SPRING/SUMMER 2023

myeloma matters

Spotlight on
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Our new website

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MyelomaUK

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DEAR READER

Alice Baron
Myeloma Matters Editor

Welcome to this edition of Myeloma Matters.

We've had a number of changes here at Myeloma UK over the last few months. Firstly, I'm pleased to highlight the appointment of a new trustee, Karen Paul. Karen is a smouldering myeloma patient and will be using her passion for fundraising to help us grow and be able to support even more people affected by myeloma and its related conditions.

As well as appointing a new trustee, we have a new advisory position. Many of you may be familiar with Professor Graham Jackson through his work as a haematologist in Newcastle for many years. He's joined Myeloma UK as our first Chief Clinical and Scientific Advisor. Enclosed is an interview with Graham to find out why he's chosen to take up this role with us.

If you've ever called our Infoline or written us an email, chances are you'll have spoken to our longest serving member of staff, Ellen Watters. Ellen has been part of our Myeloma Information Specialist team for over 20 years.

We've included a special "Ask the Nurse" and asked her some questions about why she's still so passionate about supporting patients. You can find our chat on pages 22 and 23.

In May, we were delighted to have a garden at the RHS Chelsea Flower Show. This garden was designed specifically for people living with myeloma, and we were thrilled it won not only a gold medal, but the BBC/RHS People's Choice Award. Read more about the design and inspiration for the garden on pages 14 to 16 with our designer, Chris Beardshaw.

As well as these interviews, this edition has information about blood cells, our new website and financial support.

Don't forget that our Infodays are back – we are holding two this year so book yourself on if you're interested in spending time with other people living with myeloma and learning from experts.

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

Mass spectrometry successfully predicts treatment response

A German study reveals that mass spectrometry (MS) is a promising way to measure myeloma treatment response. MS is a more sensitive way to measure paraprotein levels from blood tests than the standard practice (serum protein electrophoresis).

To investigate MS accuracy, researchers explored data from 480 transplant-eligible newly diagnosed myeloma patients and measured paraprotein levels at induction, maintenance, and one year after.

Patients with a complete response at all time points had no detectable paraproteins (MS negative), coinciding with prolonged remission. By combining MS data with patients' genetic information, the team could successfully predict which patients would have longer progression-free periods and better treatment responses.

Although results look promising, more research is needed to see if MS can guide treatment decisions, to support MS use in routine clinical practice.

New immunotherapy drug shows promise for heavily pre-treated myeloma patients

Results from MonumenTAL-1, a Phase I/II clinical trial, indicate that talquetamab is safe and effective for treating relapsed and refractory myeloma.

Talquetamab is a new bispecific antibody, a type of immunotherapy drug that helps the immune system recognise and kill cancer cells. Talquetamab attaches to a protein called CD3 on the surface of T cells, and a protein on myeloma cells' surfaces called GPRC5D.

This brings the patient's T cells close to myeloma cells, allowing them to kill the myeloma cells.

The trial included heavily pre-treated myeloma patients and looked at the safety, efficacy, and dosing of talquetamab.

Results showed at least 64% of patients responded to treatment. More than half of those achieved a very good partial response or better.

Talquetamab was generally well tolerated, with manageable side effects. Further trials are investigating how well talquetamab works in combination with other drugs and compared to other treatments. These include two trials that are recruiting in the UK.

Genetic test can guide myeloma treatment to help prevent relapse

Scientists have found a new way to predict which myeloma patients may benefit most from lenalidomide maintenance after stem cell transplant (SCT).

Researchers at The Institute of Cancer Research analysed data from the Myeloma XI trial, which aimed to evaluate the effectiveness of a range of drugs, including lenalidomide, in newly diagnosed myeloma patients.

They found that patients with one high-risk genetic abnormality particularly benefitted from lenalidomide maintenance after SCT.

The average time to progression was almost five years, compared to 10.9 months for those on observation alone. Patients with more high-risk genetic abnormalities, or no high-risk markers, still benefited from lenalidomide maintenance.

However, this trial highlights the need for novel treatments to target individual genetic profiles.

These findings strongly support using lenalidomide maintenance after SCT and routine genetic testing in myeloma patients to identify those most likely to benefit from specific treatments, ultimately leading to more personalised care.

A nationwide study uncovers the rate of myeloma precursor conditions

Researchers for an ongoing Icelandic study have published results that show that national screening programmes might help to diagnose more patients with myeloma precursors.

The iStopMM study is a national study in Iceland that screened participants for precursor conditions like MGUS and smouldering myeloma.

The study has recruited more than half of the Icelandic population over 40. The screening study allowed researchers to reveal the prevalence of smouldering myeloma in the population for the first time. Data shows that 0.5% of people over 40 are living with the condition.

Last year, Myeloma UK released the 'A Life Worth Living' report, which identified the importance of diagnosing myeloma early to reduce the chance of life-changing complications.

iStopMM will now monitor patients to understand if screening, diagnosing, and treating precursor conditions can improve myeloma patients' quality of life and help them live longer.

MY LIFE WITH MYELOMA

NAME: Sue Fleck

LIVES: Walton-on-Thames

AGE: 67

I was lucky, I had a good life. I had a privileged childhood. I'd had an interesting career visiting many countries lately in Africa where I met intelligent, passionate, dedicated colleagues working in medical research. I moved to a lovely little house, on the banks of the Thames, near my mother, 10 years ago. I have loyal, interesting and stimulating friends.

Work took up a lot of my time but I had planned to go back to hobbies such as skiing and horse riding in my retirement. I had started rowing traditional skiffs and ran 5km at the parkruns.

Then, in September 2020, I got a pain in my lower leg, which I thought was from running but just didn't go away. I went to the GP on 1 October and they did a D-dimer test to ensure it wasn't deep vein thrombosis.

In November, I started getting groin pain. I noticed that I couldn't bend down very easily and found myself stooping to get items out of the fridge or switch off electric sockets.

By December I started to get sharp shooting pains on laughing, sneezing or coughing in my ribs and struggled to get out of bed and chairs, because of back pain.

I went back to my GP and screamed out in pain when they touched my ribs (it wasn't until several months later that an X-ray showed that my ribs had been broken in several places).

I contacted the GP several times again because of the unrelenting pain and was referred for a physiotherapy appointment in early February.

From early January I was very bloated, nauseous, lacked appetite. I was very tired and had lost weight. I noted my urine was very frothy.

On 20 January, I moved in with my 91-year-old mother as I couldn't manage on my own any more. I was mostly bedridden.

I struggled to walk to the toilet, so my sister bought me a bedpan. I had to give up work. I could no longer sit at the computer as I needed both arms to support me.

I had a lump on my forehead which the GP told me was a fatty lump – however, this was a bony lesion from the myeloma.

Following the chemotherapy, I am left with a permanent dip in my forehead the size of a 2p piece and another on the left of my head.

Catching my reflection in the mirror after I got back, it dawned on me for the very first time that I could possibly have cancer.

In retrospect I should have gone to A&E but I had already had eight face-to-face or phone consultations with five different doctors and I didn't think seeing another, even in the different setting of A&E, would change the outcome.

With symptoms of backache, I thought they would just send me home again with more painkillers.

Also, at the time, the NHS was heaving under the number of COVID infections; so much so that when I was admitted I often saw soldiers in uniform in the hospital corridors, who had been recruited to help with the pandemic.

