SPRING/SUMMER 2020

myeloma matters

Spotlight On
Mental Health

My life with myeloma
Scott Meech

Message from
Myeloma UK

My myeloma story
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MyelomaUK

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Alice Baron

Sandra Quinn

We have been working hard to support you during this time and answer all your COVID-19 related questions and concerns.

The extra resource this has needed has meant we had to make the difficult decision to reduce the number of editions of **Myeloma Matters** this year.

We know this will be disappointing, but we hope you understand the prioritised need and we thank you for your continued support.

We hope you enjoy this Spring/Summer edition and we'll see you again in the Autumn/Winter edition.

DEAR READER

Welcome to this special edition of Myeloma Matters.

It has been widely said that we are in extraordinary times and the last few months have not been easy for anyone. The COVID-19 pandemic has taken over all of our lives and has radically altered how we are functioning day to day. For many of you, this will be especially true as you have been asked to shield yourselves for the past weeks and months. We know this has been a big ask for you and it has been a challenging time.

Many people have been finding it particularly hard and may be experiencing grief, depression, anxiety and other mental health concerns. To help you through this time, we have put mental health in the Spotlight On section of this edition. The information included, though it primarily addresses mental health in the context of COVID-19, is by no means limited to this period of time. It is our hope that more conversations around mental health will be started and our tips and information will be of benefit to all our readers.

This edition also features some of the good things that have come out of this unusual situation. Inside, you'll find some lovely photographs that showcase some of the things you have been doing to keep yourselves occupied. Plus, you can read how Mark Jones has been keeping busy with a virtual paddle around the Welsh coast. If any of these ideas inspire some creativity of your own, we'd love to hear from you.

Finally, we have patient and carer experience stories from Scott and Ethel, respectively. They have provided insights into their lives with myeloma and how they have been doing during lockdown. We are also delighted to introduce our new CEO Laura Kerby who shares her thoughts from her first few weeks in the role.

We hope that you are keeping well and safe. We want to echo the message inside this edition from the Myeloma UK staff – we are here to support you, so please do get in touch if you need to.

Best wishes

Sandra Quinn & Alice Baron
Co-Editors,
Myeloma Matters

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INTERVIEW WITH LAURA KERBY

CEO

Laura joined Myeloma UK at the start of May 2020 as our new CEO. We caught up with her to hear about how she's found the role so far.

What drew you to Myeloma UK?

I have worked in healthcare for over 20 years and my passion has always been to help patients to live as well as they can for as long as they can. Having spent the last six years leading a cancer charity, I have met hundreds of patients and found many of their stories inspirational. It has therefore been important to me to stay in the cancer field and find an authentic patient-centric charity that makes a significant difference. Myeloma UK absolutely does and I am privileged to be their new Chief Executive.

What has it been like to start as CEO in such unusual circumstances?

I think it is fair to say I have had to learn extremely quickly to support the dedication and commitment of our hard-working teams to myeloma patients and their families. I am inspired and impressed by our agility to respond to the fast-moving implications of the pandemic with such timely, accurate and quality work.

Due to the COVID-19 pandemic, there are significant uncertainties in the whole cancer space which means I have been working extremely hard with the team to make sure myeloma patients do not become a forgotten group. However, it is a challenging time for us all and here at Myeloma UK, we are experiencing high demands for patient services, information and advocacy at a time when we are also financially challenged by a significant reduction in funds. Our supporters' response to our COVID-19 appeal

was life affirming and we clearly have a highly engaged community, to which I am very grateful.

You have been deeply involved with the experience of cancer patients for the last six years. What has that taught you that resonates the most with you?

I think there are two things that immediately come to mind – firstly that society has not found a language to talk openly about cancer and talk to people who have cancer. As a result, I have had lots of conversations with patients about how isolating a cancer experience can be. At worst, patients experience stigma associated with the disease and can be culturally ostracised as a result, and at best everyday conversation becomes very uncomfortable. For me, I've learnt an incredible amount from patients which has enabled me to find different ways to mindfully converse and engage, and to try and craft new language, particularly on topics that are difficult to talk about.

