AUTUMN/WINTER 2023

myeloma Matters

Spotlight on Remission

Hot topics
Living well in winter

My life with myeloma
Mark Davies

Research focus
Just one thing

MyelomaUK

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DEAR READER

Alice Baron
Myeloma Matters Editor

Welcome to this edition of Myeloma Matters.

As we come to the end of the year, many of us will be getting together to celebrate and spend quality time with loved ones. However, it's important to take a moment to acknowledge that not everyone will be spending their time how they would like. Challenges can arise within families, complications may cause disruptions and, sadly, there may be loved ones no longer with us to celebrate.

By naming those challenges and acknowledging them, we're not diminishing the joy that can be found, but we are helping to normalise the hard parts too. People will be feeling a mixture of emotions and facing different challenges, and we need to help people feel able to talk about them. It can be easy to feel guilty or ashamed for not always feeling bright and positive, so I hope that by calling out the hard parts and facing them together, you know that you're not alone, and, however you feel, your feelings are valid and there is support available for you.

This theme is highlighted within our Spotlight on remission.

Although it is a time for joy and celebration, it can be easy to sweep some of the difficulties people face during this time under the carpet. I hope you find it a helpful section and know that you're not alone if you're facing difficulties alongside the joy of remission.

As always, thank you for being part of our community – for supporting us and each other this year. As Mark so beautifully says in his story, it's not a community anyone wanted to join, but it is a wonderful thing. I see frequently the power of the collective in our Support Groups, Peer Buddying and Discussion Forum, and this is echoed in the teamwork displayed between patients and healthcare teams in our Clinical Service Excellence Programme in improving and changing care together (see pages 14 to 17).

On behalf of all of us at Myeloma UK, I wish you the best for the festive period. Whether you're facing hard times or joyful times, or both, I'll leave you with words of advice from our myeloma community – be kind to yourself.

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

Breaking down barriers: Racial disparities in myeloma clinical trials

Although myeloma affects a diverse population, clinical trials often lack this diversity, undermining progress in treating this cancer. A recent American study has shown that certain eligibility criteria might contribute to this problem.

Myeloma is twice as common in African Americans than in white Americans, yet Black people comprise less than 5% of myeloma trial participants in the USA.

A recent review of myeloma trials, 2006–2019, submitted to the US FDA (Food and Drug Administration) found that Black patients were often excluded from trials because of blood count eligibility requirements.

For example, 19% of Black patients were excluded for failing to meet laboratory benchmarks for different blood cell counts, compared to 10% of white and 11% of Asian patients.

The researchers say that, because measures like white blood cell (WBC) counts may be naturally lower in Black people than white, it's unsurprising that Black patients are not meeting criteria.

Researchers and clinicians must consider normal racial and ethnic variation in blood counts when setting eligibility criteria, to ensure future representation.

Establishing inclusive trial designs will better reflect real-world populations, promising improved care and outcomes for all myeloma patients.

Physiotherapy prehabilitation before stem cell transplant can improve outcomes

Researchers have found that myeloma patients who commence a physiotherapy exercise programme before (prehabilitation) undergoing high-dose therapy and stem cell transplantation (HDT-SCT) experience improved post-transplant outcomes.

ASCT is the standard of care (SOC) for newly diagnosed myeloma patients considered 'fit' enough. However, the intensive treatment often leads to deconditioning, with lasting effects.

Researchers investigated whether provision of individualised, physiotherapist-led exercise programmes before, during, and after HDT-SCT could improve outcomes.

Participants were randomly allocated into two groups. The control group (27 patients) received the usual SOC throughout treatment.

The intervention group (23 patients) followed personalised exercise protocols, including supervised and unsupervised sessions, in addition to usual SOC.

Patients who received a prehabilitation programme generally reported reduced fatigue, improved quality-of-life scores, and improved physical capability over the course of the study, compared to the control group.

Findings of this small-population study suggest that implementing adaptable exercise programmes before HDT-SCT, and continuing until several months post-transplant, can have beneficial physical and psychological impact for patients. These insights will benefit from further future studies with larger populations.

Intensive new treatment approach offers improved responses for hard-to-treat myeloma

Results from OPTIMUM/MUK nine, a phase II clinical trial, reveal that intensive treatment can improve outcomes for patients identified with ultra-high risk (UHiR) myeloma.

Patients who have 'high risk' genetic markers are typically less likely to respond well to routine treatments. The trial is the first of its kind to use genomic profiling to identify patients with UHiR myeloma who could benefit from more intensive treatment approaches.

107 newly diagnosed patients with UHiR myeloma were recruited for treatment.

Participants received an intensive five-drug induction treatment, before high-dose therapy and stem cell transplantation (HDT-SCT), followed by consolidation and maintenance treatments.

At the end of induction, over 95% of participants had responded to treatment. 100–120 days after HDT-SCT, most of these patients had achieved a very good partial response, or better.

At an 18-month follow-up, 84 of 103 patients (81.7%) still showed no signs of active myeloma, indicating that responses were long-lasting.

These results suggest that targeting UHiR myeloma with intensive treatment approaches can improve outcomes for patients.

However, even with this rigorous approach, small numbers of patients did not respond or relapsed early, showing that more research is needed for this hard-to-treat group.

MY LIFE WITH MYELOMA

NAME: Mark Davies

LIVES: London

AGE: 56

I was sitting in a tiny office in the hospital on a gloomy autumn evening when I was told I had myeloma. It was 2016 and I was 49. It seemed like an out-of-body experience: unreal and so difficult to come to terms with that I'm not sure I really believed it.

I had never heard of myeloma until a few weeks earlier and, even then, I was told it was very unlikely to be that, which had led to loads of tests. I was just too young and fit, they said, which was nice as I didn't feel young and fit at all. As it turned out, myeloma was a reality for me. I was "smouldering", the consultant explained, but could expect the disease to become active at some point. He reckoned that, once that happened, I might survive long enough to see my kids off to university.

> **Only a dark cloud hanging over me rather than the full-on thunderstorm so many people face.**

I'd gone to the GP partly because I am a hypochondriac and partly because the feeling in my feet and ankles was really strange. It was painful, but also odd: it felt as though I was wearing wet socks. The doctor was puzzled too, but ordered some blood tests and she must have added paraprotein levels to them.

It meant that we got to the myeloma early, a blessing I know I am lucky to have had. I was on "watch and wait", a grim-enough prospect in itself, but only a dark cloud hanging over me rather than the full-on thunderstorm so many people face as myeloma attacks their bones.

Eventually, more than four years after that diagnosis and a few false alarms, the haematology team at King's College Hospital in south London decided that my paraprotein levels had crept up too much. Sure enough, the MRI showed that I had lesions on my spine and it was time for treatment.

The world was in the depths of the Covid pandemic and at least that meant I wasn't exactly missing out on things as I started VTD chemotherapy. I couldn't really find the energy to do very much – and everyone else was supposed to be staying at home too.

I didn't work during that time, partly through exhaustion but also because I found the drug regime difficult. Steroids kept me awake all night and prone to delusional behaviour: I signed up for endless self-improvement classes, which I had to keep cancelling, and wrote emails which I am relieved I kept in drafts.

I still get neuropathy and cramps, apparently as a result of the Velcade, which I learned to inject myself at home – another way of keeping away from Covid. Three years on I've still managed to avoid the illness, I am glad to say.

