SPRING/SUMMER 2026

myeloma Matters

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My life with myeloma
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Supporter story
London Paris Ride
10th anniversary

MyelomaUK

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DEAR READER

Nicola Lamb
Myeloma Matters Editor

Welcome to the Spring/Summer 2026 edition of Myeloma Matters.

If you have received a print copy of this issue, you may notice something new inside. We've included an invitation to get involved in Myeloma Awareness Week (15–21 June).

This year's 'Know the Warning Signs' campaign uses bold, eye-catching visuals to encourage healthcare professionals and the public to recognise the symptoms of myeloma earlier. You can display this poster in your community to help us raise awareness. Read more about how to get involved in our interview with Mel Tottoh on page 23.

With the rising cost of living and unpredictable global events, we know that money worries are becoming increasingly common. For people affected by myeloma, these concerns can be compounded by the often 'hidden' costs of myeloma, such as travelling to hospital appointments or increased energy bills at home.

That's why, in this edition, we're shining a spotlight on financial support. This section is full of practical advice and signposting to help you find the support you need. Please remember: help is available, and there is no shame in seeking it.

On pages 4–6, Sarah O'Fee shares her journey to diagnosis and explains how myeloma has not stopped her from travelling the world with the people she loves.

On pages 24–25, we're taken on another journey, from London to Paris, as we celebrate the 10th anniversary of the Myeloma UK London Paris Bike Ride. Bob Munro reflects on how it all began, while members of the Myeloma UK team share what the ride means to them today.

We're also delighted to include expert insight from Joanne Sowter, Clinical Academic Myeloma Physiotherapist, who shares practical advice on exercise in our Hot Topic on page 20. Whether you're a seasoned athlete or simply looking to incorporate more movement into your life, we hope you'll find her guidance helpful and motivating.

This edition is packed with real stories from real people in the myeloma community, alongside practical tips and expert advice. As always, we hope you find these pages useful, uplifting and inspiring.

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

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MY LIFE WITH MYELOMA

NAME: Sarah O'Fee

LIVES: West Wick, North Somerset

AGE: 65

I thought I had the flu. Every bone in my body ached. I could barely move. I was really tired. We'd gone away to Dartmouth for the New Year, and I was struggling to walk up the hill to the little cottage we had rented. I was getting out of breath. It wasn't normal for me.

I remember going to work one morning and one of my colleagues said to me, 'Look, Sarah, you've been like this for weeks, you've got to go and see somebody.' I went to see my GP. She was a bit concerned, did a few tests and sent me away. That same day at half four or five o'clock in the afternoon, I got a call from her. My blood test showed I had a blood clot and I needed to go to A&E. I didn't realise how serious it was, so I told her I'd go in the morning. She said, 'You are to go now'. That's how it all started. It took them a few weeks to really put their finger on what it was.

"They kept asking if I had been in a serious car accident."

They realised I had a couple of broken ribs and they kept asking if I had been in a serious car accident.

I hadn't. There was also quite a bit of skeletal damage, and they found all these lesions but they couldn't put two and two together until I finally had a bone marrow biopsy. Then they told me I had myeloma. I was 48. My now husband Pete and I had never heard of it. We hadn't got a clue.

They couldn't tell me how long I had. They didn't know what the future held for me. It was 2010, so back then there were probably about 2 treatment options. Now, of course, things are completely different, which is brilliant.

I had radiotherapy because of the broken bones, and I started my first treatment, which included thalidomide. I remember having to sign a consent form every time they prescribed it, saying that a) I wouldn't give it to anybody else, and b) I wouldn't get pregnant.

It was very upsetting and emotional. Every time I went in for treatment, it was gut-wrenching. I'd sit in that chair for hours with a drip and this stuff going in me. I didn't know how my body would react.

> **My consultant smiled at me and said: 'Sarah, I wouldn't leave you with nothing'.**

In the early days, the treatments would only last about 2 years at the most, before they had to change to the next one. I've had at least 6 treatments and 2 stem cell transplants over the last 16 years. During the pandemic, I was told I only had 1 option left: pomalidomide and cyclophosphamide.

It was worrying to think that I'd be on my last treatment option, but my consultant smiled at me and said: 'Sarah, I wouldn't leave you with nothing. I would find a trial for you.' I've been on pomalidomide and cyclophosphamide for 5 years now and it's still doing brilliantly. I'm stable and at least in partial remission, and obviously new treatments have become available since then.

At the end of April, I started my 80th cycle of treatment. It's crazy to think about how many cycles of various chemotherapies I've been on over the last 16 years.

I was so pleased to finally be taken off the steroids last September, after being on them for 15 years. They'd caused me all kinds of problems: I had put on weight. I also had this awful bump, like the Hunchback of Notre Dame, at the nape of my neck, which I hated. Now this great big bump is almost gone.

> **I've learned to stop thinking about myeloma.**

It's not been easy. The treatments have given me all sorts of side effects. But over the years, I've learned to stop thinking about myeloma. It's there and it will probably come back but, in the meantime, I get on with it.

There are days when I don't feel so great, so I don't do much. I stay in, go into my little work room and do a bit of crafting. On good days, I do as much as I can because nobody knows how much longer they've got. I'm out and about, I meet friends, I go out for coffee or lunch. I have a lovely close-knit group of friends and family and I'm very lucky and forever thankful for their support and love, especially my wonderful sister Lyn. I've also started going to an Aquafit class once a week for people with limited mobility. It's important that you don't let myeloma rule you.

> **It's important to have hope and to trust in your healthcare team.**

My team at Weston General Hospital have been amazing. All the oncology and haematology nurses are brilliant. I've been with my consultant now for quite a few years and we have a very good patient-doctor relationship. She knows me very well.

She is upfront and honest and I appreciate that. I don't like things to be sugar-coated.

It's important to have hope and to trust in your healthcare team. They are there to look after you. Use them. If you're worried or if you have questions, don't hesitate. Don't mull it over in your head. Just talk to them.

Having Pete with me at every single appointment that first year was so important. My mind was in turmoil. It just wouldn't take everything in.

I met Pete on the internet and within 6 months of us meeting I was diagnosed. I said to him at the time, 'Look, you don't have to hang around. It's a big ask and I won't be upset or think any less of you if you turn around and run.' And he didn't, bless him.

He was in his last couple of years in the RAF. He asked for permission to help me go to appointments, and his sergeant said to him, 'You take as much time as you like, Pete. You've been with us 30 years, you've not had a sick day. The least we can do is help you to help Sarah.' It took me a while to find Pete, but I'm glad I did.

We'd always planned to get married. So, in 2013, my consultant stopped treatment for a week and we did. Of course, we weren't allowed to go away for at least 6 months afterwards so our honeymoon was delayed. But we did get to go in the end: to Disney World in Florida.