Finally, I had a call with a physiotherapist. I explained my symptoms and he said my medical issues needed to be sorted out and that I needed to go back to the GP.

When I was told I had weeks to live without treatment, I was utterly devastated and completely distraught and sobbed at the thought of the loss of my future.

On 9 February, it took about an hour with my sister's help to get downstairs and into the car to go to the GP surgery. There, a phlebotomist came outside and took my blood in the carpark so that I didn't have to get out of the car.

Catching my reflection in the mirror after I got back, it dawned on me for the very first time that I could possibly have cancer as my face was gaunt with pallor and I looked like someone from films I had seen depicting the disease.

The GP phoned back in the afternoon. The blood tests showed kidney failure. An ambulance arrived to admit me to hospital. I had a definitive diagnosis of extensive, multiple light chain myeloma after a bone marrow biopsy on 16 February – four and half months after I first went to the GP with symptoms.

I had the full gamut of extensive myeloma symptoms: broken ribs, a broken back with fractures in four collapsed vertebrae, lesions in the sternum, skull, pelvis and leg, a lesion encroaching on the spinal cord, kidney failure with a glomerular filtration rate of 13, hypercalcaemia, anaemia and cachexia.

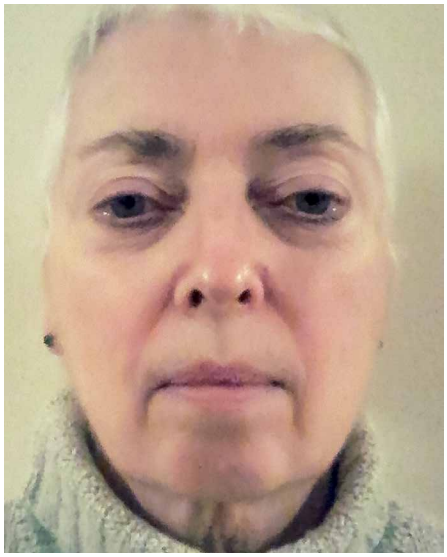
When I was told I had weeks to live without treatment, I was utterly devastated and completely distraught and sobbed at the thought of the loss of my future.

By the time I was admitted I was bedridden. I was envious of the elderly lady in the bed next to me. She was able to sit on the bed, to stand and she was able to walk to the toilet.

I could do none of these anymore. I was too weak to even wash myself, so was washed in bed by the healthcare assistants for many months. One day in hospital I had a glimpse of my lower leg. My skin was dangling off the bone, the muscles in my calves had disappeared from cachexia – the muscle loss associated with late-stage cancer.

My friends knew exactly how to help and what to say, especially those who had experienced some loss in their own lives.

I had spine jack kyphoplasty for the four fractured, collapsed vertebrae in May and an autologous stem cell transplant in October. In total, I spent almost four months in hospital and the hospice in 2021.



I wasn't able to work for over a year. I feel a million miles from where I was – running 5km, rowing in skiffing regattas, travelling to Africa for work, which it is unlikely I will be able to do now or in the future. I have been advised that I should never go jogging again nor to bend and twist or partake in any high impact sports. Life has changed dramatically.

I was concerned how my friends would react. Would they say something unintentionally upsetting or grating? Or find it difficult to say the right thing? But I was completely overwhelmed by their constant support.

Although I suffer the consequences of a late diagnosis, I was shocked to read the statistics from the Myeloma UK's 'A Life Worth Living' report.

My friends knew exactly how to help and what to say, especially those who had experienced some loss in their own lives. Thankfully no one said, 'Stay positive' or 'Keep battling'. I know that how I feel will not have any impact on whether the cancer comes back or not. Although, I still don't feel equipped to best respond and support others with their losses; we are all so different.

From a late diagnosis, I am left with deformity/kyphosis as a result of the four fractured vertebrae and I am reminded that I have lost 2.5in in height on a daily basis.

I can only see the top of my head in the bathroom mirror now. I need a stool to reach the top shelf in the kitchen cupboards and a cushion in my car to see over the top of the steering wheel and to sit at the kitchen table.

I used to love the feeling of being physically exhausted after a day's hike in the beautiful Yorkshire Dales,

Exmoor or the Pembrokeshire coastal path but it grates now when someone says they feel tired or exhausted as the fatigue I've felt over the last two years has been debilitating.

If you are tired, you can still function and manage daily activities but there have been times when I was just too fatigued to have a shower.

A healthcare assistant would need to wash me in my bed, it took me two goes to load the dishwasher after the carers had stopped coming as I just did not have the energy to do it in one go. I had no energy to read, focus on watching television or even sometimes to chat with friends on WhatsApp, for many months, whilst I was in hospital.

I have not had a relapse. I have returned to part-time work from home and can focus on something other than the cancer.

Although I suffer the consequences of a late diagnosis, I was shocked to read the statistics from the Myeloma UK's 'A Life Worth Living' report.

I have joined the Myeloma UK Patient and Carer Research Panel and I would like to help in a tiny way towards the research on the two things which still anger me: avoiding a late diagnosis so that no one has to end up with a permanent disability and identifying the cause of myeloma so others have the choice of modifying their lifestyles to reduce their risk.

I am lucky. I have survived more than two years after my diagnosis. I am not paralysed by the 'enlarged lytic lesion at T2 and a soft mass encroaching onto the spinal cord' or the compressed vertebrae fractures. The induction chemotherapy and stem cell transplant were successful.

I only take painkillers if I need to stand for any length of time like preparing meals or watering the garden and I can now sit at the computer. I can stand and walk again.

The lesions in my skull had no effect on my brain, my kidney function was mostly restored, the muscle lost from the cachexia has grown back.