And it all worked. My paraproteins came down, quickly at first and then more gradually, but enough to make a stem cell transplant possible. I had that in July 2021 and, after a three-month recovery, I was pretty much back to where I had been, maybe 80%, before treatment started.

As I write it now, this all feels like something that just happened: difficult, grim and hard, but manageable. Back then it felt very different. If you'd said to me three years ago that I was about to have chemotherapy and a stem cell transplant I would have felt it was impossible. I would have either tried not to think about it or to hide away as much as possible.

"I am not thankful to myeloma for very much, it did bring me a moment of love and tenderness with my father, which we had often struggled with over the decades before."

And, of course, it has been hard, physically and mentally. I got depressed before, during and after. The anxiety I've had all my life got a lot worse. I'm in a very good remission but I still find it hard to come to terms with the uncertainty of living with myeloma, knowing that more likely it'll come back one day and we will start to work through it again.

And I do mean "we". Like any serious disease, myeloma takes its toll on everyone affected. My sons were just nine and seven when I was diagnosed and while we kept it from them then, they were only 14 and 11 when I started treatment and we had to explain why their dad spent most days lying on the sofa and took a lot of tablets. My wife Fiona has been an incredible source of love and support to me. My mum and dad were well into their 80s when I had to break the news: their love and support too was a source of such strength. Dad died this year, and while I am not thankful to myeloma for very much, it did bring me a moment of love and tenderness with my father, which we had often struggled with over the decades before.

My wonderful brother and many friends were similarly incredible. I genuinely could not have coped without their love, and that too from so many others, from former colleagues to strangers and many in between.

The people who work for Myeloma UK fall into that category too. When this all hit me, I had to try to understand it and the charity was the obvious place to go. I found expertise from the website and from the Ask the Nurse and Infoline services. I found support and fellowship from the forum, and I found a life-changing experience from doing the London Paris Ride.

"I felt lonely at first, lost and confused. But I soon realised that I was not alone... This community, a group we didn't want to join, is a wonderful thing."

On the forum I made friends, not least with someone who was in almost exactly the same place as me on this journey. We remain friends to this day and always will. Through the wider community I found a man called Kev who is now also one of my greatest friends. Kev had been through a stem cell transplant and talked me through what would happen in a language I could understand (not least because we are both north easterners!). I have tried ever since to be the kind of friend that Kev is to me.

It's so important to talk when something like this comes into your life. I've had counselling and reached out to friends. But talking to others going through the process, or with experience of it, has been precious beyond words. I felt lonely at first, lost and confused. But I soon realised that I was not alone. If it happens to you, reach out. This community, a group we didn't want to join, is a wonderful thing.

If I had a magic wand, what would I do? I'd find a cure, and more life-enhancing treatments.

I'd also insist that standard blood tests, the first port of call for GPs when a patient knows that something isn't quite right, include a check for paraproteins. There must be a better way than just waiting for bones to break and a diagnosis in an A&E department.

Not everyone feels comfortable about speaking up about their mental health. We should do all we can to make that easier.

I'd also do more to make it easier for myeloma patients to lead as full a life as possible. I've stopped doing things because of my damaged immune system, though I push things as far as I can. And I've also asked entertainment venues to find me a safe space for going to a concert or play. Usually they are very helpful. But widening awareness of a largely hidden disease like this remains a pressing need. And, finally, I would invest in more emotional support for those of us living with the uncertainty of myeloma. I often struggle with my mental health, sometimes really badly.

I'm told it's not surprising, the trauma of treatment, the uncertainty of the future. I mourn my old life, when I felt fitter, stronger and less tired all the time, free of the pain caused by the side effects.

I've had some amazing support in terms of facing that mental struggle and it's an ongoing project. But I think I'm lucky – I am happy for people to know that I get depressed and anxious. My employer is very understanding.

That is not always the case as I am sure many people will agree. And not everyone feels comfortable about speaking up about their mental health. We should do all we can to make that easier.

I've also taken great joy from doing the things I love and doing them without worrying about things too much.

I've been a football fan since I was six, and I'm as much in love now with my club – Middlesbrough – as I was back in 1973.

It's given me great joy – and lots of pain – over the years and I've combined that with my love of writing, another lifelong passion, to write a book about my experience with myeloma and how I've handled it. More than anything else I hope it helps anyone who finds themselves affected by myeloma, even if football isn't their thing.

The little joys, the connections, the friendship – they really do make a difference.

I'm not saying that football has been able to take away the difficulties of treatment but it has been a wonderful distraction in difficult days, and at times brought me levels of joy that are enough to make me forget all those difficulties and feel about as happy as it is possible to be.

It works for me, but it may not for you. I suppose what I'm saying is that, whatever it is in life that you love, in these situations it makes sense to reach out for them with more intensity than ever.

The little joys, the connections, the friendship – they really do make a difference.

Mark's book **A Love Letter to Football: From the Terraces to a Transplant and Back Again** is out now. To order a copy, go to: **pitchpublishing.co.uk/shop/love-letter-football**

You can contact Mark through his X/Twitter **@markdavies67** or via email at **mark.davies67@gmail.com**

SPOTLIGHT ON REMISSION

“The way I see it, there’s a volcano inside me. At the moment, it’s dormant, but at some point in the future, it’s probably going to erupt again. But while it’s dormant, I’m going to get on with things and do as much as I possibly can.”

INTRODUCTION TO REMISSION

While we don't yet have a cure for myeloma, putting myeloma into remission is the goal of treatment.

Myeloma is a relapsing-remitting cancer, which sets it apart from many other cancers. 'Relapsing-remitting' means there are periods when the myeloma is active and causing problems in the body and needs to be treated. Treatment aims to bring the myeloma back under control and provide a period of remission or plateau (where the myeloma is under control at a steady level). After reaching remission or plateau, many patients will remain well for some time – it may be months or years before the myeloma becomes active again.

Being in remission is a time for celebration. But for many, it can bring a different set of challenges.

Many people have told us that they have found hard and emotionally challenging moments during this time. It can feel like you've reached the peak after a long and difficult hike, but there are clouds obscuring the view or you're too tired to take it in, thinking only of the next climb to do.

Normalising difficult emotions and thoughts is important – especially when you weren't expecting them or you feel ashamed or guilty for not enjoying or making the most of your remission.

So often people say how valuable speaking to other people living with myeloma is, so in this Spotlight on, we have thoughts from the community on their experience of remission and of what advice they'd give to others facing challenges during remission. If your remission isn't what you expected, I hope you'll feel less alone and more prepared for it by hearing from others on their experiences.

Lastly, I want to acknowledge that for those of you who may be looking forward to remission or you've not had as long or deep a remission as you'd hoped, this can be incredibly difficult. Talking to someone about this can help – our services are available to support you.

WHAT MIGHT YOU NEED SUPPORT WITH DURING REMISSION?

Not feeling how you expected

With the relief of treatment being successful, you'd be forgiven for thinking everything will go back to "normal". So how do you cope when you don't feel how you thought you would? Speaking to others, understanding that everyone is different and there's no right way to feel can help normalise any negative feelings and help you learn to manage them, so they don't take over.

Uncertainty of relapse

Some people describe remission as a period of waiting – as one person put it – waiting for the volcano to erupt again. This uncertainty can hang over you and loiter in the background. Learning to live with uncertainty is challenging but there is support available to help you manage and learn to enjoy this period.

People's misunderstandings

Because myeloma is different from other cancers, people may think that you're cured or back to how you were before your diagnosis, and having to explain to people that you are being monitored and that you may need further treatment in future can be draining and disheartening.