> **I will live each day as it comes and if I can keep going, I'll keep going.**

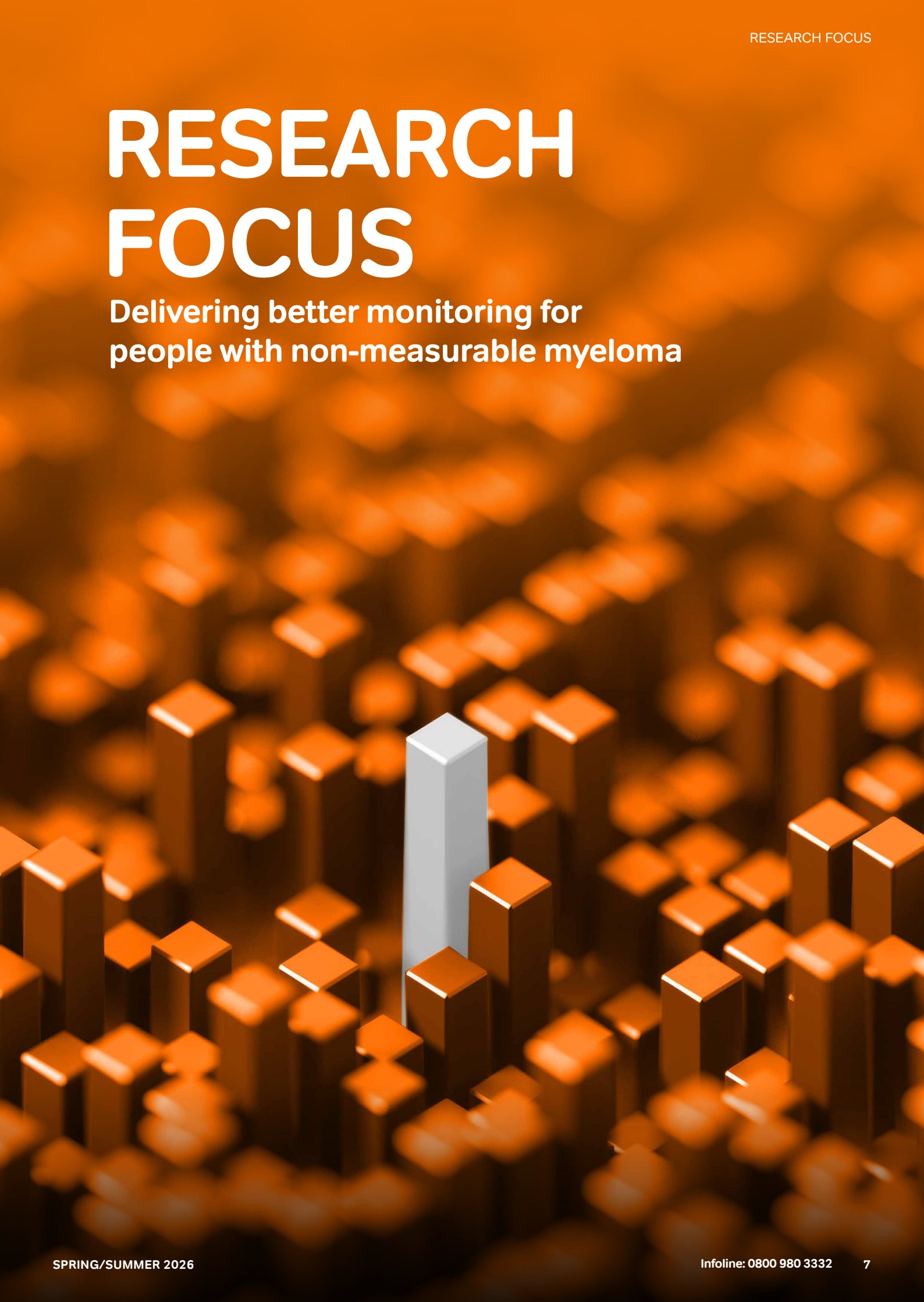
Pete has always made sure I have something to look forward to, to help me focus on something positive and take my mind off things. We'd planned to go to the Maldives so, when I had my first stem cell transplant, Pete printed out a load of pictures of the Maldives and stuck them all over the wall in my hospital room to give me something good to think about and look at when I was at my worst.

Pete plans to retire next June and then we would love to be able to get away when we can, book cheap last-minute holidays and spend time together. We love cruising and we're always planning our next holiday. We've booked a cruise in September: we start off in Barcelona and go to Naples and Corfu. Look out Pompeii, here I come.

We're looking forward to that next stage in our lives. When I was first diagnosed, I didn't think I would reach my 60s. It never really crossed my mind. I thought, I will live each day as it comes and if I can keep going, I'll keep going. And now, crikey, I can't believe I'm 65. I really feel that I have made it.

RESEARCH FOCUS

Delivering better monitoring for people with non-measurable myeloma



Delivering better monitoring for people with non-measurable myeloma

The Applied Health Research Team in Myeloma UK is working with an innovative team of researchers at the Universities of Birmingham and Leeds as part of an exciting study funded by the Matthew Wilson Multiple Myeloma Fund (MWMMF) at Blood Cancer UK to improve monitoring of non-measurable myeloma.

What is non-measurable myeloma?

Most people with myeloma have a blood test that can show how myeloma is behaving in the body, which is called a paraprotein test. In non-measurable myeloma, the cells do not make this protein, or they make only a very small amount of it. This means the usual blood test cannot detect myeloma or assess how the myeloma is behaving in the body.

You might hear doctors use different names for non-measurable myeloma including:

- **Non-secretory myeloma**
  This means no protein is made
- **Oligosecretory myeloma**
  This means only a very small amount of the protein is made

How are patients currently monitored for non-measurable myeloma?

People with non-measurable myeloma receive bone marrow biopsies and imaging (such as MRI and PET-CT scans) more frequently, instead of the usual blood tests.

This type of monitoring is more invasive than blood tests and can be distressing for people living with non-measurable myeloma. It can have a large negative impact their daily lives.

What are researchers doing right now?

Researchers recognise the challenges faced by people living with non-measurable myeloma. That is why we are dedicating ourselves to developing a new test for people with non-measurable myeloma. The new test works by looking for specific proteins in blood samples that would not normally be detectable with standard blood tests. We are working to understand what people affected by non-measurable myeloma think and feel about monitoring, and what they think about this new test. We are also looking into how much it would cost to use this new option in the NHS.

What impact could this have on me?

If the research is successful, it would mean the new test could change how people living with non-measurable myeloma are monitored. One of the things we want to know is whether using the test would mean people made fewer visits to the hospital if the new blood test was being used. If that is the case, it would potentially free NHS staff and resources to use elsewhere.

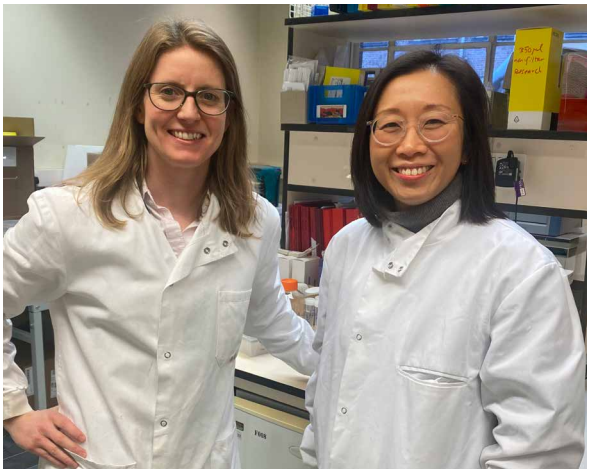
It is important to know that the new blood test **would not replace the need for bone marrow biopsies and imaging**, as these are needed to confirm if treatment is required. Instead, regular monitoring would use the blood test, and if your clinical team thought your myeloma was becoming more active, they would then decide whether a bone marrow biopsy or imaging was needed to confirm whether you needed treatment.

> **"Everyone affected by myeloma deserves to have access to the best ways of monitoring. This research will help people with non-measurable myeloma to live better. We are committed to making that happen by working collaboratively with researchers in Birmingham and Leeds. I'm delighted to see this research come to life."**
>
> **Dr Sandra Quinn**, Myeloma UK

Potential to open the door to clinical trials

For people living with non-measurable myeloma, many clinical trials are sadly unsuitable. If the new blood test is successful and approved for use on the NHS, clinical trials may open up to people living with non-measurable myeloma for the first time. This would give them the possibility to receive new treatments.

