SUMMER 2024

myeloma Matters

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Pippa Foster
Myeloma Matters Guest Editor

Welcome to the Summer 2024 edition of Myeloma Matters.

I am delighted to be the guest editor for this important edition of the magazine. We have much to celebrate and share. I am particularly proud to present our new strategy: Together, we are the cure (**myeloma.org.uk/about-us/our-strategy**).

Here, we set out our ambitions to expand our reach and support more people, doubling our impact. This means creating opportunities for more conversations with a broader range of people across the whole myeloma (and associated conditions) community and learning from lived experience partners, healthcare professionals and researchers, so we can truly coproduce what we do, and how we do it, *together.*

We are taking even more action to address and tackle inequalities making sure people affected by myeloma and associated conditions have a voice, and access to timely diagnoses and treatments. You can read more about this focus on early diagnosis in our latest report (**myeloma.org.uk/nss-pathway-review**) and in our policy briefing.

For me, being neurodivergent, recognising and celebrating diversity and difference is incredibly important. And in this edition, we start conversations about how different people and communities may experience living with myeloma, for example individuals from LGBTQIA+ communities and younger people. We will be exploring this more as we move through our new strategy and develop what we do, and how we do it.

We meet Paul, who is a friend of mine, so it is especially humbling to share his story and reflect on his wise words *"if something doesn't bring me joy, I just don't do it anymore"*.

Anyone who knows me, knows I couldn't miss the opportunity of talking about the therapeutic nature of animals! You can find out more in our 'Power of Pets' Hot Topic.

And finally, we introduce you to our new Chair David Ereira and our Director of Fundraising, Matt Wynes. Both are key in the delivery of our ambitious strategy. Matt describes our fundraisers as the lifeblood of Myeloma UK. We could not do what we do without you. So, a heartfelt thank you to each and every one of you – together, we are the cure!

If you'd like to add your voice and your experiences, we're particularly interested in hearing from people from minority groups who are currently under-represented in our work. You can respond to our advert to join a panel, or you can fill in our form at **myeloma.org.uk/tellusyourstory**

Visit the **Myeloma UK COVID-19 Information Hub** for the latest information on COVID-19, vaccinations and research.
myeloma.org.uk/covid-19

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MYELOMA RESEARCH NEWS FROM AROUND THE WORLD

New bispecific antibody drug found effective compared with current HCP-recommended treatment options

In a clinical trial, teclistamab has been found to be highly effective for treating relapsed and/or refractory (RR) myeloma, compared to healthcare professionals' (HCPs') recommendation based on currently available treatments.

Teclistamab is a new bispecific antibody, a type of immunotherapy drug that helps the immune system recognise and kill myeloma cells. Teclistamab attaches to a protein called CD3 on the surface of T cells, and a protein on myeloma cells' surfaces called BCMA. This brings the patient's T cells close to myeloma cells, allowing them to kill the myeloma cells.

Outcomes from the MajesTEC-1 clinical trial, in which 165 patients with RR myeloma were treated with teclistamab, were compared with control data from two other international trials.

In these trials (LocoMMotion and MoMMent), patients were treated with their HCP's recommended treatment (RT).

Results showed patients receiving teclistamab (63%) were more than twice as likely to respond to treatment than those receiving HCPs' RT. Almost all patients responding to teclistamab treatment experienced a very good partial response (VGPR) or better, whilst fewer than half of those responding to RT achieved VGPR. Teclistamab also induced longer lasting remissions (average 11.3 months) compared to RT (average 4 months).

For now, clinical trials are still exploring the best way to use teclistamab treatments but it is one of several bispecific antibodies showing promise in treating myeloma which could, in future, give more, and better, options to patients.

Together in care: the ripple effect of myeloma

When a person is diagnosed with myeloma, the impact of the condition can extend to their loved ones. Together, family and friends share in some of the challenges a life with myeloma can bring. Often, caregivers (typically partners, children or parents) emotionally and practically support their loved ones through the journey of treatment and care.

A recent study exploring the impact of myeloma and other haematological conditions on family members shed light on this impact. Over 95% of family members taking part in the study reported that worry related to the condition affected them.

The impact of myeloma on family members was also found to be greater than for those affected by non-cancerous conditions, highlighting the emotional toll for those living with myeloma.

This study serves as a reminder that while caregivers can be pillars of strength for patients, they also need understanding and support to maintain their own well-being. Research like this reinforces the need for caregivers to be recognised and supported, alongside patient care.

Myeloma UK are here for everybody affected by myeloma.

If you would like to talk to somebody about how myeloma affects you as a family member, friend and/or caregiver, you can contact us through the **Myeloma Infoline** at **0800 980 3332** (UK) or **1800 937 773** (Ireland) or use our **Ask the Nurse email service** **AskTheNurse@myeloma.org.uk**

Interplay between new drug and immune system could inform myeloma treatment planning

A recent study sheds light on how a new oral CELMoD drug, iberdomide, can help to activate the immune system to effectively kill myeloma cells.

CELMoDs are an emerging group of drugs that work in a similar way to immunomodulatory drugs (IMiD's) like lenalidomide (Revlimid®), but often still work even when the patient has resistance to IMiD's.

Iberdomide has previously been found to be safe and effective in clinical trials for relapsed and/or refractory (RR) patients, and as a maintenance treatment following high-dose therapy and stem cell transplantation (HDT-SCT).

In this trial, 93 patients with RR myeloma were treated with iberdomide and bone marrow samples were examined to understand how the treatment affects the environment for myeloma cells.

Results showed that treatment led to a substantial increase both in the number and the activity of the patients' immune cells within the bone marrow.

Findings also indicate that previous treatments impact the bone marrow environment in which myeloma cells are active, with different prior treatments influencing the number, type and responsiveness of immune cells.

This research not only confirms the therapeutic effect of iberdomide but also provides deeper insight into how different treatments can shape the immune system and affect efficacy of future treatments.

This could inform better planning of treatments to maximise future therapeutic options for myeloma patients.

MY LIFE WITH MYELOMA

NAME: Paul Caulfield

LIVES: Nottingham

AGE: 56

I had never heard of myeloma when I was diagnosed, not a word.

I started getting noticeable symptoms in July 2018. I was very tired for months and I couldn't break that tiredness pattern.

I was Head of Executive Education at Nottingham Trent University and I thought it was just stress through work. I had always been quite reluctant to access healthcare in the classic male sense. And until that point, I'd never really needed to.

"They found some kidney damage, I also had type 2 diabetes and high-blood pressure. I was treated for everything."

By November 2019, things had got worse and worse, but I just carried on. I was running the leadership programme for the Integrated Care Partnership of Nottingham and Nottinghamshire and in that first cohort, on the first day, was my doctor.

He looked at me and said, 'You don't look well. I'm going to book you for an appointment right now. You need to be in my office tomorrow'.

