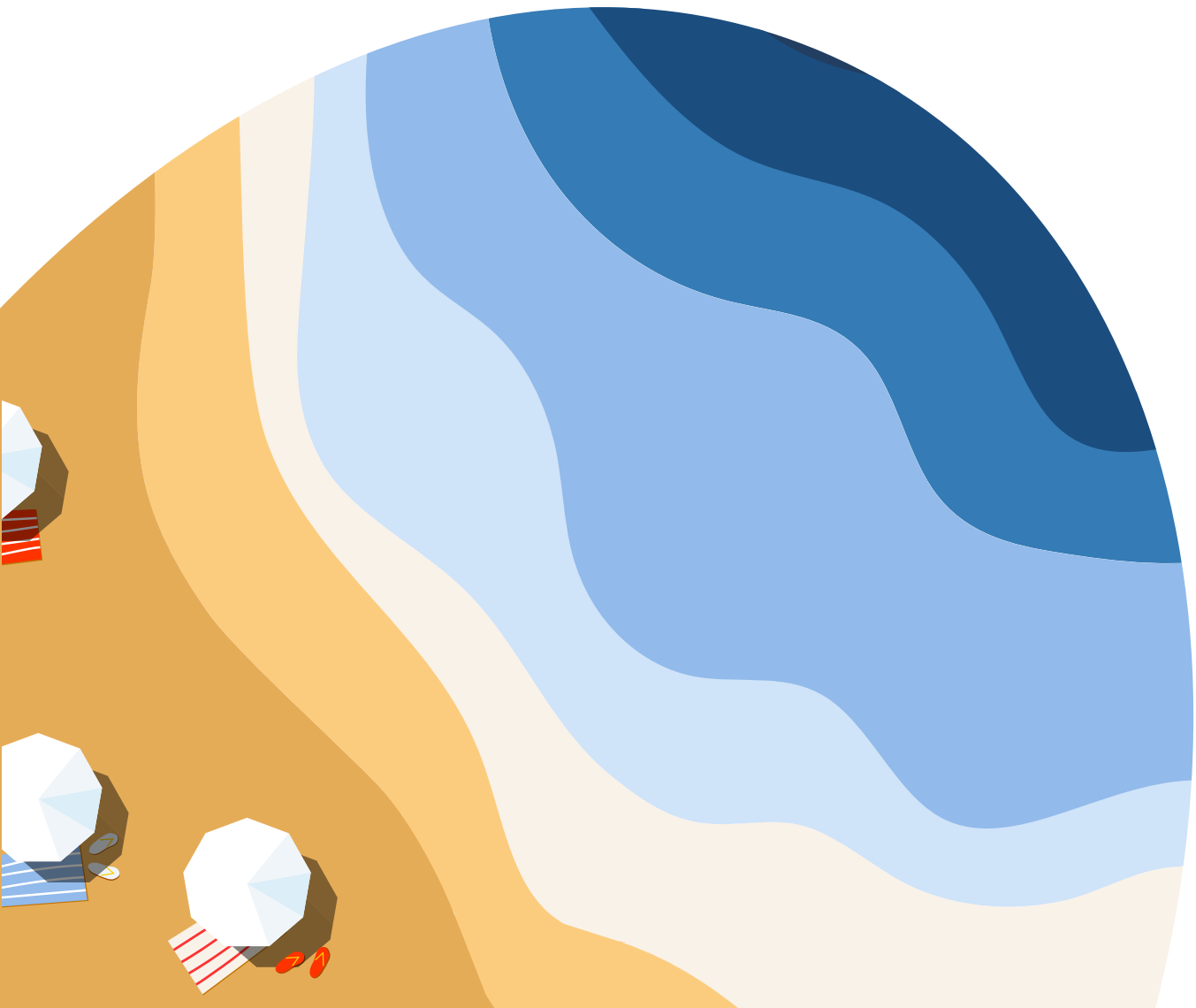
SPRING/SUMMER 2025

myeloma Matters



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MyelomaUK

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Nicola Lamb
Myeloma Matters Editor

Welcome to the Spring/Summer 2025 edition of Myeloma Matters.

I am delighted to be stepping into the role of Editor for Myeloma Matters, and to share with you this first issue of 2025. As I take on this meaningful role, I feel incredibly proud to help share the inspiring stories, milestones, and progress that shape the Myeloma UK community.

This issue offers a powerful mix of reflection, progress, and forward-looking ambition. We meet Marriane, a real-life superhero who shares her remarkable journey to diagnosis and how she continues to move forward with her life with myeloma today.

We'll take a deep-dive look at travelling with myeloma – reminding us that joy, connection, and adventure are still very much within reach. More than just navigating logistics like insurance and medicines, we focus on the importance of spending time in places and with people that bring you happiness and energy. Whether it's exploring somewhere new or returning to a familiar favourite, we remind ourselves that life's best moments often come from connection, laughter, and new experiences. Look out for the handy travel checklist on page 11.

We also take a moment to celebrate a remarkable milestone – 10 years of our transformative Clinical Service Excellence Programme. Over the past decade, this national awards initiative has raised standards for how myeloma care is delivered across the UK. We hear directly from the patients and healthcare professionals who have shaped and benefited from the programme. This includes Doug, who shares his fundraising success in our Supporter Stories section.

Looking ahead, we will focus in on our new research strategy, setting out our bold vision to accelerate research to prevent, treat and live well with myeloma, and find new ways to a cure. Whether you're a long-time supporter or reading for the first time, we hope this gives you a clear view of where we're heading – and how you can be a part of it.

None of this would be possible without the incredible support of the Myeloma UK community – patients, families, friends, carers, healthcare professionals, researchers, and volunteers. Thank you for all you do. I am excited for what lies ahead, and I look forward to sharing this journey with you.

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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Myeloma UK, 22 Logie Mill,
Beaverbank Business Park, Edinburgh EH7 4HG
0131 557 3332
myelomauk@myeloma.org.uk
Registered Charity No: SC026116

For feedback, comments and questions about content or subscriptions please contact:

Services Admin
0131 557 3332
ServicesAdmin@myeloma.org.uk

Call our Infoline
0800 980 3332
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MY LIFE WITH MYELOMA

NAME: Marianne Williams

LIVES: Cowbridge, Wales

AGE: 50

I'd always been pretty healthy and had an active life as a busy mum, looking after my daughter, working as a PA and going ice-skating or crafting when I had the time but I kept getting ill.

I had tonsilitis, an eye infection, a tooth infection that resulted in a root canal, sore throats, conjunctivitis, labyrinthitis and generally felt very unwell.

"It was like being on a spinning fairground ride and I couldn't get off."

In August 2016, I went to bed as normal. There was no hint of anything that was wrong. I woke up in the night and the room was spinning.

For 48 hours I was vomiting and off-balance. I could barely move. It was like being on a spinning fairground ride and I couldn't get off. I had to crawl to the bathroom on all fours.

Over the next year, I had recurring episodes. Sometimes I'd walk along feeling vertigo and sick. I went back and forth to the doctor and got my bloods checked. I had headaches a lot and was given tablets or antibiotics when things were inflamed.