Secondly, I live my life more spiritually and mindfully. I learned Tai Chi alongside patient groups and often use it to calm my mind. I try to appreciate the small yet significant things in my life and I realise I have much to be grateful for.

What is your vision for myeloma patients?

At the moment, I see two key areas where the brilliant work Myeloma UK does needs to focus – hopeful patient futures and empowering patient support.

Hopeful patient futures mean patients having access to a timely diagnosis and the right treatments when they need them. To achieve this, we need to raise awareness of vague symptoms amongst referring clinicians so they suspect myeloma sooner, a strong treatment pipeline and provide robust support for treatment appraisals. Both require a commitment to financial investment in research and an expert knowledge of the diagnosis and treatment appraisal process.

Empowering patient support is all about improving what is happening for patients right now. Myeloma patients need to be at the centre of care planning and need the right information and emotional support at every stage. This also means enabling delivery of best practices for myeloma patient care at GP and hospital level. We always need to make sure that patients are living as well as they possibly can be.

> **"We will always pursue hopeful patient futures by exploring impactful ways to move forward research, diagnosis and treatments, despite the recent challenges."**

What do you think the biggest challenges are for charities right now?

COVID-19 has been game changing – many charities are being relied on heavily to support beneficiaries at a time when they are simply unable to generate sufficient funds to cover core costs, let alone the high demand for services.

The financial impact of COVID-19 on the health economy will need to be carefully navigated and every charity will be challenged on their agility of thinking and ability to adapt over the next 18–24 months

What have you learned from the lockdown period?

Mostly, I have learned about the ramifications of COVID-19 on myeloma patients and how it has impacted every part of their lives. I believe in compassionate healthcare which takes into consideration the holistic and lifestyle needs of patients, families and carers, alongside their medical requirements. It is important to recognise the whole person approach and advocate accordingly.

On a personal level, I've been reminded of how vital our mental wellbeing is, especially because I have found some of the restrictions challenging and have needed to be gentle with myself and my family. To that end, I am sure our Thursday cinema night will become a permanent feature in our household!

What would you like to say to patients and families at this time?

I would like myeloma patients and their families to know that we are doing everything we possibly can to ensure their voices are heard by decision makers. We are focused on making sure that, as cancer services are restored across the NHS, the priorities you have identified through the patient and family survey are championed.

We will always pursue hopeful patient futures by exploring impactful ways to move forward research, diagnosis and treatments, despite the recent challenges. We will continue to take a 360-degree view to ensure we understand the complete support package myeloma patients and their families require and do everything we can to understand the impact the pandemic is having today and to anticipate the future implications.

We will be right alongside you.

You can hear more from Laura on our website

myeloma.org.uk

Follow Laura on Twitter

MyelomaUK_CEO

Find us on social media

myelomauk

MY LIFE WITH **MYELOMA**

NAME: Scott Meech

LIVES: Loughton, ESSEX

AGE: 54

Scott Meech is 54 years old and lives in Loughton, Essex with his wife Samantha. Scott and Samantha also have a son and daughter. This is Scott's story.

Around the time of the 9/11 attacks on the World Trade Centre in 2001, my eldest sister Anita was diagnosed with myeloma. After an incredibly brave fight with the disease and intensive treatment, she died around a year later. Whilst I was being tested as a potential stem cell donor for my sister, we discovered I had monoclonal gammopathy of undetermined significance (MGUS) and with that my own journey began.

I was born in Bristol in 1966. Consequently, I can say England won the football world cup in my lifetime. I was a late addition to the family as my two sisters were 12 and 14 years older than me when I arrived. I may have been a mistake, but hopefully I was a happy one.

I had a happy childhood. My two sisters seemed like additional, young and fun mothers as I grew up. By the time of my sister's diagnosis, I was settled in London with my lovely wife Samantha and our two children. The MGUS revelation and my sister's passing made us wonder what the future would hold.

