SPRING/SUMMER 2022

myeloma matters

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MyelomaUK

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Alice Baron
Myeloma Matters Editor

Welcome to the Summer 2022 edition of Myeloma Matters.

In this edition of the magazine, I'm delighted to include an interview with our new CEO Sophie Castell. Sophie joined Myeloma UK in May 2022 and you can find out what drew her to the role on pages 22-23.

As Sophie says in her interview, for us to work with and for those we represent, we need to "Firstly, always be in listening mode and, secondly, embed the voice of community".

Our diagnosis report, A Life Worth Living, is a prime example of our commitment to those principles. This report is the first of its kind looking at the impact of late diagnosis of myeloma on people's quality of life. We hear the impact late diagnoses have on patients' lives every day and knew that this has to be taken into account by policy makers. This report is the evidence we need to take what you've been saying to us and call for change.

I'd like to signpost to another way we're listening to you, and that's through our services feedback survey. The feedback you give us helps us improve and adapt our information and support to better suits your needs. If you've used any of our information and support services, including our Infoline, information booklets or Digital Infoday Sessions, we'd love to hear from you.

Our survey runs all year and you can fill it in at any time by going to **surveymonkey.co.uk/r/MUKservicessurvey**.

We always appreciate people giving their time and thoughts that help shape our work.

On the second point about embedding the voice of the community, we want to do more to ensure we're listening to all voices within the myeloma community. In this edition, both Dr Popat and Dennis Smith highlight the disparity in representation of people from minority ethnicities within the myeloma world. We want to make sure that's not the case at Myeloma UK and that we're representing the whole myeloma community. If you want to add your voice, we're particularly interested in hearing from people from minority groups who are currently under-represented in our work. To partner with us and share your experience of living with myeloma, get in touch and we'll tell you more about how you can get involved or fill in our form at **myeloma.org.uk/tellusyourstory**

We can only do what we do because of the generous way you all share your experiences with us, so for that I'd like to say thank you on behalf of everyone at Myeloma UK.

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 Early Diagnosis Research Programme launched

Myeloma UK has launched a new Early Diagnosis Research Programme, which aims to find new, better approaches to diagnosis, so more patients get a timely diagnosis. The Research Programme, part of Myeloma UK's ongoing Early Diagnosis Programme, is investing £500,000 in two innovative research projects. The first project, led by Prof Chris Bunce at the University of Birmingham, aims to help address two of the main barriers to a myeloma screening programme, making screening more feasible.

The second project, led by Prof Kwee Yong at University College London, will help develop tools to accurately predict the patients likely to develop cancer and treatments to slow down or prevent the development of myeloma.

It is hoped that the research will transform myeloma diagnosis giving every patient the best chance of living a long life, free from restrictive complications caused by late diagnosis.

New blood tests could replace biopsies in the assessment of minimal residual disease status

Scientists in Germany have been investigating whether blood tests could be used instead of bone marrow biopsies to test whether small amounts of myeloma cells (minimal residual disease) are detectable following treatment.

The research used two methods to test for signs of minimal residual disease in the blood. One method measured and analysed cell-free DNA (cfDNA), small fragments of DNA released into the blood when cells die.

The other measured and analysed the plasma cells circulating in the blood. Genetic sequencing technology was used to determine whether any cfDNA came from myeloma cells or if any of the plasma cells were myeloma cells.

The results show that the tests successfully detected signs of minimal residual disease in the blood.

This suggests that the blood tests could be used as well as biopsies to detect minimal residual disease. This could be particularly beneficial for non-secretory myeloma patients who rely heavily on biopsies to monitor their myeloma.

Although these results are promising, more research in larger patient groups is needed to support their use in routine clinical practice.

Evusheld approved to prevent COVID-19

Evusheld has the possibility of being used as a "passive vaccine" for COVID-19. Passive vaccines are when a person is given antibodies to a virus rather than producing them from their immune system. For most people, the best way to prevent infection is vaccination. Evusheld may help people who have not had an antibody response to COVID-19 vaccines or have not been vaccinated. It is designed to prevent COVID-19 before the risk of being infected and does not treat people infected with COVID-19.

Developed by AstraZeneca, Evusheld (also known as AZD7442) was licensed for use in the UK by the Medicines and Health Products Regulatory Agency on 17 March 2022. The global phase III, AZD7442 PROVENT trial, supported the approval. The clinical trial results from over 5000 participants showed that Evusheld, a combination of two antibodies called tixagevimab and cilgavimab, reduced the risk of developing symptomatic COVID-19 by 77%. Protection from the virus continued for at least six months following a single dose.

Evusheld is administered as two separate injections into the muscle. The omicron variant was not in circulation when the trial ran, so the effectiveness and duration of Evusheld against certain variants is not yet known. The UK Government has not currently released information on the distribution of Evusheld.

UK trial bringing personalised treatment to myeloma patients

A UK clinical trial called RADAR is testing whether tailored treatment strategies could optimise patient care, reduce the risk of early relapse, and increase life expectancy.

The trial is open to newly diagnosed myeloma patients who are suitable for high-dose therapy and stem cell transplantation. It will tailor treatments to individual patients based on how well they respond to initial treatment and the genetic risk status (high or standard) of their myeloma.

This approach gives UK patients with the highest risk of relapsing early (within 18 months of treatment) the opportunity to receive more intensive treatments not currently available through the NHS to help improve remission times.

The trial aims to provide evidence to support the use of personalised myeloma treatment in everyday care.

MY LIFE WITH MYELOMA

NAME: Dennis Smith

LIVES: Lewisham

AGE: 55

I had a somewhat tumultuous childhood and subsequent teenage years. After my mother left me at her friends' house, disappearing for weeks, I was sent to live with my grandparents, who raised me from the ages of five to 14.

> **I did not have many family ties. The ones I did have were not, let's say, the ideal people to guide a lost child.**

Due to failing health, my grandparents decided to return to Jamaica. I chose to remain in England and was placed in foster care. At 18, I was given a flat and discharged from care.

I had no life skills. I slowly drifted into a life of crime and drug use. Within two years I'd abandoned the flat that I was given.

> **I thought about not seeing my youngest child reach adulthood. It was heartbreaking.**

I probably would have been evicted anyway. I was in debt with rent and utilities and had no idea of how to sort it all out.

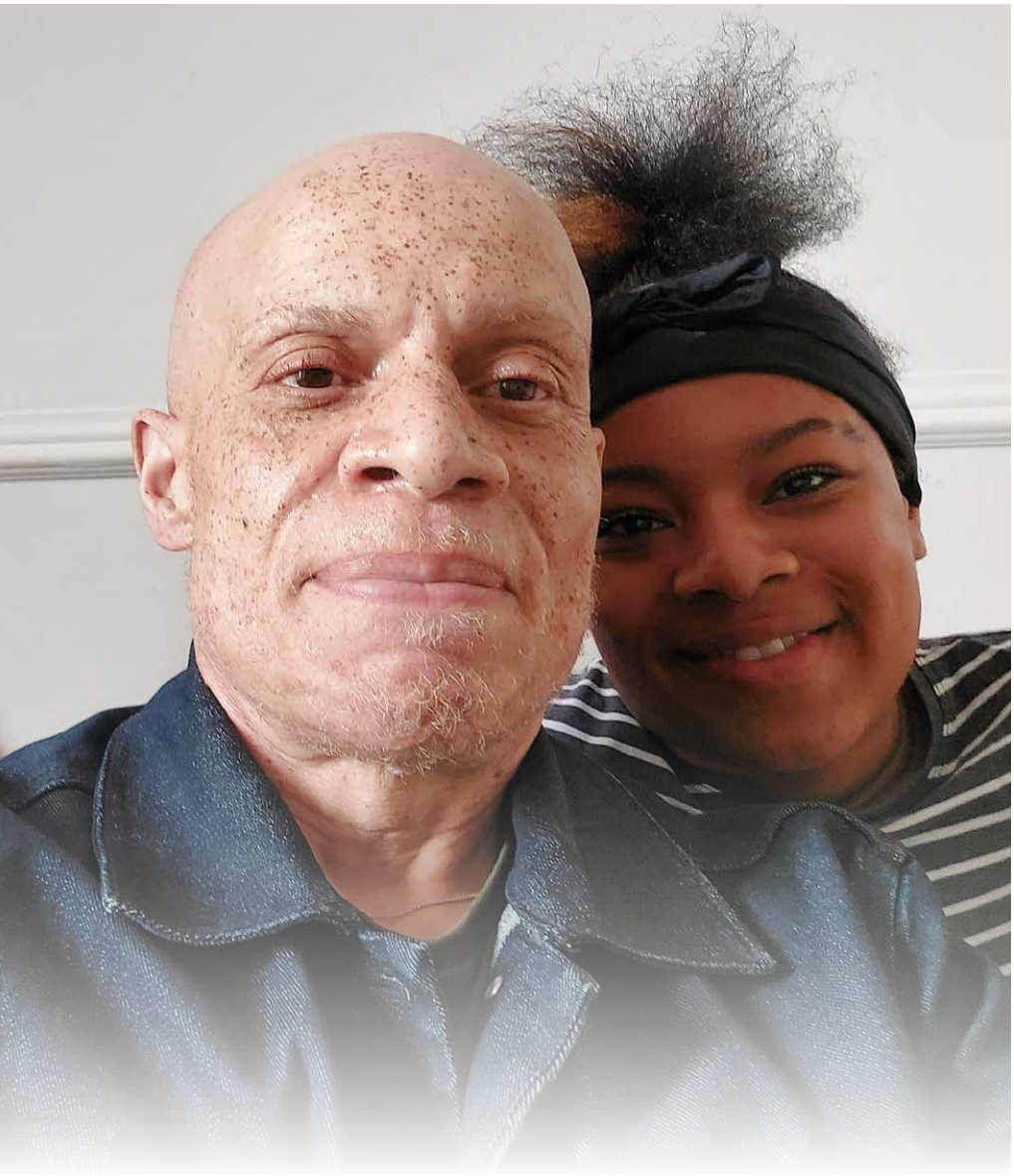
I did not have many family ties. The ones I did have were not, let's say, the ideal people to guide a lost child. I had my first child when I was 20. Her birth was the catalyst for me to change my life. I gradually turned away from street life. I eventually went back to education.