They found some kidney damage, I also had type 2 diabetes and high-blood pressure. I was treated for everything.

The next day, I went to hospital straight from his office. It's not until January 2020, after doing some blood tests that I was sent to haematology. They gave me the diagnosis of myeloma. I was 53.

I've never understood why they didn't put me on a plan for a transplant. But it was on the non-transplant line one – velcade, thalidomide and dexamethasone – and that set of drugs caused severe side effects.

It made the diabetes considerably worse, so I had to start taking insulin. I had terrible weight gain of up to 20kg from water lymphoedema. So, in March, at the very beginning of the pandemic, I was taken to hospital and caught COVID. I was patient 48 in Nottingham. I was told that I wouldn't survive the night and I should start ringing people to say goodbye.

I refused to accept this as my ending, so, I just walked out of the hospital.

By that point I was in a coma and I spent six weeks in and out of a vegetative state.

I got home and my partner rang 111. They connected him to the Red Cross and they brought oxygen round and a bed. By that point I was in a coma and I spent six weeks in and out of a vegetative state.

I started second line treatment, which was much better, but it wasn't long before the light-chain count started climbing again. Third line didn't really work either, but I've been on fourth line since November 2023, taking isatuximab, pomalidomide and dexamethasone and it's working better than anything I've had. But it's not been easy, I had to stop taking it when my kidney finally packed up and I had to go on dialysis. I'm on home dialysis now.

One thing that's been really difficult and, that not a lot of people know about, is dealing with pensions and finances through all of it. One pension provider tried to withhold 75% of all my pension funds.

The thing I've had the most trouble with and is still ongoing after a year and a half is student loans. I had to find a financial advisor who could help sort through everything and deal with a lot of paperwork. Trying to navigate your future is just battle after battle. We need a lot less bureaucracy, especially after a diagnosis like myeloma. Going through the PIP process can be quite soul-destroying.

Working was always so important to me and, after recovering from COVID, I knew I couldn't work anymore. But I was desperate for something to keep my brain active.

I'd had high-profile jobs, teaching and in finance and business. Doing nothing wasn't an option. So I decided to do a Master's in public health. I didn't have any medical background but I wanted to understand the system I've been in.

I struggled several times with my health and getting things done, and I noticed quite a lot of cognitive problems which still remain now.

I also do some patient research for Myeloma UK and recently presented Nottingham University Hospital Trust with their Clinical Services Excellence Programme award.

I just can't do as much as I used to. Before my diagnosis I was doing easily 12–15-hour days. Now I can't stare at the computer for more than three hours. The disease progression has forced me to slow down quite a lot. But I'm still trying to do what I can. For me, it's important to be making an active contribution and not be passive.

I'm a trustee of Nottinghamshire Hospice, I'm a lay member of the National Institute for Health and Care Research, and I'm on NICE's technical appraisal committee, Committee D.

I'm absolutely loving it. I also do some patient research for Myeloma UK and recently presented Nottingham University Hospital Trust with their Clinical Services Excellence Programme award.

When you're diagnosed with myeloma there is a lot of work you need to do, reconnecting with yourself and your identity. Suddenly there were lots of things I couldn't do. I've got about 50% of the capability that I used to have but I'm just trying to achieve as much as I can. Sometimes it can feel like you're lazy, like you're letting yourself down. For example, if you need a nap in the afternoon, it might feel like a terrible waste of time, but without it you get fuzzier and fuzzier.

Having myeloma, waiting and waiting to see what happens, feels like rolling the dice sometimes. Or having a ticket to a lottery you didn't want to join. It's a bit of an overload.

The worst thing about myeloma is that it does come back and it comes back hard. I never know how it will go. You can feel great today and be in the ICU tomorrow. That's not a great feeling. It really gets in the way of organising life. So I swing around a little bit from one extreme, which is long-term planning, to the other, trying to fit everything into one week in case that's my last. I can be a little erratic.

I have a tendency, and I've noticed it in other people, to withdraw. I think as soon as you start down that path, part of your brain doesn't function as quickly. I get stimulated by social situations. It's important to stay busy, and use your skills. I think it really helps me make sense of things.

I've learned some valuable lessons along the way too. If something doesn't bring me joy, I just don't do it anymore. When you're diagnosed with something like myeloma, you have to be a little bit selfish and you've got to create a world around you that's best for you.

"I've learned some valuable lessons along the way too. If something doesn't bring me joy, I just don't do it anymore."

You have to be brave enough to do that and not pander to other people's demands. You need to take charge. You have to make time for things that you enjoy. For me that's cooking.

Continuing to learn is also essential. I'm going to do study health economics next.

I like being creative, so my husband Greg and I have been doing jewellery classes for about a year and a half. We got married in September last year and actually made our wedding rings. Getting married had been on our minds and then everything went pear-shaped but we finally got back to it. We didn't have a wedding list, we had experiences instead, so we've been working through the experiences that people have gifted us. We had a luncheon at a Michelin-star restaurant; we've been to Scotland several times and had stays at various hotels.

"I like being creative, so my husband Greg and I have been doing jewellery classes for about a year and a half. We got married in September last year and actually made our wedding rings."

We had spas, massages, and theatre tickets, all sorts of things.

I still think I've not come to terms with my diagnosis somewhat, because we were almost immediately in a battle against COVID. Dealing with all these different things stimulated my fight engine but I also shut down the emotional side of it. There was too much going on to think about the diagnosis and to go to those places.

So going through our list of experiences and going through that process helps me, it gets me from day to day.

SPOTLIGHT ON STRATEGY

INTRODUCING OUR STRATEGY

Our new strategy, Together we are the cure

Together, with our dedicated community, we have transformed treatment and care for people affected by myeloma in the last 25 years. But when you're living with myeloma, every day counts. We have more to do to find a cure and make sure that everyone can have the best life possible, today and tomorrow.

Our vision is the same as it has always been – a world where myeloma doesn't exist. But we need to go further, faster because people affected by myeloma can't wait. This is how Myeloma UK will drive our work forward so that everyone affected by myeloma can look forward to a longer and better future.

The outlook for someone diagnosed with myeloma today has transformed since Myeloma UK was founded in 1997. Life expectancy for many has quadrupled. Far more treatment options are already available. Others are on the horizon. There are plenty of reasons for hope.

But that optimism has to be balanced with realism. People affected by myeloma and related conditions still face stark challenges at every stage – from delays in diagnosis to the psychological impact of living with a cancer that could come back at any time.

> **"Money for new treatments is growing tighter. So, it's time for Myeloma UK to plan the next stage in our journey."**

Clinicians' time is being stretched more than ever as pressures on the NHS grow. Government funding for research is harder to access. Money for new treatments is growing tighter. So, it's time for Myeloma UK to plan the next stage in our journey.

We spent 12 months gathering insights from over 700 people with lived experience of myeloma – both people with the disease and those closest to them.

We spoke to UK and international myeloma experts – researchers, clinicians, drug developers, policymakers and more.