The Myeloma UK-led part of the project is vital to ensure we understand how best to embed the test into care. It will also allow us to understand what people living with non-measurable myeloma and healthcare professionals need to make it work well.



Meet the **team**

The Principal Investigators **Dr Jennifer Heaney** (Translational Researcher) and **Dr Tracey Chan** (Consultant Haematologist) have developed a new blood test at Birmingham to improve monitoring for patients.

This study has been funded by the **Matthew Wilson Multiple Myeloma Fund** (MWMMF) at Blood Cancer UK. **Dr Sandra Quinn** (Principal Researcher in Applied Health Research, Myeloma UK) worked with the team on the grant proposal to help secure the funding to do this groundbreaking research.

We are also working with a team at the University of Leeds including **Professor David Meads** and **Dr Paola Cocco** (Health Economists) who will evaluate the cost effectiveness of the new test compared to current monitoring methods.

The team in Birmingham

have developed the new test and are analysing how well it performs against existing methods

If the new blood test from Birmingham is successful, it would offer an innovative alternative, requiring only a blood sample rather than bone marrow samples to find out how myeloma is behaving inside the body.

Myeloma UK

is asking people with non-measurable myeloma and healthcare professionals across the UK to take part in a new study

People will be asked about their current experiences with monitoring their non-measurable myeloma. They will be shown a short video on how the new blood test will work and then be asked to provide their thoughts on the new test. We will also interview healthcare professionals to see how things currently operate in their hospitals, find out what they think about the new test, and how we can best fit this into their ways of working.

The team in Leeds

are evaluating the cost of the new test to the NHS

Our initial assessment of the costs at the stage of writing the grant suggested the new test would be significantly cheaper than current monitoring for this group of patients. We now need to take a more in-depth look at the cost. The team in Leeds will provide more detailed information on what that looks like for the NHS.

Have patients and carers been involved in the design of the study?

The Myeloma UK Patient and Carer Research Panel led by **Danielle Romaniuk** (Research Officer, Myeloma UK) helped us co-design the MWMMF-funded study.

Members of the panel have worked with us to ensure the study carefully considers their lived experiences, views and perspectives.

Danielle is working to ensure we keep the voices of people living with non-measurable myeloma front and centre by leading a Service User Advisory Group. It consists of patients and carers who will provide their opinions on the study results and help us ensure we include what matters most to them.

> **"This is very exciting for a non-secretary person and I can't help but add in my perspective that this blood test would make such a huge difference to me and my Haematology team."**
>
> **Service User Advisory Group member** with non-measurable myeloma

How do I get involved?

We will be launching recruitment to the Myeloma UK led phase of the study soon.

If you are interested in being involved, please get in touch with us when we launch. You can also find out more by contacting us at **research@myeloma.org.uk**

MYELOMA RESEARCH NEWS FROM AROUND THE WORLD

CAR-T cilta-cel: promising trial results in relapsed myeloma

CAR-T cell (chimeric antigen receptor T cell) treatment is an exciting emerging treatment group that uses the body's own immune system to kill myeloma cells. Updated results from the international phase 3 CARTITUDE-4 clinical trial bring encouraging news about ciltacabtagene autoleucel (cilta-cel). Cilta-cel is a personalised CAR-T cell treatment for people with relapsed and refractory myeloma, who have received 1 to 3 previous treatments and have stopped responding to lenalidomide (Revlimid®).

Over 400 participants took part and were assigned randomly to receive either cilta-cel or treatment combinations that are already standard of care (SOC). After nearly 3 years following a single treatment of cilta-cel, participants showed significant improvements – their myeloma was kept under control for longer and they lived longer, overall.

Whilst those receiving SOC treatment showed signs of active myeloma again within 1 year on average, more than half of people receiving cilta-cel continued to experience stable myeloma after nearly 3 years.

So far, survival data is also promising for cilta-cel, demonstrating an improvement compared with SOC. Responses were also deeper for those who had cilta-cel, with 77% of people showing no detectable myeloma on standard tests at the time of follow-up, nearly 3 years on, compared with 24% of those receiving SOC. Side effects were similar across both groups, with infections and low blood counts being most common.

Why this matters

These latest results suggest cilta-cel could become an important earlier treatment option in the future, even after first relapse.

As a one-off, personalised treatment, it has the potential to offer longer periods without ongoing treatment, fewer hospital visits and more time focused on living well.

Whilst not yet in routine use in the UK, these findings highlight progress towards treatments that may offer not only a longer remission, but meaningful improvements in quality of life and renewed hope.

When a fracture isn't just a fracture: a chance to spot myeloma earlier

Myeloma cells in bone marrow can disrupt the normal maintenance of healthy bone, causing the bones to become thinner, weaker and more prone to fractures and breaks.

Now, researchers are exploring whether screening people for myeloma when they present with unexplained new fractures, could help with earlier diagnosis.

A UK-based study explored the frequency of people presenting with fractures in routinely collected healthcare data between 1995 to 2017. They included 1,972 people with myeloma and investigated the incidence of major fractures for 2 years before and after diagnosis. This data was compared to a matched control group for the same period.

The research team found that people with myeloma had a higher rate of fractures even before diagnosis compared to people without myeloma.

In women, this increased rate was seen in the year before diagnosis, when new major fractures occurred around 3 times as often in women later diagnosed with myeloma compared to those who weren't.

For men, this sign showed up earlier. Men with myeloma had higher fracture rates up to 2 years before diagnosis, with rates rising steeply in the year immediately before diagnosis, when fractures occurred more than 6 times as often compared to men without myeloma.

Why this matters

Delays to spotting myeloma means delays to diagnosis and treatment, increasing the risk of serious, life-changing complications. This study shows that fractures were significantly more common in people who went on to be diagnosed with myeloma, suggesting that unexplained fractures in adults may act as an early warning sign – and a clinical marker to prompt myeloma testing.

This low-cost trigger could help more people to get a diagnosis sooner, start treatment earlier, and avoid preventable complications.

ASK THE NURSE

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

I've heard belantamab mafodotin can cause eye side effects; what are these?

Belantamab mafodotin (Blenrep®) was recently approved for use on the NHS as part of two treatment combinations in England and Wales, and one in Scotland, for patients at first relapse (second line). These are:

- Belantamab mafodotin, bortezomib (Velcade®), and dexamethasone (BVD)
- Belantamab mafodotin, pomalidomide (Imnovid®), and dexamethasone (BPD)

To be eligible for either of these treatment combinations, your first treatment must have included lenalidomide.

Eye complications associated with belantamab mafodotin typically include cloudy or blurred vision. Patients should be seen by an eye specialist (ophthalmologist) before starting treatment and will be monitored regularly throughout treatment. Patients are advised not to wear contact lenses during treatment with belantamab mafodotin. You may be prescribed eye drops.

As with all side effects of treatment, any vision changes should be discussed with your healthcare team (haematologist and clinical nurse specialist). Eye complications experienced because of belantamab mafodotin are generally temporary and are often managed by reducing the frequency of this treatment. Patients who had treatment breaks in the clinical trial for belantamab mafodotin did not have any difference in their remission times compared to patients with no treatment breaks.

Listen to Episode 13 of The Myeloma Minutes podcast for more information about belantamab mafodotin. Myeloma UK are the official charity partner of The Myeloma Minutes.

What is intravenous immunoglobulin (IVIg) therapy?

Immunoglobulins, also known as antibodies, are a type of protein which help the body to fight infection. Myeloma and some of the treatments for myeloma can cause the levels of immunoglobulins to be too low. This is called hypogammaglobulinemia. This can affect how well the immune system works, leaving you at greater risk of infection. Intravenous immunoglobulin (IVIg) therapy uses immunoglobulins from donated human blood plasma to increase the levels in patients whose levels are low. This helps the immune system function better. IVIgs are given as an infusion into a vein (intravenously) or as an injection under the skin (subcutaneously).