The worst bit was that I was having episodes at work and my husband would have to pick me up as I couldn't drive home. I'd be lying on the floor under my desk with the room spinning.

Being so unwell really took its toll on me. I am a sociable person and love seeing friends. I am one of four daughters.

If I was invited for a coffee, lunch or a meal I found myself thinking twice about accepting it. I was worried about not feeling well. I'd look fine and feel okay and then ten minutes later I'd be curled up under my desk.

I felt paranoid that people might not believe me as I could be laughing and joking one minute and the next curled up on the floor. My employers were fantastic, but it was how it made me feel.

"I said, 'I just don't feel like me. I'm not right'."

I did think: Is this just getting older? I was very tired and had backache. You explain it away. I had a sedentary job in an office and wasn't getting much exercise.

Was I tired because I had a primary school aged daughter? But I was only 43.

A year in, I spoke to the doctor to ask if they could do a full body MOT. I said, 'I just don't feel like me. I'm not right'. I felt down, I kept getting infections. I was told my white blood count was up but there was no further action. I think it's because I didn't fit the demographic. I was a young, white female, not overweight. Myeloma tends to affect more men than women, people in their 70s and there is a higher rate in people who are black. I didn't fit the profile. Cancer just wasn't on their radar, and I do understand that in some ways my symptoms were vague.

"I was shocked but also relieved. At least there was a reason I was so unwell. I wasn't imagining it."

Things came to a head in November 2017. I had all the signs of a urine infection so I dropped a sample at the doctor and then went to the cinema to see A Bad Moms Christmas with a friend but had to go home.

The doctor had called to say he had prescribed antibiotics, but the pain was so bad I went to A&E. I knew something was different and didn't feel right. I had pain around my ribs – higher up than when I had urinary infections before. The amount of pain I was in wasn't normal. I knew I couldn't wait until the morning for antibiotics.

I went to the Princess of Wales Hospital in Bridgend on the Monday. I was dismissed as having 'just a urine infection' and was sent home with antibiotics. Two days later, my GP called me to say it was E. coli and I needed different antibiotics. By the Friday I was in so much pain that the GP sent a paramedic and I was told to go back to hospital.

The pain was constant, around my side and back. I had no idea at the time that rib pain is often experienced with myeloma.

By the Saturday, I had been vomiting for six days, couldn't keep anything down and the pain was much, much worse. My husband came with me to A&E. I felt wretched. They ran blood tests and an hour later they returned and their whole demeanour had changed. Within a few hours, it became clear my kidneys weren't functioning. I was shocked but also relieved. At least there was a reason I was so unwell. I wasn't imagining it.

I looked a state. My face, head, hands and feet had swollen because my body couldn't process fluid. My stomach was enormous – I looked like I was pregnant. I just managed to get my ring off my fingers before it had to be cut off.

I was transferred to Morriston Hospital and hooked up to kidney dialysis with a stent in my neck, like a long straw that fed into my veins and kidneys. Two days later I realised it was serious because I was sent for X-rays on my whole body.

I later found out this is because myeloma can cause bone damage. I had a bone marrow biopsy too. Six days after I'd first gone to hospital, I was diagnosed with myeloma. I'd never heard of it and had to say: 'Is it cancer?'

"I felt so grateful and happy to be home that I dressed in a Wonder Woman outfit."

It was a huge shock but there was also a sense of relief. I'd known something was seriously wrong. When I found out it was incurable I misunderstood and thought it meant I would die any day, it was so frightening. But then doctors explained that it can be treated, though it will return.

The chemotherapy made me very, very sick and I was already very poorly with kidney failure, it was brutal. I was told it gets worse before it gets better with dialysis. I was out of hospital on 18 December and I felt so grateful and happy to be home that I dressed in a Wonder Woman outfit.

In January, I told my daughter Ruby and she was really angry and asked why I didn't tell her. I said that it was a horrible time and I knew she was worried about me already with the kidney failure and I didn't want to spoil her Christmas. She was anxious after that, making sure I told her the ins and outs of any doctor's appointments. My husband took her to the specialist kidney unit in Cardiff and the doctors explained all the equipment to her, gave her a soft toy and answered all her questions.

> **Having myeloma makes you realise tomorrow isn't a given and it has made me think about what is important.**

When I was diagnosed, I looked at Myeloma UK's website and found the information easy to read. There was no jargon and it was so helpful when there was already so much to take in. I also went to a Myeloma UK open day in October 2018 and found it very useful, meeting lots of people connected to myeloma. I gave a talk of a patient's overview at a Myeloma Infoday the following year.

Ruby cut her hair the day before her 12th birthday – 11 inches as it was long enough to reach her bum and raised £4,235.

A year after my transplant, I also raised over £500 doing a pub quiz and gave out Myeloma UK fact sheets.

> **When I see the photos over the years I can see how far I've come.**

I've been in remission since my first cycle of chemo, over seven years ago. However, my recent bloods have shown my levels are starting to rise again, so my consultant has mapped out what he wants to do. Although I'm quite a way off starting treatment yet. Having myeloma makes you realise tomorrow isn't a given and it has made me think about what is important. That first year after my diagnosis I took the entire summer off to spend time with my daughter and that meant so much.

My husband, daughter and I went on a family trip to Center Parcs and my sisters and I went on a spa weekend. I'm now focusing on my health, eating healthily, walking more and doing online fitness classes.

Every year on the anniversary of my diagnosis I dress in my Wonder Woman costume. When I was diagnosed and first wore it, I had a Zimmer frame and when I see the photos over the years I can see how far I've come.

SPOTLIGHT ON TRAVEL

“Visit people and places that uplift you”

YOUR ADVICE ON TRAVELLING WITH MYELOMA

As we get closer to summer, people often start thinking about going on holiday. Whether it's a staycation in the UK or a trip abroad, a holiday can be a great way to relax and unwind. However, living with myeloma can make travel preparations more complicated.

You may be left wondering whether you are well enough to travel, where to go and how to stay well while you are there.

It is not unusual to feel worried about leaving your home, routine and healthcare team, even for a short time. But many people living with myeloma will tell you that it is important to have things to look forward to.

Doing things that you love and spending time with people that you love is a good way to feel like your life is more than any treatments or appointments you have booked.

Some common concerns during the summer months, and when on holiday are staying hydrated, taking care of your skin in the sunshine, avoiding infection in new environments, and managing fatigue when routine changes.

There are preparations you can make, and precautions you can take, to manage these worries. Then you can focus on having a restful and relaxing trip.

> **"Remember you can start small if going abroad feels overwhelming."**

In this section, we will provide some hints, tips and considerations to make when planning time away from home.

Remember you can start small if going abroad feels overwhelming. There are many ways to enjoy a break without going far away. Please read the Hot Topic on Sun safety on page 21 to find out more about protecting your skin this summer.

"There is life after myeloma, but you have to grab it."

"Don't let myeloma hold you back. If you are well enough, do it – whatever 'it' is."