Three core areas will now define our work

Driven by the insights we gained during our consultation, we identified three areas that will underpin everything we do – **preventing myeloma, treating myeloma, and living well with myeloma**. These areas reflect people's biggest priorities today and reflect where we believe we can deliver the greatest progress between now and 2028.

Preventing myeloma

Treating myeloma

Living well with myeloma

Preventing myeloma

Why it matters

MGUS and smouldering myeloma are both precursor conditions to myeloma. Estimates show that over 6,000 people are diagnosed with MGUS each year in the UK. And we know half of people diagnosed with smouldering myeloma will progress to active myeloma or AL amyloidosis within the first five years after their diagnosis.

So, by focusing on earlier diagnosis and on precursor conditions that can develop into myeloma, we want to radically reduce the proportion of people who are affected by myeloma.

The questions we want to answer

- Is it possible to prevent myeloma from developing?
- Could screening be a way to identify people who are most at risk of developing myeloma?
- How can we engage with a broader range of people to improve the support we offer and keep building our understanding?

What we need to achieve

Improving our knowledge of precursor conditions

By focusing on the biological changes that mean MGUS and smouldering myeloma become active myeloma, we will investigate whether it could be possible to prevent myeloma from developing in the first place.

Improving detection

We will support efforts to identify those who are most likely to develop precursor conditions, and so help people to be effectively monitored and treated at the right time.

Exploring precursor treatments

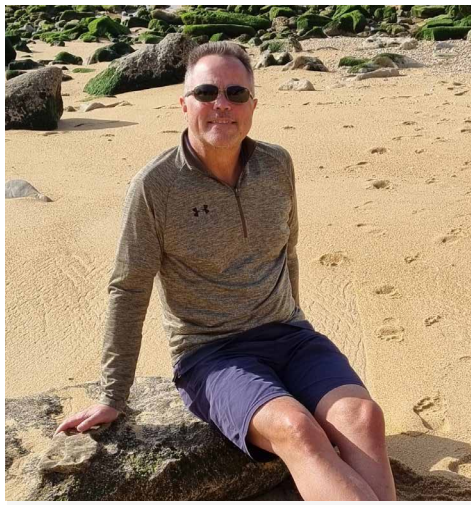
We will build our knowledge of when to treat precursor conditions, and increase our understanding of how this could affect quality of life and life expectancy for people affected by myeloma.

Targeting higher-risk and under-represented groups

By learning more about who is at greater risk of developing myeloma, we will seek to improve detection rates and monitoring while making sure everyone's needs and preferences are met.

Accelerating earlier detection of active myeloma

By supporting medical professionals to consider, diagnose and treat myeloma earlier, we will work to reduce myeloma's physical and psychological impact.



"Through my work as a Myeloma UK peer buddy, I have spoken with many fellow patients.

The complications and difficulties faced by those patients who are diagnosed late are distressing and avoidable, and I believe Myeloma UK can make a big difference to life quality and expectancy through our focus on awareness and more timely diagnosis."

Scott was diagnosed with myeloma in 2018. He now volunteers with Myeloma UK as a peer buddy and patient advocate.

SPOTLIGHT ON

Treating myeloma

Why it matters

When people with standard-risk myeloma respond well to treatment, their time in remission is almost twice as long, on average, as people who do not respond well to treatment.

By helping to deliver cutting-edge treatments, policies and care standards, we want more people to move into remission for longer, and we want to help people feel a greater sense of control over their situation.

The questions we want to answer

- How can we convene partnerships that lead to clinical breakthroughs and more personalised treatments?
- How can we improve support for people who are less likely to respond to current treatments?
- How can we help to define and share excellence in myeloma care?

What we need to achieve

Championing individual needs and preferences

No two myeloma journeys are the same. We want to ensure that healthcare systems and treatment options reflect what every person affected by myeloma needs, when they need it.

Supporting patient access and decision making

Treatment options can be complicated to understand and access. We will work to ensure people have the information and opportunity to access effective treatment, wherever they live.

Developing the right treatments

We want to bring more breakthrough treatments into the UK, so people affected my myeloma can look forward to their best future – wherever they are on their myeloma journey.

Building an impactful clinical community

We believe change is driven by powerful partnerships. So we will work closely with the clinical community, focusing on the opportunities that mean most to people affected by myeloma.

Reaching excellence in universal care

Everyone should experience high quality, expert care – regardless of who they are and where they live. We will work with clinical teams to drive up standards of care across the UK.

"Continued research into new treatments is crucial because it's the only path towards discovering a cure. Organisations like Myeloma UK play a vital role in this quest by relentlessly seeking new treatments and bringing us closer to curing multiple myeloma – a journey I've seen progress significantly over the last 12 years."

Antoinette was diagnosed with myeloma in 2012

Living well with myeloma

Why it matters

Since we started our work, the average length of time someone with myeloma can expect to survive has quadrupled. But 8 out of 10 people say their mental health has been affected by living with myeloma, and we know that a diagnosis of myeloma or a related condition can also have a big impact on family and friends.

By improving our understanding of living longer with myeloma and by offering the best support, we want to help everyone live a full life after diagnosis – regardless of their background and the type of treatment they receive.

The questions we want to answer

- How can we understand more about living longer with myeloma?
- How can we be a catalyst for new drugs that help people stay in remission for longer?
- Can we make people's quality of life one of the defining aspects of our work?

What we need to achieve

Understanding survivorship

More and more people can expect to live longer with myeloma, but we need to know what that means for their wellbeing. We will fund research into answering key biological and psychological questions.

Maintaining quality of life

Life continues after diagnosis. So we will work to provide treatments, information and support that means everyone affected by myeloma or a related condition can look to the future with confidence.

Guaranteeing high-quality ongoing support

We will keep improving our information and support so more people can find guidance and comfort, whatever their diagnosis brings.

Growing opportunities to meaningfully participate

Our work is powered by our community. We will look at new ways to involve more people's voices in all of our decision making.

Expanding support for psychological and emotional needs

We will develop new ways to support everyone affected by myeloma – no matter who they are and how they are affected. No one should face myeloma alone.

"I was told myeloma was incurable but treatable, and that with treatment you can expect a life expectancy of seven years. That was in 2006. Now, with incredible advances in pioneering treatment, life expectancy has increased dramatically. I am one very lucky person – I have a loving wife, children, grandchildren and great grandchildren. Life is wonderful.

Myeloma UK increasing its focus on living well with myeloma means that thousands of patients never need to feel alone and can share their feelings and concerns with a team of trained professionals."

Andrew was diagnosed with myeloma in 2006

Focus on Early Diagnosis

A Myeloma UK Rapid Review of Non-Specific Symptom Pathways

What are Non-Specific Symptom Pathways?