IVIg replacement therapy may be recommended if you meet one or more of the NHS eligibility criteria:

- Frequent or severe bacterial infection despite continuous oral antibiotics for 6 months
- Serum IgG level below 4g per litre (excluding paraprotein)
- Documented failed response to the pneumonia vaccine

Your consultant can apply to use IVIg replacement therapy. IVIg therapy is generally given until your level reaches the lower limit of the serum IgG reference range.

What are the surgical treatments for spinal fractures?

When myeloma bone disease occurs in the spine, fractures can develop in the bones that make up the spine (the vertebrae). These are called spinal fractures, or vertebral compression fractures (VCFs). They can often result in a forward bend of the spine (kyphosis), pain, height loss, a stooped posture, and mobility problems.

VCFs can be managed in a few ways. Non-surgical treatments include back braces, adequate pain management, bisphosphonate treatment, and radiotherapy.

Surgical options can stabilise fractures and relieve pain. Percutaneous vertebroplasty injects bone cement into the vertebrae. Balloon kyphoplasty reshapes the vertebrae by putting a balloon into the vertebrae before filling it with bone cement. This is the only treatment option which may restore height loss. Both these surgeries can treat multiple fractures at once and is often done as a day case.

However, not all myeloma patients will benefit from surgical treatment of their spinal fractures. Surgery is usually only considered in patients who have ongoing pain after 2 months of non-surgical treatment but are still within 12 months of the initial fracture.

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

SPOTLIGHT ON FINANCIAL SUPPORT

THE HIDDEN FINANCIAL COSTS OF MYELOMA

If you have myeloma, or you are a carer for someone with myeloma, you may be aware of the financial benefits available to you for financial support. In general, the benefits system is the same across the UK.

Benefits are payments from the government to people who need financial help. The type and number of benefits you may be entitled to will vary depending on a range of factors, such as your income, age, and where you live.

Benefits fall into 4 categories:

1

Disability benefits

such as Personal Independence Payment, Universal Credit, Adult Disability Payment, Attendance Allowance, and Disability Premiums

2

Low-income benefits

such as Universal Credit, Housing Benefit, and Council Tax Reduction

3

Workers Allowance

such as Statutory Sick Pay and Employment and Support Allowance

4

Carers benefits

such as Carers Credit and Carers Allowance

You may find that there are unexpected or 'hidden' costs to your life with myeloma. These may include transport and petrol costs, increased utility bills, childcare, additional toiletries, changes in diet and food expenses, or higher insurance premiums.

You may also need to take some time off work to manage your treatment or symptoms. This can reduce your income during a time when your spending has increased.

Facing these additional costs may be scary or overwhelming. Alongside formal benefit programmes from the government there are other ways you can access financial support.

Over the next 2 pages you will find a selection of organisations, schemes, and tips for managing financial challenges. These have been grouped into the most common areas that myeloma patients find unexpected costs.

The information in this article is **not** financial advice. Always do your own research to make sure you are making the best decision for your specific circumstances. You can consult a financial expert for help. Remember that thresholds for benefit eligibility change every year with new government budgets.

Tips for managing...

Transport costs

Travel discounts and schemes

Blue badge scheme
Visit gov.uk

Bus passes and disabled persons railcard
Visit gov.uk and nationalrail.co.uk

Dial-a-ride schemes
Check your local council website

Taxi schemes
Offering subsidised rides for cancer patients

Free hospital parking
for cancer patients (not always advertised, ask your healthcare team for details)

Organisations offering transport support:

- The Motability Scheme for mobility vehicle adaptations, scooters, and wheelchairs
- Royal Voluntary Service Community and Patient Transport service provides volunteer drivers to help you travel if you cannot drive or use public transport

Utility costs

Utility support schemes

Winter Fuel Payments
Cold Weather Payment; Warm Home Discount
Visit gov.uk

Household Support Fund
Check your local council website

Where to find out more:

- **Ofgem** and **Consumer Council for Water** have information about support available for energy bills and water suppliers
- **The British Gas Energy Trust** is an independent charitable trust that supports people across England, Wales and Scotland who need help paying their bills. This support is not limited by who your energy supplier is

Remember:

- Tell your utility providers about your myeloma diagnosis as most have hardship funds available for people finding it difficult to pay their bills
- Ask your energy supplier for 'emergency credit' if you use a prepay meter and cannot top up
- Ask your energy provider to add you to the Priority Services Register which gives extra protection and support

Food costs

Food providers in your community

Food banks give out free emergency food packages
Visit trussell.org.uk to find your nearest food bank

Community supermarkets
that sell surplus stock at reduced prices

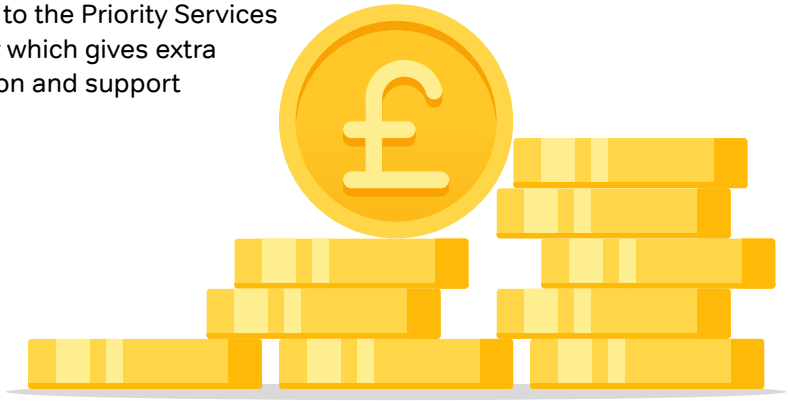
Community fridges
Visit communityfridgemap.org.uk to find your nearest fridge

Community meal schemes in local places
Visit foodcycle.org.uk

Your local council
They can also direct you to food support in your area

Remember:

- Food banks exist to make sure no one is hungry. You will not be judged for needing support



Additional healthcare costs

Additional healthcare support

Free prescriptions

for everyone living in Northern Ireland, Scotland, and Wales

Medical exemption certificate

In England, if you are having treatment for cancer, the effects of cancer, or the effects of cancer treatment, you can get all your prescriptions for free using a medical exemption certificate

NHS certificates

The NHS have certificates to cover dental costs as part of the NHS Low Income Scheme. These are HC2 and HC3 certificates

The Anthony Nolan Grant

is a small, one-off payment to help with unexpected costs of a stem cell transplant
Visit anthonynolan.org

Macmillan Grants

are small one-off payments to help with unexpected healthcare costs

Remember:

- Check your eligibility for help with dental and eye care, prescriptions, and travel costs for hospital appointments, using the **NHS Help with Health Costs Survey**

Housekeeping challenges

Housekeeping support

Age UK

can provide a handyperson service for maintenance work in your home. The availability of this service varies by location across the UK. They also provide a home help service for day-to-day domestic tasks in your home such as laundry, housework, and preparing light meals

Your local council

may provide domestic housework support, for example if you find you are unable to vacuum clean because of pain or other symptoms

Carers Trust, Carers UK, and Care Rights UK

are all charities that can provide housekeeping help for people needing additional support around their home

Dealing with financial anxiety

Worrying about money is common for people with myeloma. Many people do not realise that support is available, or they feel worried about asking for help. You are not alone if you are feeling stressed about your finances.