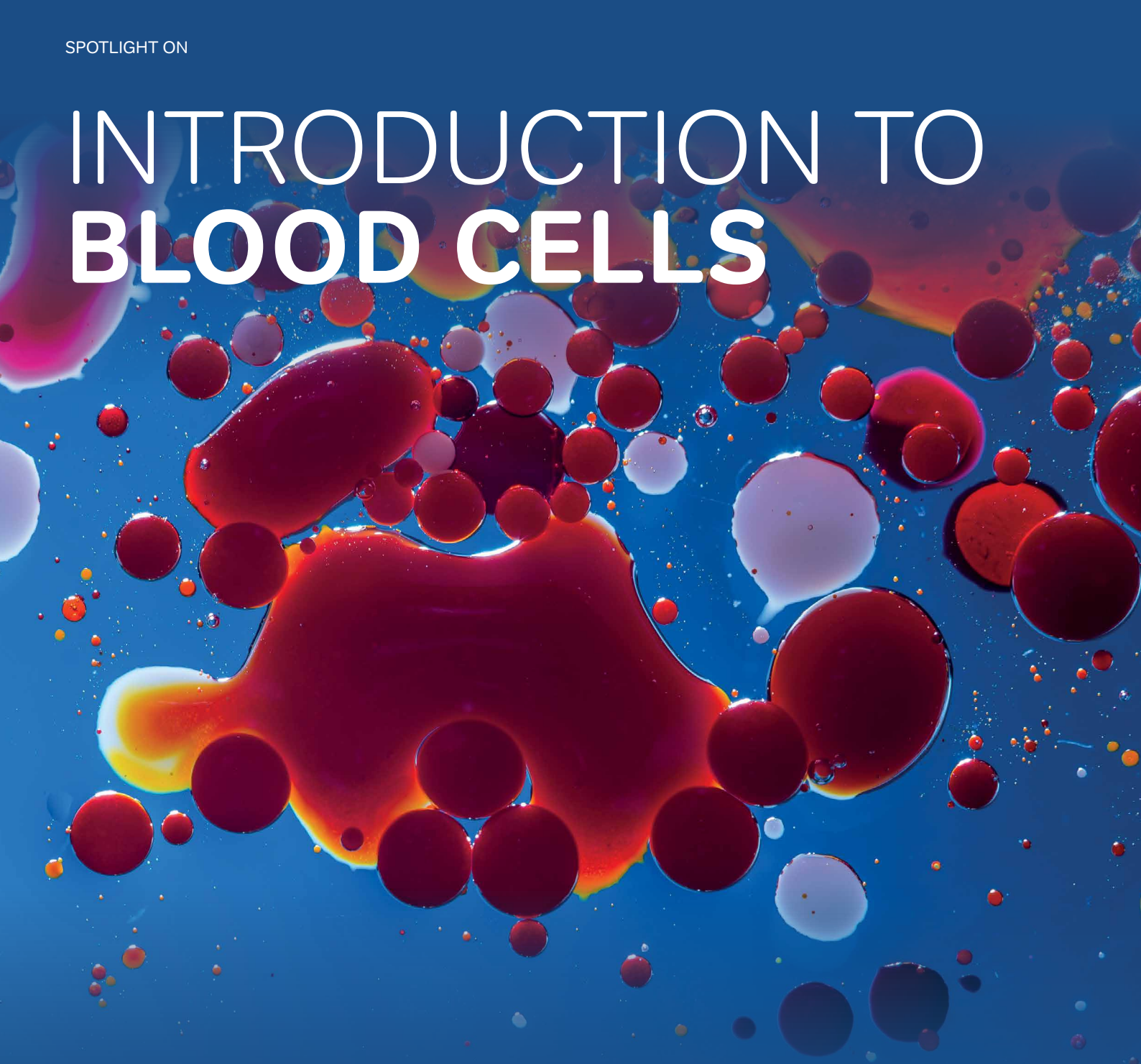
I have only lost 2.5in in height when some myeloma patients have lost 6in. I have only had minor infections apart from COVID (which I caught during my stay in hospital) since diagnosis.

I have not had a relapse. I have returned to part-time work from home and can focus on something other than the cancer.

I felt defined by the myeloma but I need to move on from that and remember who I am and who I was before the diagnosis and embrace the 'new normal', for however long that may be.

SPOTLIGHT ON BLOOD CELLS

INTRODUCTION TO **BLOOD CELLS**



Blood tests are a regular feature for anyone living with myeloma. But behind the numbers are some incredibly hard-working cells.

Recurring blood tests are a staple of myeloma monitoring, as they give you and your healthcare team insight into how you are and what the myeloma is doing.

The information provided through a blood test helps to build up the picture of the activity of the myeloma and often the paraprotein level is a key indicator of this.

However, the levels of blood cells are a very important part of the picture too. Many of you will be familiar with the consequences of the levels of blood cells dropping. Many of the symptoms and complications of myeloma are caused by these levels not sitting within the normal, healthy range – fatigue, infection and bruising to name just a few.

As you'll see from the following pages, your blood is an incredible and complex substance made up of many different specialised cells. Understanding your test results and the levels of these different cells can be extremely helpful.

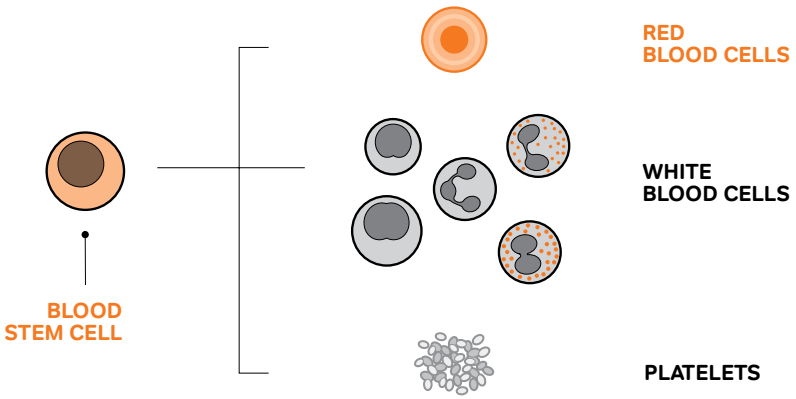
Understanding your white cell count, for instance, can help inform your infection risk and any steps you may need to take to reduce this risk.

The Myeloma UK patient diary has space for you to record your test results and track them over time. Call us or visit myeloma.org.uk to order a copy.

If you ever have any questions about your test results, or want to know more about what to do when your blood cells are affected, you can get in touch with our Myeloma Information Specialists who will be more than happy to help.

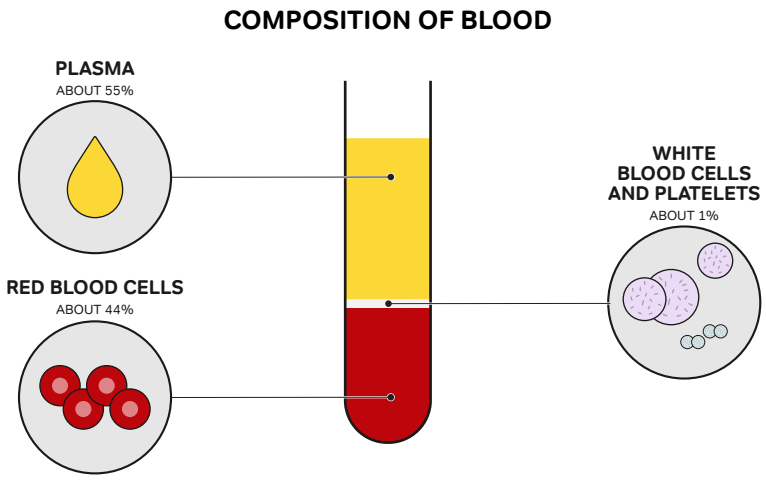
DID YOU **KNOW?**

Blood cells are produced in the bone marrow, which is the soft spongy tissue inside bones. All blood cells come from specific cells found in the bone marrow called stem cells. Stem cells are special, because they have the ability to multiply and produce different kinds of specialised cell. Haematopoietic stem cells have the ability to develop into blood cells.



Stem cells can produce the three types of blood cells: red blood cells, white blood cells and platelets. There is only one type of red blood cell and one type of platelet, but white blood cells have many different subtypes that each have a different role to play in the immune system.

About 1 in 20 million bone marrow cells is a stem cell

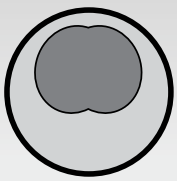


One stem cell can produce about 1 million mature blood cells

Top 5 types of white blood cells

1 Neutrophil

2 Lymphocyte



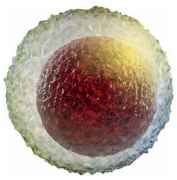
3 Monocyte

4 Eosinophil

5 Basophil

WHITE BLOOD CELLS

White blood cells form part of the immune system, which protects the body against infection and abnormal cells. There are different types of white blood cell, each playing a role in protecting you from disease.