"You can still travel the world with myeloma, albeit with a suitcase full of drugs."

"Fill that diary. Always have something to look forward to."

All quotes have been provided by myeloma patients, or their carers and families about their experiences living with myeloma.

VISITING PEOPLE AND PLACES THAT UPLIFT YOU, **AND RETURNING RESTED**

Spending quality time with loved ones or visiting meaningful places can be exciting, but it may also feel overwhelming or tiring. When planning a trip, it's important to pace yourself, be mindful of your environment, and consider any changes to your routine. This is true whether you're traveling abroad for two weeks or staying somewhere nearby for two days.

Choosing a suitable travel destination

Each person's idea of a relaxing trip is different. Some people like sun and sand whilst others like art and museums. When planning your trip, it is important to think about a good break for you.

Which destination is right for you will depend on your health and personal preferences at the time.

It may be wise to avoid places with extreme temperatures, as very hot or cold climates can affect your hydration, blood pressure, and energy levels while your body works to regulate its temperature.

You might also feel more at ease in quieter locations. Wherever you go, it's important to check the local medical facilities – know where the nearest hospital is and how to get there if needed.

If a big trip abroad seems too daunting, you can start small and have a weekend away somewhere nearby. If you are worried about your mobility, look for trips with less walking. You can ask your travel provider for assistance. If you are concerned about infection, you may want to avoid crowded areas.

Remembering your routine

Travelling can mix up your routine, changing mealtimes and rest times. This is especially true when the journey time is long or you're travelling to a different time zone. Try to rest when you need, eat balanced meals regularly, and take food and water with you. It's important to continue taking your treatments at the right time. Set reminders on your phone's calendar or clock app to help you remember. Speak to your healthcare team if you have any concerns about taking treatments while travelling.

Managing fatigue

Think about the activities you enjoy and tailor your holiday around what you feel able to do. Try to choose things that aren't too physically demanding, so you can fully take part without overexerting yourself. Focusing on enjoyable moments and spending time with your family and friends can lift your spirits and help take your mind off myeloma.

Staying hydrated

It is important to keep well hydrated. If you are in a hot climate, you may need to drink more than you usually would. If you have been advised to limit your fluid intake, you should ask your healthcare team for advice on how much fluid you should drink per day while you are in a hot or dry climate. You may be advised to drink bottled water while away from home to minimise the risk of infection.

TRAVEL VACCINES

Vaccines are treatments which boost the body's immune system and help to protect against specific infections. A vaccine is made from a weakened or harmless version of the virus or bacteria it has been designed to protect you from.

Depending on where you are visiting, you may need vaccinations before you go. For country-by-country advice, you should check the UK government's Foreign travel advice webpage.

It is recommended that myeloma patients do not have live vaccines. This is because their immune systems are weakened and might not be able to handle even small amounts of virus or bacteria in the vaccine. This could lead to getting the illness the vaccine is meant to prevent.

Discuss your travel plans with your healthcare team for advice on vaccines. Allow for plenty of time to organise travel vaccines because it can take a few weeks for vaccines to be effective.

Sources of information

Vaccines and myeloma Infosheet

gov.uk/foreign-travel-advice

TRAVEL INSURANCE

When applying for travel insurance it is important to read the details of a policy thoroughly.

Many travel insurance companies will ask questions to decide whether they can offer you an insurance policy. The questions will be about your myeloma and any treatment you have had or are having. You must tell the insurance company about any other health conditions. If you do not, they will be able to declare your policy invalid, should you need to make a claim.

Your insurer will likely want to know about both physical and mental health conditions, any conditions you have been treated for, gone to A&E for, or discussed with your doctor. You might be able to exclude certain conditions from your policy.

This means you would still be covered for other health issues, but not for anything directly related to the excluded condition.

It is essential to check:

- The cost of the insurance, called the premium
- The amount you have to pay if you make a claim, called the excess
- Exactly what is included and excluded in the policy
- That the company will not only cover you because you are a myeloma patient, but will cover any claims resulting directly from your myeloma
- That any medical equipment and medicines you need to take with you are protected if they are damaged, lost or run out
- Whether the policy covers cancellation of your trip

Sources of information

Travel insurance and myeloma Infosheet

Infopack for Living well with myeloma (section 8)

moneyhelper.org.uk and search 'travel insurance directory'

CHECKLIST
FOR A SMOOTH TRIP

Before you book your trip

Ask your healthcare team

- [ ] Am I fit to travel?
- [ ] Can I have the travel vaccines needed for my destination?

To do

- [ ] Check your passport is in date until at least 6 months after your trip ends
- [ ] Check any visa requirements

When booking your trip

- [ ] Check any restrictions on medicines you can take abroad
- [ ] Check your accommodation has a fridge to store medicines if you need
- [ ] Take out travel insurance

8 weeks before

- [ ] Have a Global Health Insurance card (GHIC) or apply for one if needed
- [ ] Get any travel vaccinations you need

4 to 6 weeks before

Ask your healthcare team

- [ ] Can I have a 'fit to travel' letter, detailing my diagnosis, treatment and any other medicines?
- [ ] Do I need a letter from my doctor if I am carrying any controlled medicines?

To do

- [ ] Inform your airline or travel organiser if you require transport assistance at the airport
- [ ] Check airline security guidelines for carrying medicines or medical equipment
- [ ] Check the Embassy or High Commission of your destination for any restrictions on taking in medicines
- [ ] Check the driving rules of your destination and prepare any documents required if you plan to drive

3 weeks before

Ask your healthcare team

- [ ] Should I pack a course of emergency antibiotics?
- [ ] How should I reduce the risk of blood clots during my journey?
- [ ] How should I stay hydrated in a hotter climate if I have been advised to limit my fluid intake?

To do

- [ ] Pack some extra medicines to manage any diarrhoea, constipation or pain
- [ ] Add your health and emergency information to your smartphone
- [ ] Check you have your healthcare team's out-of-hours and emergency contact information

During your journey and holiday

- [ ] Carry medicines in their original packaging, in your hand luggage and with a copy of your (repeat) prescription
- [ ] Travel with your GHIC card
- [ ] Regularly move your feet and legs during long journeys and consider wearing flight socks (compression stockings)
- [ ] Stay well hydrated – try to bring bottled water
- [ ] Take sensible precautions when eating out
- [ ] Use sun cream regularly and stay in the shade
- [ ] Store any medicines that need to be below room temperature in a fridge