After completing an access course, I attended university and graduated with a Higher Education Diploma in Youth and Community Work at the age of 28.

I went on to work for 25 years in social care; although, prior to my studies, I had trained and was employed as a youth worker for approximately three years. Throughout my career, I primarily worked with the homeless, young people and people with mental health challenges. I found my work highly rewarding and fulfilling.

Other than the usual trials, life was pretty much going well. I had two more children. I was in a profession that I thoroughly enjoyed. It all changed when I reached the age of 48. Throughout my life I've been actively involved in sporting activities: football, cricket, gym, cycling. But I began to experience severe, debilitating back pain which would leave me bedridden. Initially I thought I was overdoing the exercise. Despite reducing my physical activities, the pain persisted. I went to my GP who referred me to the hospital.

After blood tests and X-rays, I was told that I had degenerative discs in my lower back along with the possibility of having a condition called ankylosing spondylitis. I was also told that my blood tests showed the presence of abnormal proteins, which were probably nothing to worry about.



> **The pain was so bad that I could not walk. Being an outreach worker, I eventually had to give up work.**

As you can imagine I was not satisfied with being told that the abnormal proteins in my blood were nothing to worry about.

I went back to my GP and demanded another referral in order to get another opinion. I was sent to the haematology department at Guy's Hospital in December 2014.

After the relevant blood tests and a bone marrow biopsy, I was told that I had smouldering myeloma on New Year's Eve.

I had no idea what myeloma was. The consultant told me it was a type of blood cancer.

After receiving my diagnosis, despite not having any of the classic symptoms such as kidney problems or hypercalcemia, I immediately thought I was going to die. Indeed, the first year after diagnosis was the hardest.

I thought about not seeing my youngest child reach adulthood. It was heartbreaking.

I was offered and accepted a course of six counselling sessions which were provided by Dimbleby Cancer Care. It helped me to put everything into perspective regarding my diagnosis. I continued to work.

At that time, I was employed in the position of homeless outreach worker.

After two years symptoms-free I began to experience swelling then pain, numbness and pins and needles in my feet.

The pain was so bad that I could not walk. Being an outreach worker, I eventually had to give up work.

After seeing a neurologist, I was diagnosed with chronic inflammatory demyelinating polyneuropathy (CIDP).

In an attempt to find the cause and remedy, I went through various treatments and tests such as plasmapheresis, intravenous immunoglobulin infusion (IVIG) and amyloid testing.

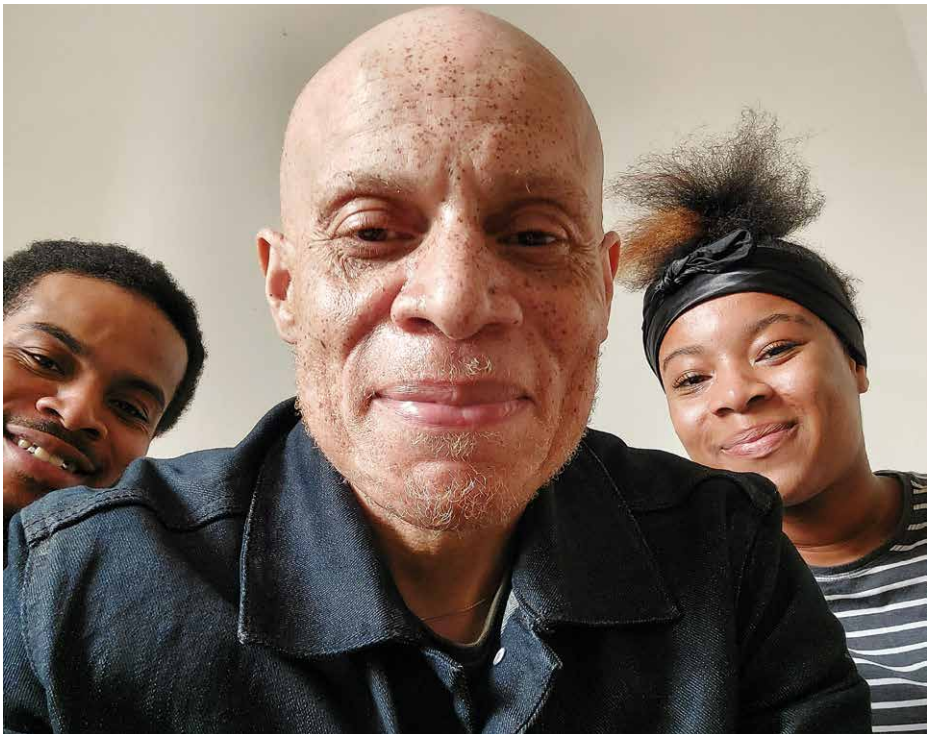
I was amyloid-negative and the plasmapheresis treatment failed to alleviate the symptoms in my feet. My hands were also beginning to be affected with the same symptoms.

After discussions between the haematologists and neurologists, I was told that the neuropathy I was experiencing was presumably caused by myeloma. Apparently this can be the case with some patients. I was told that my myeloma had progressed from smouldering to stage 1. I took it on the chin and prepared myself mentally for what was to come.

Between May and July 2018, I was placed on a course of cyclophosphamide, thalidomide and dexamethasone (CTD). This did not have the desired effect. It was stopped and, after a while, my paraprotein levels went up.

From January to April 2019, I was placed on another course of cyclophosphamide, velcade and dexamethasone (CVD). This took my paraprotein levels down but it did not have the effect that my doctors had hoped for.

This treatment was stopped. My neurological issues worsened. I experienced falls and I began to walk with a stick. In 2019, I was put on lenalidomide. This seemed to keep the myeloma in check. I was on lenalidomide for approximately three years.



Meanwhile, I was also diagnosed with hypertrophic cardiomyopathy, a genetic heart condition I inherited from my father, which can cause sudden death. Initially this excluded me from having a stem cell transplant but after having a series of intensive tests I was deemed a suitable candidate for high-dose therapy and an autologous stem cell transplant.

I would like to raise awareness of myeloma particularly among the Caribbean community.

In November 2021, my stem cells were harvested from my blood. They were then frozen to be used in early 2022. I made a request for the high-dose therapy and stem cell transplant to happen in the New Year so I could spend Christmas with my family. I had the stem cell transplant in April this year and was in hospital for three weeks. The side effects were like none that I had experienced with previous treatments. I experienced mouth sores, loss of appetite, hair loss and, worst of all, diarrhoea like I had never had in my life.

Previous courses of chemotherapy had, at worst, caused constipation and fatigue. I must say everyone's experience of treatment is different. I can only describe mine. The ward nurses were fantastic in helping me to manage the side effects.

They were also very supportive generally. After 19 days in hospital I was discharged. I am now at home completing my recovery. My immune system has yet to fully recover. As a result, I am in semi-isolation. I regularly attend the hospital for testing. In a few weeks I will have a bone marrow biopsy to determine how successful the procedure was.

Myeloma is more prevalent in the Caribbean community. Nevertheless, most people in the Caribbean community have never heard of the condition. Indeed, most people generally have not heard of the condition despite it being the third most prevalent type of blood cancer.

I would like to raise awareness of myeloma particularly among the Caribbean community. I would also encourage the Caribbean community to get involved in any studies and trials related to myeloma as they ultimately have the most to gain since they are the ones who are mainly affected by the disease.

I share my story in order to possibly help others who may be affected by myeloma: patients, friends, family and carers included. As I have come to know, a myeloma diagnosis is not all doom and gloom. I have found that developing and having the right mental attitude greatly helps with managing diagnosis and treatment.

Don't give up. Stay optimistic. For those who are struggling I say seek strength and support from family and friends. Failing that there is support out there. Macmillan Cancer support and Dimbleby Cancer Care are both fantastic.