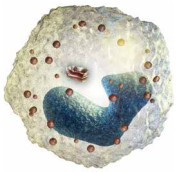
Lymphocytes

Produce antibodies, destroy virus-infected cells and cancer cells. They can be further subcategorised into:

- T cells – Destroy infected cells, control the immune response
- B cells – Produce antibodies as part of the body's defence system
- Natural-killer cells – Destroy infected cells or tumour cells

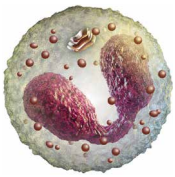
Monocytes

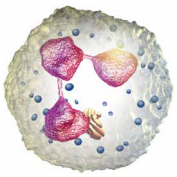
Destroy some types of bacteria, help lymphocytes to produce antibodies.



Basophils and Eosinophils

Destroy parasites, involved in allergies.



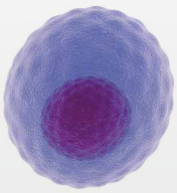


Neutrophils

Destroy bacteria and breakdown dead cells. These are the most common type of white blood cell. Neutrophils are the first of all the different types of blood cells to decrease in number when the bone marrow is not working properly.

This lowering of neutrophils is called neutropenia and leads to more frequent infections, which can last longer and be more severe than normal.

Plasma cells and myeloma



Myeloma is a cancer of a particular type of white blood cell called a plasma cell. This type of white blood cell develops from a B lymphocyte. Plasma cells normally help fight infection by producing antibodies (also known as immunoglobulins).

In myeloma, the plasma cells become cancerous and instead of producing the normal range of different antibodies, they produce an abnormal antibody called a paraprotein. Unlike normal antibodies, paraprotein has no useful function.

In myeloma, measurement of paraprotein is used to diagnose and monitor myeloma, although approximately 1% of patients will not produce any detectable paraprotein and will, therefore, have their myeloma monitored by other types of tests.

Producing lots of this one type of abnormal antibody, instead of the normal range of antibodies, means that myeloma patients are less able to fight infection.

RED BLOOD CELLS

About 70% of all cells in your body (by number) are red blood cells (also known as erythrocytes).

Red blood cells contain a protein called haemoglobin, which carries oxygen to all cells and tissues. Anaemia is when there are too few red blood cells or too little haemoglobin. Many patients will have anaemia at diagnosis. Anaemia can be caused by the myeloma cells crowding out the number of healthy red blood cells in the bone marrow. Symptoms of anaemia include fatigue, shortness of breath, weakness and paleness. Anaemia can be treated with blood transfusions or erythropoietin (EPO), which increase the production of red blood cells.

Usually measured in amount of haemoglobin, healthy levels are 13.5–18.0 g/dL in men and 11.5–16.0 g/dL in women.

Low levels mean you're likely to feel fatigued, short of breath and weak. You'll need to rest, eat a well-balanced diet and take gentle exercise when you can.

PLATELETS

Platelets (also known as thrombocytes) are fragments or parts of cells.

They play a vital role in forming blood clots, which help to stop bleeding. Myeloma can cause low numbers of platelets, which is called thrombocytopenia. This often causes bruising and bleeding, including spontaneous bleeding in mouth and gums, nosebleeds, red pinpoint rash and cuts that don't heal.

Severe thrombocytopenia can be treated with a platelet transfusion.

Normal level of platelets is 150–400 × 10^9/L.

If you have low levels of platelets you'll be more prone to bleeding and bruising. Try to take extra care not to injure yourself.

Myeloma and blood cell counts

In myeloma, blood cell counts are often reduced. This is because, as myeloma cells multiply, they crowd out the bone marrow, causing fewer healthy blood cells to be made.

Usually, as the myeloma comes under control, blood cell levels will increase as the body is able to produce new blood cells.

However, some treatments for myeloma can also affect blood cell production. Treatments, such as melphalan or cyclophosphamide, bortezomib (Velcade®) and lenalidomide (Revlimid®) can all cause low blood counts. This is why blood counts will be carefully monitored in myeloma patients, especially when they are on treatment.

Supportive treatments may be given alongside anti-myeloma treatment to deal with low blood counts, for example antibiotics to help fight infection, platelet transfusions and/or erythropoietin to treat anaemia.

A LIFE WORTH LIVING GARDEN

INTERVIEW WITH CHRIS BEARDSHAW

Ahead of this year's RHS Chelsea Flower Show and the grand unveiling of the Myeloma UK – A Life Worth Living Garden, we caught up with award-winning designer Chris Beardshaw about his creative process, his firm belief in nature's mood-boosting powers, and how your stories inspired this unique show garden.

Take us through your design process.

Whenever we're developing a design for any garden, especially for Chelsea Flower Show, the point is to really allow a narrative to become the guiding light. We start with a series of disparate ideas and then gently weave them together in a horticultural tapestry to create something which, first and foremost, is beautiful but also has a transformative effect as we progress through the garden.

We all know the benefits of being in and amongst nature, especially well-designed and curated nature. Our mood shifts, our emotions are transformed and that's all as a direct consequence of being in a garden space.

So, the principle of the Myeloma UK garden is to create a space specifically aimed at anyone struggling with myeloma; anyone in need of a jewel-like space in which to reinvigorate and reinvent themselves and find a new perspective on life that celebrates the detail of the moment that we're in.

How did the myeloma community, their stories and experiences, help to shape the garden?

One of the most important things when embarking on a project like this is for the resultant scheme to be intricately linked to the cause – in this particular case, intricately linked to Myeloma UK. We do this by harvesting information and listening to the stories of those people who are struggling with and have experienced myeloma. Listening to what would have made their life different or what does make their life different, improved and embellished, is really important.

That's the beauty of creating a garden at Chelsea Flower Show. I'm responsible for sharpening the pencil and doing the colouring in, but it's about drawing on all of those experiences and producing a garden which is relevant to anybody who knows about myeloma.

What came out of those varied conversations was the idea that because myeloma is a condition with no cure yet, there is no logical conclusion.

So many gardens at Chelsea Flower Show represent a straight-line path with a celebratory point at the end.

But it struck me that myeloma, in the way it was being described to us, was much more about creating a transition through the space. It was about travelling and slowing the pace rather than marching towards a conclusion.

In a way it becomes a metaphor for considering every embellishment, every detail and every enjoyment that we have in life. We very deliberately created a garden that is slightly concealed.

The Myeloma UK – A Life Worth Living Garden is about encouraging people to consider every step that they take.

The 10m boundary on Main Avenue is a floral border, much as people would expect. But tucked behind that floral border and only accessed through a little slip path is a woodland garden at the rear. The path becomes circuitous, with no obvious destination.

People then encounter not just a varied tapestry of horticultural specimens in all of their guises, mercurial in their shape and form and colour, but two temples.

The first has a three-dimensional gold-leaf artwork – in which each gold leaf represents, and is an accurate cut-out of, plants within the garden space.

Turning round and looking back out into the garden from the artwork, you are faced with an octagonal reflective pool. There's a very fundamental reason why it is an octagon.