My regular blood tests were stressful at first as I worried about the possibility of a change in diagnosis. We read all the research we could find about the chances of progression to myeloma and whenever I had a bad back or an infection, my anxiety levels crept up. Over a decade of tests revealed no real change, so it all became quite routine and our concerns were put aside during that time. I thought of it as a 'A distant ship smoke on the horizon', as the Pink Floyd lyric goes.

This was a good time for us as we renovated a new home, I changed jobs and our children Henry and Lily grew into wonderful young adults. I even completed the London Triathlon; raising vital funds for Myeloma UK.

Following other myeloma stories has made me realise that everyone has a different journey in terms of symptoms, treatments, side-effects and outcomes, but there are commonalities. Everyone attaches some form of personality to their myeloma. I have heard people refer to it as 'the brute', 'bad boy' and 'the beast'. I guess this gives us all a bit of a mental image to focus on rather than perceiving it as an invisible and somewhat intangible foe that floats around our bodies.

> **"Everyone attaches some form of personality to their myeloma. I have heard people refer to it as 'the brute', 'bad boy' and 'the beast'."**

The mental image I created was a big black dog. I think this may have come about because of our folklore; the black dog is generally a ghostly beast that unleashes terror in the night time. This creature is immortalised by Conan Doyle in The Hound of the Baskervilles. He describes it in the following way: 'A hound it was! An enormous coal-black hound, but not such a hound as mortal eyes have ever seen!'

During 2018, my blood tests and scans showed signs of a turn for the worse. Despite having some anxieties about my appointment with my consultant on the 19 October 2018, we calmed ourselves with the thought that I felt fit, healthy and my blood counts were not too bad. However, the bone marrow biopsy told a different story and my myeloma was much more active than we had thought. Although I had no bone damage, I was quickly developing myeloma. The black dog had finally caught up with me and was at the doorstep.

Despite the knowledge that I had a predisposition to the disease, confirmed by 'high risk' genetic test results, the news was a terrible shock. All I can remember saying was 'I thought I had more time'.

Samantha and I used the time well before treatment began. There were many people we needed to tell and it took time and care. Communicating bad news can be difficult and exhausting. You have to pick your moments and different approaches work better for different people. We had the opportunity to see all our close family in person and spoke with many friends.

The support was and continues to be wonderful and overwhelming. Many people including myself, find it hard to know what to say in these situations. However, some people are eloquent in their approach and deliver some gems! I received an email from a friend that left an indelible impression on me:

"I am so sorry to hear about the unexpected and distressing news that has turned your life and your family's life upside down. Nothing prepares for this news and it takes a lot of courage to face this situation. But I trust that your calm, bright and positive frame of mind and the love of your family have kept the clouds of doubt and anxiety at bay and kept you focused on the steps to remission."

The French do have a way with words!

I found the start of my treatment cathartic. The positive feeling of getting started and fighting back began. Taking on the black dog involved the three pillars of knowledge, positivity and my support team.

From the early days of my diagnosis, I wanted to understand as much as possible and engage in decision making with my consultant. Knowledge restored some sense of control and I became fascinated by the new drugs, genetic research and the stem cell transplantation process. Months later when my own stem cells were being returned to my body, I watched in wonder as the process took place and pondered how this would help my immune system to recover.

I have written a blog to chart my progress and help my family and friends keep up to date. I find it therapeutic to write down my thoughts and sometimes it stops my head from spinning with ideas and questions. It also provides a great feedback loop from my support group, who often post encouraging comments to help keep me positive during the treatment rollercoaster.

I often write about things I have researched such as the heritability of myeloma, something I have been asked and have asked myself given my own experience.

The great leaps being made in understanding the influence of genetics on myeloma may give us an answer one day, but there are other factors that may also increase the likelihood of developing myeloma. My family history gave me a slightly higher chance of developing myeloma, but the incidence of more than one family member having the disease is extremely low.

My blog often strays onto other areas, usually things I love doing like watching rugby, walking, fishing or my terrible golf. There are some silver linings that come with a challenging cancer like myeloma and the discovery that I really enjoy writing is one of them.

“I find it therapeutic to write down my thoughts and sometimes it stops my head from spinning with ideas and questions.”