I say that from my own personal experience. Myeloma UK also provides support. Myeloma Matters is so informative in all areas related to myeloma, from diagnosis to treatment and available support. I find reading it uplifting. It feeds my optimism. I have also found that speaking to other cancer patients is invaluable. There are ups and downs during a myeloma journey but it's a journey you do not have to experience alone. Myeloma may put limitations on your daily life but focus on what you can do and not on what you can't do. That's what I do and it works. There's still life to live. I have a greater appreciation for the simple things in life.

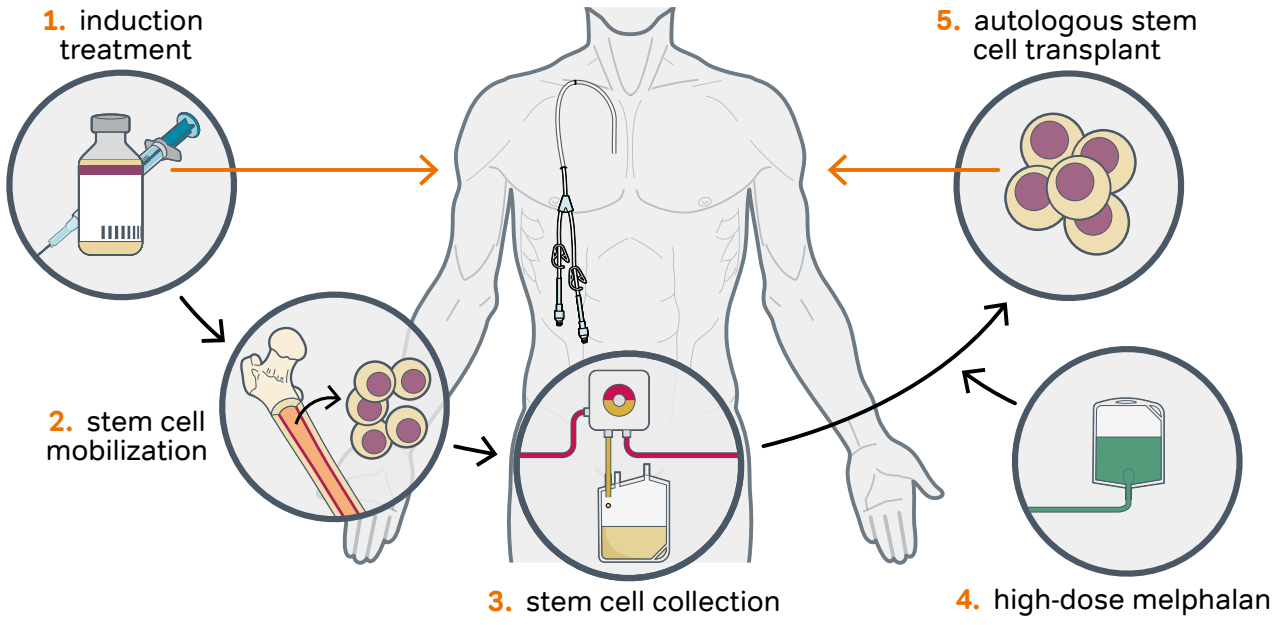
I have found that developing and having the right mental attitude greatly helps with managing diagnosis and treatment. Don't give up. Stay optimistic.

Myeloma is currently still an incurable disease but there are new treatments coming out all the time. We are well on the way to eventually having myeloma firstly as a chronic condition and, secondly, to finding a cure. I look forward to this. The future is bright.

SPOTLIGHT
STEM CELL TRANSPLANTS

"The transplant was one of the hardest things I have ever done in my life but it was all worth it"

INTRODUCTION TO STEM CELL TRANSPLANTS



Stem cell transplants, or to give the full name, high-dose therapy and stem cell transplantation (HDT-SCT), is commonly used as a treatment in myeloma for newly diagnosed patients.

They offer a chance to hit the myeloma with a higher dose of chemotherapy, while protecting the healthy blood cells of a patient. This is through removing the stem cells before the chemotherapy is given and reinfusing them afterwards. As you can see in the following pages, this treatment is a multi-stage process and takes place over months.

Unfortunately, this higher dose of chemotherapy comes more severe side effects, so this treatment is only suitable for patients who are more likely to be able to withstand them. Doctors take into consideration age, frailty and things like other conditions to determine if someone is a suitable candidate.

Although the majority of stem cell transplants are carried out using a patient's own cells, which is known as an autologous stem cell transplant, there are a few patients who have stem cells donated to them. These transplants are known as allogeneic stem cell transplants, and they're used very rarely and most usually in younger patients with very aggressive myeloma.

This is a huge topic, so we've included some key pieces of information here. If you're going through this treatment or want to find out more, you can find videos and written information on our website. You might want to start with our HDT-ASCT Infoguide and Digital Infoday Session on the topic.

Patients and their carers who have already gone through this process can also be a helpful source of information.

Ask around at your local Support Group, post a message on our Discussion Forum or refer yourself into our Peer Buddying service. You can always call or email us as well to find out more.

DID YOU **KNOW?**

There are 42 stem cell transplant centres for adults in the UK.

The number of patients receiving stem cell transplants is increasing year on year. In 2001, there were only 525 stem cell transplants carried out at first line in the UK in myeloma patients and in 2019 there were three times as many – 1506. Only 24 of these were allogeneic.

However, in 2020, the pandemic meant not as many stem cell transplants could go ahead as planned. This meant there were there were only 1134 first line transplants carried out.

A third (1 in 3) of stem cell transplants carried out in the UK each year are in myeloma patients.

You need 2 million stem cells per kilogram of body weight for a stem cell transplant.

Stem cells are very special cells, because they have the ability to divide into different types of cell.

Haematopoetic stem cells are the ones used in stem cell transplants in myeloma and these have the ability to divide into any type of blood cell.

Maintenance treatment was approved for use on the NHS in the UK in 2021. Patients are given lenalidomide (Revlimid®) until their myeloma comes back.

This was approved on the basis of the Myeloma XI trial that showed maintenance treatment significantly improved progression-free survival (time until the myeloma came back).

Top 5 most common side effects of HDT-SCT

1. Risk of infection

2. Fatigue

3. Nausea

4. Mucositis

5. Hair loss

1 Induction treatment

The first stage of a stem cell transplant is a normal course of treatment to try and reduce the myeloma as much as possible. The newest option for induction treatment is the quadruplet daratumumab (Darzalex®), bortezomib (Velcade®), thalidomide and dexamethasone (DVTD).

Your transplant team will usually try and collect enough stem cells for two transplants.

"One thing my husband really appreciated when he was in hospital having his transplant was soft toilet roll. Bouts of diarrhoea were not made any easier by NHS standard issue toilet paper... shea butter, quilted, cocoa butter, cushioned, you name it! It's the small but not always obvious things that can make a big difference."

2 Stem cell mobilisation

G-CSF is given by injection over a number of days. You might have some bone pain when this is happening.

Normally your stem cells stay put in the bone marrow, where they can become new blood cells. For stem cell transplants to work, we need to get these stem cells circulating in the blood stream and we need lots of them. This is where a drug called G-CSF (granulocyte stimulating factor) comes in. This causes the stem cells to multiply and get less 'sticky' so rather than sticking to the bone marrow, they get moved out into the blood.

3 Stem cell collection

Apheresis the process by which stem cells get sifted out of the blood. It works by taking blood and passing it through a machine that spins it very quickly (a centrifuge) which causes the blood to separate out into its component parts (this is because the forces exerted on the blood when spinning it causes items of different weights to fall to different levels). The machine then siphons off the stem cell layer and returns the rest of the blood back to the body. This can take a number of hours and may even need two days to collect enough stem cells. The stem cells are then stored in a freezer, after a chemical mixture that keeps them safe while frozen is added.

4 High-dose melphalan

This stage is the 'high-dose therapy' part of HDT-SCT. The high-dose of melphalan is the key part that kills the myeloma cells and is why you need the stem cells reintroduced into your body. This is the stage that causes the most side effects and may cause you to lose your hair.

"My sense of taste went very quickly so I laced everything with any type of sauce, which meant I could at least taste something."

If you lose your hair, the charities Look Good Feel Better and Cancer Hair Care can help with advice and workshops.

"Before and during your dose of melphalan, suck on ice cubes or ice lollies to prevent mouth ulcers – my husband did this and didn't get any soreness in his mouth."

"Prepare yourself for the taste of sweetcorn at the back of your throat the minute you start to receive your stem cells back."

5 Stem cell transplantation

Your stem cells are reintroduced into your body a day or so after you've had your high-dose melphalan. It normally takes only an hour to put the stem cells back. The process of re-engraftment is the when the stem cells multiply and differentiate (become the different types of blood cells). While your blood counts build up again, you'll be kept under close observation.

"Don't believe all you hear about transplants. I only had four really bad days, which felt like I had a huge, long hangover."