Architecturally, octagons are considered imperfect, earthly, slightly out of kilter. They're not quite fully formed. Yet, the pool's reflection is a perfect circle. It's a reminder of the beauty but also the fragility of the world around us. It only takes a mere droplet from the tip of a leaf on an early spring morning to fall into the reflective surface and disturb that perfect picture.

We then continue through the garden to a second, more embellished temple, where everything that we've experienced is harnessed and celebrated. Where we can sit and reflect on the passage taken.

Outside the temple is a fountain constantly overflowing, just gently rippling with water. This constant cleansing of overflowing water and the sound of trickling water are a great way of distracting ourselves from the noise which surrounds our lives. From this vantage point at the end of the garden, secluded from everyone and everything, we have the opportunity to contemplate, relax and reconsider what is important in life.

What is your favourite part of the garden?

It's always difficult to pick a favourite part of a garden or a sequence of gardens. It's a bit like asking a chef to choose their favourite ingredient. So much depends on context.

I think the most dramatic element, the one that is going to create the strongest mood and should hopefully take people's breath away, is the multiple layers of canopies.

On a May morning, when you have azure blue skies and mist coming off the Thames at Chelsea Flower Show, the real delight, I think, is going to be standing in that woodland garden space, completely surrounded by the beautiful fragrance of fresh vegetation and watching shafts of sunlight pierce through the canopy and spotlight the jewel-like flowers of the canopy floor.

See the finished garden by heading online to our website **myeloma.org.uk** and social media channels.

MYELOMA

HOT TOPICS

OUR WEBSITE – WHAT'S NEW?

Many of you will have discovered already that our website has changed – read on to find out more about what's new.

Listening to our website users

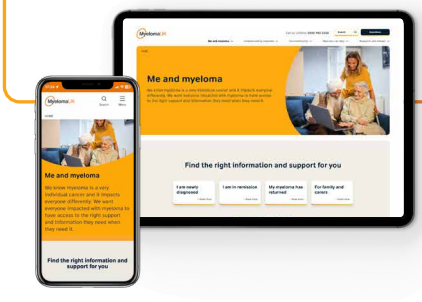
Central to this update was you, our audience. We asked a wide range of myeloma patients, family members and carers for their views on our website and what they needed from it.

We asked about the content of the website, how easy it was to find the information you needed, how represented you felt, and the "feel" of the website.

This conversation continued throughout each part of the development process.

What's new on the website?

- Relevant information is now easier to find
- Navigation around the website reflects the stages people are at in their myeloma
- Searching for topics is easier
- More patient stories, from a wider range of people
- New, more legible font
- Text translation and text-to-speech options



Finding relevant information

You told us that you really like our patient information, but that it is not always easy to find the information you need on the website.

When you look for information, you may be at very different stages in your life with myeloma.

If you are a newly diagnosed patient, for example, it can be overwhelming to have to scroll through a lot of information, much of which may not be helpful to you at your stage.

To help with this, we've developed hub pages to help you get straight to the information that's relevant for where you're at.

These hub pages are tailored to a specific point in your myeloma and has curated information and links that you may find helpful. You'll find an introductory video from one of our team to help guide you through the information.

There are also pages for the related conditions that we cover, such as smouldering myeloma and MGUS.

> **"Patient information is key, and the foundation of Myeloma UK as an organisation. Nothing can get in the way between patients and the information they need."**
>
> **– Michael Heins at More Yum, website development agency**

All our resources in one place

If you'd like to browse all of our resources, you can do so with our new all in one information hub.

The information hub has our patient information booklets, videos and blogs organised into topics to help you find the information and support you want in all our available formats. It also conveniently hosts stories and experiences from other patients and carers.

Accessibility

We know how important it is for you to be able to access the information you need in the way you need it. We're pleased to share our new accessibility tools to help you navigate the website.

We have translation tools built into every page, so you can translate any piece of information into over 150 languages. This includes our information booklets.

We also have text to speech buttons, so if you want to listen instead of reading, you can do so.

We are also using a new typeface, Atkinson Hyperlegible, created in 2019 in partnership with the Braille Institute – it is designed to increase legibility for readers.

Tell us your thoughts

We hope you will find the new website easy to use. We'd love to hear your feedback so do get in touch. If you have any queries, contact us using the links below.

To visit the new website go to **myeloma.org.uk**

If you have links to pages on the old website, they should take you to the right place on the new website.

Contact us by email **patientinfo@myeloma.org.uk** or phone **0131 557 3332**

FINANCES AND COST OF LIVING

Having myeloma (or caring for someone who does) often puts extra pressure on your finances.

These pressures add to the challenges of dealing with a myeloma diagnosis. You may have to reduce working hours or change jobs, or you may have extra expenses. When we surveyed myeloma patients and their carers in 2018, more than 9 in 10 said their (or their partner's) myeloma had affected their finances, and 6 in 10 said it had greatly affected them. The current cost of living crisis has increased these pressures. Below is some information about sources of advice and support available.

Benefits

Benefits you can claim as a myeloma patient or carer depend on criteria such as your income and savings (your means), your age, whether you work, and the degree to which your myeloma is affecting you. Benefits do not all have the same criteria.

The following table shows some of the main benefits you may be able to claim, and there is more about them in the Myeloma UK Benefits and financial support Infosheet.

Make sure you ask for advice and help with claiming benefits if you need it, rather than missing out on benefits that could make a real difference to you. Contact your local Citizens Advice, your social worker, or a benefits advisor at your local cancer centre. For PIP and AA, you will be asked to explain how your carry out daily tasks: keep a diary of any challenges, and make sure you give detailed answers.

There are currently extra cost of living payments for people on certain benefits including ESA, PIP and AA.

Benefits you may be able to claim

Personal Independence payment (PIP) and Attendance Allowance (AA)
Non-means tested benefits for people who need help with personal care

Employment and Support Allowance (ESA)
Benefit for people whose health condition affects how much they can work

Universal Credit
Means-tested benefit for people on a low income, who are out of work, or who cannot work

Carer's Allowance
Means-tested benefit for people who care for someone for at least 35 hours a week

You don't need to apply for these, and you may receive several of the payments if you receive more than one qualifying benefit.

Budgeting and debt

Working out your budget (money coming in and going out) will help you feel more in control of your finances, and help you avoid debt as far as possible. Read more about budgeting in the Myeloma UK Infopack for living well with myeloma.

> **Seek advice early and don't bury your head in the sand.**

If financial problems mean that you are getting into increasing debt, or you cannot pay off debts you already have, look for help early on. Try to deal with any essential debts first (such as mortgage, rent or energy bills).

The National Debtline and Advice NI, Citizens Advice, and the charity StepChange, can all provide expert help on debt. Contact details are in the Myeloma UK Benefits and financial support Infosheet.

Energy costs

Increased energy bills such as those in recent months can have a severe impact if your income has been reduced. You may also need to use more heating in the colder months if you are at home more than usual (for example if you have cut your working hours). Chemotherapy treatment can mean you feel the cold more.

Tell your energy supplier straight away that you have myeloma, and contact them if you are struggling to pay your bills, as there are schemes and protection to help you.

Organisations providing support and advice on energy are listed in the Myeloma UK Infopack for living well with myeloma.