Giving people information or signposting them to Myeloma UK can help them educate themselves and learn how best to support you.

Staying vigilant

It's crucial to stay vigilant about possible signs of relapse, so it can be caught as early as possible. However, it is possible to a balance this with enjoying your life and worrying consistently.

Continuous treatment

With treatments increasingly being given until progression, many patients these days are still on treatment even during remission.

Some people find it comforting to be taking something to help control their myeloma consistently, but for others it can be a reminder of their myeloma at a time when they're trying to put it to the back of their mind. You can speak to your healthcare team about this if you'd rather not be on treatment consistently so you can figure out the best option for you together.

Ongoing symptoms or side effects

Unfortunately, there are some symptoms, side effects and complications of myeloma and its treatment that are ongoing into remission.

For example, even when not on treatment, myeloma patients are generally regarded as more susceptible to infection than people generally. Some people experience ongoing pain or bone complications. These symptoms and complications will be managed as best as possible by your team.

Less frequent appointments

You may have less frequent blood test and appointments with your healthcare team. This is done when healthcare teams are happy that this level of monitoring is sufficient, but sometimes it can make it feel like you have less support from them.

It's important to remember you can always talk to your team between appointments and whenever anything is bothering, even while you're in remission.

More support about remission and living well is available in our resources:

Psychological wellbeing and myeloma Digital Infoday Session

Living with uncertainty Digital Infoday Session

Emotional wellbeing tool

Infopack for living well with myeloma

Peer support and discussion forum

Find out more about these resources on our website, or call or email our **Myeloma Information Specialists**

PATIENT PERSPECTIVE

We asked what people's experience of remission was.

"Being currently in remission is an amazing feeling, but I am also aware that I'm a possible ticking time bomb. After being diagnosed, I had to cancel three holidays due to my treatment, so I have now booked several holidays to spend precious time and make memories with family and friends. I am also looking forward to returning to work in some capacity."

"Hearing that I was now in remission was so good. Not having to take so much chemotherapy, I began to feel better, and my sense of well-being improved."

"Although I was very tired for a couple of months after my SCT, I began to start doing 'normal' things thereafter, like going to gigs and having weekends away (all of which I discussed with my consultant beforehand, to check that nothing was too 'risky'). It was bliss to have a period of time during which I didn't need to take any medication and had fewer hospital appointments."

"It was a relief to be able to do 'normal' things again. I visited several places that I'd always wanted to see."

"My energy after a double transplant was slow to rebuild – it's taken over a year. But now I'm on lenalidomide maintenance and having regular check-ups at the hospital I feel confident I'm in remission for a long while."

"[I experienced] complete exhaustion – physical, emotional, psychological."

"These things never leave you once you have been diagnosed, so yes, the mental part was often worse than the physical part."

"Far better than expected. Over the last 20 years we have travelled the world, enjoyed both daughters getting married and three grandchildren. Have always accepted that I had cancer and decided to continue life in a very positive way. My family are all very supportive. Age is more of a barrier now as fitness restricts some activities."

"I've been pleasantly surprised that remission has enabled me to lead a life little different from that before my diagnosis."

"When you're on active treatment you're working towards getting the myeloma back under control and into remission which is a positive. When you're in remission you've peaked and are then waiting for it to come back."

"I had no idea what to expect."

ADVICE FROM THE COMMUNITY

We asked people living with myeloma what message or advice they would give to someone about remission.

"We are all going to feel different receiving the brilliant news of being told you are in remission. I think when you're in remission you feel you should not bother people, especially the medical professionals, with your fear and worries, and there are plenty of others who are not as fortunate as you, but mental support is still so important."

"The reality is that some people aren't lucky with myeloma and it's very unpredictable and despite best efforts and the best mentality you have around it, it may still never be enough, but I'm still here eight years later."

"Enjoy life to the full, but please do not overdo it. Your body is not the same as before. Listen to your body and take the advice of your consultant."

"Enjoy the time and don't worry about what 'might' happen."

"Enjoy the things in life that bring you pleasure whenever you are able."

"Enjoy every moment. We all understand that myeloma is a relapsing-remitting condition, so you need to make the most of the times when your myeloma is in remission and you hopefully feel pretty well in yourself. Having myeloma has taught me to live in the moment more; now, I try not to dwell on things that maybe haven't gone so well in the past and which I can't change, and I try to not look too far ahead either – I just do my best to enjoy and be grateful for each day."

"Keep as healthy as you can and get as much sleep as you can. Talk to others who are in similar situations. Finding others on social media and talking is really a great way to build your own confidence."

"Be kind to yourself – learn to adapt to a new way of living. Be open to changing your expectations."

"See as much as possible of your family and friends, and work down your 'bucket' list."

"The simple advice of take each day as it comes, talk to others in the same situation – we get it! Hospital teams are great and have all the knowledge but us living with it have the real-life experience."

"Seek support – talking is the best therapy. What helps me is participating in the myeloma community and setting myself manageable goals and doing things I enjoy."

Just one thing

What would patients, nurses and consultants change about their myeloma service?

BY JESS TURNER,
CLINICAL PRACTICE SERVICES
PROGRAMME MANAGER

The Clinical Service Excellence Programme (CSEP) is a Myeloma UK best practice initiative, designed to support hospitals in delivering patient-centred myeloma care. The programme was piloted in 2015. Since then, 59 hospitals have been accredited, with 15 returning to reaccredit.

The Clinical Service Excellence Programme (CSEP) is a Myeloma UK best practice initiative, designed to support hospitals in delivering patient-centred myeloma care. The programme was piloted in 2015. Since then, 59 hospitals have been accredited, with 15 returning to reaccredit.

The programme involves myeloma patients, families and carers, alongside all the healthcare professionals involved in myeloma treatment and care. This includes clinical specialist nurses, haematology consultants, allied healthcare professionals like physiotherapists, and administrative staff.

The accreditation process takes several months, and the Myeloma UK CSEP team work very closely with each hospital as they progress through the programme. Hospitals have to complete an initial application and an online self-assessment as well as gathering responses to our patient experience survey.

Seeking feedback from patients enables healthcare professionals to evaluate the standard of care they provide, identify positive aspects of the service, and highlight any areas of improvement that would positively impact patients.

Myeloma patients from hospitals going through the CSEP process are invited to complete an anonymous patient experience survey.

The survey ends with the optional question **'If you could change one thing about your myeloma treatment and care, what would it be?'**

In 2022, the CSEP team used this data to present a poster at the Annual Scientific Meeting of the British Society for Haematology. We had lots of interest in the poster throughout the conference and were very pleased to be sharing what patients had told us.

In 2023, we decided to combine the data with answers from myeloma nurses and consultants, with the hope we could present a poster at another conference.

We submitted abstracts for the Annual Meeting of the International Myeloma Society (IMS) and the International Conference on Cancer Nursing (ICCN) and were delighted to be asked to give an oral presentation at each conference.

I presented at ICCN on the healthcare professional data, and another member of the CSEP team, Monica Morris, presented on the combined data at IMS.

For the healthcare professional data, we used answers to the online hospital self-assessment form, as well as questions in emails and Microsoft Teams calls, we gathered feedback from clinical specialist nurses and haematologists working with myeloma patients.