6 Recovery and maintenance treatment

The recovery period varies greatly from patient to patient, but it's usually estimated at 6 months to a year before you're fully recovered. During this time your immune system is redeveloping and you'll need to have all your childhood vaccinations again. Patients are now offered maintenance treatment that starts around 100 days after their stem cells are transplanted. This is a low dose (10mg) of lenalidomide that's taken on days 1 to 21 of a 28-day cycle to try and maintain the remission.

"Before you are admitted, think about how you will occupy yourself whilst in isolation. You can expect to be on the ward for at least two weeks and often quite a bit longer. This could be the time to spoil yourself and buy a new gadget or tablet – check the local hospital rules about using mobile phones, and don't forget chargers!"

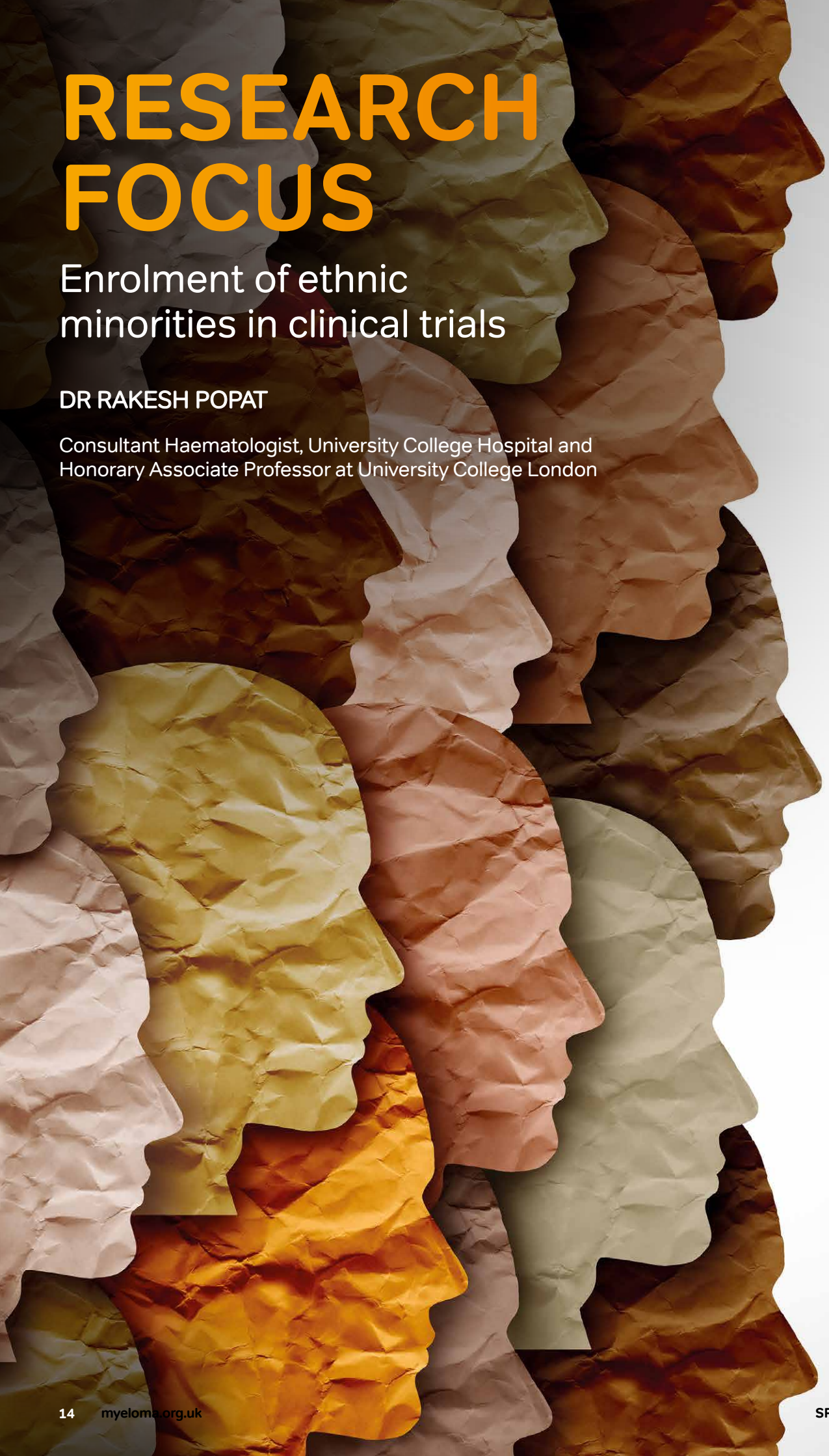
"Concentrating is very difficult after a transplant so I found magazines and TV easier than a book."

RESEARCH FOCUS

Enrolment of ethnic minorities in clinical trials

DR RAKESH POPAT

Consultant Haematologist, University College Hospital and Honorary Associate Professor at University College London



In 2021, Dr Rakesh Popat and a team of researchers investigated the ethnic diversity of myeloma patients in clinical trials in the UK. This work was presented as a poster at the American Society of Haematology (ASH) conference in December 2021. We caught up with him to find out more about this crucial piece of research and what its findings mean for myeloma patients.

What was your motivation behind conducting research into the involvement of myeloma patients from ethnic minorities in clinical trials?

There has been a lot of literature coming out from the US that has demonstrated unequal enrolment into clinical trials for patients of different ethnic groups.

This is a problem for two reasons. Firstly, it's very important that the population you're working with in clinical trials is representative of the real-world population that you're going to give the treatment to eventually. In myeloma, this is particularly relevant, because the incidence of myeloma varies by ethnicity.

People from Black ethnic groups are approximately two to three times more likely to develop myeloma compared to white or Asian, with men having a higher likelihood than women.

A lack of patients from ethnic minority groups in myeloma trials, therefore, means you're not representing the real patient population.

> **"It's very important that the population you're working with in clinical trials is representative of the real-world population"**

The second problem is to do with access to new treatments. Survival for myeloma has improved over the years and that's predominantly due to the advent of novel treatments. If patients from ethnic minority groups aren't participating in the trials, they are potentially missing out on survival benefits, particularly in the late phase trials.

Although much of the research on this topic is coming from the US, which has a very different healthcare system mainly based on insurance, the problem is prevalent in the UK too.

> **"If patients from ethnic minority groups aren't participating in the trials, they are potentially missing out on survival benefits"**

I run a phase 1 trials programme for myeloma at University College London Hospitals (UCLH) and realised when we looked at our patients in our phase 1 trials programme that the majority of them were white.

For us, a big hospital in London, that's not representative of the ethnic makeup of our patients, which is a very diverse population. We decided to collect the data on ethnicities of patients in our phase 1 trials at UCLH, and it showed that there was quite a skew towards the white ethnic group.

Having seen that that skew on a local level, I wanted to look on the national level.

What was the research you carried out?

The team pulled together all the data from the UK-MRA (UK-Myeloma Research Association) clinical trials from the last 18 years. This gave us a total of 18 years' worth of patients, which was over 7000 patients.The trials we looked at are academic clinical trials, which means they're designed and led by hospitals and universities rather than pharmaceutical companies. Academic trials are usually designed to address gaps in treatment and care for a specific country. Industry trials, on the other hand, are focused on getting a drug approved and usually have a narrower remit in trying to show a certain treatment has benefits to patients.

We compared the ethnic breakdown in these trials to the incidence of myeloma in the UK. These trials were recruiting from over 120 sites across the country, which gave us a much broader representation compared to the London-based analysis my team and I had done previously.

What were the results of the study?

As we saw in London, there was a striking difference between incidence and enrolment across ethnic groups across the whole UK. Black and Asian patients were under represented, and that was statistically significant across all trials.

Patients from Black ethnicities made up only 2.2% of the trial participants, despite making up 5.4% of myeloma diagnoses. Similarly, Asian ethnicities made up 1.8% of trial participants, which is half the proportion of myeloma cases.

Ethnic Group	Myeloma Incidence (%)	Trial Enrolment (%)	Difference between trial enrolment and incidence (%)
White	85.5	93.8	+8.3
Black	5.4	2.2	-3.2
Asian	3.6	1.8	-1.8
Other	1.9	0.6	-1.3
Unknown	3.6	1.6	-2.0

Figure 1: The study showed that there was a significant difference in ethnic minority enrolment to clinical trials compared to the incidence of myeloma.

The biggest difference was in the non-transplant eligible trials, where patients have less intensive treatment due to their fitness, usually older patients. For example, one trial at the time of analysis, Myeloma 14, had recruited approximately 120 patients and not a single Black patient had been enrolled.

> **Our patients are missing out on new drugs, and that's a major problem**

That tells you that we've got a major problem. The reason why this is important is because academic trials generally have quite relaxed entry criteria. They're designed to be representative of the real-world population. Despite being designed to take everyone, what this data told us is that we weren't taking a representative population, even though we thought we were.

We looked a bit deeper at the data from these trials and we found that when you look at survival by ethnicity, the survival was exactly the same across each group.

There was no worsening or improvement in survival according to the ethnic groups. This is reassuring, because it shows that if you do enrol patients into the trials,it doesn't matter what ethnic group they're in, they will do as well as any other ethnic group.