Non-Specific Symptom (NSS) pathways are essentially a diagnostic route for patients which can be used by GPs to refer people who present with very vague and non-specific symptoms. The pathway aims to speed up diagnosis, reduce the number of times people visit their GP before referral and reduce the number of people diagnosed via Emergency Departments in hospitals at an advanced stage. The pathways offer a diagnostic route for patients who otherwise may not have met existing criteria for an urgent suspected cancer referral.

Why did we undertake the rapid review?

There is an urgent need to improve diagnosis performance in myeloma. Currently, myeloma patients experience some of the longest times to diagnosis of any cancer.

On average patients wait 163 days from their symptoms first becoming apparent to a diagnosis. This can severely impact both survival and quality of life. We also know that inequalities exist in diagnosis times, for example Black people with myeloma are more likely to experience longer delays (37%) from first symptoms to diagnosis compared to white people.

> **On average patients wait 163 days from their symptoms first becoming apparent to a diagnosis.**

The NSS Pathway represents a huge opportunity to improve diagnosis performance in hard-to-diagnose cancers. It is the only policy initiative we have seen designed solely to address the diagnosis challenges that arise from non-specific or vague symptoms in cancer. We therefore undertook the project to identify how NHS England and Cancer Alliances can maximise the potential for the pathway to improve diagnosis in myeloma and other cancers with similar challenges.

NHS England describe Cancer Alliances as:

Bringing together clinical and managerial leaders from different hospital trusts and other health and social care organisations, to transform the diagnosis, treatment and care for cancer patients in their local area. These partnerships enable care to be more effectively planned across local cancer pathways.

What did we do?

We undertook a rapid review of available documents and held interviews with NSS pathway managers across four Cancer Alliances. Key interventions to improve myeloma diagnosis via an NSS pathway were identified, including haematology input into the multidisciplinary team (MDT), improving GP awareness of the pathways, and incorporating a myeloma screen as a filter function test (FFT) before NSS referral. FFTs are pre-referral tests (such as blood tests) that are requested to assist GPs in triaging and referring patients to the most appropriate referral route.

The research we obtained from the rapid review informed two interactive workshops, bringing together expertise in haemato-oncology, laboratory science, primary and secondary care, operational management and patient representatives. Some had expertise in designing, implementing, and evaluating NSS pathways. Others were more familiar with existing routes to myeloma diagnosis.

What were our findings?

The research revealed significant variation in NSS pathway implementation, influenced by the flexibility given to Cancer Alliances by NHS England. Key differences include how the pathway is delivered and the pre-referral testing available. Our research indicates promising data in NSS pathways delivering higher conversion rates than overall figures for urgent suspected cancer referrals. This means that the percentage of NSS pathway referrals that result in a diagnosis of cancer is higher than the percentage of urgent suspected cancer referrals which result in a cancer diagnosis.

However, there are gaps in the data collection of pre-referral tests and cancer site-specific conversion rates. This data could validate the importance of including myeloma-specific filter function tests. Such tests may further streamline patients to an appropriate urgent cancer pathway, speeding up the time to diagnosis.

What happens now?

We produced accompanying recommendations in our report. Our focus centred on best practice in diagnosing myeloma through NSS pathways, however our findings include recommendations that can support the earlier diagnosis of all cancers. These include improving access to data, raising GP awareness of NSS pathways, ensuring adequate financial support and resources for NSS pathways and greater collaboration between NHS England, Cancer Alliances and third-sector organisations.

We are calling for our recommendations to be enacted by NHS England, Cancer Alliances and NSS pathway providers to ensure that the innovative NSS pathway is an effective alternative route to diagnosing myeloma early. Over the next year, we will share this with key policy makers to encourage them to take on our recommendations.

Read the full report at: **myeloma.org.uk/nss-pathway-review**

KEY RECOMMENDATIONS

1 Myeloma screen availability and commissioning

Cancer Alliances and Integrated Care Boards should ensure the availability and routine commissioning of a myeloma diagnostic filter function test before NSS pathway referral.

2 Access to data

NHS England to publish analyses and timelines of myeloma conversion rates in NSS pathways, differentiating between pathways with and without myeloma-specific FFTs across all 21 Cancer Alliances.

3 GP education

Cancer Alliances should provide educational support to healthcare professionals, including GPs, to raise awareness of a possible myeloma diagnosis in primary care. NHS England should offer learning materials and events for NSS clinical leads, ICB (Integrated Care Board) commissioners, and Cancer Alliance NSS programme leads.

4 Support for the timing and the interpretation of results

Cancer Alliances should support GPs in determining when to use myeloma screens or myeloma-specific FFTs if these are optional criteria before NSS pathway referral. Collaboration with diagnostic providers and laboratories is crucial for reporting test results in a format that aids interpretation, reducing time to myeloma diagnosis.

5 Collaboration

NHS England, Cancer Alliances, and third-sector cancer organisations to collaborate and share data, best practice, and outcomes to improve NSS pathways.

6 Finance and Resource

NHS England to continue financially supporting the flagship NSS programme, which has proven to be critical adjunct to the urgent cancer referral pathway. To fully optimise myeloma diagnosis in NSS pathways, there should be no financial barriers to implementing myeloma-specific filter function tests in NSS pathway design.

THE EARLY DIAGNOSIS POLICY LANDSCAPE

NSS pathways are not the only early diagnosis initiative we are watching closely for developments which could have a significant positive impact on diagnosis for the myeloma community. We outline below areas of our policy focus we are currently monitoring to ensure what matters to myeloma patients is echoed through national policy.

Community Diagnostic Centres (CDCs)

CDCs are diagnostic hubs which are located outside of acute hospitals. The aim of CDCs is to increase diagnostic capacity and ease the burden faced by hospitals. Many tests such as CT's and MRIs can be undertaken there. They are often located in areas with good transport links which are easier to access for the public, such as supermarket carparks and shopping centres.

As of April 2024, there are 160 live CDC sites. We know that CDCs undertake investigations for suspected cancer, and we welcome any initiative which makes access to diagnostic tests easier and faster. Hospitals which have NSS pathways may utilise the diagnostic capabilities of CDCs in the future.

We will continue to monitor the progress of CDCs and engage with NHS England to fully understand how CDC's are performing for blood cancer patients.

Multi Cancer Early Detection Tests (MCEDs)

Multi Cancer Early Detection tests are blood tests which can help to detect different types of cancer. The NHS is currently trialling the use of the MCED Galleri test, which is due to end in July 2024. In May we heard the news that the NHS will assess the trial data from the full 3 years of the trial before committing to a larger scale pilot programme in the future. This decision to wait, will ensure that the NHS can assess the success of the test's performance and accuracy. The NHS are also seeking to determine whether the test will have delivered improved outcomes for patients and detected cancers at an earlier stage.

We are excited by the test as we know myeloma is one of 50 types of cancer which can be indicated as a possible diagnosis by the test.

Many sites in the NHS Galleri trial utilise NSS referral pathways to ensure safety netting and appropriate signposting of patients.