It is 17 months since my treatment started. It really has been a rollercoaster with many changes along the way. My first four cycles of treatment went very well with little sign of any side effects. However, the wheels came off a bit when I suddenly suffered from severe peripheral neuropathy. The fifth cycle was stopped and the drug that caused my neuropathy was switched. By then the damage

was already done. I experienced excruciating pain. My consultant said it’s amongst the worst nerve damage he has seen and it still causes a major problem with numbness and tingling in my hands and feet. However, the pain passed a couple of months ago with the help of a pain consultant.

My stem cell transplantation last September went very well. I am now having a few cycles of consolidation treatment to try and reduce the minimal disease that remains. The early signs are good and we are optimistic.

I have spent a lot of time over the last year or so contemplating what life might be like when my treatment ends and I can begin to enjoy what is hopefully a lasting remission. The 'to do' list is pretty extensive and includes travel, socialising, walking, golf, fishing, and watching rugby. Whilst I don't have a ‘what not to do’ list, I would definitely say it would not include staying at home or being shielded. However, Samantha and I decided to observe the shielding recommendation whilst our grown-up children stayed with their partners. Although this has worked well, we really miss them.

I’ve been using Zoom, gardening, reading and making bread. There is of course the endless struggle to get supermarket delivery slots and the sheer joy of getting a delivery. Those are great days. It almost brings a tear to my eye just visualising the lovely delivery vans!

Returning to the subject of silver linings. I have spent some time reflecting on life over the past year or so and I really appreciate our family, friends and my life. There is so much more that I want to do and share with the wonderful people around me, and so much to be positive about and strive towards.

You can read my blog here:

scottsmyelomadiary.home.blog

SPOTLIGHT ON MENTAL HEALTH

"Looking after your mental health in the same way you would look after your physical health is vital"

INTRODUCTION TO MENTAL HEALTH

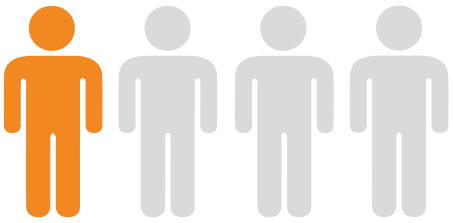
During this time of COVID-19, mental health concerns have been on the rise. This is particularly relevant for patients who have been asked to shield; to not leave their home and to distance themselves from everyone they know and love. Many will have experienced low mood, loneliness, anxiety, depression and grief to name a few things.

Mental health worries do not only concern shielding and lockdown, but extend to the opening up of the country and restrictions being lifted. As things change, myeloma patients and their loved ones are likely to have concerns around being able to leave the house and the potential risk this poses to them.
In addition, the existing worries and concerns many patients and family members have about their myeloma and treatment are still there and may be heightened due to changes in treatment and care. It is therefore easy to feel overwhelmed.

Looking after your mental health in the same way you would your physical health is vital, so in this 'Spotlight On' we've included several things you can do to support your mental health and wellbeing during this time.

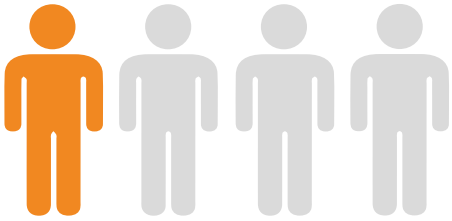
With any mental health concern, it is crucial that you reach out and seek help. Our Myeloma Infoline is available Monday–Friday, 9am–5pm, and we welcome anyone who needs a listening ear or practical advice to get in touch. There are also many other organisations out there who can help you with your mental health, including Mind who have many resources to help you cope during the COVID-19 pandemic. Of course, you should also speak to your GP about your mental health if you are concerned.

DID YOU KNOW?



Approximately 1 in 4 people in the UK will experience a mental health problem each year.

Anxiety and depression affects 1 in 4 myeloma patients.