We also found the ethnic makeup across the trials was the same across the 18 years. This is despite the fact that the ethnic distribution of the population of the UK has changed in that time and it's more diverse now. So again, these results show we're failing to enrol patients proportional to the diversity we see in the UK. As we're failing to enrol these ethnic minorities, they're not benefiting from survival improvements because our patients are missing out on new drugs, and that's a major problem.

Why do you think there is this discrepancy?

That is the crux – why is this happening? We see this pattern across all trials and locations in the UK, which this tells us that, even though we're working within the NHS structure, which is a state funded healthcare system and access to trials and treatments should be the same (unlike the US insurance-based system), something's not right as we're still seeing disparities.

The data on why this is happening is coming from questionnaires and there's been the recent piece of work, in which Myeloma UK was involved, that picks up a wide variety of social and cultural reasons why patients from different ethnic groups aren't enrolling.

> **There can be a mistrust of all phases of clinical trials (early or late), meaning fewer people willing to participate.**

Many of the factors we've seen involve socio-economic class, so we'd like to do the same analysis as we did with ethnic groups but according to social deprivation index. This will help us understand whether it's purely ethnicity or if socio-economic class is contributing to these differences in enrolment. That's work in progress.

The second problem is that we know that there are differences between cultures when it comes to trusting the medical profession.

This stems back to historical problems which have happened and mistrust in authoritarian establishments. There can be a mistrust of all phases of clinical trials (early or late), meaning fewer people willing to participate.

> **Clearly, it's quite a complex issue with varied factors**

The other problem is that, whilst the NHS workforce is quite diverse, the doctors who may be explaining the trials may not be from the same

cultural identity as those patients being enrolled and communication can be more difficult with a lack of understanding of the patient's cultural background and beliefs.

Clearly, it's quite a complex issue with varied factors. What I think we need to do is actually go and ask those groups of patients what the barriers are and how we can help.

What we have is retrospective data and what we need to be doing is doing prospective data to understand what exactly the problem is.

What are the next steps?

There are a number of things that we're doing as a result of these findings. The first thing we need to do is get this message out, so we're currently working to publish our work.

Secondly, what I'd like to do is to set up a study where we can give a questionnaire to everyone who's been newly diagnosed with myeloma to ask what their views on clinical trials are so that we can understand what the reluctancies are.

> **The first thing we need to do is get this message out**

The last thing is that the NIHR (National Institute for Health and Care Research) has an initiative to try and improve research participation in underserved communities.

This is wide ranging as under-served communities are not just different ethnic groups. It's social classes.

It's disabled patients. It's patients who have non-secretory disease that miss out on clinical trials as well.

One of the things we're looking to apply for in North Thames is a diversity ambassador.

This would be a post whose purpose would be to talk to patients about clinical trials from different backgrounds and to try and engage with them in a culturally sensitive way.

I would envisage that they would be working in the regions where these populations are and to try and encourage them to come into trials because I think we need someone who's from the same cultural background to bridge that gap.

The ideal would be to have one of these ambassadors in every NHS Trust, but we have to demonstrate that this approach would work and hence we're going to try and do this in a targeted fashion through the NIHR clinical research networks to prove if this is beneficial.

I think myeloma isn't the only condition that could benefit from this. Myeloma is important because the incidence of myeloma is more frequent in patients from Black ethnic groups than white, but the same is true in prostate cancer.

We can look at this across different groups of patients in the pilot to see if this approach is beneficial.

What would you say to patients, particularly patients who are from minority ethnicities, on the back of these findings?

What I'd like to do is to provide some reassurance that all the clinical trials in the UK go through an ethical review process, as well as a regulatory approval process through the MHRA (Medicines and Healthcare products Regulatory Agency), so you can be confident that if we are offering a trial then you will be safeguarded within that trial.

I hope that patients will have an open mind in considering clinical trials and understand what the potential benefits for them might be, as well as the potential benefits for research and future myeloma patients.

The flip side of the coin is they also need to understand the risks of them getting involved in a study, so I encourage patients to speak to their healthcare teams about clinical trials and what their options are.

> **I hope that patients will have an open mind in considering clinical trials and understand what the potential benefits for them might be**

I also want to highlight that myeloma treatments are moving incredibly rapidly and if they do want to benefit from some of these advances, then the only way is to enrol into clinical trials.

The last thing is that I would recommend that patients bring a carer, family member, or friend to the consultation, particularly the more elderly patients because we're seeing this problem with the elderly ones specifically. If they're able to bring another person to the consultation then that might help.

If that is not possible or it is impractical, then the other option is to have the person on speakerphone during the consultation, so they can participate in the conversation.

DID YOU KNOW?

Myeloma UK has a Myeloma Trial Finder that lists clinical trials ongoing in the UK. Visit trials.myeloma.org.uk to view it.

MYELOMA

HOT TOPICS

THE DEVELOPMENT & EVOLUTION OF MYELOMA

Our bodies are made up from billions of different cells and each of these cells contains DNA, which has all the instructions the cell needs to grow and function.

Sometimes when our bodies are making new cells, the DNA isn't copied properly causing mutations or changes in the DNA. Some of these mutations can mean that the cell no longer understands its instructions. They start to dysfunction and even start to grow uncontrollably.

How myeloma develops

For cancer to develop there have to be several different mutations that change the instructions controlling the production of new cells and breakdown and removal of dysfunctional cells. Myeloma starts when the DNA of one plasma cell, or a small group of plasma cells, mutates. These genetic errors can build up and change the genetic instructions contained within the cells to the point that the plasma cells can uncontrollably produce new cells.

Mutations and precursor conditions

Before developing myeloma, all patients have two earlier non-cancerous conditions, monoclonal gammopathy of undetermined significance (MGUS) and smouldering myeloma. These are also caused by faulty plasma cells. MGUS does not cause any symptoms and is usually diagnosed incidentally when tests are performed to investigate other problems. While most MGUS patients have a stable condition that has no effect on their general health, a small proportion of patients will go on to develop myeloma. Smouldering myeloma is the intermediate stage, which usually progresses to active myeloma, but at a slow rate.

Research has shown that some of the mutations associated with the development of myeloma are also associated with the development of MGUS and smouldering myeloma. However, it is still not fully understood why some MGUS patients go on to develop myeloma and some don't and why this occurs quite quickly for some patients and more slowly for others. Researchers have, however, identified that myeloma cells gain more genetic mutations as MGUS progresses to smouldering myeloma and smouldering myeloma progresses to myeloma. It is hoped that a better understanding of the genetic changes will help to identify ways to prevent MGUS and smouldering myeloma patients from progressing to myeloma, or at least to identify which MGUS and smouldering myeloma patients are more likely to develop myeloma, and when.

Why myeloma can be hard to treat

Recent studies show that a patient's myeloma cells are not all genetically identical at a given time.

Some myeloma cells may acquire further genetic changes over time, creating several sets of myeloma cells, known as clones. This concept is known as 'clonal evolution' (see Figure). Each cell within one of these clones is genetically identical, but different clones differ genetically from each other. This leads to a patchwork effect of myeloma cells.

The genetic differences in one clone can make these myeloma cells grow faster than the myeloma cells in other clones, becoming stronger and more aggressive and resistant to treatment. This slight genetic variation between groups of cells is thought to be one of the main causes of relapse in patients, when one or some of the clones become resistant to treatment. Different clones can become resistant to different treatments and if this occurs, it can make the patient's myeloma more difficult to treat.

Summary

Plasma cells can undergo genetic mutations that lead to conditions, such as MGUS, smouldering myeloma and active myeloma. Research is looking more into these genetic changes to help us understand why myeloma evolves and develops.

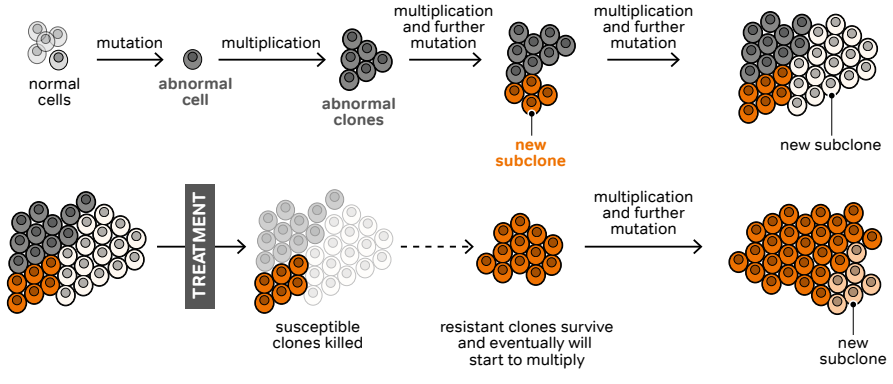


Figure: The clonal evolution of myeloma cells leads to a patchwork of groups of cells with different genetic mutations.

MYELOMA, SEX AND INTIMACY

Experiencing difficulties with sex, intimacy, and feeling a loss of libido is common for myeloma patients and their loved ones.

This Hot Topic aims to be honest and open about overcoming physical barriers to sex when living with myeloma and contains frank information around sex.