We are having ongoing discussions with Cancer Alliances, NHSE and GRAIL the company who developed the test to inform our knowledge base whilst we eagerly await the full trial results in 2026.

Best Practice Timed Pathways (BPTPs)

BPTP's are documents published by NHSE which provide a framework for the optimal order of tests to ensure a timely diagnosis for different types of cancer. The BPTP support the NHS ambition for all suspected cancer patients to have a diagnosis of cancer either ruled out or diagnosed within 28 days.

Currently there are nine published BPTP. The NHS plan to create a BPTP for all cancer pathways including NSS pathways. However there has not been a BPTP developed for blood cancer or NSS pathways.

We continue to campaign for a BPTP for blood cancer and are having active discussions with senior NHS leaders to advocate for initiation and development of a BPTP to ensure there is equity of access to supportive frameworks outlining the tests and checks needed to ensure the timely diagnosis of blood cancers, including myeloma.

MYELOMA

HOT TOPICS

HEALTHCARE HURDLES: LGBTQIA+ INEQUALITIES IN MYELOMA TREATMENT AND CARE

What are health inequalities?

Health inequalities are the unfair but preventable differences in health outcomes that exist for different groups within society. For example, sadly , people who identify as lesbian, gay, bisexual, transgender, queer, intersex, asexual or other members of the LGBTQIA+ community can experience poorer mental health and overall wellbeing than those who do not. This is one of the many factors, including race, ethnicity, geographical location, and income, that can affect someone's life expectancy, access to care, and their overall experience and satisfaction of the healthcare they receive.

Tailored treatment and care

No two people are the same. We all have unique and personalised needs and wants in life, and in relation to healthcare. Myeloma treatment and care is tailored to the individual patient; from the drug combinations used, the doses administered, and the supportive care given alongside active treatment.

However, this should extend beyond drug treatments to the social, psychological, and emotional support offered to everyone, regardless of their background, including those in the LGBTQIA+ community. This holistic support can help to build trust between you and your medical team, improve wellbeing and the overall satisfaction with the care you receive.

What you tell us

At Myeloma UK, we speak to myeloma patients whose medical teams have assumed a partner attending appointments is a friend, based on their gender or presentation:

"We've had all sorts of mixes and muddles where people made assumptions about our relationship."

These oversights may be accidental – but they still negatively impact the experience and wellbeing of LGBTQIA+ patients.

Some people worry about being themselves in healthcare environments:

"At first, I was really worried about showing [my partner] affection on the ward and causing some upset. I worried that people wouldn't be able to handle it, or that another patient wouldn't like it."

"Thinking about it, the times where I felt I could really relax in hospital were when I'd notice staff wearing rainbow lanyards or wearing ID badges with rainbows on them. It was reassuring to see. I knew that, in their presence, I could be completely myself."

What can I do?

Some NHS healthcare professionals wear rainbow badges or lanyards to signify they support the LGBTQIA+ community or that they have received specialist training. If you see this, you could start a dialogue by asking about it.

If you are comfortable doing so, it could help to share the following with your medical team:

- The people who support you and are important to you, plus their role in your life
- Your preferred name, title, and pronouns. These should be respected, even if they differ from information on your medical records
- Whether you are 'out' or not. Your personal information, including your sexual orientation and gender identity, is confidential and cannot be shared with anyone outside of your medical team without your consent

DID YOU KNOW?

A 2018 study by Stonewall, a charity standing for LGBTQIA+ people everywhere, revealed that 13% of respondents reported experiencing unequal treatment from health care staff because they were LGBTQIA+.

What is Myeloma UK doing?

As part of our new five-year strategy, we are starting conversations about health inequalities across the myeloma community. We want to identify the barriers preventing people accessing the treatment and care. To understand how the LGBTQIA+ community is affected, to generate insights and determine our actions, we need more information. If you would like to be part of this conversation, share your story with us by emailing comms@myeloma.org.uk

Where can I find support?

outpatients.org.uk

macmillan.org.uk/lgbtq

MyelomaUK

If you want to talk, the **Myeloma Infoline** offers information, support, and a listening ear for anyone affected by myeloma – you can call us on **0800 980 3332**

CHALLENGES FACED BY YOUNGER PEOPLE LIVING WITH MYELOMA

Although more common in older people, around a quarter of myeloma patients are diagnosed under the age of 65.

Younger people living with myeloma can often have different circumstances and needs when compared to older patients.

You told us:

We recently asked the 50s and under myeloma Support Group how they feel their support needs differ. Over 90% of those we surveyed thought that younger people faced different challenges to older people living with myeloma.

"Working and supporting a family with teenage children without myeloma is exhausting enough. Now throw in an incurable cancer diagnosis and the mental health impact on me and my family is huge."

"I've attended support groups where I have been by far the youngest there, the issues raised were not particularly relevant to me."

"We need better support regarding trying to get back to work."

If you are interested in joining our 50s and under Support Group, you can email **supportgroups@myeloma.org.uk** or visit our website for more information: **myeloma.org.uk/supportgroups**

Working and myeloma

Work can be a big part of our lives, and many may consider their job to be a part of their identity. After being diagnosed with myeloma, many people can continue to work with the right support from colleagues, family members, friends, and their healthcare team.

Legally, you don't have to tell your employer about your diagnosis, but it may provide an opportunity to discuss any support needs or reasonable adjustments.

It can also help your employer understand what challenges you may be facing. When an employer is aware of your situation, they are can make adjustments that allow you to continue working whilst balancing your health needs. Through our work, we speak to many people who find their workplaces to be considerate and supportive.

If you want to talk about working and living with myeloma, you can call the Myeloma Infoline on 0800 980 3332 or email **AskTheNurse@myeloma.org.uk**

Early menopause

Menopause occurs naturally with age, but certain myeloma treatments can induce early menopause, for example it is particularly common after high-dose therapy and stem cell transplantation (HDT-SCT).

Going through menopause whilst living with myeloma can be stressful. It is a significant change and can affect how you feel about yourself and how you cope with myeloma and its treatment.

Hormone replacement therapy (HRT) can be used to manage the symptoms of menopause. There are benefits and risks associated with HRT, which vary according to each person.

The risks will depend on different factors including when a patient starts HRT treatment, how long they take it for, their age and general health.

Fertility Issues

Your hematologist should explain the possible risks to your fertility and if your planned treatment might prevent you from conceiving a child in future. It may be worth exploring the option of having your sperm or eggs frozen and stored. Referrals can be made to a fertility clinic and a specialist fertility counsellor will be available to support those affected. More information can be found at **myeloma.org.uk/library/ask-the-nurse-myeloma-and-fertility/**

Talking to children

Discussing myeloma with children can be particularly difficult and it's natural to want to protect them from sad news. However, children are often more astute than we give them credit for and may well 'sense' that something is going on. It is sometimes best to speak to a child in an environment they are comfortable in, this can lessen the stress of the situation. It can be helpful to prepare a child that a serious conversation is planned and to put things in simple terms and to repeat key points.