Sources of information and advice about finances and cost of living

Benefits and financial support Infosheet

Infopack for living well with myeloma

0800 980 3332

AskTheNurse@myeloma.org.uk

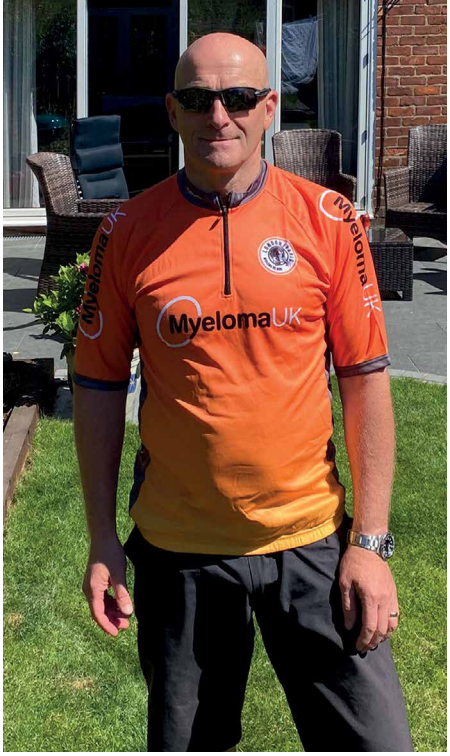
helpforhouseholds.campaign.gov.uk

citizensadvice.org.uk

moneyhelper.org.uk

INTERVIEW WITH GRAHAM JACKSON

CHIEF CLINICAL AND SCIENTIFIC ADVISOR



Myeloma UK's newly-appointed Chief Clinical and Scientific Advisor, Professor Graham Jackson, has spent the last 27 years supporting those affected by myeloma, AL amyloidosis and related conditions. And he's only getting started. Here he reflects on nearly three decades spent at the forefront of research and innovation, shares his hopes for patients, ambitions for Myeloma UK and what remains to be done to finally make myeloma history.

Tell us about your background.

I have been a consultant haematologist for 27 years and myeloma has always been one of my main areas of interest. I've been involved in a wide range of myeloma clinical trials over the years. I helped deliver the Myeloma IX trial, comparing new treatment combinations for treating myeloma, including thalidomide, as one of the chief investigators, after running one of the first-ever studies on thalidomide maintenance.

I also contributed to the Myeloma VII trial, looking into the impact that high-dose chemotherapy with melphalan and stem cell transplants has on myeloma. Later I became the chief investigator on Myeloma XI, investigating lenalidomide (Revlimid®) maintenance.

I am now co-chief investigator on Myeloma XIV, researching whether people can cope with treatments better by changing the doses of ixazomib (Ninlaro®), lenalidomide and dexamethasone. The trial is also looking at whether adding ixazomib to lenalidomide maintenance works better than lenalidomide on its own.

I have been involved in monitoring many other national and international myeloma clinical trials with an emphasis on safety and design.

What made you decide to specialise in myeloma?

Back in 1991, when I was a haematology registrar, I was asked by my consultant colleagues to set up a disease-specific myeloma clinic in Newcastle.

They had the foresight, even then, to realise that myeloma and other paraprotein diseases were sufficiently complicated to merit a clinic that specialised in the care of these patients. I have run and been part of this clinic ever since and am proud of the work of our team, who have received two CSEP clinical excellence awards from Myeloma UK over the years.

"I have been part of and led over 25 Infodays, spoken at patrons' meetings, provided patient information videos and been a director of the charity on two occasions."

How long have you been involved with Myeloma UK?

I have been involved with Myeloma UK since the organisation began with Eric Low 25 years ago. He recognised the unique challenges facing patients, their relatives and the teams treating them.

I have been part of and led over 25 Infodays, spoken at patrons' meetings, provided patient information videos and been a director of the charity on two occasions. I've also cycled from London to Paris three times and taken part in two triathlons to raise money for Myeloma UK.

All this has been fuelled by an acknowledgement of the fantastic work Myeloma UK does across the fields of research, advocacy and information. The charity has been and will continue to be a tremendous support to patients and their relatives.

What does your new role at Myeloma UK involve?

I am here to provide clinical support and research insights, offer advice, help advocate for patients and promote the charity locally, nationally, and internationally.

Do you think more charities would benefit from enlisting the help and expertise of clinicians?

I think clinicians do have a role to play in charities that support patients. A clinician can support, advise and give a sense of what is going on in the clinic and in research and help find solutions to the issues that patients face.

We have some fantastic myeloma nurse specialists and consultants around the UK who work incredibly hard. Liaising with these teams is also an area where I believe I can help, as well as promoting excellence, teaching and supporting healthcare professionals to give our patients the best possible care.

What have been some of the key changes and breakthroughs in the treatment of myeloma since you became a consultant?

The treatment of myeloma has changed out of all recognition over the last 30 years. Many new treatments are now available, including immunomodulatory drugs, proteasome inhibitors, bisphosphonates and anti-CD38 antibodies.

We are witnessing the development of some really exciting treatments including CAR-T cell therapies and bispecific T-cell engagers, a type of immunotherapy that helps the immune system to recognise and kill cancer cells.

> **We have brought together the UK's leading experts, hospitals, and research centres to conduct clinical trials and give patients access to new, innovative myeloma treatments.**

Another novel approach on the horizon is the development of CelMods. These drugs are like lenalidomide but often work when patients have developed resistance to lenalidomide and pomalidomide (Imnovid®). We have seen the important recognition of nurse specialists' key role in making sure our patients get the best and safest treatments.

We have brought together the UK's leading experts, hospitals, and research centres to conduct clinical trials and give patients access to new, innovative myeloma treatments. And we have worked hard to make sure myeloma patients, carers, family, and friends are kept informed with high-quality, reliable, and accurate information.

What are some of the challenges still facing myeloma patients?

Patients are still facing significant delays in diagnosis and should be diagnosed before they develop bone or renal disease.

We need to reduce the side-effect burden of our treatments and offer better therapies for higher-risk patients. We should also work harder to make sure elderly patients are treated as safely and effectively as possible.

Finally, we need to work out how current and future therapies can be combined to deliver the longest possible remissions, if not a cure.

What are your goals, hopes and ambitions for the myeloma community?

A cure, and generally an answer to the unmet needs listed above. There is still so much work to be done and I hope I can help to build on the team's incredible achievements over the last 25 years.

POLICY BRIEFING

CAR-T TREATMENT UPDATE

With the disappointing announcement that no CAR-T treatments will be going through the health technology appraisal process this year, we ask what's next?

CAR-T was being hailed as the next big change in myeloma treatment, so what happened?

In March 2023, pharmaceutical company Janssen made the decision not to pursue approval for its CAR-T cell treatment, cilta -cel (ciltacabtagene autoleucel, Carvykti®) for UK myeloma patients.

The novel treatment was in the process of being assessed by the National Institute of Health and Care Excellence (NICE) to make the treatment available on the NHS. But Janssen opted to withdraw its submission to NICE.

The submission wasn't withdrawn because of efficacy or safety concerns, but rather because of manufacturing issues. CAR-T cell treatments are very complex and made in a different way from other myeloma treatments.

CAR-T cell treatment uses the body's own immune system to kill myeloma cells. CAR-T cells are made by taking T-cells (a type of immune cell) from the patient's blood and genetically modifying them in a laboratory, so they are much better at finding and killing myeloma cells.