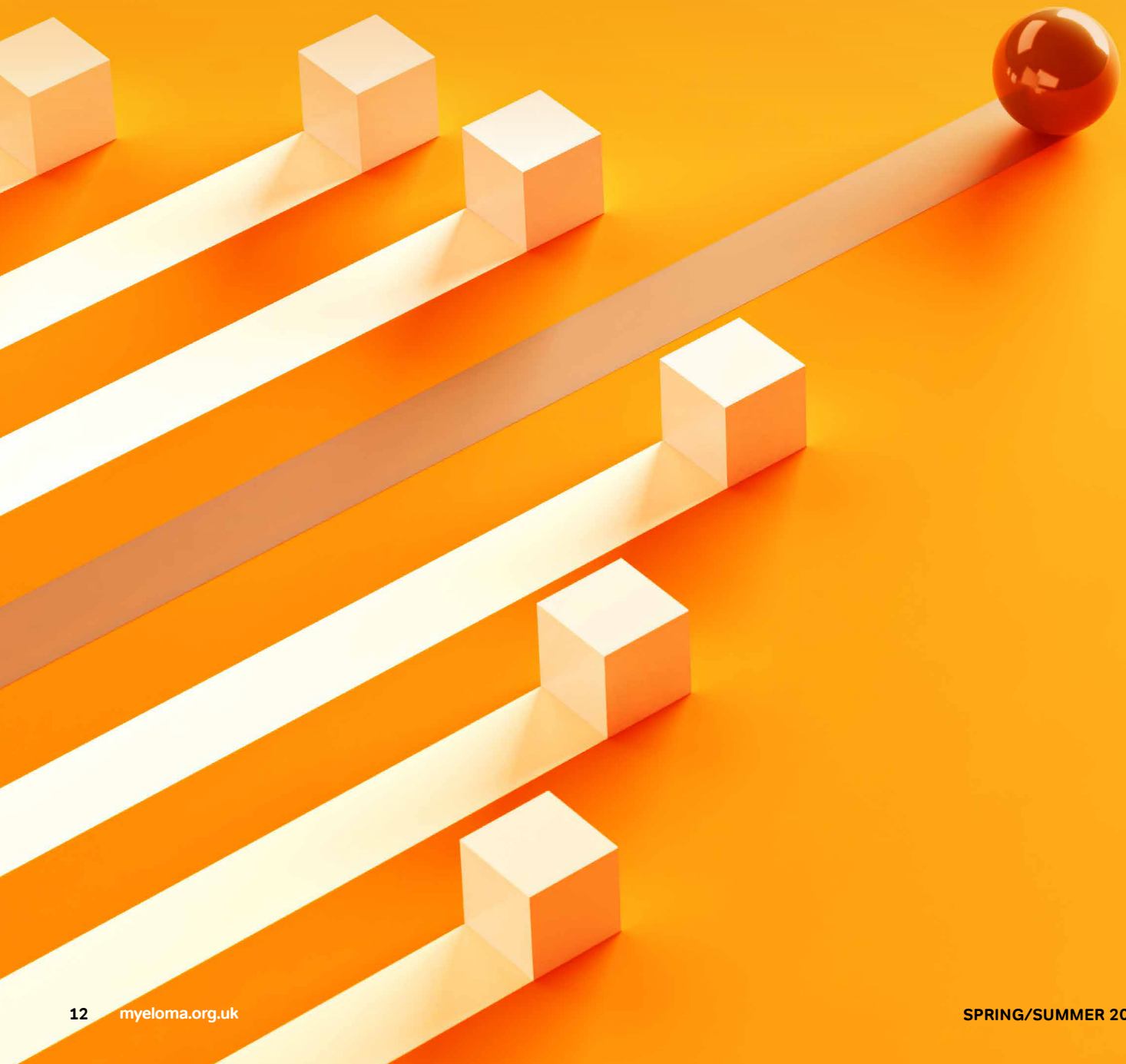
Notes

CUT HERE

RESEARCH FOCUS

Introducing our new Research Strategy

Brogan Ashley Head of Research, Myeloma UK



Our new **Research Strategy**

Together, with our dedicated community, we have transformed treatment and care for people affected by myeloma in the last 25 years.

In 2024, Myeloma UK launched our new organisational strategy, setting out the three areas that will underpin everything we do – preventing myeloma, treating myeloma, and living well with myeloma. Research will be a key tool for delivering our organisational strategy, and it is important that we ensure our research is aligned with the changing needs of the myeloma community.

It is important that we look back every few years and review where our research activities have delivered most value. From this we learn how to make even better decisions moving forwards.

Developing a new research strategy has given us the opportunity to realign our research goals with the needs of the community and to gather evidence to support how we can best achieve those goals.

What we did

We undertook a review of the myeloma research landscape, as well as our own research portfolio. We then used the insight gained from that to inform discussions with:

- People affected by myeloma
- Haematologists
- Nurses
- Scientists
- Policy makers
- Other research funders

These conversations allowed us to understand what matters most to people affected by myeloma, and how people view Myeloma UK as key to creating change.

What we found

This work has allowed us to develop our new vision for research, setting out at the highest level what we aim to achieve.

Our research vision will:

- Accelerate work towards preventing myeloma
- Improve outcomes for people with difficult to treat myeloma
- Ensure fair access to treatment and care for all
- Reduce the burden of treatment and improve supportive care

This vision for research will allow us to take steps forward towards truly personalised care.

> **Personalisation is key throughout the research strategy, and this is reflected in our conversations with people at every stage of their myeloma journey.**

We are thinking about personalisation in a very broad sense. Whilst we are certainly interested in how we can ensure an individual receives the best possible treatment for their myeloma, we are also interested in how we support that individual as a whole person.

Our research will...

Grow our understanding

of those who are at greatest risk of progression or relapse

Support development

of diagnostics to better match people living with myeloma to the most effective treatments

Improve

how we assess whether there are any detectable myeloma cells and improve access to these tests

Secure equal and fair access

to treatment, care and clinical trials through identifying and overcoming demographic and clinical barriers

A new approach to a cure

People living with myeloma can't wait. They need to live longer, better lives today, not in twenty years' time. That is why we are thinking about a cure in different ways.

What a cure means to an individual can be different depending on where they are in their myeloma journey.

In our strategy we have defined this as absolute cure and functional cure.

An absolute cure is when someone will spend the rest of their life with no detectable myeloma cells, without being treated.

A functional cure is when myeloma cells may still be detectable, but the condition is kept under control for long periods. The right treatment is available when necessary, but is manageable and has little impact on everyday life.

While an absolute cure remains our ultimate goal, focusing solely on that would mean we miss opportunities to deliver improvements in treatment, care and quality of life for people living with myeloma today.

A functional cure is a step towards an absolute cure. That is why we have made a commitment to focus our core resources on seeking a functional cure, and approach research on an absolute cure in partnership with other funders.

> **"We need to go further, faster for people affected by myeloma."**

"Myeloma UK are not standing still; they're always looking for the next thing for people with myeloma. There's constant research and investigations. It gives me a lot of hope."

Louise, diagnosed with myeloma in 2021

Looking to **the future**

Partnering with the University of Leeds Clinical Trials Research Unit (Leeds CTRU)

Clinical trials are vitally important. They give us the information that is needed to change practice and get new treatments available for people with myeloma. That is why we are building on our relationship with Leeds CTRU to tackle some key challenges in this space.

We will be working directly with people living with myeloma to co-design trials that answer the questions that are most important to them. These are often things that are not of interest to other companies designing trials.

> **"Leeds CTRU have expertise in researching novel ways to deliver trials that allow more people to benefit who would traditionally have been excluded."**

Opening access to clinical trials for more people is another key issue we are addressing – tackling things like clinical, geographic and cultural barriers to entry. Leeds CTRU have expertise in researching novel ways to deliver trials that allow more people to benefit who would traditionally have been excluded.