We used the (slightly altered) question **'If you could change one thing about your myeloma service, what would it be?'**

Our aim was to compare patient and healthcare professional feedback on changes they would like to see in their myeloma service. We thought it was likely there would be at least some similarities, and that we would then know how best to inform service development to improve patient experience.

Between 2015 and 2023, over 1000 responses were gathered from patients, nurses and consultants.

> **"By combining the voice of both patients and the healthcare professionals caring for them, a stronger case for change can be made."**

Patient responses with suggested changes were included in the analysis, but purely positive responses were not.

NURSES

"More access to a dedicated palliative care professional with their main focus on myeloma pain. Myeloma pain can be very tricky to manage"

"I would want to change the service so that I could have more time with the patients. Sadly, it is very production line treatment currently"

CONSULTANTS

"Allied healthcare professional support in clinic"

"Working on community administration of chemotherapy closer to home"

All healthcare professional responses were included as they all mentioned at least one change they would like to see. As a result, over 500 responses were analysed and organised into themes (see the pie charts for these results).

Patient responses were grouped into eight themes: clinic waiting time, communication, continuity of care, coordination of care, holistic care, hospital facilities, travel to access treatment and care, and treatment options.

Nurse and consultant responses were grouped into seven themes: clinic waiting time, community delivery of treatment, dedicated hospital space, holistic care, research and treatment options, staffing resources, and other resources.

For patients, waiting time in either myeloma outpatient clinics or hospital pharmacies was the greatest concern. For healthcare professionals, having adequate staffing resources (particularly of clinical nurse specialists) was the main priority.

We believe these two sets of results are closely linked. Increased waiting times in clinic and pharmacy may reflect the greater numbers of myeloma patients being monitored, as treatment options increase and survival rates improve.

> **“Ultimately, what affects healthcare professionals also affects patients, and both groups are aware of the current missing gaps and future service changes.”**

Both of these extremely positive advances have resulted in increased pressure on nurse time, as their caseloads expand, and more myeloma patients are on treatment and needing review.

Unfortunately, what we hear from hospitals is that increasing time constraints mean less capacity for holistic needs assessments, formal frailty tools, or the emotional support that can make all the difference.

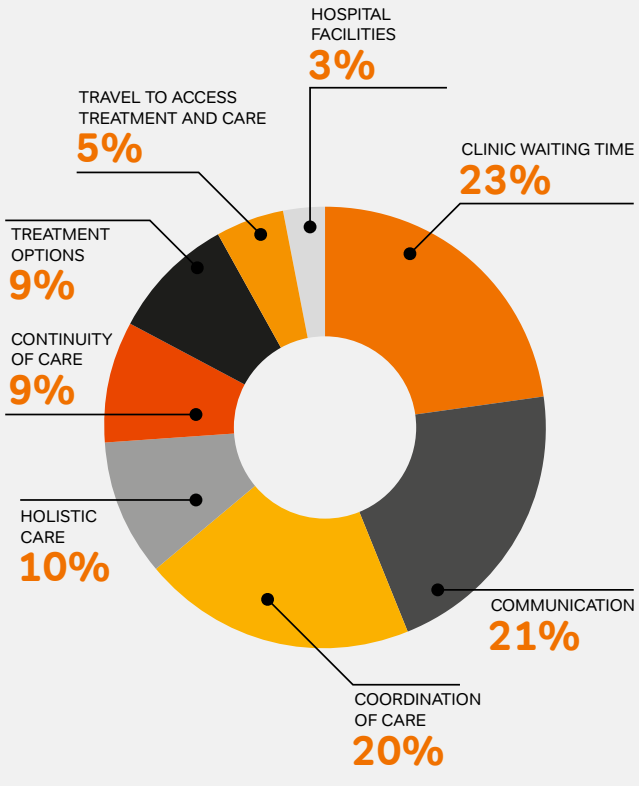
As a result, myeloma patients are being impacted by longer waiting times as their healthcare professionals have longer clinic lists, whilst nurses struggle to find the time to manage the individual needs of their patients.

The themes indicate the key areas of improvement which are important to patients, nurses and consultants.

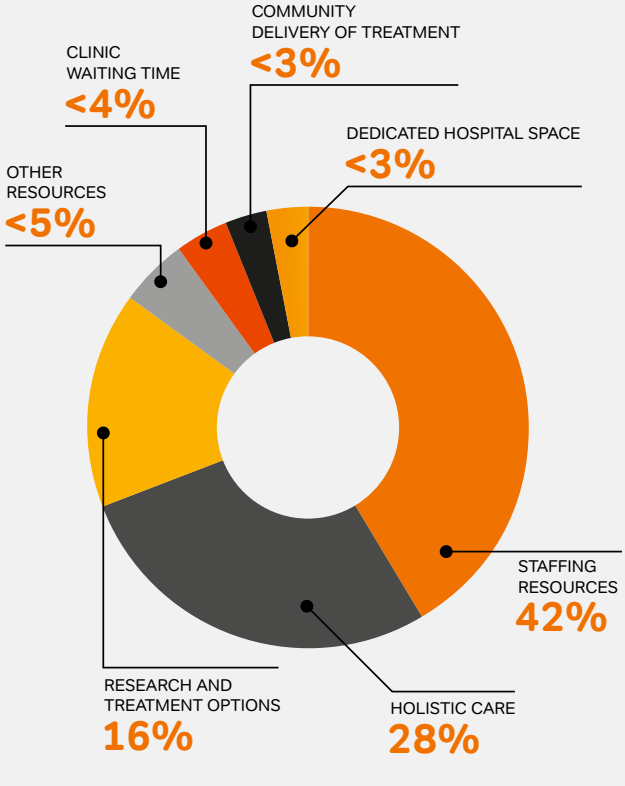
Some of these themes highlight systemic logistical problems within the NHS that the nurses and consultants cannot change, such as hospital space and facilities, waiting times, staffing, resources, treatment options, and travel for treatment and care.