You may find it awkward or difficult to start talking about this with your partner or healthcare team, but being honest about how you are feeling is the first step to improving things.

Using protection

If you have sex while on myeloma treatment, it is essential to use barrier protection to keep you, and your partner, safe.

Types of protection and when to use them:

Male condoms

- Penetrative sex (anal or vaginal)
- Receiving oral sex

Female condoms/ femidoms

- Penetrative sex

Dental dams

- Oral sex (cover the female genitals of a partner receiving oral sex)

Condoms and dental dams protect you from infection, your partner from chemotherapy, and prevents pregnancy.

Some treatments, including thalidomide and lenalidomide (Revlimid®), require you to follow a Pregnancy Prevention Programme, where contraception must be used.

Orgasms

You may find that you cannot achieve orgasm like you used to. As people age, it can be harder to achieve orgasm, or it may take longer. This can also be true for patients that have been treated for myeloma.

Achieving orgasm does not have to be the 'end goal' of sex. Concentrate on enjoying what you are doing. You may want to spend more time on foreplay or try touching new areas on your body to see what you respond to.

Loss of libido

Myeloma and its treatment can affect your desire for sex (libido). Your sex drive might be lower because of:

- Pain
- Tiredness (fatigue)
- Anxiety or depression
- Treatment side effects

As with all side effects and symptoms, it's important to let your healthcare team know what you are experiencing. They may be able to help you towards a solution that improves your quality of life. Many of these problems will disappear once your treatment finishes, and you may find your desire for sex returns.

Overcoming physical barriers to sex

You may want sex but find that physical issues, like fatigue or pain, become barriers. One solution is to find positions with your partner where your partner is willing to do the more strenuous activity during sex. Alternatively, you can choose positions where the sex is gentler, but both partners are active in the act. Receiving and giving oral sex is a way for partners to feel very intimate with one another that can be gentler than penetration. You may receive oral sex, but shouldn't give it, while on immunosuppressive treatments due to infection risk. Other strategies that can help physical barriers include:

- Planning to avoid times when you know you will be more fatigued or nauseated
- Using vaginal lubricants and moisturisers
- Using erectile dysfunction equipment, e.g., vacuum pumps or constriction rings
- If you are worried about mild pain during sex, take painkillers 30 minutes beforehand (if it hurts at any time, stop)

Penetrative sex may need to be temporarily avoided if you have a low blood cell count. This is because you might be at risk of bleeding or infection. If in doubt, ask your healthcare team (don't be embarrassed, they are there to answer your very normal question about sex).

Alternatives to sex

Exploring different ways to show intimacy can be fun and a good opportunity to try something different to see what you enjoy. You could try:

- Bathing together
- Touching each other
- Masturbation
- Using sexual aids such as vibrators
- Communicating sexually

Even if you don't feel like being sexually intimate, you can still enjoy kissing, cuddling, and being close to your partner. The important thing is to do what feels comfortable and enjoyable for you and your partner.Intimacy is an important part of a relationship. It can help you express your feelings and make your partner feel valued. Set aside quality time for each other to do the things you enjoy.

Read more in our **Infopack for living well with myeloma**

THE IMPORTANCE OF CLEAR LANGUAGE

Myeloma is a complex cancer and its diagnosis and treatment often requires being given a large amount of information. The information provided can be of great use. However, it can be difficult to understand, particularly if medical jargon is used.

Health literacy

The average reading age of a UK adult is nine years old, 1 in 6 people in the UK have very low literacy skills and almost 1 million people cannot speak English well, or at all. However, patients do not need to have low literacy to have low health literacy.

Health literacy is the personal characteristics and social resources needed to access, understand, appraise and use information and services to make decisions about health.

Health literacy, therefore, has the added layer of not just understanding the information, but of knowing where to find it, what to do as a result of it and how to use it to make decisions.

What does this mean for health?

A misunderstanding of information given has been shown to result in feelings of anxiety, depression, and a decreased involvement of patients with their healthcare team. There can also be a general negativity towards health and healthcare when there is a lack of understanding. At the same time, understanding medical information can lead to improvement in patient-doctor relations, improve the ability to self-care and can reduce the occurrence of preventable ill health and complications.

Put simply, suitable health information leads to better outcomes for patients. For example, if you understand the potential side effects of a treatment, you'll know what to look out for and you can then tell your team if you experience any side effects. They will be able to support you with those side effects and you're more likely to have a better quality of life on that treatment. You're also more likely to take it as prescribed and have maximum efficacy, leading to better remissions. Ensuring patients have information they can understand is, therefore, crucial in ensuring reducing inequality in patient outcomes.

Talking to your healthcare team

A key source of information for a patient should be their healthcare team, but what if you are confused about the language they're using and information they've given you? What if you can't get your questions across because you don't feel confident in what you're talking about? How are you supposed to tell those close to you what the doctor said if you don't understand it yourself?

This can lead to feeling overwhelmed during appointments and not getting the most out of them. Here are some tips to help you manage the information given at these appointments and with your understanding of this information:

- Try not to be embarrassed if you are not sure what you are talking about. Your healthcare team are there to help you
- Think of what you want to say before going to appointments and make a note of it, no question is too silly or small
- Make a note of anything you don't understand and ask your healthcare team to explain and provide clarity
- You can rehearse your questions in advance with someone to help find the right words and find an easy way to get your point across
- Don't worry about asking for things to be repeated if they aren't clear or to interrupt if you need something to be explained
- If possible, take someone with you to your appointment. They can help write notes, ask questions and discuss what was said with you afterwards

You leave your appointment with more questions than you came with, but remember, you don't need to wait until your next appointment to contact your healthcare team, you can call and ask questions in between.

Making language simple

Myeloma UK can also help clarify what your healthcare team has said or to work out questions for your next appointment via our Myeloma Infoline and Ask the Nurse email service.

We always aim to provide information that is clear and easy to understand, and our patient information is accredited by the Patient Information Forum (PIF), which is the UK membership organisation for people working in health information and support. This means all our patient information follows best practice to make it easier to understand and read. Using plain language, short sentences, bullet points and describing any medical terms are all examples of how we aim to make language easier to understand.

INTERVIEW WITH SOPHIE CASTELL

CEO OF MYELOMA UK

We're delighted to welcome Sophie Castell as our new Chief Executive. We sat down with her to get to know her.

You bring a wealth experience from previous roles, how will your experience inform your work at Myeloma UK and what drew you to this role?

It is clear that people are at the heart of Myeloma UK, and it was that which drew me to this role. The commitment from Myeloma UK to improve the lives of patients and families, as well as ensuring patient-centred input at every stage of the myeloma journey strongly resonated with me. I firmly believe that empowering patient voice is critical to driving positive change.

I started my life as a scientist and then after gaining my PhD, I went to work in the commercial sector. There I put my research training to good use in market research. It was there that I became really interested in what motivates people. I found it fascinating to look at people's hopes, aspirations and then use these insights to develop new products and services that actually meet the needs of the people who use them.

> **"I'm excited to bring my experience and the values that underpin it, to my role at Myeloma UK: as we work as a community to transform the lives of people with myeloma."**

From there, I moved into innovation and marketing roles, and I made the move to working in the third sector after my son's diagnosis as autistic. All my experience – third sector, commercial and research – has shaped how I approach my working life. From my research background which instilled in me the importance of listening to the needs of the people that an organisation serves. To my commercial experience which taught me how think to strategically. And lastly to working with a range of third sector organisations which has made me think about culture and how to build an open, positive ethos where people know they are truly valued. I'm excited to bring my experience and the values that underpin it, to my role at Myeloma UK: as we work as a community to transform the lives of people with myeloma.

In 2005, you co-founded the Enfield branch of the National Autistic Society and you've since joined the charity's Board of Trustees. What prompted you to support the National Autistic Society?

When we came back from living in the USA, my son was diagnosed as autistic. I remember the day very clearly. It was a bright, sunny winter day and his hands ruffled through my hair as we left the diagnostic centre with him astride my shoulders, protesting at having to leave a family of plastic pigs that he been playing with.

Over the next few years, we started the search for support, and it became clear to me that there were real inequities in access to the support available and I wanted to change that. My part of north London is pretty diverse and the health inequalities across the Borough are very stark. The local branch I set up developed a range of innovative peer-to-peer support programmes and joining the Board of the national organisation has meant that I can influence change more widely.

Do you think your own experience gives you an insight into why patient experience is so important? How can charities best work with those that they represent?

In addition to supporting my son, my mother was recently diagnosed with Alzheimer's, so I understand the complexities of caring for someone with a progressive degenerative condition. I have also seen the power of combining lived experience with research and clinical practice to develop new solutions first hand.

My professional journey has involved working with people living with autism, visual impairment, life limiting conditions, special educational needs, dementia, and their families and I am committed to addressing the inequalities experienced by people living different conditions or disabilities and supporting them to live well, with the best possible quality of life.

I think there are two important things for charities in terms of representation. Firstly, always be in listening mode and, secondly, embed the voice of community they serve in strategy development. As a parent I led a consultation with families and professionals for The London Borough of Enfield.