M is for... management

There are a variety of methods to help manage your mental health, from mindfulness to medication. Finding out what works may require trial and error and a combination of tools. Some things that may help include:

- **Mindfulness** and/or meditation
- **Movement** – exercise can help boost mood in the short term, with regular movement shown to be effective over the long term
- **Medication** – many people find their mental health is improved with medication and your GP may recommend this for you
- **Mobile apps** – there are many apps available which can help manage your mental wellbeing in various ways. For example, mindfulness or meditation apps like Headspace may be helpful
- **Mutual support** – Support Groups or group therapy allow you to share your experiences with others and learn from their experiences
- **Mates** – talk to your friends and/or family members and stay in touch regularly

I need to talk to somebody

If you're struggling and need help, you can get in touch with these organisations

- **Samaritans** – call 116 123 for free anytime
- **Shout** – text SHOUT to 85258 for free anytime
- **Campaign Against Living Miserably (CALM)** **0800 58 58 58** (5pm–midnight every day) or use their webchat service
- **Mind** – find their resources at mind.org.uk/need-urgent-help/using-this-tool
- **Your GP**
- **999** – if you're feeling suicidal or have seriously harmed yourself

SPOTLIGHT ON

TOP TEN TIPS
TO HELP YOU LOOK AFTER YOUR MENTAL HEALTH DURING COVID-19

1 Be kind to yourself

Adapting to any change is hard, especially when you don't know how long it will last and how it will affect your future. Try not to feel bad about having a bad day. Think about the advice you'd give a friend or family member; you'd want to make sure they're looking after themselves, so you should look after yourself too.

2 Check your mental health and wellbeing

Regularly taking stock of how you're feeling and making a note of it can be helpful. It's important to acknowledge how you feel and writing it down regularly may help you identify potential patterns or triggers. You can use these notes to take measures to help yourself. For example, scheduling a call with a friend in the evening, if that's when you feel most anxious or low, may help to improve how you are feeling and take your mind off your current situation.

3 Define your new routine

COVID-19 and shielding measures in particular have disrupted regular routines and forced us to be at home more than usual. Giving yourself a simple daily or weekly routine can help make sure you add structure to your day. Try to continue to do the things you enjoy where you can and the things you need to do for your own health and happiness.

4 Take the pressure off

Whilst ticking things off a to-do list can give you a sense of accomplishment, setting yourself overly ambitious targets can affect your motivation and make you feel worse. Try to set realistic and achievable goals for the day and work through your lists one task at a time. Don't forget, you don't always have to be productive; sometimes just getting through the day is enough.

5 Stay healthy

Getting some exercise, eating well and staying hydrated are important for your mental health and wellbeing. Unfortunately, these are often the things that slip first when we're not feeling well. To try and avoid this from happening, make sure you plan in regular mealtimes daily and some exercise each week. If you want more information on tailoring your diet and exercises that can be done at home, please get in touch with us at Myeloma UK or have a look at our website for more information.

6 Keep doing what you enjoy

Staying at home shouldn't mean you have nothing to do or need to stop making plans. Doing things you enjoy, including hobbies, keeping in touch with people, and spirituality can make a big difference. If you are unable to do the things you are used to, you may be able to modify them. Eating a meal with a friend or family member via video call can be a nice alternative to going out for a meal. If you want some more ideas, have a look at the things our readers have been doing during lockdown to keep busy (see page 18 and 19).

7 Make your surroundings work for you

Having to spend more time at home might start to feel restrictive and claustrophobic, so it's important to spend some time making your home comfortable and relaxing. Your surroundings don't need to be immaculate, but making time each day to keep things tidy and organised can help you feel more in control and minimise stress. Some people find that having nice things around them that make them smile helps to boost their mood and make their time inside more enjoyable – try putting out flowers, a plant or a picture of family and friends.

8 Focus on things you can control

Focusing on the things you can control or change, and working towards accepting the things you cannot, can help to improve your mood. Try not to worry too much about different possibilities and the what-ifs. Instead, try to focus on the facts and what you know to be true. Even controlling small things like your news intake can make a big difference.

9 Connect with others

Make some time to talk to other people, especially if this is something you did before. This can include spending time with people in your household or by using technology to connect with family and friends.