Signs that you might be feeling worried about money include:

- Feeling stressed, anxious, or depressed about myeloma-related costs, such as travel or heating bills
- Spending less money on other necessities such as food
- Not collecting prescriptions because you are worried about being charged

If you have had to reduce your working hours, or stop work altogether, this may affect the amount of money you are earning and cause more worry. For more information about working while living with myeloma, see the Hot Topic on **page 19**.

There are small steps you can take to help reduce your financial stress.

1

Ask for help

There are different financial and mental health support services you can access for help with money worries.

2

Make a budget

Write down all of your medical and non-medical expenses to help you see where you might be able to spend less.

3

Speak to your healthcare team

Your team may be able to help you consider your treatment options and how they impact your financial situation (such as, switching to an at-home treatment to reduce travel costs).

4

Talk to people you are close with

This can help reduce your stress and it may help to share what you are finding difficult so they can help you with things such as transport or food shopping.

5

Call your insurer

Many health insurance companies can help you to manage extra costs and make the best use of any benefits you receive.

I need more support or information

We know that living with myeloma can affect finances. With the rising cost of living we know many people are struggling even more.

If you are concerned about a change in your finances, you do not have to work it out alone.

For more information

Benefits and financial support Infosheet

Infopack for Living well with myeloma (section 7)

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

WORKING WHILE LIVING WITH MYELOMA

Being diagnosed with myeloma can affect every part of your life, including work.

Many people continue to work for reasons including financial stability, professional goals, or maintaining a sense of self. It is a very individual decision whether you continue to work after a myeloma diagnosis.

Financial support

If you do decide to continue to work, or to return to work after a period of absence, there are 2 schemes that are important to know about. These are:

1. **Statutory Sick Pay (SSP)**
   This is paid by your employer

2. **Employment and Support Allowance (ESA)**
   This is a government benefit that you can apply to receive

These have separate criteria, and different allowances. Both are there to financially support you if your health or disability is affecting how much you can work.

For more information

gov.uk/statutory-sick-pay

gov.uk/employment-support-allowance

Reasonable adjustments

By law, myeloma and other cancers are considered a disability, which protects you from discrimination in the workplace. One of these requirements is that your employer must make reasonable adjustments that help you to continue doing your job.

Possible adjustments will vary depending on your job.

Below are some common reasonable adjustments that people with myeloma have told us they found useful:

- **Phased return**, such as working half your weekly hours for the first 6 weeks
- **Working from home** some or all the time
- Changes to **working hours**
- Taking on **lighter role responsibilities**, especially during treatment periods
- **Provision of taxis** to avoid infection and fatigue on public transport
- **Workspace assessments** to ensure desks are set up at home and office to help any ongoing symptoms

You can ask for reasonable adjustments to be made at any time, not just when you first disclose your diagnosis. Your myeloma symptoms, and any side effects from treatments, may change over time.

It is important to regularly review your needs and adjustments with your employer.

"Working is a part of who I am, more than my myeloma, but it has to be right to make it worth me giving up free time."

Deb

"Be kind to yourself and – to the extent circumstances allow – embrace rather than fight the change."

Paul

"Talk to your employer and make sure your job fits around you and not the other way around."

Anonymous

For more information

Read the Benefits and financial support Infosheet

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

Quotes have been provided by myeloma patients about their experiences living with myeloma.

EXERCISE

Joanne Sowter née Land is a Clinical Academic Myeloma Physiotherapist at University College London Hospital. Joanne has over 10 years' experience in both research and clinical care of myeloma patients.

She shares her reflections on the role of exercise in helping people with myeloma rebuild strength, improve quality of life and overcome fears around being active.

Breaking the cycle of fear

Many people feel nervous about exercising when they first start. Without clear guidance about when or how to start exercising again, and how to move safely, it can be tempting to avoid exercise or being active. Over time, this can make you gradually get 'out of condition' (losing muscle strength and fitness). As a result, everyday tasks can start to feel more difficult and tiring.

In a recent large study, myeloma patients rated their ability to do moderate and vigorous physical tasks. Their scores were lower than patients with many other types of cancer. This shows just how common these challenges are.

This cycle of inactivity can worsen pain, reduce your quality of life, and make it harder to return to doing the things you enjoy.

For those who were active before their myeloma diagnosis, this change can feel very frustrating. Not being able to do what you once could, can be physically and emotionally difficult.

The good news is that, with the right support and guidance, it is possible to safely rebuild strength, confidence, and function over time.

Why is exercise important?

Physical activity and exercise are not the same.

Physical activity includes any movement in your daily life, such as walking, housework, or gardening. Exercise is more structured and planned, with the aim of improving strength, fitness, or balance. Both are important, and even small increases in daily activity can make a difference.

For me, exercise and being active is the key to breaking the cycle of fear. By showing you how to move safely, and helping you rebuild strength and fitness, you will be able to do daily tasks more easily, and will also have the confidence to get back to the activities you love.

This all brings a huge boost to your quality of life, and as a result boosts your mental wellbeing. It can even help you tolerate your treatments more easily.

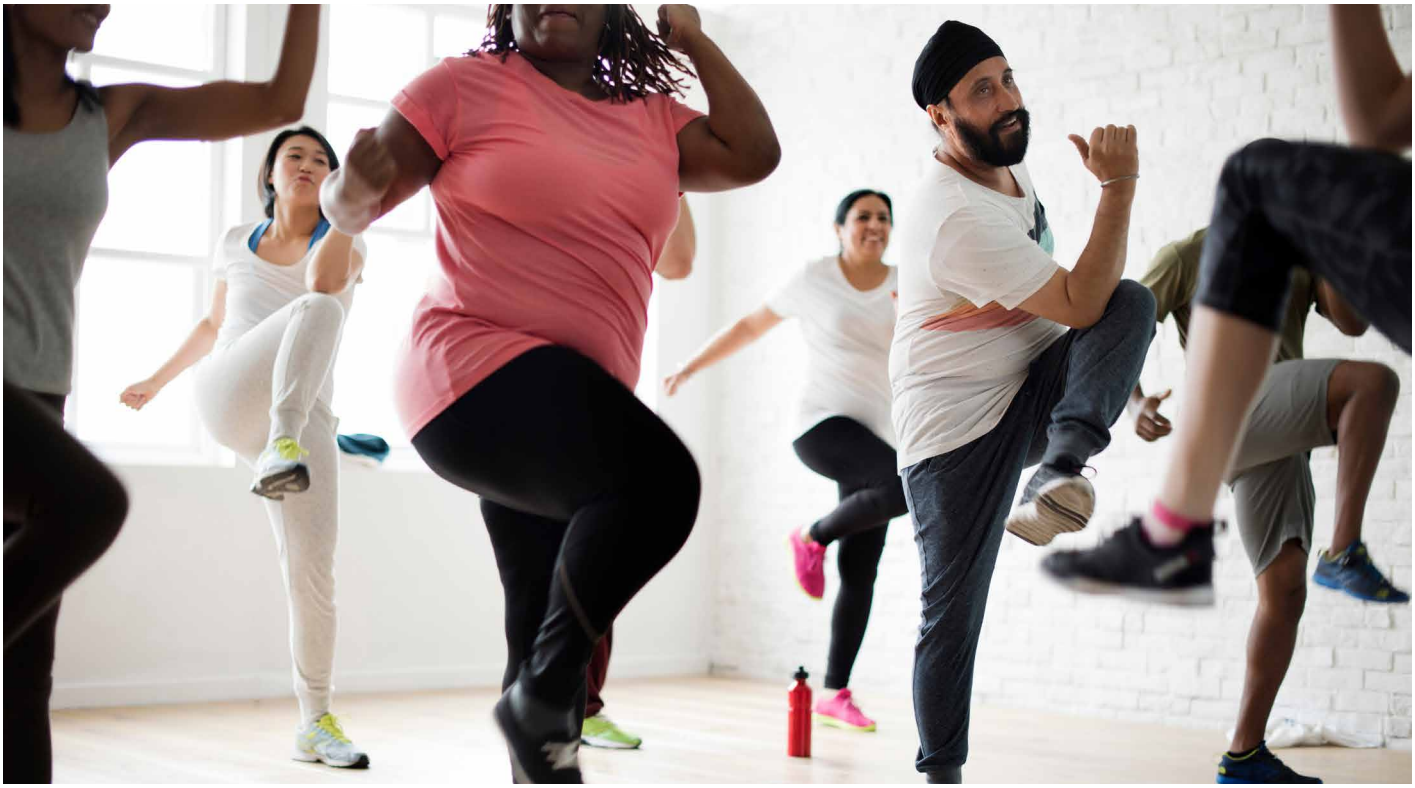
Myeloma patients now live much longer with their condition, and it is so important to support patients to live well for longer too. Exercise has a key role to play in this.