Delivering on our goals

We have set ourselves some ambitious goals. Just because myeloma is a rare cancer, it doesn't mean that people living with myeloma should accept less than the best. We will achieve these through a stratified delivery model to make sure we use our expertise, funds and influence in the most impactful way.

The Myeloma UK portfolio covers projects which connect most closely to our unique organisational capabilities and insights.

We will deliver projects, both through our in-house Applied Health Research team and through funded grants. We see value in these projects where others may not.

The Myeloma UK partnership portfolio will deliver projects where we can accelerate outcomes or increase impact through a partnership with another aligned organisation.

The Myeloma UK landscape portfolio will focus on projects which seek to influence the wider direction of research in the UK through an advocacy and influencing agenda, rather than direct funding or research.

Get involved

We can only do this with your support. Your experience and insight are invaluable to helping us make this vision a reality.

To be part of the ongoing conversation about our research, join our mailing list by visiting **myeloma.org.uk/newsletter**.

"Research into quality of life and psychological wellbeing is paramount for those of us already diagnosed and doing our best to live well with myeloma. Where the patient voice is embedded robustly into research and project design, the outcome is most likely to address the issues that will make the greatest practical difference to those living with myeloma and their loved ones."

Rachel, Living with myeloma; Patient and Carer Research Panel member

MYELOMA RESEARCH NEWS FROM AROUND THE WORLD

Daratumumab treatment from the comfort of home

A recent trial has shown encouraging results for myeloma patients receiving daratumumab (Darzalex®), a monoclonal antibody treatment that helps the body's own immune system to recognise and kill cancer cells. Researchers explored a new approach that allows patients to receive daratumumab at home or at a local healthcare clinic, rather than in a hospital.

Eligible patients were identified and followed cycles of treatment administered either in the hospital, or by trained primary care nurses at the patient's home or a local healthcare clinic.

Results showed that home-based daratumumab treatment was just as effective as hospital-based treatment. It was well tolerated, and side effects experienced were similar to those seen in the hospital setting.

Home-based treatments offer patients more flexibility and convenience, making it easier to manage treatment while maintaining daily routines. This could be an exciting step forward in improving quality of life for people living with myeloma.

Powerful new treatment combination

A phase 2 clinical trial has explored an exciting new treatment combination for patients with relapsed and/or refractory myeloma. Researchers investigated a four-treatment combination of elotuzumab (Empliciti®) with pomalidomide (Imnovid®), bortezomib (Velcade®) and dexamethasone.

Elotuzumab is a monoclonal antibody that targets a protein called SLAMF7, found on the surface of myeloma cells. By binding to this protein, elotuzumab helps activate the body's immune system, helping it to identify and kill cancer cells. This activity can be further enhanced when combined with other treatments.

The results were encouraging, especially for patients who had received just one prior treatment. In this group, almost 3 in 4 patients responded to the treatment, and the average remission time was almost 2 years before relapse.

These findings highlight the potential of this treatment combination and suggest that further research could lead to more effective treatment options for myeloma patients in the future.

ASK THE NURSE

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

Why do myeloma patients call the Myeloma UK Infoline?

The Myeloma Infoline is staffed by trained Myeloma Information Specialists. We get calls every day from patients with myeloma and related conditions such as MGUS, smouldering myeloma, and AL amyloidosis. We also support carers, family members, and friends of myeloma patients.

People call us for a variety of reasons. We can give general information, practical advice, emotional support, or simply provide a listening ear if you want to speak to someone who understands myeloma. Lots of people like to ring us after they have an appointment with their medical team (GP, haematologist, or clinical nurse specialist) to help process the information they have received or to clarify anything they are not sure of.

Sometimes, you may have forgotten to ask a question during an appointment, didn't get time to ask what you needed, or you have thought of more questions since the appointment. Because we do not have access to any medical notes, we can only give general information.

We may sometimes need to direct you back to your medical team who will be able to give a more specific answer. Our Infoline is open Monday to Friday 9am to 5pm. You can call as many times as you like and talk for as long as you need.

I have been diagnosed with MGUS; will it progress to myeloma?

Monoclonal gammopathy of undetermined significance (MGUS) is a non-cancerous condition that is often diagnosed by chance when tests are performed to investigate other problems. MGUS does not usually cause any symptoms or require any treatment.

A very small proportion of MGUS patients go on to develop a more serious condition such as myeloma. For this reason, MGUS patients are regularly monitored with various tests. This includes a blood test to monitor the blood levels of the abnormal antibody produced in MGUS, known as paraprotein. It is worth noting that it can be normal for paraprotein levels to fluctuate in MGUS. A steady or large rise in paraprotein levels over two or three readings may warrant further investigation.

It is important that MGUS patients report any new or increasing symptoms such as pain (especially in the back or ribs), fatigue, breathlessness, and recurrent infections. If you do experience any of these symptoms, please get in touch with your GP even in between routine monitoring appointments. Even if your symptoms are not related to a potential progression of MGUS, it is important that they are investigated.

Why am I more at risk of infection if I have myeloma?

Patients with myeloma have an increased risk of infection due to the direct effects of myeloma on the immune system and the effects of myeloma treatments.

This is especially true when myeloma is active, for example at diagnosis and/or relapse. Those on active treatment for myeloma are also at a greater risk of infection. Myeloma treatment can suppress the immune system by affecting the production of healthy blood cells.

Myeloma cells are abnormal plasma cells which multiply in the bone marrow. Myeloma cells 'crowd out' the healthy plasma cells within the bone marrow, which produce different types of antibodies (also called immunoglobulins) to help fight infection.

As well as being at increased risk of infection, myeloma patients are more likely to become very unwell if they do develop an infection, so prompt treatment is often needed.

It is important that patients are aware of the common signs and symptoms of infection and to report them promptly to their medical team (haematologist and clinical nurse specialist).

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**

MYELOMA

HOT TOPICS

BEHIND THE HEADLINES: HOW MANY PEOPLE ARE LIVING WITH MYELOMA?

You may have noticed a change in the number of people we report as living with myeloma. There are now over 33,000 people living with myeloma in the UK.

We know that every person affected by myeloma is one too many, so Ali Allen, Senior Scientific Knowledge & Communications Officer at Myeloma UK, explains more about this change in number and what the statistics really mean.

What's changed and why?

Myeloma UK have a team that manages and maintains the statistics that we use. There was a recent update to these figures. This means that the number of people living with myeloma has increased from 24,000 to over 33,000.

Whilst this may seem like a big change, the number of people living with cancer in general is increasing, both in the UK and globally. So, we expect to see this reflected for myeloma too.

Why are there more people living with cancer?

It's common to hear about increasing numbers of people living with different kinds of cancers. There's no single explanation for this; it's a complex picture with lots of contributing factors.

> **We know this means that there is more to do but Myeloma UK is here for the long term – for everyone, every day. We are here so that no one faces myeloma alone.**

Why has the increase been so big?