10 Access help

Talking to someone about your mental health concerns can help you identify what they are and what steps you can take to improve them. You may find confiding in a loved one or friend helpful. Others may find it more beneficial to seek professional help. It may be worth talking to your GP or healthcare team at the hospital to find out what services are available. Whatever you do, don't suffer in silence; reach out to others who can help you.

Whatever a diagnosis brings...

MyelomaUK

Call our **Myeloma Infoline** for practical advice, emotional support and a listening ear

0800 980 3332

Get answers to your questions by emailing **AskTheNurse@myeloma.org.uk**

Check our website for more information and advice **myeloma.org.uk**

SUPPORTER STORIES

Mark Jones lives in Wales and is a myeloma patient. He updated us on 'The Virtual Welsh Coast Paddle' he is doing to support Myeloma UK.

In the summer of 2018, my family's world was turned upside when I received a diagnosis of myeloma.

Myeloma is normally associated with people in their 60s and 70s, so it was a huge shock when I received a confirmed diagnosis. Words cannot describe the emotions and feelings that hit you when you are told you have an incurable illness. It's like being permanently winded or kicked in the 'crown jewels'.

Starting in November 2018, I received chemotherapy for 11 months. I wanted to tackle the illness in a positive manner and head on. Refusing to let myeloma get the better of me, I got myself into the best physical condition possible to fight the illness. I never took a backwards step or looked over my shoulder. I trained every day at the gym, surfed as much as possible (until September 2019 when the doctors said I wasn't allowed to go into the sea) and did that on top of work and the day-to-day challenges of family life.

In October 2019, I underwent a stem cell transplantation at University Hospital Cardiff that was straight out of a sci-fi movie. On day one, I received chemotherapy treatment. For over a week, I self-administered a stem cell boosting injection every day. These prompted my bone marrow to produce more stem cells and forced them into my bloodstream. After a week, the NHS staff wired me up to a machine and harvested my stem cells.

Over two successful days they managed to collect enough for two full transplants and cryogenically froze my cells. One transfusion was used in late November 2019, leaving a future 'Jock' transplant on ice!

At the beginning of November, I was called into hospital two weeks earlier than expected, to have my stem cell transplant. I immediately panicked because I had not finished decorating my house!

After spending the first night in a single room, I unfortunately had an accident and slipped. Aggravated by a previous rugby injury, my knee popped out which left me unable to walk. I was then moved to a double room with Steve Millichamp, who was undergoing the same treatment.

"At the beginning of November, I was called into hospital two weeks earlier than expected, to have my stem cell transplant. I immediately panicked because I had not finished decorating my house!"

Day one consisted of treatment with high doses of melphalan to destroy the existing myeloma cells. This would make room for the transplanted cells and destroy any existing myeloma cells to reduce the risk of the transplant being rejected. I was told that the procedure would slowly make me ill over the next two to three weeks. To this day, I still cannot get my head around the idea that a treatment would make you feel ill before it made you feel better!

Once the stem cell transplantation was finished, I was on lockdown

in my room at the hospital. During this period, the doctors warned Steve and I that we may feel weak, experience vomiting, diarrhoea and/or a loss of appetite. If an infection set in our throats, which we were told was common, we would be given food through a nasogastric tube running from our nose into our stomachs, to prevent malnutrition. If our blood counts stayed low, we were told that we would have regular transfusions.

Our room was a special germ-free space and visitors had to be illness-free if they chose to visit, as we both had a low number of infection-fighting white blood cells. Whilst many people are well enough to leave hospital between one and two months after their transplant, the only thought I had in my mind was to break all of the records possible and get out of hospital as soon as I could – I'm a very competitive person. My plan to beat the effects of chemotherapy

was training. Whatever advice the doctors gave me, I would double. If they told me to drink five litres of water, I drank seven to eight. If they said you need to eat, I forced down food and drank protein shakes. I also took into hospital a mini gym that included resistance bands and my mini portable bike, which can be used as a normal foot bike or a hand bike. Unfortunately, my slip meant I could not put weight on my knee and the doctors and physiotherapist encouraged me not to aggravate the injury in my leg. The fight my chemotherapy was having with my myeloma had to take precedence.