> **"[Exercise] has changed me, it has, in a positive way."**

Exercise safety tips

1	Talk to your healthcare team before starting exercise to make sure it is safe for you to begin.
2	If you have bone disease, ask where your bone lesions are so you can be mindful during exercise. If you feel pain in that area, stop and seek advice.
3	Check with your healthcare team when it is safe to return to gyms or swimming pools, particularly due to infection risk.
4	Avoid activities that could increase your risk of falling.
5	Wear supportive, well-fitting shoes, and make sure your exercise space is clutter-free.
6	Stop to rest if you feel very breathless.
7	Stop if you feel any new or increasing pain, and tell your healthcare team.
8	Pace yourself and listen to your body – do not push through pain, as this may be a sign that the exercise needs modifying.
9	Build up your activity gradually over time.

Quotes have been provided by myeloma patients about their experiences living with myeloma.



How to start exercise

Always start by talking to your healthcare team, or ask to be referred to a physiotherapist, to find out what exercise is suitable for you personally.

If you have bone disease, it is common for your medical team to recommend some temporary restrictions to keep you safe. As your myeloma comes under better control, these restrictions may change, and you may be able to gradually increase your activity.

For example, some activities that place more stress on the bones may need to be adapted, particularly early on.

> **Really make the effort to take gentle exercise every day, or as often as you can.**

A physiotherapist can help tailor an exercise programme to your individual needs, and this can change over the course of your treatment.

Look at the physical activity you are currently doing each week. The World Health Organization (WHO) recommends:

- At least **150 minutes** of **moderate-intensity** activity each week
- **2 or more sessions** of **strengthening exercises** each week

These guidelines apply to all adults, including those with cancer, although factors such as fatigue or treatment side effects may limit the amount you can do at different points in your treatment.

Recent medical reviews have highlighted that appropriate exercise programmes are safe for myeloma patients.

Start simple: for example, walking, using an exercise bike (static bike), or swimming. Try to exercise at a level where you can talk but not sing (that would be moderate intensity exercise).

Start with 10 to 15 minutes and gradually build up to 150 minutes per week if you can, or less if that is what you can manage.

For more information

Exercises for myeloma patients Infosheet

NHS guidelines on physical activity for older adults

Ask your healthcare team to refer you to an exercise scheme

AMBULATORY CARE

Frequent appointments and long hospital stays have been a mainstay of myeloma treatment for many years.

A newer approach allows people having high-dose therapy and stem cell transplant (HDT-SCT) to recover at home, without hospital admission. This is called ambulatory care.

What is ambulatory care?

Ambulatory care refers to healthcare services that are given without the need for an overnight hospital stay.

This type of care allows you to attend hospital for HDT-SCT treatment and monitoring, then return home to recover.

> **"While on treatment I value time away from hospital. Getting a balance in life is so important."**
>
> **Anonymous**

Where does ambulatory care take place?

Ambulatory care centres are often based within cancer centres or haematology units.

If you do not live locally to an ambulatory care unit, arrangements can sometimes be made to stay in a hotel or a charity funded 'home-from-home'. These are normally within an hour's travel of the ambulatory care unit.

Benefits of ambulatory care

- Fewer overnight hospital stays so it is easier to rest
- More comfortable environment to spend time
- More privacy and normality during treatment
- Can prepare and eat your own food on your own schedule
- Can exercise or move about more than in hospital
- Reduced risk of hospital acquired infections

Can I have ambulatory care?

Ambulatory care can benefit many people with myeloma, however it is not suitable, or available, to everyone. You may be offered ambulatory care if you:

- Are medically stable
- Live near the unit or can stay at nearby accommodation
- Can travel to and from clinic, likely with a family member or friend
- Have support at home

What should I expect during an ambulatory care visit?

On arrival, you will be assessed by your healthcare team to discuss any side effects, and ensure you are well enough to have treatment.

Your treatment will take place on the unit. A short time after treatment has finished, if you are well, you will be discharged home with follow up instructions.

Tips if you are receiving ambulatory care

1. Tell your healthcare team as soon as possible about any new or changing symptoms.
2. Wear comfortable clothing as you may have to sit or wait for a while.
3. Plan your transport and who will come with you.
4. Keep a note of any emergency numbers provided and any information about caring for yourself at home.
5. Bring something such as a book or iPad to help pass the time.

For more information

Read our Ask the Nurse blog on Ambulatory care

High-dose therapy and autologous stem cell transplant Infoguide

Patient Diary

Email AskTheNurse@myeloma.org.uk

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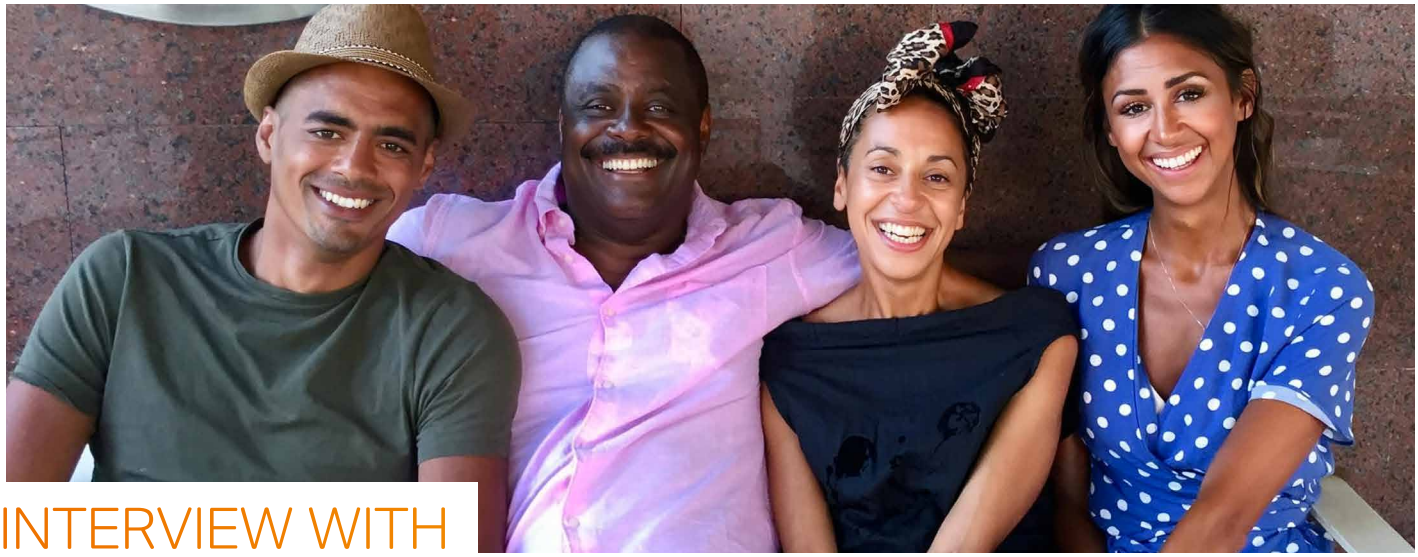

INTERVIEW WITH

MEL TOTTOH

Myeloma Awareness Week: Know the warning signs

Mel Tottoh was 65 when he was diagnosed with myeloma in August 2021. By the time his myeloma was caught, the cancer had started weakening his bones and he had holes in his ribs, thighs, spine and skull.