The sources of data that we use to calculate the number of people living with myeloma in the UK do not typically provide updates every year. For example, the data we have been using until recently, 24,000 people, covered a 20-year period from 1995 to 2015.

This was only recently updated to a 20-year period from 2001 to 2021. This means that instead of seeing a gradual increase, changing just a little each year, we see 6 years' worth of combined increase all at once. It's important to understand that on a year-by-year basis, this increase is gradual and that the figures also reflect positive developments in healthcare.

We know this means that there is more to do but Myeloma UK is here for the long term – for everyone, every day. We are here so that no one faces myeloma alone.

Where does Myeloma UK collect data from?

We use data from national cancer registries to determine the number of people living with myeloma in the UK.

These are databases which contain information about people who have had a cancer diagnosis, collected directly from hospitals and healthcare professionals.

These registries carefully anonymise the data, removing any person-identifiable information and rigorously check the data before releasing it to the public. This is why they are considered the gold-standard for this type of data.

By using these sources, Myeloma UK can be sure we are using the most reliable statistics we can.

We also explore data from other databases and peer-reviewed literature to produce other statistics – our team is always careful to critically examine possible sources to make sure we bring the most accurate information to you.

Some of the key reasons more people are living with myeloma:

We have an ageing population

Myeloma, like many other cancers, is more common in older people. This means as more people live longer, the number of people diagnosed and living with myeloma naturally rises.

We have better detection and earlier diagnoses

Better diagnostic techniques, and awareness, are leading to earlier identification of myeloma. This means the number of recorded cases increases. Preventing myeloma is one of our three areas underpinning everything we do.

We have more and better myeloma treatments

From no myeloma-specific cancer treatments 25 years ago, we now have a range of treatments that can be given in multiple combinations. This means that over time, more people are living longer with myeloma, and so the number of people living with myeloma rises.

Read more in our **Behind the headlines news** article

SLEEP AND MYELOMA

For people with myeloma, sleep is as important as ever, but it is something many people struggle to get enough of.

Sleep is essential to maintain both our physical and mental health. It allows the body time to rest and repair itself and regulates our mood and emotions.

If you are not getting enough sleep, you may find it hard to concentrate or relax and may need to nap during the day. People with myeloma may face additional challenges when it comes to getting a good night's rest.

How much sleep should I be having?

In general, the advice for adults is to have around 7 to 9 hours of sleep a night. This varies from person to person and some people will need more or less than this. Certain treatments can make you fatigued, so you may feel like you need more sleep at night or a small nap in the day.

Unfortunately, some people struggle with insomnia, where they find it difficult to get to sleep or to stay asleep. Improving your nighttime routine or addressing underlying causes of insomnia can often improve sleep. However, speak to your healthcare team if you continue to struggle with insomnia.

"Work out the best time of day for you and try to do things then. For me, it's the morning and I often feel tired in the afternoons so will have a doze."

What might cause sleep problems?

For people with myeloma there can be a number of different causes including:

- Pain
- Steroid use
- Anxiety and depression
- Night sweats
- Fatigue causing you to have frequent daytime naps

How can I improve my sleep?

Speak to your healthcare team about any sleep problems as they can help manage any underlying causes. For example, taking painkillers as prescribed or changing painkillers to control any pain.

You might also find it helpful to write down any feelings or explore counselling to help manage anxiety or depression.

Some people may also be offered a short course of sleeping tablets by their healthcare team. Sleeping tablets often have side effects, so these are not usually a long-term solution to sleeping problems.

Tips for a good night's sleep:

- Have a regular sleep routine with set times for going to bed and getting up
- Listen to calming music, podcasts, sleep meditation or reading can help relax and prepare you for sleep
- Try relaxation techniques, such as mindfulness, meditation and breathing exercise
- Keep your bedroom dark, quiet and cool
- Wear light, breathable fabrics such as cotton
- Wear an eye mask and ear plugs
- Do some physical activity during the day to make you more tired in the evening

Things to avoid:

- Electronic devices for at least an hour before going to bed
- Eating a large meal just before bedtime
- Caffeine in the afternoon and evening (tea, coffee, fizzy drinks and chocolate)
- Alcohol and other stimulants, like nicotine

"Take a long walk to tire yourself out, have a paper to read or a programme to watch if you wake and can't get back to sleep."

Sources of information and advice on sleep:

Fatigue and myeloma Infoguide

Infopack for living well with myeloma

AskTheNurse@myeloma.org.uk

Read our Ask the Nurse blog about myeloma and sleep:
myeloma.org.uk/atn-myeloma-and-sleep

nhs.uk/every-mind-matters

All quotes have been provided by myeloma patients, or their carers and families about their experiences living with myeloma.

SUN SAFETY

Did you know that some myeloma treatments can make your skin more sensitive to the sun?

It is important for everyone to protect their skin while having fun in the sun. However, this is especially important if you are having, or have recently completed, treatment for myeloma.

Sun sensitivity and myeloma

If you are having, or have just completed, chemotherapy or radiotherapy treatment, your skin will be more sensitive to damage from the sun. This is because these myeloma treatments cause your body to absorb the sun's rays more easily.

Chemotherapy and radiotherapy treatments can also make you more sensitive to warm weather.

Suncream

Use a suncream with a sun protection factor (SPF) of at least 30 and that protects from UVA and UVB rays. This can be a lotion, pump spray or gel. Apply the suncream generously and regularly, even if the label says, 'once a day' or 'water resistant'.

It is especially important to reapply suncream if you have been sweating or swimming.

It is important to check the expiry date on your suncream. There will be a symbol of a jar with an open lid. This will have the letter M and a number. That tells you how many months the suncream will last once it has been opened.

It is still possible to get sunburnt on cloudy, windy or cooler days. You can check the UV levels wherever you get the weather forecast which tells you how strong the sun is throughout the day. Anything above a level 3 (medium) up to 11+ (extremely high) requires protection from the sun, including wearing suncream.

Recognising sunburn

Symptoms of sunburn include redness, swelling, blistering, weeping and peeling skin. Your skin might feel painful, tight, or hot to the touch.

For people with darker skin tones, sunburn may feel tender or itchy. For people with lighter skin tones the sunburn may also look pink or red.

How to stay safe in the sun

- Stay in the shade 11am to 3pm when the sun is at its strongest
- Wear a hat that shades your face, neck and ears
- Wear sunglasses that filter out the sun's ultraviolet rays
- Wear loose-fitting cotton clothing. The more skin that is covered by clothing, the better you will be protected
- Stay hydrated, drinking plenty of water and limit caffeine or alcohol. If you have been advised to limit your fluid intake you should ask your healthcare team for advice on how much fluid you should drink per day while you are in a hot or dry climate
- Ask your healthcare team if you can go swimming – some treatments can make your skin more sensitive to chemicals such as chlorine, found in swimming pools. You might also be at higher risk of infection from bacteria in swimming pools or natural water like lakes and rivers

What to do if you get sunburnt

1	Get out of the sun as soon as possible
2	Cool your skin down with a cool shower, bath or damp towel
3	Apply aftersun cream or spray
4	Drink water to cool down and prevent dehydration
5	Cover sunburnt skin from direct sunlight until it has healed
6	Do not put ice or ice packs on burnt skin
7	Do not pop any blisters
8	Do not scratch or try to remove peeling skin
9	Do not wear tight-fitted clothes over burnt skin
10	Speak to your healthcare team if you have any concerns

Sources of information and advice on sun safety:

nhs.uk/conditions/sunburn

cancerresearchuk.org and search 'sun safety'

CELEBRATING 10 YEARS OF THE CLINICAL SERVICE EXCELLENCE PROGRAMME

This year marks the 10-year anniversary of our Clinical Service Excellence Programme (CSEP) – a national awards programme dedicated to raising standards of care for people living with myeloma.