The new CAR-T cells are then given back to the patient and they can then find and kill the myeloma cells.

This process is very specialist and requires different materials, processes and controls to make and deliver the treatment. Issues with the supply of CAR-T cell treatments have increased as demand has grown globally.

The manufacturing issues have impacted the growth of all CAR-T cell treatments, not just cilta-cel.

Are there any ways patients can still get access to CAR-T treatment in the UK?

Yes, patients can still access CAR-T treatments through clinical trials in the UK. Several pharmaceutical companies are still developing CAR-T cell treatments. Clinical trials are ongoing for cilta-cel and other CAR-T treatments.

Will CAR-T cell treatments come to the UK in the future?

Yes, CAR-T cell treatments could be available to myeloma patients in the future. The pharmaceutical company hopes to seek NHS approval for cilta-cel later.

There are also other CAR-T cell treatments in development, including ide-cel which is approved for use in the US. The manufacturer of ide-cel, Bristol Myers Squibb, halted its UK drug approval plans in 2020, due to a combination of factors including the impact of the pandemic on its clinical trial delivery. BMS still plan to launch ide-cel in the UK in the future.

Myeloma UK will continue to work with clinicians, pharmaceutical companies, NICE and the NHS to advocate for myeloma patients and ensure they have access to treatments.

We will be working with industry experts and clinicians to understand what can be done to speed up UK access to CAR-T cell treatments.

Is there space for optimism about what's coming down the pipeline?

Whilst the withdrawal of the cilta-cel submission is upsetting, there are reasons for hope. CAR-T cell treatments are not the only innovative myeloma treatments in development. In the years since CAR-T cell treatments were first trialled, huge strides have been made in developing other life-extending treatments with new mechanisms of action.

This year NICE will evaluate a novel T-cell engager (elranatumab) and antibody-drug conjugate (belantamab mafodotin) for myeloma.

We will keep striving to ensure these promising treatments and the many more in the pipeline are made available to those who need them most. Giving patients access to the latest, most effective treatments remains our top priority.

Find out more about drugs in development with our **Horizons Infosheet series** or by visiting our **Drug Tracker** at **myeloma.org.uk/drugs**.

ASK THE NURSE

INTERVIEW WITH ELLEN WATTERS

Ellen Watters, Myeloma Information Specialist, celebrates her 20th anniversary with Myeloma UK this year. In this special "Ask the Nurse", we ask Ellen about her time supporting patients over the last 20 years.

What drew you to Myeloma UK and what's kept you here?

I had been working in the Royal Infirmary Edinburgh as a staff nurse and during my time there had looked after many patients with different cancers, and I knew that oncology was going to be the focus of my career path. I worked through various in-house training courses in managing patients with cancer, in chemotherapy administration and safety, in good communication skills/breaking bad news and was put through a diploma in Cancer and Palliative care.

> **"MUK has provided access to reliable information, compassionate support and this has only gone from strength to strength."**

Shortly after this I bought a Big Issue and saw the post advertised in that and I applied. I went for an interview with the then founding CEO and a board member and was called that day to say I'd been successful.

It was a bit daunting though to leave the huge organisation of the NHS to join a tiny, pretty newly started charity to do a job quite different from what I was used to in my previous 20 years of hands-on clinical nursing.

But I made the decision to take the step and have never looked back or regretted it.

Myeloma UK has seen many changes in my 20 years, but it has always been an excellent resource for patients and their loved ones that has meant they have some guidance, some hope, and information to ease their feeling overwhelmed and hopeless.

MUK has provided access to reliable information, compassionate support and this has only gone from strength to strength.

I think I realised fairly quickly that I had joined a charity on the way up and I was excited and proud to play a small part in that.

Initially I did miss direct patient contact but what keeps me here is the job satisfaction, knowing that I am actually playing a part in making a huge difference to people's lives, people who are perhaps in the most vulnerable place they have experienced.

What are your favourite parts of this job?

Undoubtedly answering the Infoline. You never know who might be at the other end of the phone, what their questions may be and what sort of frame of mind they may be in.

> **"The research pipeline is a busy one so I need to know what's going on in that world in order to answer and clarify questions around 'what next'."**

That keeps me on my toes but, more often than not, I get a sense of someone's anxieties falling away as I answer their questions, clarify things they aren't sure of and provide them with information and support to help them take back some control.

What do you find hardest about your role?

The ever and rapidly changing dynamics of myeloma treatment and care. When I first started in 2003 there were very few options for patients. Today there are many and new ones coming along all the time. The research pipeline is a busy one so I need to know what's going on in that world in order to answer and clarify questions around 'what next'.

Myeloma patients are living better and living longer and I know that Myeloma UK has played a very important role in this.

I hear a range of experiences and listening to someone who isn't in a good place who perhaps isn't getting the care and support they need and deserve is hard.

How has this role changed you as a person and how have you changed within this role?

I did have a lot of learning to do but have always been able to reflect on my clinical experiences which has been a great help. But I needed to come at patient care and support from a slightly different angle.

> **I had to learn to really listen – not just hear.**

I needed to hone my communication skills to develop an ability to build a rapport with a caller without the help of facial expressions, body language and eye contact – not easy sometimes. I had to learn to really listen – not just hear.

During my time at Myeloma UK I have completed a few challenges to help fundraise, I've abseiled off the Forth Bridge and cycled from London to Paris – something I never thought I'd do.

Have any patients or particular stories stuck with you?

Yes, many. Difficult calls, rewarding calls, sad calls and happy calls. Patients and their loved ones grateful to be heard, given a plan of action, knowing what questions to ask.

Mrs H is a regular caller and always very anxious, but each and every time she called, she told me she was glad she did so.

Mr G, who was caring for his wife who had a very challenging myeloma that did not respond to treatment, who was young (in her 40s) and who had a young family. He was so lovely and clearly loved his wife so much and was there to become informed, to know what to do to enable them both to move forward, to take the pressure off her so that she could focus on treatment and getting well. Unfortunately, it was not to be, her myeloma was so aggressive and I will never forget his final call.

When she died, I received a lovely thank you card, he was still thinking of others even in his grief.

What do you hope for the future of Myeloma UK and for patients?

That Myeloma UK continues to be a resource for those affected by myeloma and its related conditions. We know we fill a gap that the stretched resources in the NHS and the busy doctors and nurses just don't have the capacity for.

> **We have become a well trusted, reliable resource that doctors and nurses are more than happy to signpost to.**

I've seen our collaboration with our colleagues working in the NHS build over the years.

We have become a well trusted, reliable resource that doctors and nurses are more than happy to signpost to – just as I would be if I still worked in the clinical area.

ASK THE NURSE

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

I've been told that I need to have a dental check-up before starting on my bone strengthening treatment, why is this?

Bisphosphonates are a type of supportive treatment used in myeloma patients. They have many benefits, including preventing and slowing down bone breakdown, reducing bone pain, correcting high calcium levels (hypercalcaemia) and improving quality of life.

However, an uncommon but serious side effect of bisphosphonates is a condition called osteonecrosis of the jaw (ONJ). This is when the bones of the jaw are damaged and do not heal for prolonged periods of time. Invasive dental procedures such as tooth extractions and oral surgery can increase the risk of ONJ. It is recommended that myeloma patients have a dental check-up prior to starting bisphosphonate treatment to ensure that any invasive dental work required can be completed before starting treatment. ONJ is more common in patients taking intravenous (IV - into a vein) bisphosphonates such as zoledronic acid (Zometa®) and those who have been on bisphosphonates for a prolonged period of time.