To help the people spot the tell-tale symptoms of myeloma before it's too late, Mel joined Myeloma UK's 'Know the Warning Signs' campaign as part of Myeloma Awareness Week.

Along with fellow patients, Mel was painted with yellow warning signs directly onto the area of his body where his symptoms first started. "When I was diagnosed, I had had symptoms for a year and a half. I don't want people to have to go through what I went through.

"A key learning for me is to take responsibility for your health and wellbeing. In the beginning I was very deferential to my GPs but, as time went on, I became more assertive about pushing for answers and asking for investigations. If they are passive, then respectfully push them to get your needs met. Nobody knows your body better than you, so own it."

Looking back Mel had had twinges in his ribs and back for a year and a half before his diagnosis but initially put them down to playing a lot of golf.

Things came to a head in March 2021, when Mel felt such searing pain taking a swing on the golf course he thought he might have broken a rib.

"I had to walk off the golf course," he said. "It felt like there was some serious damage there and I knew I needed to pick up the cudgels and get some investigations done." Mel went back to his GP determined not to leave until he'd been booked in for tests. He was diagnosed with myeloma in August. Mel had to get radiotherapy to treat the damage to his bones. He then received chemotherapy, followed by a stem cell transplant. He has thankfully been in remission since November 2022.

"My mindset is really positive," he said. "I will see my grandson go to university and get married – if that's what he wants to do. I will see my kids fulfil their dreams. My wife and I have structured our life around our family, providing for them, and doing as much as we can to make life wonderful for all of us. Right now, I'm in an amazing place and I'm on the path to living with myeloma for a very long time."

This year we're going to make Myeloma Awareness Week (15–21 June) bigger and better, and we need your help.

We'd love you to display your poster for Myeloma Awareness Week in your community. It could be in a GP surgery, a local community noticeboard, at your church or your gym. To help us track the impact of the campaign, email **campaigns@myeloma.org.uk** and tell us where you bring your poster.

Together we will make sure that more people know the warning signs of myeloma.

SUPPORTER STORIES

Bob Munro's London to Paris Ride

Now in its 10th year, the London Paris Ride has become Myeloma UK's flagship challenge, raising over £1.3 million towards research and support for people affected by myeloma and bringing together nearly 870 riders since 2016.

For many in the myeloma community, the ride has, more than any other fundraiser, come to represent hope in action: hope for new and better treatments and ultimately a cure. And this hope for a brighter future, for himself and others, is exactly what Bob Munro clung on to when he dreamed up the concept for the ride back in 2012.

"I'm really proud that I initiated it," said Bob, who was diagnosed with myeloma in January 2012 after months of debilitating infections culminated in pneumonia.

"2012 was a horrendous year of treatment and nothing really worked. I used to watch the Tour de France after work before my diagnosis but that year I was so poorly, I ended up watching every minute of it on my sofa.

It was a special year, with the first British winner Bradley Wiggins, and I imagined myself cycling past the French chateaux, the sunflower fields and through the spectacular mountain scenery. I thought, if ever I'm well enough, perhaps I could buy a bike and one day cycle in France."

After a difficult few years trying to keep his myeloma under control, Bob bought that bike in 2014 and quickly took to cycling – and the idea of fundraising.

He said: "A brand-new drug had transformed my treatment and I thought, what can I do to help myself and other patients? We need more new treatments and I can't invent them myself, but I can help raise money for research. And now after a decade of fundraising, it feels like complete karma that so many new treatments have materialised, and become more and more effective, and fortunately I'm still here to benefit from them."

In 2015, Bob brought the idea for the London Paris Ride to former Myeloma UK CEO Eric Low.

A year later, the inaugural ride was underway with 125 brave cyclists ready to take on the mammoth 450km journey from London to Paris, including 45 of Bob's family members and friends (see picture top right!).

"The first ride was very special," added Bob. It was my dream realised. The thing I had pictured on the sofa in 2012. It was such an uplifting experience, with many of us in tears at the end. There were only 3 patients including me on that first ride, but now the ride averages 10 to 12 patients each year, which is mind-blowing."

Since 2016, riders have clocked a combined 337,500km, raising more than £1.3 million to rewrite the future for people with myeloma.

Among the very first to sign up to the inaugural ride was Ellen Watters, one of Myeloma UK's trusted Myeloma Information Specialists.

She said: "I cycled alongside – well behind, I am a steady but not fast cyclist – patients, loved ones and other healthcare professionals and felt truly humbled by the enormity of what we were doing. We were raising awareness and funds, and everyone was proud to take part in this first endurance cycle for such a good cause. The camaraderie, shared purpose and passion helped push me along when I was struggling up the hills or nearing the end of a long and tiring day. The great sense of achievement at the end of the ride as we all came together in an orange peloton cycling along the Champs-Élysées toward the Arc de Triomphe to gather under the Eiffel Tower was something I will never forget."

Maggie Rankin, Senior Event Development Fundraiser at Myeloma UK, has been a fixture of the ride for many, cheering riders on from the support vehicle and keeping their spirits up with kind words of encouragement when the going gets tough.

She said: "I support the riders from the moment they sign up, so I love finally meeting everyone in person on the ride. The sea of orange cycling along the French countryside is an incredible sight. It's great to see the community that builds up over the course of the ride, as everyone chats and shares their stories. To follow them on their journey to France, knowing why they are doing it is fantastic, I always get emotional watching everyone arrive in Paris."

For Kelvin Mackay, Company Partnerships Fundraiser at Myeloma UK, joining the peloton was a way to keep the memory of his niece Bronwyn Farquharson alive, after she died of myeloma at just 7 years old.

"Sadly, Bronwyn passed away on New Year's Eve 2018, the same year she was diagnosed, aged just seven," said Kelvin. "She was full of life and loved creating characters and telling stories. She was an active member of the local roller hockey team and enjoyed watching the Dundee Ducks ice hockey team. Her dad played for them, and she surely would've joined them too one day. No parent should ever outlive their child, and certainly not at that age. 6 months or so before she died, my best friend Marc was also diagnosed with myeloma and is currently in remission and doing well. After that, I started fundraising and eventually walked away from a career that I loved to work full-time for Myeloma UK and help in the fight to find a cure. I've never looked back.

"Arriving in Paris, cycling over the Seine with the Eiffel Tower right in front of me is a memory that will live with me forever and stirs emotions even just thinking back on it now. We forged unbreakable bonds of camaraderie; each mile pedalled a testament to resilience and shared strength. I have made lifelong friends along the way and am looking forward to seeing some again on future rides and making new ones too."

Bob proudly took part in the first 3 rides. When his health deteriorated, preventing him from taking part in the fourth, he still joined in spirit as one of the ride's ambassadors. After reaching complete remission for the very first time thanks to teclistamab, Bob was keen to hop back in the saddle for the 10th anniversary ride this year.