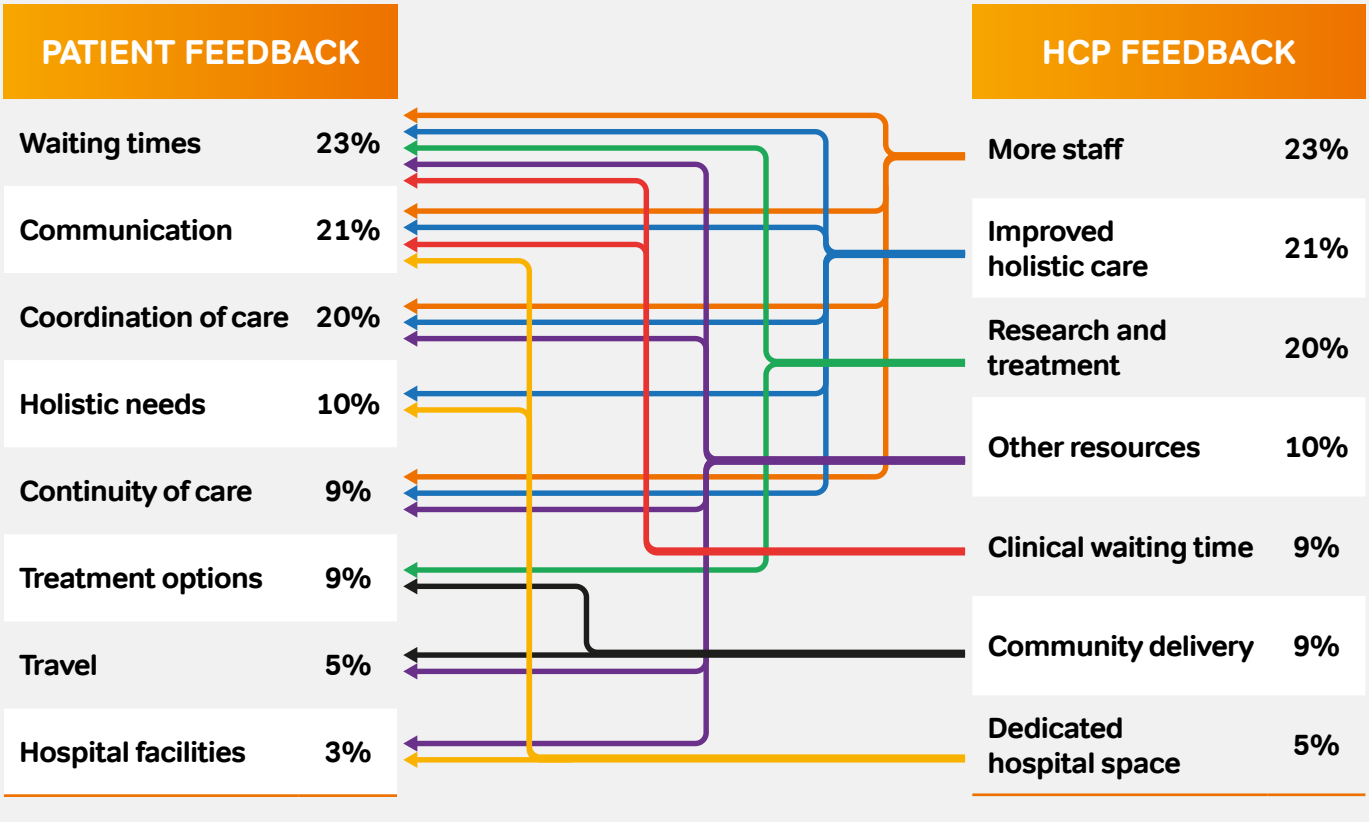
In staffing resources, the need for more myeloma or haematology clinical nurse specialists was most mentioned, including from nurses themselves.

PATIENT **FEEDBACK**



NURSE AND CONSULTANT **FEEDBACK**





Other themes underline the importance of ongoing close management in myeloma, such as continuity and coordination of care, and communication.

Finally, community delivery of treatment and holistic care highlight the importance of providing personalised treatment and care outside of the clinical hospital environment as much as possible.

There are lots of ways in which the two sets of themes are connected, as shown in the diagram above. Ultimately, what affects healthcare professionals also affects patients, and both groups are aware of the current missing gaps and future service changes.

As part of the final report we give hospitals in CSEP, we note highlights of the myeloma service but also make recommendations that would improve patient experience. Hospitals have to repeat the CSEP process every four years to stop their accreditation from lapsing. This not only ensures that standards of care stay the same or improve during that time, but it also allows hospitals to measure the impact of any service changes we recommend on their patients' experience of care.

This means that across individual hospitals, the results of the patient experience survey are part of a process that is designed to respond to patients' needs.

We hope that collectively, from hospitals across England, Wales, Scotland and Northern Ireland, the results contribute to a wider understanding of myeloma patients' experience and what matters most in their treatment and care.

If you have ever completed a patient experience survey for the CSEP team, thank you very much for contributing to not only the accreditation or reaccreditation of your hospital, but also to this piece of research.

We will continue to gather and share data from CSEP, as we believe it tracks the current issues affecting myeloma patients and the healthcare professionals working with them across the UK.

We hope that by combining the voice of both patients and the healthcare professionals caring for them, a stronger case for change

PATIENTS

"There have been times when the appointment waiting times have been rather long, which can be difficult if you are in a good deal of pain or discomfort"

"Full and frank discussion about all options available from the start. Honesty is key to establishing trust between care giver and receiver"

"More psychological support would have been very helpful, the disease is incessant"

MYELOMA

HOT TOPICS

CLINICAL TRIALS

Clinical trials are an essential part of developing new treatments for myeloma, and can offer patients the chance to access novel treatments not otherwise open to them.

What is a clinical trial?

A clinical trial of a new myeloma treatment involves a group of patients receiving that treatment under carefully controlled conditions. They are closely monitored for effectiveness of the treatment, and any side effects. Side effects are called 'adverse events' in clinical trials, because everything that occurs is recorded, even though it may not be caused by the treatment. Earlier stage clinical trials are in small numbers of patients, and mainly look at adverse events. Later trials can be much larger, and often compare the new treatment with an established one.

How can I find out about clinical trials?

Sometimes your healthcare team may suggest the possibility of taking part in a clinical trial. This may be when you are starting to relapse after previous treatments, or when you are newly diagnosed. You can also find out about clinical trials from the Myeloma UK Trial Finder, or from the Myeloma Infoline and Ask the Nurse service (details below).

How can I find out about clinical trials?

It is important to understand that not every patient is suitable for every new treatment, or for a particular clinical trial. Trials have strict criteria for who can take part.

This is to protect the patients, as well as for the design of the trial. The criteria may include age, number and type of previous treatments, and aspects of medical history such as kidney function.

There are also practical factors. You would need to be able to get to one of the hospitals running the trial, and there will often be extra monitoring visits during the trial.

How are patients in clinical trials protected?

Safety of the patients taking part is always the top priority. The clinical trial is governed by a strict set of instructions called a protocol, which is approved by an ethics committee. Monitoring adverse events is always part of a clinical trial even if its main purpose is to look at effectiveness.

Before you can take part in the trial you are given detailed information about what the trial entails and have the chance to ask questions. Only then will you sign consent to take part. This is called informed consent.

Will my care be the same if I am in a clinical trial?

Much of the care will be just the same. You may have more frequent assessments such as scans, bone marrow tests, blood and urine tests. Taking part in a trial is always voluntary, and if you decide not to take part, this will not affect your clinical care in any way.

What happens after a trial?

You will be followed up after the main trial period, often for a long time – for example to find out how long it is before your myeloma starts to come back.

In the UK, clinical trials do not count as lines of treatment, meaning that patients would re-enter the treatment pathway where they left off, but you should confirm this with your medical team before starting on a trial.

Although it shouldn't affect your lines of treatment, the treatment you receive in the trial may impact what treatments you could have in the future. Some treatments have specific eligibility requirements that depend on your treatment history, including treatment received in a clinical trial.

What happens to my data?

Long before the trial starts recruiting patients, it will have been designed to ensure that it produces reliable results, and that it includes the right number of patients and the right assessments. There are rigorous procedures to ensure that the data collected about you is anonymous and is stored securely.

Once the clinical trial is completed, the data will be analysed and written up. The clinical trial may be presented at a scientific meeting or published in a journal. If the new treatment is eventually submitted for licensing and approval for use on the NHS, the results of the clinical trial will form part of the evidence used to support the application. All the detailed 'raw data' for the trial (including your test results and how you responded to the treatment) are also kept for future reference, but always anonymously.

To find out more about myeloma clinical trials:

Go to our Clinical Trial Finder at trials.myeloma.org.uk

Read our Infosheet, Clinical trials and how treatments are developed

Speak to your healthcare team.

LIVING WELL DURING WINTER

The winter months in the UK can be a challenging time. For those living with myeloma, the season can present unique additional challenges.