Pictures or diagrams may help them understand. Try to keep them up to date with what is happening (with as little or as much information as you see fit). This will make sure they feel involved and will help stop feelings of exclusion. Give them time and the opportunity to ask questions or to say how they feel, but don't force a conversation. Myeloma UK have published an illustrated children's book "Kelsey and the Yellow Kite" which explains myeloma in simple terms. We also offer easy read guides about myeloma and its treatment.

You can order our publications for free on our website or by calling the Myeloma Infoline on **0800 980 3332**

THE POWER OF PETS

In a nation of pet lovers, the role of pets can extend far beyond wagging tails and playful antics. For many myeloma patients, these furry companions play an essential part in their lives.

Living with myeloma can be challenging, but the power of pets lies in their ability to provide a unique form of comfort and companionship.

Stress reduction

Pets possess a remarkable ability for easing stress and anxiety and providing a sense of calm. Research shows that interacting with pets increases oxytocin levels (a hormone associated with bonding and stress management) in our blood within minutes and can help to lower heart rate.

For some myeloma patients, a pet's steady presence, lovable mischief, or the act of looking after them, can also be a welcome distraction from the worries, frustration, pain or boredom that can come with extended periods of treatment or myeloma-related complications.

Colin shared **"we got an Airedale, Poppy, who helped my wife, Maragret. Just stroking the dog took her mind off the pain she was experiencing"**.

Supporting social connections

Owners love to talk about their furry companions, and others love to ask about them.

Whether out for a walk, talking to a friend or connecting on social media, pets can offer an easy and reliable topic of conversation. Creating connections and fostering social interaction can be invaluable in tackling isolation for people affected by myeloma.

Encouraging exercise

Pets encourage owners to be more active. Research shows that, in general, dog owners are more likely to walk recreationally than others, which in turn offers mental and physical health benefits. A daily stroll with your loyal companion may not be realistic for everybody living with myeloma, so keeping active could mean moving around the home and garden whilst interacting with your pet. Pace yourself – whatever the activity level, your beloved pet is bound to keep you motivated.

Companionship for all

Amidst the uncertainty myeloma can bring, pets can offer comfort to all the family. They may be a reprieve from worry and remind us how to live in, and for, the present. For those planning ahead or receiving palliative care, knowing that their pet will be there to provide comfort to loved ones can be reassuring.

Positive impact: Caring for others in a way that feels achievable can be empowering. Research with other pet-owning cancer patients shows that **70% enjoyed the opportunity to care for their pet**

Myeloma and risk-aware pet care

Some aspects of caring for pets can come with additional risks for myeloma patients.

Because myeloma (and some treatments) makes the immune system less effective at fighting infection, patients need to be more cautious of picking up infection.

Tips for safer pet care:

- Avoid tasks like cleaning chicken coops, litter trays or dog waste. If unavoidable, wear a mask, gloves and wash hands promptly.
- Scratches can increase the chance of infection so try to limit play and/or protect your skin.
- Help reduce risk to you by making sure your pet remains healthy and is up to date with vaccinations.

Myeloma and managing pet care

For all the joy pets bring, they can also be hard work to care for when feeling unwell. Living with myeloma can bring uncertainty about many things – including how to manage pet care during these periods.
If you are worried about managing to care for your pet, it's a good idea to talk to your close family and friends about this. Sometimes, somebody you already know may be happy to help. Finding a trusted pet sitter who can offer regular or occasional support can also be invaluable.

For support with feelings of isolation:

Contact us through the **Myeloma Infoline** at **0800 980 3332**

Email **AskTheNurse @myeloma.org.uk**

Find our about **Peer Buddy Service** which connects your with someone with personal experience of living with myeloma. Visit **myeloma.org.uk/peer**

INTERVIEW WITH MATT WYNES

DIRECTOR OF FUNDRAISING

For the past 18 months, Matt Wynes, Director of Fundraising has been working closely with the fundraising team to enhance our income generation, and support all people affected by myeloma. Matt talks about why fundraisers are the lifeblood of Myeloma UK and how his own cancer diagnosis spurred him on to give those affected by myeloma a hopeful future.

You've been appointed as Director of Fundraising a year after joining Myeloma UK as Acting Director. What drew you to the role initially?

Just over five years ago, I had my own cancer diagnosis and was told I had a 10% chance of living more than five years.

Fortunately for me, three months later this diagnosis was found to be a mistake but having a family and being the father of two young children, the experience gave me strong understanding of, and empathy for, people in a similar situation.

Therefore, when I saw the role of Interim Director of Fundraising come up at Myeloma UK back in January 2023, I not only felt a strong connection to the charity but a real drive and determination to use my personal and professional experience to create positive change for all people affected by myeloma.

How has your previous experience informed your work at Myeloma UK?

I spent a large part of my career in commercial banking before joining the charity sector as a corporate fundraiser 14 years ago.

This means I am both partnerships and solutions-focused, and feels like a perfect marriage in terms of the myeloma community, and how passionate and connected our supporters are to the work of Myeloma UK.

We need to ensure we meet the needs of the people who support our community and give them as many tools and opportunities as possible to do so – in a way that is both fulfilling and engaging for them.

What's Myeloma UK's biggest asset as a charity?

The myeloma community.

> **"I've never worked for an organisation that has such passionate and engaged supporters. Every time I meet them it's both a privilege and incredibly inspiring."**

I've never worked for an organisation that has such passionate and engaged supporters. Every time I meet them it's both a privilege and incredibly inspiring.

Are there any particular areas of fundraising you're keen to focus on and develop?

We've got big plans and, whilst we've done well already, I'm really looking forward to working with our supporters and our fundraising team to make sure that we realise our potential. There are many people out there who already fundraise for us in a variety of ways, and their support is hugely valued and an inspiration.

> **"There are many people out there who already fundraise for us in a variety of ways, and their support is hugely valued and an inspiration."**

We need to make sure that we are making fundraising as easy as possible for them and providing all the resources they need. We also need to look at other areas of fundraising that we can develop further, such as trusts and foundations, donations from pharmaceutical companies,

regular giving such as direct debits and lottery, gifts in wills, and philanthropy – which could help fund significant areas of our work. There's lots to do, but the future is exciting. We have a great fundraising team, big ambitions, and an incredible community behind us.

What is fundraising's role in improving myeloma treatment and support for patients and their families?

It's very simple: we get no funding from the NHS or Government. All our research and charitable activities are funded by people taking part in events, voluntary grants and donations or gifts in wills.

In short, the more money we can generate through fundraising, the more research we are able to undertake, and the more support we are able to provide to everyone affected by myeloma.

What do you see as the biggest milestone in the treatment of myeloma over the last 25 years?