Being denied a workout with my legs, I put the bike on top of a flip top bin and started pedalling with my hands and arms. A subsequent conversation with a nurse about my exercise regime gave me an idea for a charity challenge and the next thing I knew I was hand-paddling around the coast of Wales – virtually!

"The support from staff at the University Hospital of Wales and Myeloma UK has been incredible. I can't thank them enough."

After setting up a JustGiving Fundraising page, I set a target of £500 to virtually paddle 1,400km from Cardiff Bay to Deeside, then back to my hometown in Llantwit Major. I used this bike at the hospital and subsequently at home to achieve the distance. I had no intention of doing anything for charity for at least two years whilst I recovered. However, the donations snowballed and as the money got closer to my target, I excitedly reset it. I set off from my virtual position in Cardiff Bay near the hospital and I completed the challenge of 50 kilometres in 28 stages. I stopped off at various virtual locations including beaches around the Welsh coast, where my friends would 'meet' me on Facebook and I would tell my story every day. With every virtual destination I reached, the story continued to evolve.

Throughout the various discussions I had with family and friends, I quickly realised I was talking about a 'virtual paddle' and not the 'hell' I was going through in isolation. I tried to keep it humorous and light-hearted, but I was also emotional and sometimes shocking!

Monetary targets were consistently smashed as I hit different beaches on my virtual paddle. I managed to become the fastest man in isolation to leave the hospital; ten days post-transplant! Unfortunately, I didn't leave with the overall record which is still held by a lady who also used fitness to recover and left after nine days. In my defence, I could not go home on the ninth day as my daughter was having an early birthday party with a sleepover and I couldn't be around a gang of kids because my immune system was low.

Unbelievably, I managed to complete 900km of the paddle in hospital and 500km at home during my recovery.

Going through stem cell transplantation is the hardest thing I've ever had to do and I have come out the procedure as a different man, one I rather like. Because my cancer will return I know I will require another stem cell transplant in the future. At my lowest point I thought I could not go through that a second time. The elation I had when I left hospital and the reaction I had from my family, has changed my mind. I would go through that hell again in a heartbeat, as it would give me more time on this earth to spend with my gorgeous family and friends!

The support from staff at the University Hospital of Wales and Myeloma UK has been incredible. I can't thank them enough. My wife works in the NHS too, so I have first-hand experience of how amazing our healthcare services are and the difference they make to people's lives.

As I write this story, I am continuing on my virtual paddle around the British Isles. You can follow my story and travels on Facebook – just search for Mark Jones (Llantwit Major) and send me a friend request. The fundraiser is still open and my target is over £10,000 when you include gift aid. I have also produced a book "The Virtual Welsh Coast Paddle" with 50% of the profits going to Myeloma UK.

You can follow my progress and/or order a copy of the book via

Mark Jones Llantwit Major

mark.jones01@cymoedd.ac.uk

07886 654933

You can also donate by visiting my JustGiving page

justgiving.com/fundraising/mark-jones256

Help make myeloma history by fundraising and donating. Email **fundraising@myeloma.org.uk** or call **0131 557 3332** to find out ways you can help.

WHAT YOU'VE BEEN UP TO

Many of us have tried to keep busy during COVID-19 by taking up new hobbies or doing more of the things we love. We asked myeloma patients, their families and friends to tell us what they have been up to over the last couple of months. We were delighted to see so many of you provide pictures and stories about what you have been doing during lockdown. Featured here are some of the things you told us about.

Christine Thompson (left) has been busy with some arts and crafts and made these amazing decorations. She has made some lovely hearts to hang on her wall and the first letters of each of her grandchildren's names.

Julie and her family (above) have been playing daily games of table tennis (when the sun permits). They also joined TikTok!

We just loved this beautiful crocheted doll named 'Ida' (below). Linda Cooke, who made her, has just recently learned how to sew and crochet. What a great new skill to learn.

Rosy Millington (right) sewed this lovely bunny, Luna Lapin, and made her some very stylish bunny clothing.