Managing winter viruses

While it is possible to get viral infections at any time of year, viruses like the flu are often more common in the winter as people tend to spend more time indoors in close contact.

Myeloma affects plasma cells and impacts how well your immune system responds to infection.

People living with myeloma are more likely to develop infections from viruses, even when their myeloma is in remission or is stable.

Practical measures you can take to reduce the risk of infection include:

Frequent hand washing with soap and water

Avoiding contact with people who are unwell

Keeping indoor spaces well ventilated

Wearing a face covering at social gatherings

Catching coughs or sneezes and disposing of used tissues

You may be prescribed antivirals if you are considered at increased risk. For example, during treatment or after high-dose therapy and stem cell transplantation.

It is a good idea to have your annual flu jab and keep up to date with the pneumococcal vaccine (every 5 years).

If you have any concerns about any symptoms you may be experiencing, please speak to your healthcare team.

Managing mental wellbeing

It is not uncommon to feel a dip in your mood over the winter months.

You may find yourself feeling more tiredness and fatigue as the nights get longer. You may also find it more difficult to see family and friends as the cold weather encourages people to stay indoors, or illnesses limit people's ability to socialise.

The colder, darker days can present challenges for managing mental wellbeing.

Tips for managing your mental wellbeing during winter:

- Take care of your basic physical needs, such as eating well and moving regularly – take extra caution outside if it is icy underfoot!
- Make the most of the sunlight hours, even for just a short sit or walk outside
- Maintain social connections with friends and family through virtual meetings or phone calls if in-person meetings are limited
- Consider incorporating engaging hobbies or activities into your daily routine, such as reading, crafting or favourite pastime

However, there are several things you can do to help you live well during winter and embrace the unique opportunities that winter can bring.

If you feel like your changes in mood are impacting your day-to-day life, speak to your healthcare team or GP. They will be best placed to give you advice specific to your needs.

Staying warm and cosy

As the temperature outside dips, it is important to keep your body warm to reduce the risk of illness. Some myeloma treatments, such as chemotherapy, can make you feel the cold more.

Try to keep your home at a steady and comfortable temperature. Let your energy provider know if you are having trouble paying your bills.

There are also government support schemes and services to help you stay warm during winter.

Sources of information and advice on finances and cost of living:

Infopack for living well with myeloma

helpforhouseholds.campaign.gov.uk

citizensadvice.org.uk

moneyhelper.org.uk

PLASMACYTOMAS

Some myeloma patients may be aware of plasmacytomas. This rare form of cancer can occur as both a potential precursor to myeloma and a complication of myeloma.

What is a plasmacytoma?

Whilst they both involve abnormal plasma cells, myeloma and plasmacytomas are categorised differently. The key difference is the form the cancers take, specifically whether they are a lump or not.

Plasmacytoma is the medical term for a localised build-up of abnormal plasma cells.

Plasma cells are a type of white blood cell which forms part of the immune system. The plasma cells associated with plasmacytomas are malignant (cancerous).

These malignant cells can occur inside the bone (bone plasmacytoma) or in the soft tissue (extramedullary plasmacytoma).

This is different from myeloma, which can be found in multiple places in the bones, but does not exist as a lump or solid mass.

Why do myeloma patients need to know about plasmacytomas?

There are different kinds of plasmacytoma and they can exist on their own or as part of myeloma.

Solitary plasmacytomas

Plasmacytomas can occur as a single mass of abnormal plasma cells without any signs of myeloma. When this happens, the patient is diagnosed with a solitary plasmacytoma.

A person is diagnosed with a solitary plasmacytoma through tests and investigations such as a bone marrow biopsy, an imaging scan such as an X-ray/MRI, and blood tests.

Solitary plasmacytomas are most commonly treated using radiotherapy.

Solitary plasmacytomas are uncommon, with only about 300 cases per year in the UK, and they make up less than 1% of all blood cancers.

In very rare cases, patients can have more than one plasmacytomas without any signs of myeloma. This is known as multiple solitary plasmacytomas.

Can plasmacytomas develop into myeloma?

Some patients diagnosed with a solitary plasmacytoma will go on to develop myeloma. In general, the risk of progression to myeloma is higher in patients with a solitary bone plasmacytoma (approximately 50% within 10 years) compared to those with a solitary extramedullary plasmacytoma (approximately 30% within 10 years). Patients with either type of solitary plasmacytoma are monitored regularly for signs and symptoms that may indicate progression to myeloma.

Plasmacytoma as a complication of myeloma

Plasmacytomas can occur as a complication of myeloma. When this happens, patients are diagnosed with myeloma and the plasmacytoma is treated as part of their myeloma.

In these cases, treatment for myeloma also works to kill the plasmacytoma cells.

Some patients can receive radiotherapy as part of their treatment but only if the plasmacytoma causes significant pain or complications.

Plasmacytoma in relapse

Although very rare, we have received calls from patients experiencing plasmacytomas as an early sign of relapse.

These patients talk about experiencing pain or noticing lumps appearing during remission, which, after investigation, are found to be caused by the presence of a localised build-up of abnormal plasma cells.

Some of these patients worry that these new lumps are secondary cancers. In most cases, the lumps signify a relapse and the need for further treatment, rather than a secondary cancer.

As with the plasmacytomas presenting at myeloma diagnosis, plasmacytomas at relapse are treated with anti-myeloma drugs.

Queries like these further highlight that the first signs of relapse are not always changes in blood test results.

Therefore, make sure you tell your healthcare team about any changes you notice, including any increase in symptoms, new pain or lumps.

Find out more in our **Solitary plasmacytomas Infosheet**

INTERVIEW WITH PIPPA FOSTER

DIRECTOR OF PATIENT SERVICES

A firm believer in strength in numbers, Myeloma UK's new Director of Patient Services, Pippa Foster, is on a mission to help people with myeloma get fair and equal access to the right diagnosis, treatments and, crucially, support. Here she sets out her vision and ambitions and explains why the charity has an unprecedented opportunity to diversify and reach more people than ever before.

What drew you to this role?

Myeloma UK is person-centred, ambitious and packs a punch in everything that it does. Working for an organisation that delivers positive impacts for people and changes policy and practice is important to me.

As is taking a psychologically informed, holistic and evidence-based approach. So, I was immediately drawn to the role as it ticked all these boxes.

Then, as I researched more about Myeloma UK, I was determined to join the charity to ensure people living with myeloma and related conditions, and their families, have a powerful voice, live dignified lives and have fair and equal access to the right diagnosis, treatments and support by the right people, at the right time. How could I not apply?

> **The myeloma community is phenomenal.**

You bring a wealth experience from previous roles, how will this experience inform your work at Myeloma UK?

As a senior leader in health and social care, I have experience of high-level strategic thinking.

Being neurodivergent supports my creative and innovative ways of seeing, thinking and doing. And I thrive on inspiring and engaging with people – both colleagues and those with lived experience – to develop and innovate, keeping service delivery relevant and responsive.

I will combine this with my experience in designing, delivering and managing psychologically informed services, as well as with my academic background in psychology and my applied health research experience, to ensure we offer inclusive, dynamic and responsive support and information.

As a qualified coach experienced in delivering clinical and operational supervision, I also bring active listening skills, reflective practice, compassion and understanding.

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

People power. The myeloma community is phenomenal, and I am proud to become part of it.

The potential and impact we can make by working in partnership with people affected by myeloma and related conditions, clinicians, academics, digital innovators, creators, artists and many other communities is limitless. This is an exciting and pivotal time.