This was as part of the then Government's change agenda for children with additional needs.

It was important for the Joint Service for Disabled Children to hear from real parents. In my role I trained a group of parent service users to design and run the consultation. Because the parents were the consultants, they were at the heart of the service design, ensuring that the needs of their children would be met. Resulting in a new strategy for respite care and short breaks for the Borough.

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

Without a doubt it's the community around Myeloma UK that is the biggest asset. From the patients and carers who give their time and energy to influence policy or make a positive change in care. To the clinicians and researchers, we work with who are passionate about bringing together the different strands of work around diagnosis that could lead to real change for myeloma patients.

To the staff and trustees who are so dedicated to making a difference. It's early days but I can already sense that feeling of community.

I think that community aspect combined with the genuine commitment to putting patients front and centre as well as the brilliant research and policy advocacy work. These feel like extremely valuable assets that we can build on further to continue to enhance our impact.

What are the most valuable lessons you've learned in your 20 years in the charity sector?

Mmmmm, where to start? So, first up – people. A wise person once said to me 'connect before content', by which they meant that you needed to build relationships before focusing on the work you are going to do together. This has always stuck with me, and I think it is important to build relationships within an organisation and, importantly, across organisations, to build powerful alliances and coalitions – we can always be stronger together.

Second up – strategy. Strategy is about focus and making choices. Strategy is about understanding where you can have the most impact and then deploying your resources accordingly. I think there is a real temptation for charities to try and 'do everything' and the risk is then that their impact is diluted. I think it's usually better to do a smaller number of things superbly well.

> **Without a doubt the community around Myeloma UK is our biggest asset.**

Finally – charities are fuelled by their supporters. None of the great work we do can be done without the generosity of the people who donate their money and time. It's incredibly important to build a vibrant fundraising and volunteering culture so that supporters know they are valued.

Can you see any emerging challenges as a result of the pandemic? Are you concerned that focus is being pulled from very real, long-term challenges?

I think that the pandemic has been a very challenging time in a number of ways. Like many of you I have real concerns about the impact of the pandemic on the NHS and wider health and care system. We know that the most recent data shows large falls in diagnosis rates and cases in England are down by almost a quarter compared to pre COVID-19 levels. For myeloma patients we know that delayed diagnosis was a problem before the pandemic so we need to understand how COVID-19 will has exacerbated that issue. All of this will take some time to 'unwind', and we need to keep strong watching brief. However, as an organisation, we have learnt a lot about how to support our staff and volunteers and how to work in new, more flexible ways. I hope that we can build on this so that we continue to strengthen our organisation so that we do more and provide even more support for the myeloma community.

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

It's about building on things that we currently do so well. We must continue listening so that we understand how the needs of patients and their families may be changing – it's only by listening that we can adapt and plan our response. Also, again, it's about thinking about what we've learned over the last two years and building on that learning. Before the pandemic we would never have considered online Infodays, but now hundreds of patients can connect and engage from the comfort of their home.

We also need to keep a good eye on what is happening in government, both Westminster and the Scottish Parliament have announced that they intend to have 10-year cancer strategies. This is an important opportunity for Myeloma UK to influence policy and ensure that voices of our patients are heard. Lastly by continuing to build and develop our fundraising so that we can continue to support the myeloma community.

What inspires you, both at work and in life?

My son is a big inspiration to me. He is now 20 years old and working part-time – seeing how he has developed has given me huge pleasure. I take a lot of inspiration from music. I am a singer and joining my voice in a group of people to create wonderful, soaring sounds always inspires me. I take inspiration from the natural world. A grew up in East Anglia and those wide skies always seem to say 'endless possibility' to me.

I guess more specific to work, I take inspiration from women leaders and there are a couple of quotes that resonate with me. Eleanor Roosevelt – 'do one thing every day that scares you' and 'it is better to light a candle than curse the darkness'. I think both quotes will guide me in the role at Myeloma UK. In general, I am inspired by exploring future possibility and then making it happen!

POLICY BRIEFING

A LIFE WORTH LIVING

Earlier this year, we published our report, A Life Worth Living, the very first to investigate the hidden impact of delayed diagnosis on the quality of life of myeloma patients in the UK.

Why did we produce this report?

As a less common cancer with non-specific symptoms, myeloma patients continue to experience significant delays in receiving a diagnosis with 50% waiting over five months and 31% diagnosed through an emergency visit.

These are some of the longest times to diagnosis of any cancer in the UK. Improving cancer diagnosis is a key ambition for the NHS across the UK. However, the policy conversation is often driven by the characteristics of solid tumour cancers, which is not a good fit for myeloma, where the significance of staging and its link to survival differs from solid tumours.

In addition, the impact on quality of life of a delayed diagnosis, which can be particularly severe in myeloma, is also all too often overlooked. With advances in treatment meaning that patients are living longer, the quality of life of patients has never been more important. We hear this first hand on our Infoline, Ask the Nurse email service, and patient panels, to name a few. We have heard how your lives are affected by complications made worse by a late diagnosis.

We therefore decided to undertake a research project to provide us with evidence on the impact of delayed diagnosis in myeloma to enable us to make a case for change and ensure that solutions to improve diagnosis take the experience of myeloma patients into account.

What were the results of the research?

Myeloma exerts a severe toll on the quality of life of all patients, no matter who they are or when they are diagnosed. However, our survey shows that the effects are most severe in those patients whose diagnosis is delayed, and the longer the delay the more severe the consequences. The research looked at the scale and nature of delayed diagnosis, the impact of myeloma and the impact of a delayed diagnosis.

A few of our findings include:

- Women were less likely to have a timely diagnosis, as 64% of men received a timely diagnosis, compared to 36% of women
- A delayed diagnosis is significantly more likely in younger patients: 48% of patients reporting a delayed diagnosis were aged 18-64, compared to 35% of people with a timely diagnosis
- Myeloma has a significantly greater impact on black patients and patients from ethnic minorities compared to white patients, with 55% of black and minority ethnic patients reporting a high impact on quality of life compared to 37% of white patients
- Patients with a delayed diagnosis are significantly more likely to suffer a high impact on their quality of life than those who received a timely diagnosis (49% vs 30%)
- Patients with a delayed diagnosis were more likely to experience a severe impact on their mobility, ability to socialise, exercise and work with subsequent implications for their finances and mental health

What happens now?

This report demonstrates the serious impact that a myeloma diagnosis has on quality of life and provides the first evidence that these impacts are greater the later a diagnosis is made.

We will be working with NHS leaders and policy decision-makers across the UK to understand this issue further and identify possible solutions.

In particular, we're calling for:

- A new approach that puts the day to day lives of myeloma patients front and centre across research, policy development and commissioning and clinical practice
- The government to prioritise quality of life for all future cancer strategies
- A patient-centred "route map" which will, for the first time, deliver a truly holistic approach to the impact of a diagnosis on the quality of life in myeloma

Our results provide powerful evidence of the need for quality of life to be taken into account when considering appropriate policy measures for blood cancers including myeloma.

We hope that our findings can be used to inform new policy measures and metrics that will improve the timely diagnosis of myeloma and patients' experiences as they live with the disease.

We are immensely grateful to those who took the time to fill in our survey or be interviewed. We will use your insights wisely to campaign for better diagnosis, treatment and care.

Read the full report on our website myeloma.org.uk

ASK THE NURSE

Katie Fleming, Hayley Hepworth and Ellen Watters **Myeloma Information Specialists**

What are the signs of infection and how do I reduce the risk of getting one?

Infection occurs when disease-causing organisms enter the body and begin to multiply. If they survive long enough, they can cause infection and make you ill. Look out for and tell your healthcare team immediately if you have any signs of infection, such as:

- Fever (temperature of 38°C or above) or a low temperature (35.5°C or below)
- Chills/sweating
- A new cough
- A sore throat/mouth
- A blocked nose/ears
- Nausea/vomiting
- A burning sensation or pain when passing urine or needing to urinate more frequently
- Diarrhoea or pain in the stomach
- New onset of pain
- A rash
- Swelling, redness or pain at the site of catheters

Myeloma patients are at a greater risk of infection, so it's important to try to minimise your risk where you can and you may want to ask your healthcare team how at risk you are. To help reduce your risk of infection, you should wash your hands regularly (or use hand gel when out in public) and consider avoiding public places when they are busy. At home, you should disinfect surfaces frequently, ensure your food is cooked thoroughly and don't eat food past its use by date. Keep cuts and scratches clean and covered, avoid sharing towels, and it's advisable not to handle pet litter. You should also keep up to date with any necessary vaccinations.

I am experiencing intense fatigue; how can I manage this?

Many myeloma patients experience fatigue; this can be a frustrating and debilitating symptom. Fatigue is different from tiredness, as it is not relieved by rest. There are often several contributing factors. However, there are various ways to manage fatigue, some of which your healthcare team can support with, so be sure to tell them how it is affecting you.