It's quite incredible that, in the 25 years since Myeloma UK was founded, 13 treatment combinations have been developed, and people are surviving four times as long as they previously did. But we also know that this isn't the case for everyone. There is so much more for us to do.

What has been your greatest highlight since joining Myeloma UK?

There have already been lots of moments of which to be very proud, including the fundraising success we are already having, and the way in which the fundraising team is developing.

The highlights have been our 'Myeloma UK – A Life Worth Living' garden at RHS Chelsea Flower Show and the recent Gala Dinner, which was hosted at The Londoner in Leicester Square.

To deliver such impactful projects that reached huge audiences, and increased the knowledge and profile of myeloma was an incredible success, of which we should all feel very proud.

At Chelsea Flower Show, not only was our garden the very first to be featured on the BBC's coverage of Chelsea – and a firm favourite with visitors – but it won both a Gold medal and the People's Choice Award, which was the crowning glory of an already memorable experience and a real testament to the hard work of all the volunteers, supporters and staff involved.

What inspires you, both at work and in life?

I've always been a sportsman, and have competed internationally, so I always strive for progress and continuous improvement.

> **"I've always enjoyed my professional life most when I'm seeing progress and making positive change."**

Having said that, I'm now on the wrong side of 50, so I have to be realistic about how I apply that to my own sporting aspirations! But in my professional life the same concepts apply: how can we push forward? How can we achieve more and continually improve? I've always enjoyed my professional life most when I'm seeing progress and making positive change. That's why I enjoy my role at Myeloma UK so much. We have plenty of opportunities to do just that and to create positive change for everyone affected by myeloma.

ADVOCATING FOR ACCESS TO NEW MYELOMA TREATMENTS IN THE UK

The treatment landscape for myeloma is both exciting and challenging.

Over the past decade it has evolved to deliver more effective treatments and more clinician and patient choice, with further medical and technological advances offering better outcomes for patients in the future.

There are significant developments and ongoing clinical trials looking at how we can best treat newly diagnosed patients, those who relapse after first treatment and better options for people who have experienced a lot of different treatments.

New advances in the next generation of drugs with novel modes of action, including bispecific and trispecific monoclonal antibody therapies and CAR-T immune therapy show promise to deliver longer remission and drug-free treatment periods. At Myeloma UK we welcome these new developments, however, we recognise our UK community is waiting longer than European and American patients to be treated with the best available options.

Therefore, we are advocating for an end to UK variation so people can be treated with the newest medicines, where ever they live. We are taking action to fight the inequalities that exist in timely diagnosis, treatment and optimal supportive care.

You can read more about myeloma and bispecific antibodies on our website at **myeloma.org.uk/atn-bispecific-antibodies**

The current UK access to medicine situation

We are now at a crunch point where new barriers are emerging which will test how the UK government and devolved nations make new medicines available to patients as quickly as possible. Examples of this include:

- Restricted NHS drug budgets.
- Lack of flexibility in National Institute for Clinical Excellence (NICE) and Scottish Medical Consortium (SMC) cost-effectiveness methodologies.
- Reluctance of the pharmaceutical industry to commit to supporting access for UK patients. This includes a decline in commercial clinical trials, academic partnerships, manufacturing, and research hubs.
- A reduced number of applications for funding from the NHS by pharmaceutical companies.

How Myeloma UK is advocating for patient choice and access to new treatments

Over the last 25-years our success includes diagnosing myeloma patients earlier and campaigning for treatment for all patients with the best medicines available.

We have advocated and delivered **10 new myeloma drugs in 13 combinations resulting in a quadrupling of life expectancy, with 3 out of 10 patients living for 10 years or more**.

We seek to bridge the gap to cure by delivering access to current and next generation myeloma treatments and advocate for personalised diagnostic and treatment pathways. To support this ambition, we are working together with our community based on three principles:

1. Amplify the voice and experience of our myeloma community.
2. Represent all our myeloma communities.
3. Utilise evidence-based policy to deliver our advocacy campaigns.

Our policy partnerships

We campaign for access to the best treatments for all people living with myeloma. We provide lived experience insights and work closely with those making the key treatment decisions. Those who decide how drugs are approved for use, when and where they are available, and advocate for the support services needed to deliver the medicines. This includes working with the UK government, the devolved nation governments, the UK regulatory authority MRHA , the cost-effectiveness decision makers NICE and SMC and the NHS.

We are proud to be a core founder member of the **Blood Cancer Alliance (BCA)**, the **Cancer 52 Alliance**, **National Voices** and Chair and Secretariat of the **Charity Medicines Access Coalition (CMAC)**.

Together we partner to ensure access for everyone, no matter what stage of myeloma they are experiencing and no matter where they live, to expect and receive the highest standards of myeloma diagnosis, care and treatment.

ASK THE NURSE

Rebecca Huntley, Em Silver and Ellen Watters **Myeloma Information Specialists**

What does a "line of treatment" mean?

When referring to where someone is in their myeloma treatment, you may hear the terms "lines of treatment" or "first-line", "second-line" and so on. This refers to the number of periods of treatment a patient has received for myeloma, with each separate period being referred to as a different "line of treatment".

A newly diagnosed myeloma patient starting treatment for the first time is having "first-line" treatment. Sometimes, there may be several planned interventions that would all class as one line of treatment.

For example, a newly diagnosed patient may have induction treatment followed by high-dose therapy and stem cell transplantation, then lenalidomide maintenance treatment until relapse and this would all still class as one line of treatment as all these stages are planned as one treatment period. Following from this, a patient who is at their first relapse and being treated again would be starting a "second-line" treatment and so on.

Certain treatment combinations are only available on the NHS at certain points in the treatment pathway and so may also be referred to using this terminology. For example, a treatment which is only approved for NHS use for patients who have had two previous periods of myeloma treatment may be said to be "only available at third-line".

If you are unsure what point you are at in the myeloma treatment pathway, your medical team (haematologist and/or clinical nurse specialist) will be able to clarify this for you.

What are free light chains and the free light chain ratio?

Plasma cells are a type of white blood cell found in the bone marrow. They produce antibodies, which are also known as immunoglobulins (or Ig for short). Antibodies help us to fight off infection. In myeloma and related conditions, the plasma cells become abnormal and produce large amounts of a useless antibody known as paraprotein.

Like all antibodies, paraprotein is a 'Y-shaped' molecule made up of heavy chains and light chains. There are five types of heavy chain (IgG, IgA, IgM, IgD and IgE) and two types of light chain (kappa and lambda).

When making antibodies, the plasma cells produce more light chains than are required. These light chains enter the blood and are then known as 'free light chains'. It is normal for low levels of free light chains to be found in the blood and the level of kappa and lambda light chains are usually evenly balanced. This balance of kappa and lambda light chains is known as the 'free light chain ratio'.

When abnormal plasma cells (myeloma cells) produce the paraprotein antibody, they produce large amounts of one type of light chain – either kappa or lambda – which tips this balance and causes the ratio to become abnormal.