> **There is a fierce commitment to discovering how we can continuously improve what we know and, therefore, what we do to enhance the lives of everyone in the myeloma community.**

How can we continue to support patients, their families and carers?

We must continue to ask, listen and learn from experts with lived experience to codesign support and services that meet the needs and wants of all our community. Whilst we deliver brilliant services, we have an excellent opportunity to increase our knowledge and understanding, to diversify and widen our support offers and reach more people so they can live well with myeloma.

What have you learnt during the first 6 months of this role?

I love my role and serving Myeloma UK. I have the privilege of work with inspiring, kind and incredibly bright colleagues that all have a shared desire to improve the lives of people living with myeloma and associated conditions.

There is a fierce commitment to discovering how we can continuously improve what we know and, therefore, what we do to enhance the lives of everyone in the myeloma community. This can be a complex and challenging landscape but working in partnership we achieve more.

People power, community connection, collaboration, creativity, and communication are key.

What are you looking forward to over the next 6 months?

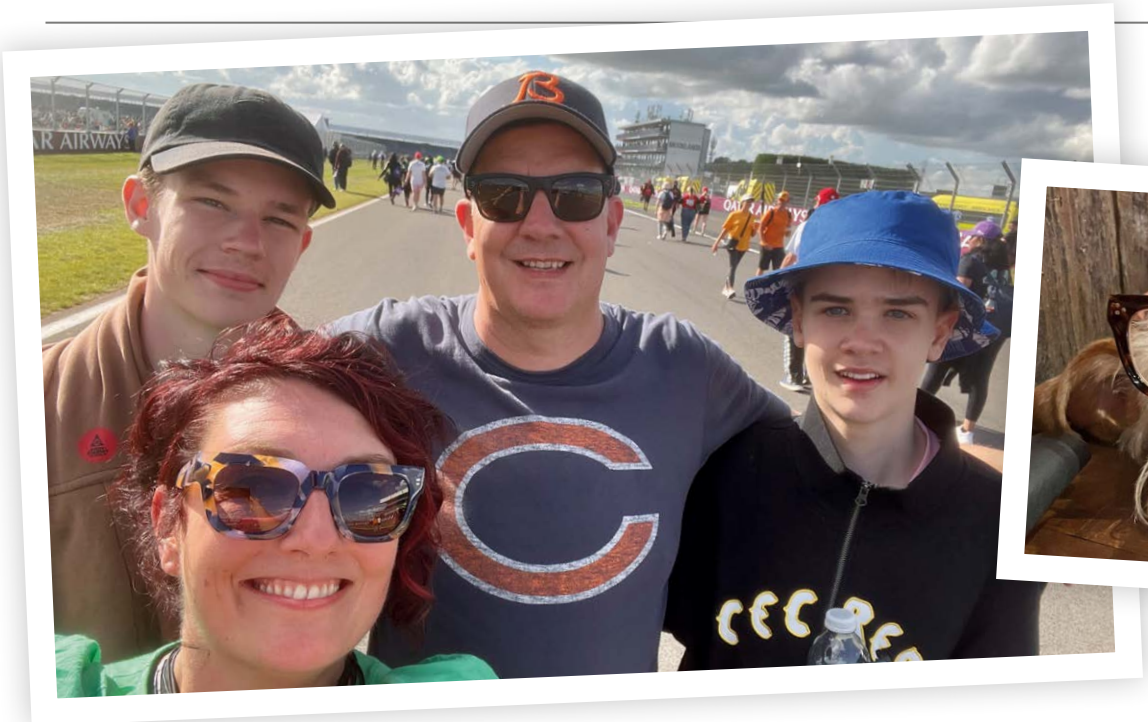
We are launching our next 5-year strategy which clearly sets out the direction of travel for us as an organisation. It is bold, ambitious and incredibly exciting. We will connect with more people, expand our reach and work collaboratively to seek creative and innovative ways to deliver our services, tackle inequalities and improve lives. So, I am really looking forward to sharing our strategy with the world and then getting down to delivering it.

What inspires you, both at work and in life?

Nature, travel, music, my gorgeous family and friends. I am nourished by spending time outside, swimming in open water, dog walking and visiting exciting places but I am also uplifted and energised by a good old kitchen disco, a delicious meal and beautiful company. Connecting with people, working collaboratively to tackle injustice and/or inequalities and seeing positive outcomes inspires and motivates me. Watching people shine and step into their power/potential is high up on my agenda too; and if I can be a small part in supporting this journey then this also makes my soul sing.

What is the most valuable lesson you've learned in the many years you've spent supporting people and their families to live positive and fulfilling lives?

We cannot do it alone. People power, community connection, collaboration, creativity, and communication are key. And, that vulnerability is strength.



POLICY BRIEFING

MYELOMA TREATMENTS AND THE NHS

There are several new treatment options in development for myeloma. Some of these treatments are in the early stages of development and just beginning clinical trials. Others are reaching the final stages of securing approval for use on the NHS.

How do new treatments get approved on the NHS?

There are two approvals drug manufacturers need before a new drug or combination treatment can be approved for use on the NHS.

1. Approval to market and sell the new drug or combination treatment in the UK

A new drug or combination treatment needs a licence before can be sold in the UK. The Medicines and Healthcare Products Regulatory Agency (MHRA) is the regulatory body in the UK that decides whether a product can be licenced. They review the clinical data and assess manufacturing processes for the new treatment to ensure it is safe and effective before issuing a licence for the drug. Once the drug is licensed, doctors can prescribe it. However, at this stage, it is not guaranteed to be funded by the NHS. The scope of the licence including who can have the treatment, how is given, and how often will depend on the clinical data. For example, a combination that has only been tested in relapsed myeloma patients will only get a license for relapsed myeloma patients. This is because there is no evidence to prove the safety or effectiveness of the new treatment for newly diagnosed patients.

The drug manufacturer can apply to change the scope of the licence when they have new clinical evidence.

2. Approval for use on the NHS

For a new treatment to be approved for use on the NHS it must go through a review process called a technology appraisal. During technology appraisals, a committee will assess the cost-effectiveness of the new treatment based on how well the treatment works compared to the current standard of care and how much the new treatment will cost the NHS.

The organisations (drug approval bodies) deciding whether a new treatment should be funded by the NHS varies across the UK:

- **England** – the National Institute for Health and Care Excellence (NICE)
- **Scotland** – the Scottish Medicines Consortium (SMC)
- **Wales** – the All-Wales Medicines Strategy Group (AWMSG) or NICE (all NICE decisions are automatically approved in Wales)
- **Northern Ireland** – the Department of Health (usually follow NICE or SMC decisions)

How is cost-effectiveness measured?

Cost-effectiveness is measured by comparing the added benefit to the added cost of the new treatment. The benefit of a treatment is measured based on how long and how well a patient lives after treatment. It is measured in units called quality-added life years (QALYs). One QALY is equivalent to one added year in perfect health.

The cost of the new treatment is measured based on the cost of the drugs and the cost of administering the drugs. This includes nursing, pharmacy and clinician time and the cost of any hospital administrations or supportive treatments.

Why are some treatments approved in other countries but not in the UK?

Often treatments are not available through the NHS because the drug manufacturer has not applied for the necessary approvals. If they don't apply for a licence the treatment can't be sold in the UK. If they don't submit evidence to a technology appraisal its cost-effectiveness can't be assessed, and the treatment can't be approved for use on the NHS. Sometimes treatments aren't available on the NHS because they were not recommended by NICE or the SMC.