"Cycling has been my salvation, boosting my overall health through years of multiple treatments, and I'm so proud of the ride," said Bob, who has welcomed 2 grandchildren since his diagnosis. "It is probably my greatest ever achievement. We've lost people along the way, but I also hope it can inspire people and show them what's possible, what we can achieve and have achieved together."

"I've lived longer than I ever thought I would and I'm living proof of the impact the ride has had."

10 years of the Ride...

Over £1.3m raised

337,500km
(**209,712 miles**) covered

Nearly 870 riders
have crossed the finish line, including **62 patients** and **79 healthcare professionals**

£30,872
the largest amount raised by a single rider

145 people
have joined the ride **more than once**

5 times
the most rides **completed by a single participant**

78 the age of the **oldest rider**

19 the age of the **youngest rider**

MYELOMA ADVOCACY

IMPROVING QUALITY OF LIFE MEASURES FOR NEW TREATMENTS

People with myeloma are living longer and spending more time on treatments.

While this is positive, it also means living with side effects that impact daily life for longer. Quality of life is therefore becoming an increasingly important part of how new treatments are assessed.

What is 'quality of life'?

Quality of life describes someone's overall wellbeing. It includes physical symptoms, emotional and mental health, the ability to do daily activities, relationships, independence, and more. For people with myeloma, this can cover anything from fatigue, pain, and sleep, to the emotional impact of ongoing treatment, or uncertainties about the future.

How is quality of life measured?

There are lots of different ways quality of life can be measured. In clinical trials, patients are often asked to complete questionnaires at different points during treatment. They often ask about symptoms, side-effects, and how treatment affects daily life. The responses help researchers to understand how a new treatment might improve, or worsen, someone's overall wellbeing.

How does quality of life shape decisions about new treatments?

The health body NICE (the National Institute of Health and Care Excellence) look closely at quality of life data when assessing new medicines for use on the NHS.

They use a standard questionnaire, called the EQ-5D-3L, which produces a single score that feeds into cost-effectiveness calculations. There are other questionnaires designed specifically for myeloma. However, NICE uses EQ-5D-3L because it is standardised across all conditions. If a clinical trial uses a different questionnaire, then NICE will 'map' the answers onto the EQ-5D-3L.

The EQ-5D-3L asks about 5 areas:

1	Mobility
2	Self-care
3	Usual activities
4	Pain and discomfort
5	Anxiety and depression

For each area, people choose 1 of 3 levels: no impact, moderate impact, or severe impact.

What is missing from this?

Many people with myeloma tell us things that are important parts of their experience, but which are not captured by the EQ-5D-3L. Cognitive changes like brain fog, sleep problems, emotional strain, thoughts about the future, and impact of treatment on family members or carers often fall outside the 5 areas EQ-5D-3L measures.

Usually, only myeloma-specific questionnaires capture information about symptoms and side effects such as mouth changes, peripheral neuropathy, and uncertainties about the future. Patients tell us that these are important and impact their quality of life.

There are also often missing, but important, quality of life considerations, such as what impact a treatment has on families and carers. Even if these things are recorded, because EQ-5D-3L does not consider these within its 5 domains, the survey calculation can risk being missed when it comes to mapping data for medicines appraisals.

The gaps are important because they can influence how quality of life is discussed, calculated, and considered for potential new treatments. If important aspects are missing, discussions and calculations around a new treatment may not consider all the impacts or benefits a treatment could bring.

What does this mean for patients?

Over the coming months, we will speak with patients, family members, and carers, to understand more about what aspects of quality of life matter most, what is currently overlooked, and what evidence should be prioritised. This will help shape the focus of the evidence we provide to health bodies when new myeloma treatments are being considered for the NHS.

We will also be taking these insights to NICE as they review their approach to quality of life methods, ensuring that we keep the things which matter most to people living with myeloma at the centre of our advocacy work on potential new treatments.

We will continue to share ways to be involved through our monthly email newsletter. If you would like to find out more or share your thoughts, please get in touch by emailing **policy@myeloma.org.uk**

myeloma INFODAYS 2026

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**

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@MyelomaUK

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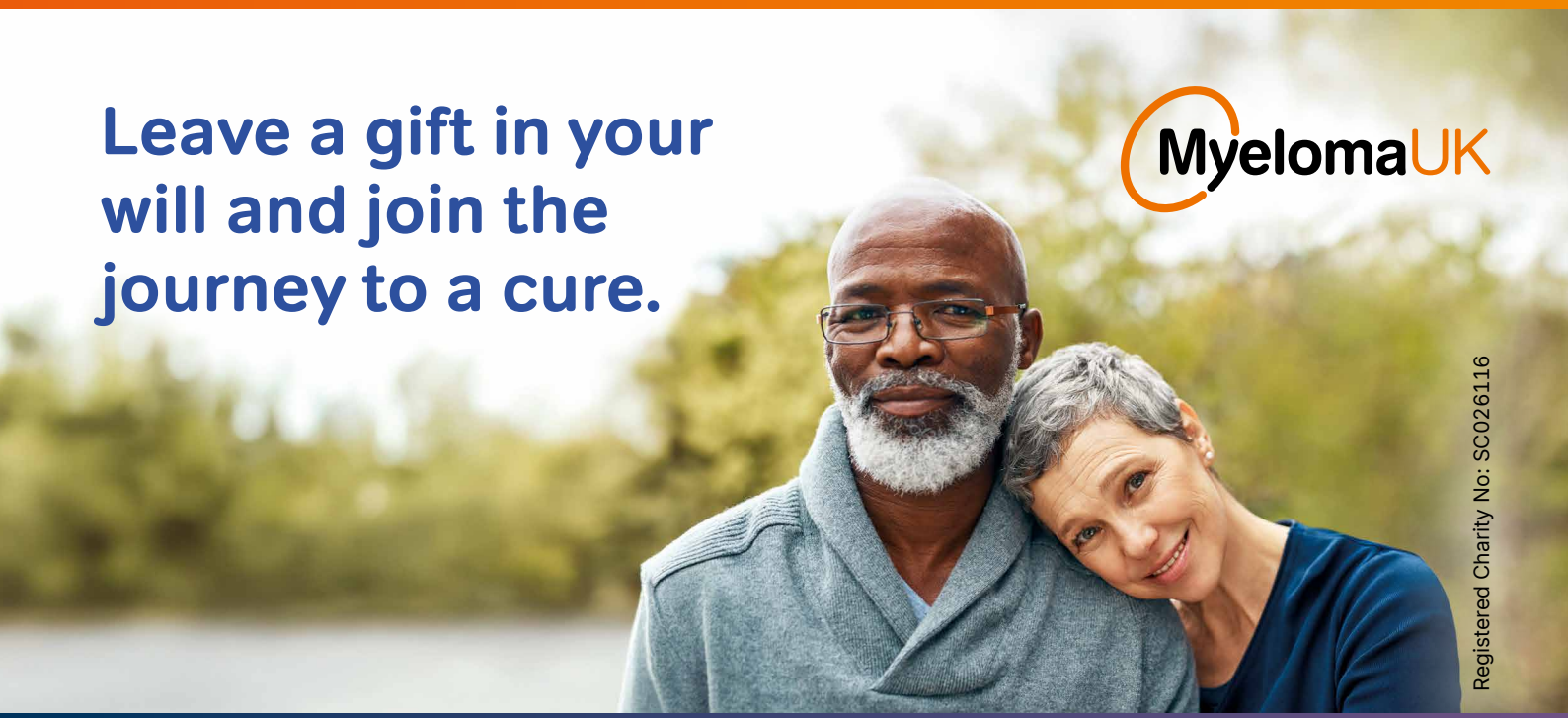

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MyelomaUK

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

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