Anaemia can cause or contribute to fatigue; this often improves when myeloma is successfully treated. Your healthcare team may also be able to offer some supportive treatments. Getting specialist support can help. For example, fatigue can be mentally wearing and affect your mood, so accessing psychological therapies can be helpful. Pain can also contribute to fatigue, particularly if it is poorly controlled, so a referral to a pain specialist may help. Eating a healthy, balanced diet and undertaking regular gentle exercise can help boost energy levels and you can ask for a referral to a physiotherapist or dietitian if you need support with this.

Although fatigue is not directly eased by sleep, difficulty sleeping can contribute. Keeping to a regular sleep routine and implementing relaxation techniques such as meditation or breathing exercises may help to ensure a good night's rest. Remember the three Ps – plan, prioritise and pace. Keeping a diary of your fatigue can be useful to identify when your fatigue is less intense. This way, you can plan activities for the times you feel less fatigued. For more information and tips, read our 'Fatigue and myeloma Infoguide'.

I've noticed my ankles are swollen, what could this mean?

Swollen ankles, particularly with tight shiny skin, can be a symptom of fluid retention (oedema). Other symptoms include feeling bloated and shortness of breath. In myeloma, fluid retention can be caused by the abnormal proteins produced (specifically the light chains) damaging the kidneys. It can also occur as a result of high levels of calcium in the blood and as a side effect of treatment (e.g. dexamethasone). In some cases, it may be related to another health condition.

Kidney function is routinely monitored with blood tests so your haematology team will be able to identify any kidney issues promptly, but it's important to report any new or increasing symptoms to them.

Fluid retention caused by myeloma often resolves once the myeloma has been brought under control or the treatment that has caused it has been stopped, the dosage reduced, or the schedule changed. In some cases, diuretics (water tablets) are part of a management strategy for fluid retention and swelling. However, this may not be appropriate in all cases as these drugs can put an additional strain on the kidneys. Some self-care measures for managing fluid retention can include limiting salt intake, taking gentle exercise, and sitting with the legs elevated when possible.

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

We were really grateful to discover earlier this year that Peter Gore had left Myeloma UK a gift of £500 in his Will.

Peter was an active member of the myeloma community, attending our Infodays, taking part in our patient panel, attending his local Support Group in Derby as well as being a faithful supporter, buying Myeloma UK Christmas cards every year to help spread awareness. We spoke to his niece Ann-Marie Boyle to find out a bit about his life:

"Peter began his 25-year career with the BBC in 1973, joining BBC Radio Solent. He presented the Breakfast Show, Afternoon Show, Weekend phone-ins and Deep South Country. He was part of the small team that set up BBC Radio Jersey. On 15 March 1982, his was the first voice to be heard on the new station.

In the early 1980s Peter moved to BBC Radio Derby, presenting 'Up and About'. On one occasion he presented the whole show from a hot air balloon. During this period a colleague wrote of him:

"Peter sits in the studio serene, chatting to you and generally keeping his head when all about him are losing theirs." (John Brooks, BBC Radio Derby 269 Magazine, 1984)

Until his retirement in 1999, Peter continued at BBC Radio Derby, presenting, producing, programming, reporting and as a senior journalist. He was born in London on 22 August 1945, growing up in Bristol and Southampton. Teaching himself to play keyboards and guitar, he began gigging in pubs and clubs around Southampton.

In 1963, Peter joined the army and was posted to Bielefeld, West Germany where he served

in 14 Squadron, Royal Corps of Transport. He continued to play in local venues and at The Waggoners Club.

His army testimonial describes his service as 'exemplary':

> **"An intelligent and capable young man who has done well in the service. A hardworking and most willing individual... with a flair for the entertainment world musically. A charming and cheerful personality."**

After leaving the army in 1969, Peter continued gigging and worked as a DJ at the Silhouette Club and the Bird's Nest in Southampton. In 1972 he was the winner of the BBC Radio London Silver Microphone Award.

In recent years, Peter travelled widely, his long holidays regularly seeming to coincide with other unexpected events – a volcanic eruption, a tsunami and a military coup. The postcards and messages he sent would simply say 'having a lovely time in the sun'.

Peter was diagnosed with smouldering myeloma in 2007 which later progressed to myeloma.

Sadly, Peter passed away on 11 March 2021 but will be remembered with affection by all who knew him. He was supportive, endlessly curious, adventurous and fun.

In 2017 he made a video for Myeloma UK talking about how he coped with his illness: **The Emotional Effects of Living with Myeloma**.

To watch the video, go to the Myeloma UK website by scanning the QR Code:

One of the quotes from his video encapsulates his characteristic optimism: "You've got to make the most of your peaks... Do everything that you want to do, that you are physically and mentally capable of doing during the peaks, and, during the troughs... look forward to the next peak. That's all you can do."

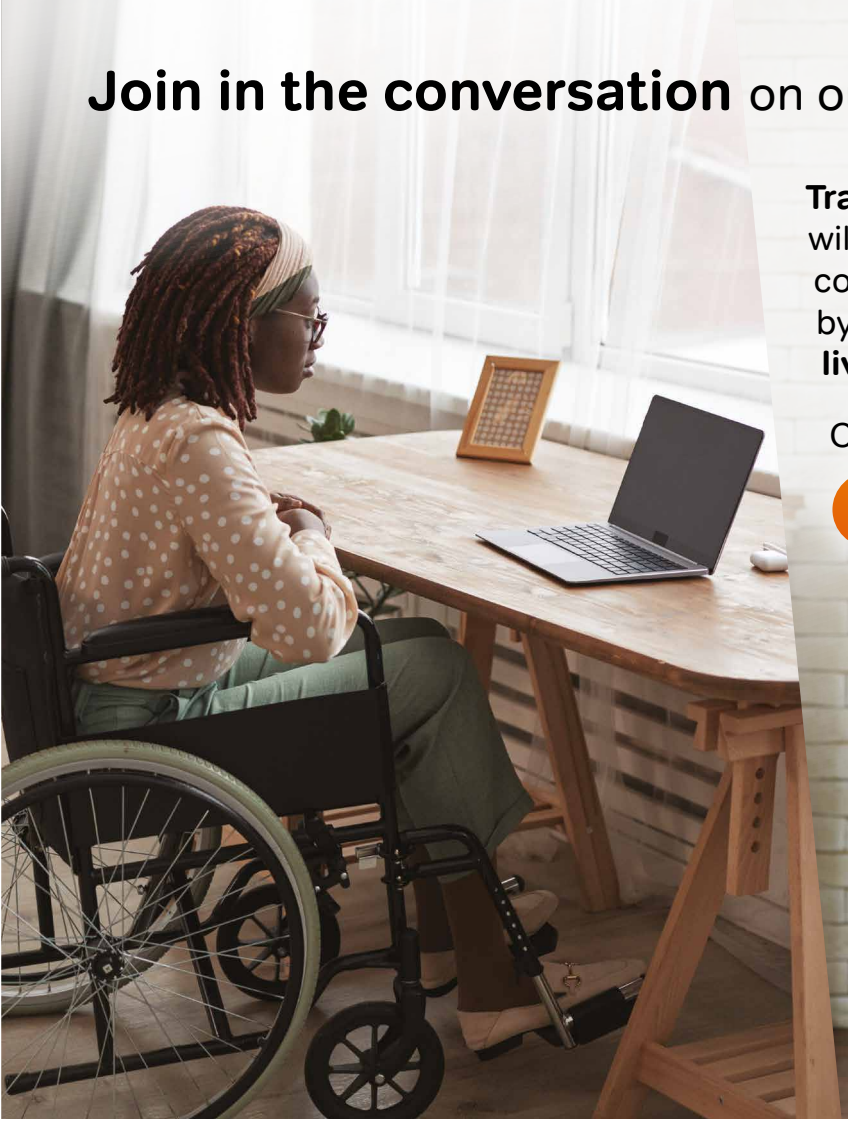
Individual and Planned Giving Manager Claire Holmyard said:

"When he passed away, Peter's family and friends raised £595.07 for Myeloma UK to honour his memory. We were moved to receive these funds and Peter's legacy gift to help invest in our work. We know he wanted more attention brought to myeloma to help accelerate research into better treatments.

"He was looking forward to the day when myeloma might be classed as a "chronic illness". It's thanks to the support of incredible people like Peter who donate, raise funds, and leave a gift in their Will, Myeloma UK can continue to fund key research to increase our understanding of myeloma and its treatment. We are determined that one day Peter's hopes might become a reality."

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

Join in the conversation on our Discussion Forum



Trained Peer Discussion Forum Volunteers will respond to messages, so you can feel confident knowing you'll be supported by people who **understand what it's like living with myeloma**.

Chat and connect with others at:

myeloma.org.uk/forum

MyelomaUK

MyelomaUK Lottery

Changing lives every week

Win up to £25,000

Play our lottery for just £1 per week and help Myeloma UK to provide advice and support to myeloma patients and their families, as well as supporting our work to improve diagnosis, treatment and care for patients across the UK.

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or call 0131 230 0429
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myeloma.org.uk/mylottery

Small Society Lottery
Registration No: 466890

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

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