2: Estimate the added cost of treatment

The second step is to determine the cost of the new and the comparator treatment.

The cost of a treatment includes:

Cost of buying the treatment

For combination treatments, this includes the cost of all the individual medicines.

Cost of resources needed to deliver the new treatment

This includes:

- Tests before or after giving the treatment
- Hospital equipment to deliver the treatment
- Pharmacist's time to prepare the treatment
- Nurses' and haematologists' time for delivering the treatment

Cost of any supportive treatments or services

This includes:

- Pre-treatments or medicines to manage side effects.
- Hospital or community services used to manage side effects (e.g. dieticians, optometrists)

Step 3: Estimate the benefit of treatment

The benefit of a treatment is calculated using clinical evidence. It is assessed using a measure called a Quality-Adjusted Life Year (QALY). QALYs consider how long people live and how good their quality of life is because of treatment.

One QALY represents one year of life in full health. When health is affected by factors such as pain or limited mobility, the quality of that year may be considered lower. For example, a year lived with moderate fatigue might be valued at 0.8 QALYs, reflecting a reduced quality of life compared to perfect health. Myeloma UK works to make sure that patient experiences are heard when estimating the benefit of new treatments.

Step 4: The calculation

The ICER can now be calculated. It is usually given as the cost per QALY gained. NICE typically considers treatments with ICERs up to £30,000 per QALY to be cost-effective. Since January 2024, 6 new myeloma treatments have been approved for use on the NHS, and 4 more are being reviewed by UK health bodies now – a huge win for the myeloma community.

STEP 1	STEP 2	STEP 3	STEP 4
Treatment A is the new treatment. **Treatment B** is the current treatment identified as the comparator.	**Treatment A** will cost the NHS £50,000 per patient. **Treatment B** costs the NHS £30,000 per patient. The incremental cost of **Treatment A** is £20,000.	Data shows that people who get **Treatment A** live 3 years longer than people who get **Treatment B**. However, both treatments cause moderate fatigue and increased risk of infection, so each year is 0.7 QALYs. **Treatment A** delivers an added benefit of 2.1 QALYs compared to **Treatment B**.	The ICER is £9,534 per QALY gained (20,000 ÷ 2.1). **Treatment A** is below £30,000 per QALY, so it is cost-effective and approved for NHS use.

Note: The information in this table is not reflective of real-life examples and is used for the purposes of illustration only.

SUPPORTER STORIES

It is thanks to clinical trials and research into new treatments that Chris is here today.

Chris has lived a longer, better life thanks to the many advancements in treatments since his myeloma diagnosis. He passionately wants to carry this on into the future. That's why he has included a gift in his will to Myeloma UK.

Chris is a retired Sales Manager who worked for an engineering company based in Bradford. Chris and his wife, Carmel, are now enjoying their retirement in Yorkshire, but it hasn't all been plain sailing.

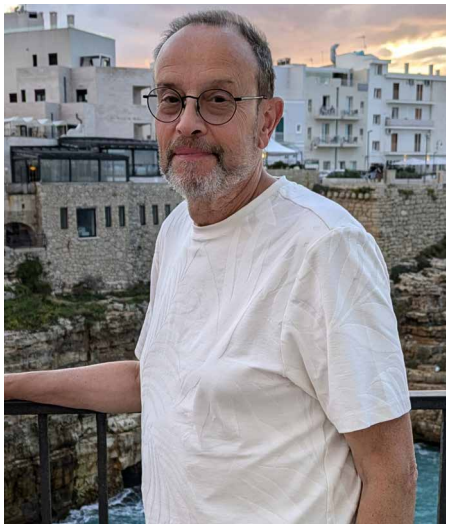
Chris' story

Chris was diagnosed with myeloma in February 2010, a week before his 48th birthday. He had been experiencing bone pain in his thighs and arms, and fatigue. Carmel persuaded him to go to the doctor. The doctor sat and listened and arranged for him to have blood tests. Chris was referred to the Haematology Department at Bradford Royal Infirmary where he was told he had myeloma.

Chris had his first stem cell transplant in September 2010 but unfortunately relapsed within 18 months. After Chris relapsed following his second stem cell transplant, he was offered a place on a clinical trial for a then-new drug called daratumumab (Darzalex®).

"I was the first patient in the UK registered for that trial, which started in September 2014 at St James' Hospital in Leeds. I have always believed that if the clinical trials are not of a benefit to me then they will be to someone else."

Within 12 months, Chris was in remission, which lasted until 2023.



Thankfully, with further treatment he has had the good news that his myeloma is no longer detectable.

"There are plenty of options developing all the time. The advance in medicines is coming on so much that you don't know what's around the corner. When I originally went on the daratumumab trial, the remission period was 18 to 24 months – I got 8 years. Things are always changing."

Thanks to Chris' successful treatments, he is now enjoying a medicine-free period – having his sense of taste back after nearly 12 years, not getting as fatigued as easily and feeling healthy again. His myeloma hasn't stopped him from doing what he loves and he is being as active as he can be. But he knows his limits when he does too much.

Chris' Wish

"I hope my gift in will goes towards research into new treatments. It is going on all the time, but it is costly. I also want it to go towards Myeloma UK because they are working on behalf of patients to get treatments accepted. That's such important work that Myeloma UK does. It never stops. Myeloma UK are always pushing and fighting for patients."

Chris wrote his will for free

Chris and Carmel used Myeloma UK's partner, National Free Wills Network, to write their mirror wills for free.

"My wife and I had been talking for some time about writing our will. Sometimes people wonder how much it will cost to leave money to charity. The Myeloma UK website explained it was a free will writing service. The information on the website was useful, and we made an enquiry to receive a free will writing information pack. We found a solicitor close to us who was really good. They help you think through things and questions and scenarios. It was a painless process.

I think you should consider leaving a gift in your will to Myeloma UK because charities are reliant evermore on donations nowadays. Myeloma UK helps those in a situation similar to you."

Join Chris and leave a gift in your will and join the journey to cure myeloma.

We would like to thank Chris and Carmel for pledging a gift in their wills to Myeloma UK. We would also like to thank Chris for kindly sharing his story.

To find out more about our free will writing service, scan the QR code or go to **myeloma.org.uk/gifts-in-wills**, or get in touch by emailing **giftsinwills@myeloma.org.uk** or phoning **0131 230 0429**.

Can you help end delays in diagnosis?

This Christmas, we're determined to tackle delays in myeloma diagnosis.

But we need your help.

Find out more about the progress your support is making, what's coming next and how you can help at **myeloma.org.uk/xmas**

Scan me!

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If you or any friends or family want to find out more about taking part please email the Ride Team at **ride@myeloma.org.uk** We'd love to hear from you!

MyelomaUK

Sign up today at ride.myeloma.org.uk

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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