Through CSEP, we recognise outstanding myeloma care and help hospitals continually develop their service by guiding improvements and sharing best practice.

A key part of the CSEP process is hearing directly from patients. Your feedback on the care you receive plays a vital role. It helps the healthcare professionals caring for you, and our CSEP team, understand what's working well and where things could be better.

Being awarded with CSEP shows that a hospital:

- Provides a myeloma service centred on the needs of patients and families
- Offers an individualised approach that supports people with the challenges and complexities of living with myeloma
- Is committed to service developments that are patient-driven and improve patient experience

"We know there is always more we can do to improve our services. CSEP helped us to become more aware of patients' priorities. Seeking to attain a national standard also helped us to secure the resources we needed for developments. Most importantly, CSEP gave us insight into what was happening elsewhere and opened our eyes to what was possible"

Haematologist Ceri Bygrave,
University Hospital Wales (2015)

"The fact that the CSEP exists must be even more reassuring to patients and families, affirming that they are, as we aim to convey, cared ABOUT as well as cared FOR. We welcome this opportunity and hope to learn from it to enable even better outcomes for our users"

Clinical Nurse Specialist Andie Guy,
St Bartholomew's Hospital (2024)

Here's what you told us has made the biggest difference to you at your CSEP award-winning hospital:

MY NURSE IS A PHONE CALL AWAY...

"They are so focused on the patient – they really understand. It's a miraculous service. Claire, the specialist nurse, gives us her mobile number and just says, 'Call me'. In this day and age it's very difficult to get people's contact details but hers is freely available if there are any issues. If there is a change, they catch it quickly and you're not left at home worrying whether everything is OK. It's remarkable what they've done for me."

Peter, a patient at Somerset NHS Foundation Trust

MY CONSULTANT HELPED ME EXPLAIN MY DIAGNOSIS TO MY CHILDREN...

"Dr Soutar drew pictures and diagrams and for the boys it was quite helpful. He was honest with them and very kind and it meant so much to me and to them. I have a lot of respect for Dr Soutar. He's very upfront and he's also extremely caring. I feel in very safe hands. I know they're there if I need them and I really trust them."

Donna, a patient at The Beatson West of Scotland Cancer Centre

I CAN SEE ALL MY TEST RESULTS AND FEEL MORE IN CONTROL THANKS TO THE HOSPITAL'S PATIENT PORTAL...

"Everybody with myeloma lives with uncertainty – from one test to the next. We know the cancer will come back but no one can tell you when. Things might change at any time. Having all the test results in one place and learning what signs to look for, what things to worry about or not worry about, helps. It gives patients a bit more control and certainty. Now, when I have an appointment, I can go in knowing what the results are already and it enables me to formulate some questions. It completely changes the consultation."

Jane, a patient at Addenbrook's Hospital

WE'RE ONE BIG FAMILY...

"When the consultant told me, 'If you don't start treatment, you have 4 months', I started spurting out all the things I was worried I wouldn't be there for. All these thoughts were coming out: this means I won't get to see my grandkids or get to take my daughter down the aisle. My specialist nurse Claire grabbed my hand and said, 'We will look after you'. When I walk in, every time the receptionist says, 'Good morning, Mark'. She's got hundreds of patients, but she knows me by name. They all smile, ask how I am, how the wife is. It makes a difference. They treat you like one big family."

Mark, a patient at Royal Devon and Exeter Hospital

THE CLINICAL TRIAL TEAM HAS BEEN THERE FOR ME, SO I CAN HELP OTHERS...

"For me being in a trial is a bonus. I feel I'm doing something positive to help future patients. Without trials we couldn't find any new treatments or show that a drug is working. The fact that I see the same people from the trial team every time has been invaluable."

Phyll, a patient at Southmead Hospital

Help us reach more hospitals

About 1 in 3 UK hospitals with a myeloma service are currently CSEP-accredited. That means there are around 150 hospitals we have yet to reach — and we need your help to change that. You can make a difference by nominating your hospital for the CSEP award. Simply speak to your myeloma team and ask them to get in touch with us.

CSEP'S 10-YEAR JOURNEY

Myeloma Best Practice Standards were developed by Myeloma UK. Created in consultation with patients, families and healthcare professionals, these standards are used as a benchmark for assessing hospitals

2015

CSEP tested out in 3 hospitals through a project supported by The Milly Apthorp Charitable Trust

2016–2021

CSEP rolled out to reach 36 hospitals, with continual testing and evaluation

2018

First hospital **awarded in Scotland**

2021

CSEP team expanded so we could reach more hospitals and have greater impact

2021

First hospital reaccredited

2022

First hospital **awarded in Northern Ireland**

2023

1 in 4 UK hospitals with a myeloma service accredited

2024

Myeloma Best Practice Standards refreshed and revised in consultation with patients and healthcare professionals

2024

Around 1 in 3 UK hospitals with a myeloma service now accredited

2025

New CSEP assessment and patient survey launched

2025

First hospital due to reaccredit for the second time

OVER THE PAST 10 YEARS...

73
hospitals awarded
26 of these were reaccredited

1,730
patient experience surveys collected

276
service improvement recommendations made
across 73 hospitals

37
articles published online
to share best practice between healthcare professionals

10
new myeloma support groups established
through collaboration with CSEP hospitals

THE EVOLVING HEALTH POLICY LANDSCAPE

A lot has changed in the health policy landscape since the Labour Government began in July 2024.

We have responded to a range of consultations and are monitoring the impact of new initiatives which have the potential to transform healthcare and treatment access in the UK. Here, we want to tell you more about the initiatives and announcements we believe are the most significant and how they could impact people with myeloma and related conditions

A new National Cancer Plan

On World Cancer Day, 4 February, the Department of Health and Social Care (DHSC) launched a call for evidence to develop the government's national cancer plan for England. Sitting alongside the NHS 10 Year Health Plan, the cancer plan will set out the strategy to reduce the number of lives lost to cancer, in line with the reform and three key shifts:

1. **Sickness to prevention**
2. **Hospital to community**
3. **Analogue to digital**

The cancer plan is the Government's opportunity to set inclusive targets for cancers like myeloma that are complex and difficult to diagnose. Blood cancer has not been prioritised within UK cancer policymaking. No cancer strategy from an English, Welsh or Scottish health administration has included measures to address the distinct unmet needs within this patient group.