Throughout bisphosphonate treatment, regular dental check-ups are recommended. Invasive dental work should be avoided whilst taking bisphosphonate treatment, so it is important to speak to your medical team if you find out you need some. If invasive dental work is unavoidable, you may be referred to a specialist oral surgeon experienced in ONJ. You might be taken off bisphosphonates temporarily and restarted once healing is complete.

I want to go on holiday this summer, what risks do I need to consider and how do I go about obtaining travel insurance?

Your medical team are aware of the positive impact that going on holiday can have on your emotional wellbeing, so let them know about your plans and discuss any specific risks you may need to be aware of. For instance, myeloma patients are at an increased risk of infection, though the level of risk may depend on where you are in your treatment, myeloma activity and any complications you may have.

Some haematologists will ensure patients have a supply of antibiotics to take away with them on holiday, just in case they become unwell while away. Do ask your haematologist if this is an option for you – it may put your mind at rest. Ensuring that you have received all the vaccinations you are eligible for can also play an important part in reducing the risk of infection.

It can be difficult to obtain travel insurance with myeloma. You may like to download our Travel insurance Infosheet, which has information about obtaining travel insurance, and features a list of insurance providers that other patients have told us have covered people with myeloma. It is always a good idea to phone around a few of the organisations or look at their websites to try and get the most reasonable quote.

Some travel insurance companies may ask for a letter from your haematologist stating that you are fit to travel.

Are skin rashes common in myeloma?

In myeloma, skin changes can occur for a variety of reasons – you should always inform your medical team specialist) about these. Both myeloma and its treatment can weaken the immune system making myeloma patients more vulnerable to infection. One example of a skin rash caused by infection is shingles. Shingles is caused by the reactivation of the chickenpox virus. If you have had chickenpox previously, the virus remains in your body and can be reactivated if your immune system is weakened. Shingles causes a blistering rash that only affects one side of the body. It may be associated with tingling or burning sensations to the affected area. Many myeloma patients will receive antiviral treatments such as aciclovir to help prevent shingles. There is also now a vaccine (Shingrix®) which is safe for people with a weakened immune system.

Myeloma and myeloma treatment can lower the levels of healthy blood cells including platelets. Low platelet levels can cause you to bruise more easily and may cause small red or purple dots under the skin (petechiae) that look like a rash.

Myeloma treatments can also cause skin rashes, this is a particularly common side effect of lenalidomide (Revlimid®). The rash may be itchy, and your medical team can often prescribe supportive treatments such as antihistamines or steroid creams to help with this.

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

My name is Jess Robinson and I am 31 years old. I live in Cheshire with my partner and one year old son. I run a small sheep farm that we have where we live.

My connection to myeloma is that unfortunately my mum has the disease. It came as quite a shock as she has already beaten breast cancer and Hodgkin lymphoma previously and at the time we really didn't know anything about myeloma and what it was.

When I learnt that myeloma is unfortunately an uncurable cancer, I wanted to try and raise money and awareness. I hadn't heard about this type of cancer until my mum's diagnosis and I feel like a large amount of the population would be the same as me. It is often a disease you haven't heard of until you yourself or a loved one has been diagnosed.

> **I really wanted to try and make a difference and help.**

I have done a small amount of fundraising for different cancer charities in the past. However, when I found out how small the charity is for myeloma and the fact that Myeloma UK are the only charity in the UK dealing exclusively with myeloma, I really wanted to try and make a difference and help. I feel that every penny raised for this charity will go towards the research and development of drugs to help find a lasting cure, and ultimately improve people's lives.

For my fundraising activity, I set myself a challenge of walking or running 200 km during the month of March.

As I got to mid-way through the month, I decided that I needed to up my game and add an extra challenge in. I thought a long distance walk during one of my days in March would help boost fundraising and show my commitment to the challenge I had set.

So, after some thought, I decided that I would walk from our home village to Old Trafford football stadium in Manchester, which was 30 km, and a few of my lovely friends very kindly offered to do the walk with me.

We all set off at 9am and with some very tired legs achieved the goal of 30 km!

Whilst we were out on this challenge walk, I actually also achieved my goal of 200 km, six days before the end of the month. So that was a lovely way to end my challenge and it also really boosted morale!

At the end of the month, my friend and I decided to do a charity bake sale to add to the total amount I had raised walking 200km in March and also an excuse for everyone to enjoy some home-made cakes over the Easter weekend!

I have been thinking about what the next fundraising challenge will be, and I have decided to arrange a charity dinner dance early next year, which we are really looking forward to!

> **It is an incredible feeling when you reach your goals.**

I also have a small business of my own that I am thinking of doing a sale where I donate 50% of any sales to the charity.

If anyone is thinking about doing some fundraising for this amazing charity, don't think twice about it, just sign up and get going!! It is an incredible feeling when you reach your goals.

The reward of knowing you are doing it for such a good cause will keep you going and go a long way to helping Myeloma UK support their patients and their families. I set myself a fundraising goal of £500, but in the end, I actually raised over £4500, and in only five weeks.

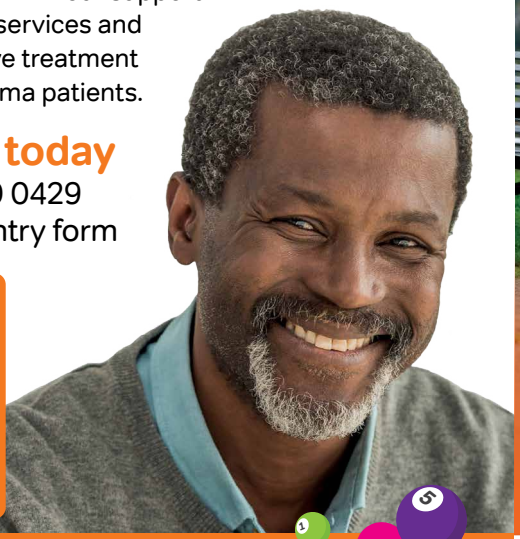
No amount is too small. Every penny counts. I have loved the start of my fundraising journey and I am overwhelmed at how much I have managed to raise in such a short time.

MyelomaUK Lottery

Changing lives every week

Would you like to win £25,000?

Enter our lottery for just £1 per week for your chance to win! Your support helps to fund vital services and research to improve treatment and care for myeloma patients.



Join online today

or call 0131 230 0429
to request an entry form

Scan me

myeloma.org.uk/mylottery

Please gamble responsibly: www.begambleaware.org

Small society lottery registration no: 490326

Complete 24 miles and raise £240 this **Myeloma Awareness Week** (19–25 June) **to help the 24,000 people** living with myeloma in the UK.

Join Team Challenge 24 today
myeloma.org.uk/challenge24

myeloma INFODAYS 2023

NORTH INFODAY

REGISTRATION £20

Newcastle
Saturday 17 June
9am–4.30pm

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

SOUTH INFODAY

REGISTRATION £25

London
Saturday 23 September
9am–4.30pm

FOR PATIENTS AND FAMILY

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

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