Myeloma patients will have regular blood tests to measure their paraprotein and free light chain levels, and free light chain ratio. If these levels begin to increase, or if the free light chain ratio becomes abnormal, this can be a sign that myeloma is becoming more active.

I have myeloma but I'm in remission, can I have a knee replacement?

All surgical procedures are associated with some risks such as infection, bleeding, blood clots following surgery, and poor wound healing.

These risks may be higher in those with myeloma, especially those with active myeloma who are on treatment for it. For patients whose myeloma is in remission, these risks may be lower.

Many myeloma patients do undergo knee replacement surgeries and recover well from them with improved mobility, physical and emotional wellbeing and quality of life.

Any surgery will require a thorough pre-operative assessment to ensure all risks are minimised as much as possible. Your surgical team and anaesthetist will weigh up the risks and benefits of your surgery whilst considering your individual medical history and take any necessary steps to reduce them as much as possible.

Preventative (prophylactic) treatment such as antibiotics and blood thinners (anti-coagulants) are often prescribed and can be effective in minimising risks of infection and blood clots.

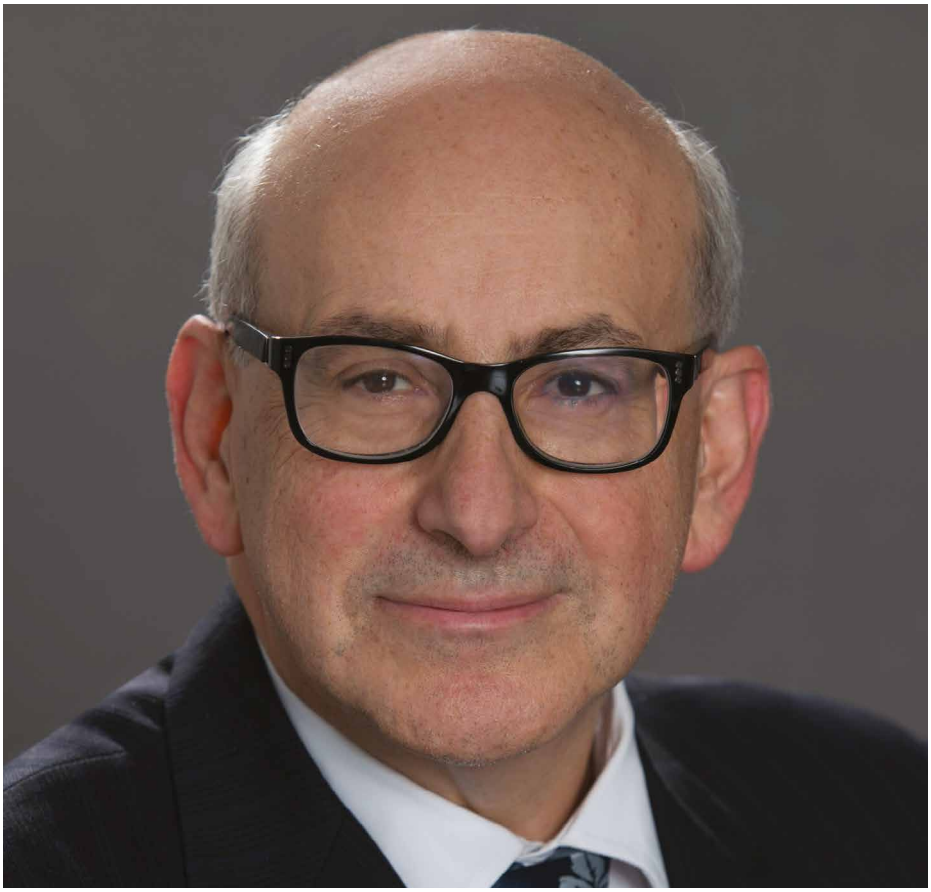
You may also benefit from physiotherapy exercises after the surgery to help you regain muscle tone and strength and to ensure your recovery is progressing as expected.

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

SUPPORTER STORIES

Myeloma UK is delighted to share the news that David Ereira OBE has been appointed as Chair of the Board of Trustees.

David, a partner at Quinn Emanuel Urquhart & Sullivan, LLP, has extensive experience working with the third sector and government agencies and is keen to help drive Myeloma UK forward and "rewrite the future for people affected by myeloma".



"Over the relatively short period Myeloma UK has been in existence, it has really contributed to making a difference to people's lives."

"I'm delighted and honoured to be taking up the position of Chair of the Myeloma UK Board of Trustees," said David, who was previously a trustee and acting chair of Marie Curie as well as chair of the Public Chairs Forum and the Insolvency Service.

"Over the relatively short period Myeloma UK has been in existence, it has really contributed to making a difference to people's lives. Not only clinically but, as importantly, in providing support, guidance and a connection for people suffering from a still under-recognised disease.

"During my appointment conversations, I have been struck by how the work of the charity reflects the whole lifetime of an individual's experience of myeloma. That concept of hope and support at every stage resonated deeply with me."

Dr Sophie Castell, Chief Executive at Myeloma UK, welcomed David's appointment.

She said: "We are delighted to welcome David to the charity and look forward to working with him as we build on our vision to provide treatments, information and support so anyone affected by myeloma can look to the future with confidence.

David brings a wealth of experience and comprehensive understanding of the third sector to Myeloma UK. His commitment to putting people affected by myeloma at the very heart of decision-making is a natural fit and will stand us in good stead as we strive to achieve our goals and break down the many barriers facing people with myeloma."

David's appointment comes at a pivotal time for Myeloma UK, following the launch of our new strategy.

"We are delighted to welcome David to the charity and look forward to working with him as we build on our vision."

David added: "Joining at the start of the new strategy gives me the opportunity to support the charity as it makes the changes that will rewrite the future for people affected by myeloma.

I'm also eager to meet people who make up our wider community: people affected by myeloma, clinicians, researchers and funders. This spirit of partnership, encapsulated by the new strategy, is one I am eager to see thrive."

Be part of a panel

and help the myeloma community go further, faster.

MyelomaUK

Myeloma UK is looking for people to join our:

- **Patient Information Panel** – Help us develop our information resources
- **Patient and Carer Research Panel** – Share your experiences with researchers across the UK

Patients with myeloma and related conditions, friends, and family members are all welcome.

We want our panels to reflect the diverse voices of the myeloma community and would encourage people from a Black, Asian or other minority backgrounds to join us.

Join a panel today: **myeloma.org.uk/panels**

Together, we are the cure.

myeloma INFODAYS 2024

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

MyelomaUK

We're here for everything a diagnosis of myeloma brings

Call our **Myeloma Infoline** on **0800 980 3332** for practical advice, emotional support and a listening ear.

Get answers to your questions by emailing our Myeloma Information Specialists on **AskTheNurse@myeloma.org.uk**

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

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

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

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

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

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

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

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