We are supporting Cancer Research UK's call for the UK government to adopt a target of a 15% reduction in the overall cancer mortality rate by 2040. However, if the focus continues to be on policy initiatives designed around solid tumour cancers, we do not believe these targets are either achievable or equitable.

Given its prevalence, no government can meet universal cancer diagnosis or survival targets without addressing the distinct challenges faced by patients with blood cancer. The current one-size-fits-all method does not work for patients with complex cancers.

We are calling for a cancer plan with strong commitment to end policymaking practice driven by the need for a 'quick win' and instead adopt an approach that can achieve real improvement in diagnosis and care for people with less common, harder-to-diagnose and harder-to-treat cancers, like myeloma.

The transition from NHS England to DHSC

In March, our Prime Minister announced that NHS England (NHSE), the arm's-length body that manages how health care services are run, would be abolished, and its functions fully integrated with the Department of Health and Social Care (DHSC), who are responsible for overall health policy, within two years. We heard that up to 50% of the workforce, potentially 12,500 jobs, could be lost to save money. Essentially, the government is taking back control of the health service into ministerial hands.

But what does this mean for people living with myeloma? Initially, we probably won't feel a change in the day-to-day delivery of services relating to diagnosis, treatment and care. However, the reorganisation brings a lot of questions and concerns about what will happen to the services we rely on. It will take time to understand the answers and solutions.

One thing that isn't changing is our offering. Myeloma UK will always be here to support people living with myeloma so that no-one faces it alone.

The relaunch of the Innovative Licensing and Access Pathway

On 1 April, the Medicines and Healthcare Products Regulatory Agency relaunched its Innovative Licensing and Access Pathway (ILAP), a UK-wide initiative designed to speed up access to new medicines.

The refined and simplified ILAP ensures medicines manufacturers engage with ILAP earlier when developing a new medicine, giving them more chances to implement the advice gained during the ILAP process.

Although there are some reservations about the refreshed ILAP, it is positive news for myeloma patients. It could speed up access to new, transformative myeloma treatments, taking them from clinical trials to the NHS more efficiently.

All these announcements highlight the government's commitment to improving the health and well-being of people in the UK and show they are open to making big changes that could transform the healthcare system.

Whilst this gives us the opportunity to call for the change myeloma patients need, we must monitor the evolving health policy landscape closely to ensure the voices of myeloma patients are heard and that the plans and policies work for them.

SUPPORTER STORIES

Working together to get closer to a cure

Doug Downing, 77, has been living with myeloma for the last five years and recently decided to take on a fundraiser for Myeloma UK 'to give something back'. Here he shares his story.

"I was diagnosed with myeloma in December 2020, 2 weeks before my wife passed away with an aggressive form of Alzheimer's.

I thought I had type 2 diabetes because of my tiredness and was so relieved when the doctor told me the blood test said it wasn't. My elation didn't last long after I asked what myeloma was."

Doug lives on the edge of the Vale of Belvoir, mid-way between Nottingham and Grantham. Luckily, he says, this puts him under the catchment area of the award-winning and Myeloma UK Clinical Service Excellence Programme-accredited **Nottingham Universities Hospitals Haematology Department**.

"The treatment, support and information I have received since diagnosis have been exceptionally good. The written information and help from Myeloma UK have proved very useful indeed. I feel the Myeloma UK Infoline and the dedicated Myeloma Nurse at Haematology give me all the information and support I need."

Doug told us about his fundraising:

"I like to keep active and have been a member of the Vale of Belvoir Rotary Club for over 30 years. I have been constantly involved in fundraising for many charities as well as hands-on activities, like running a monthly interactive Memory Café for people suffering from dementia."

"After the support I received from Myeloma UK, I wanted to give something back. It was a no brainer for me to persuade my Rotary Club to have a fundraising evening dedicated for Myeloma UK who have proved a great source of support to me."

To tell the Club more about the fantastic work of Myeloma UK, Doug was delighted when **Dr Dean Smith, head of Myeloma Haematology at Nottingham University Hospitals** agreed to attend a Rotary Cub dinner and give a very interesting and enlightening presentation to the Club.

Dr Dean Smith said:

"It was great to be invited along to the Rotary Club to talk to them about the signs and symptoms of myeloma. In my role, I understand the importance of the work Myeloma UK do in raising awareness of myeloma and providing support and information both for patients and healthcare professionals. It was great to talk to the Club and I was delighted to hear of their successful fundraiser."

The fundraiser followed in a local village hall at Aslockton. They hired a popular Irish style folk band called Kelly's Heroes, and "everyone was singing along and banging their tables". Members of the Rotary Club helped with the catering and raffle prizes.

The lively and entertaining evening raised an incredible £1,830 for Myeloma UK. We are so grateful to Doug, Dr Smith and everyone at the Rotary Club for their support.

Doug concluded:

"I will do what I can whilst I can to raise money for Myeloma UK to help them drive research in new treatments until we find a cure. It is a very sobering thought that just before the Millennium a myeloma diagnosis gave a life expectancy on average of 12 to 24 months. How lucky am I that Myeloma UK helped drive the research and access to treatment that has quadrupled that. I am into my fifth year with a good quality of life."

"I would urge everyone who is touched by myeloma, whether a patient, family or friends to get involved in whatever way they can, no matter how small, to raise funds to help Myeloma UK's drive towards a cure."

"I will be looking to another fund-raising event next year, maybe an old favourite of mine, if I can get it organised, a frog race. I'll leave that to your imagination!"

In the meantime, and after years of travelling the world with his wife, Bronwen, making many wonderful memories, he is happy spending time in this country and walking his blonde cockapoo, Belle.

To find out more about how you can fundraise for Myeloma UK visit our website **myeloma.org.uk/how-you-can-help/fundraise**, email **fundraising@myeloma.org.uk** or call **0131 230 0429** to speak to one of the team.

myeloma INFODAYS 2025

TICKETS £10

FOR PATIENTS AND FAMILY

Patient and Family Myeloma Infodays bring people affected by myeloma together to share their experiences, hear from myeloma experts about treatments and research and to learn more about the support Myeloma UK provides.

To book your place call us on **0131 557 3332**
or visit **infodays.myeloma.org.uk**

#MyelomaInfodays
@MyelomaUK

Registered Charity No: SC026116

My Coffee Morning

***Brew*tiful summer days ahead – time to plan that coffee morning!**

Sign up at **coffee.myeloma.org.uk**

Or get in touch to tell us about your other fundraising plans by emailing the team at **fundraising@myeloma.org.uk**

MyelomaUK

Leave a gift in your will and help us find new ways to a cure.

Get your free gifts in wills guide:

myeloma.org.uk/give-in-your-will
GiftsInWills@myeloma.org.uk 0131 230 0429

Registered Charity No: SC026116

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.

Myeloma UK
22 Logie Mill, Beaverbank Business Park,
Edinburgh EH7 4HG
0131 557 3332
myelomauk@myeloma.org.uk

@MyelomaUK

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