How does Myeloma UK advocate for approvals in the UK?

Myeloma UK works with clinicians, pharmaceutical companies, NICE, SMC and the NHS to advocate for myeloma patients to ensure that myeloma patients' voice is heard and considered during the decision-making processes. We are involved in every technology appraisal, submitting written evidence and providing testimony highlighting why myeloma patients should have access to the new treatment. Giving patients access to the latest, most effective treatments is a top priority for Myeloma UK. We will continue working to ensure new treatments are made available to patients, so they have access to the right treatment when they need it.

ASK THE NURSE

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

I have been diagnosed with myeloma and like to be informed. My partner doesn't want to know anything and this is causing arguments

Living with the uncertainty following a myeloma diagnosis is difficult, and it can take its toll emotionally and psychologically. It is possible that your partner may be experiencing feelings of loss for your old relationship and be finding it difficult to accept the 'new normal' which may revolve around medical terminology, hospital appointments and treatment.

It is important to be able to make informed decisions about treatment and care and being informed helps with this and also helps to build relationships. However, everyone's information needs are different; some people like to read everything and to be fully informed at all times. Others only want to know so much and feel unable to cope or feel overwhelmed with too much information.

It is quite common for two people in a relationship have different coping strategies and information needs and this can sometimes cause arguments, frustration and resentment. Sometimes being open and honest about how you feel can help, but it can be difficult to know when to broach the subject, or what to say without worrying that it may cause arguments. If your partner is aware of how the way they are dealing with things makes you feel, they may be able to open up and this may be a useful platform for a frank discussion.

You can seek out information yourself, e.g. by calling the Infoline, and sometimes having a few publications around can help spark a conversation.

I am a myeloma patient and my GP has invited me to have a vaccination for shingles. Is this safe for me to have?

Shingles is an infection caused by reactivation of a virus that is already in the body. The virus involved is the varicella zoster virus which comes from previously having chickenpox. The main symptom of shingles is pain followed by a rash that develops into itchy blisters on one side of the body. If you have a weakened immune system (are immunocompromised), the virus is more likely to be reactivated and cause shingles.

There are two vaccines used against shingles, Zostavax® which is a live vaccine and Shingrix® which is a non-live vaccine. Although no vaccine provides 100% protection, these vaccines are proven to reduce the risk of developing shingles and the risk of having serious problems if you do. Because myeloma patients are immunocompromised, they should only be offered the non-live Shingrix vaccine. This is because their immune systems may not be strong enough to fight off the weakened virus within the Zostavax vaccine.

The Shingrix vaccination is currently available to all people between ages 70-79, people who will turn 65 on or after 1 September 2023 and people aged 50 or over with a severely weakened immune system. Myeloma patients are usually considered to have a severely weakened immune system and are eligible for the Shingrix vaccination if they are over 50. However, the decision to vaccinate is a clinical one and down to each patient's healthcare team.

You can read more in our Vaccines and myeloma Infosheet.

I have myeloma and heard that I should avoid probiotic yoghurts. Is this correct and if so, why?

Yoghurt is made by the addition of bacteria to milk to cause fermentation. Usually these die off in the process. Some yoghurts, however, contain probiotics, which are live bacteria and cultures.

These probiotic yoghurts are often marketed as containing 'good' or 'friendly' bacteria, and eating these products is promoted as being beneficial to health, particularly after illness or treatment, although there is little solid evidence to support this claim.

Because probiotic yoghurts contain live bacteria which can increase the risk of infection if you have a weakened immune system (are immunocompromised), the general advice is to avoid them. How robust your immune system is is often measured during your routine blood tests. Your healthcare team will regularly check the levels of your healthy blood cells, particularly the levels of your white blood cells, which help to protect against infection.

Any yoghurt that does not describe itself as probiotic or bio is perfectly safe to eat. This includes plain, live, fruit and Greek, and these can be made more nutritious and delicious by adding fresh fruit, berries, and seeds.

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

Deborah Embley recently shared her story and why she decided to include Myeloma UK in her Will.

I'm Deborah, married to John. We've been together 25 years and finally tied the knot seven years ago. That was a year after my stem cell transplant, once I'd fully recovered.

I have myeloma and have had three lines of treatment, my last in 2015 – a stem cell transplant. Thankfully, I've been in remission and off treatment for eight years.

However, my initial diagnosis revealed that I had suffered kidney failure.

After a year on peritoneal dialysis, my brother-in-law Danny gave me an incredible gift – one of his kidneys. Unfortunately, two years post my kidney transplant the myeloma returned and my new kidney was damaged which means I now only have 15% function in my transplanted kidney. Because of that, I have three monthly kidney clinics as well as three monthly myeloma clinics. It's a lot.

On average, we live from three months to three months. That is the hardest part as you do not get much of a breather between appointments and blood tests. When I do get the results and they are good, we can relax a bit for a while and get on with life.

Why I'm including Myeloma UK in my Will

I like all that Myeloma UK is doing towards helping people secure an earlier diagnosis. If I had been diagnosed with myeloma earlier, I may not have had extra complications. It is bad enough dealing with an incurable blood cancer but then to find you have kidney failure on top of that, it is a lot to deal with.

If somebody does not have to go through what I have gone through that would be a great achievement.

If you're considering including Myeloma UK in your Will I just think – why not?

If you have myeloma or are a carer or family member of someone with myeloma, I feel it is important to support the organisations searching for a cure, early diagnosis, and better treatments for patients.

Of course, make sure your Will looks after your family first, they're your priority, but then consider a gift in your Will.

The process of writing my Will

Writing a Will was actually pretty straightforward. We prioritised each other first, then my nieces and nephew and my chosen charities, including Myeloma UK. When living with health conditions such as myeloma and kidney-related issues, I think it is particularly important to ensure your financial affairs are organised.

> **"We found when we did it, it was a weight off our minds knowing our wishes had been captured."**

It is not that scary! We had a few phone calls and Zoom calls, specified what we wanted and then we were sent drafts to review and went back and forth a couple of times until we were happy with everything.

People put off talking about death and the related administrative issues associated with dying. If you do not talk about these things including Powers of Attorney and Wills, you will not be prepared, and your family may not know what your wishes are. We found when we did it, it was a weight off our minds knowing our wishes had been captured and the instructions for our estates set out clearly for the trustees to follow.

Do it with your family. Talking about it makes it easier and everyone knows what to expect. Sorting estates without a Will can be difficult and may result in your estate being distributed according to someone else's wishes rather than your own.

Myeloma UK has a free Wills service or information on writing your Will if you already have a solicitor.

To find out more about leaving a gift in your Will to Myeloma UK visit **myeloma.org.uk/gifts-in-wills** email **giftsinwills@myeloma.org.uk** or call **0131 230 0429**

My Coffee Morning

It's beginning to look a *latte* like Christmas...

Sign up and host your own Christmas Coffee Morning at **coffee.myeloma.org.uk**

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

Myeloma UK is a registered charity, number SC026116

MyelomaUK Lottery

Myeloma UK Lottery is a fun way to help everyone affected by myeloma.

For just £1 per week you could win £25,000

Why not buy a lottery voucher for a loved one as a gift this Christmas?

Visit **myeloma.org.uk/lottery**

Myeloma UK is a registered charity, number 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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myelomauk

Registered Charity No: SC026116