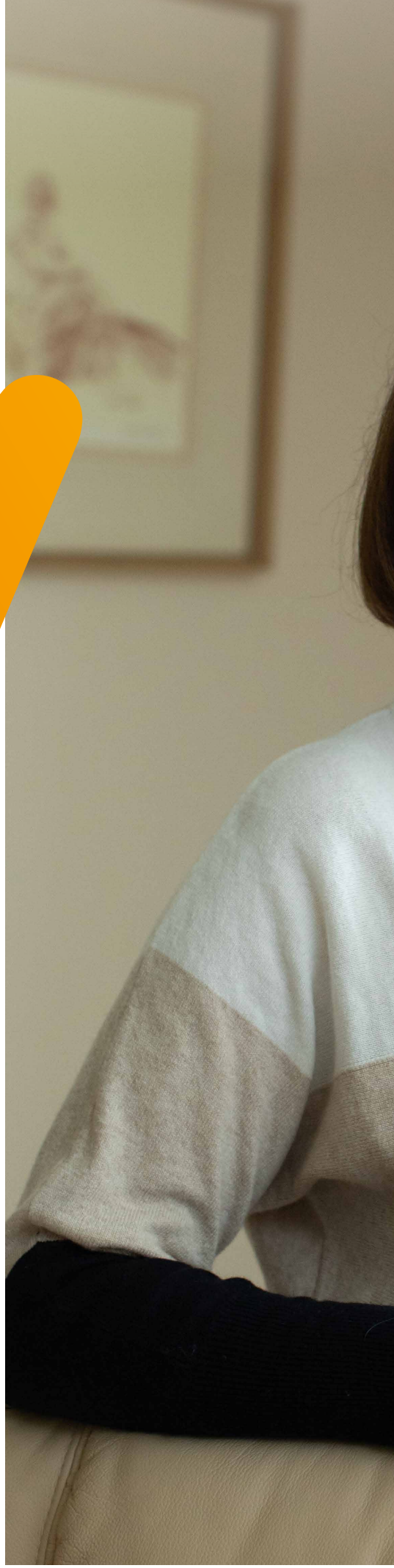
Debbie Rankin from Exeter has been busy knitting an army of our favourite Buddies (right) that are ready to go to a good home. Great going Debbie.

Nic Congdon (left) has been trying out different crafts but has enjoyed creating these amazing macramé projects the most. We particularly loved the bright red swing and glass holder.

Trevor Wells (below) has kept himself sane by making beautiful guitars.

Tammi Morrell-Knapton's five-year-old daughter (below) learned to ride her bike without stabilisers. They're racking up the miles and rode 41 in the first week. Well done!

My myeloma story



Ethel Johnson is a retired GP and lives in Bradford on Avon in Wiltshire with her husband Murray, who was diagnosed with myeloma in 2009. This is Ethel's story.

During a holiday in 2002, Murray's sweating problem reached pathological levels and I therefore suggested he see his GP for some blood tests. I suspected he had a possible thyroid problem, diabetes, and/or anaemia, but he denied my concerns as he was very well and had gained rather than lost weight.

I was shocked to find he had high protein and globulin levels and I knew this was very serious. I was grateful for the rapid actions and support of our local haematologist, who after finding a paraprotein of 25.3, organised a bone marrow test and skeletal survey. The results came as a huge relief when Murray was diagnosed with monoclonal gammopathy of undertermined significance (MGUS). We were fully aware of the potential progression to myeloma, but Murray felt lucky to have been given that diagnosis early on.

I had only dealt with a handful of myeloma cases and they included elderly patients who died shortly after diagnosis. Despite receiving a diagnosis of MGUS at 50 years old, I felt we had the Sword of Damocles hanging over us. However, life carried on as we both had busy jobs and two boys to get through University. Fortunately, our haematologist was supportive but also realistic. For the next few years, Murray had regular blood tests and his haematologist liaised with him by email and saw him a couple of times a year.

By 2007, Murray and I agreed to get on with life and do what we wanted when we could afford to do so, rather than saving for a day that might not come.

We decided to do some long distance travelling with a three-week camper van holiday in New Zealand.

Murrays' paraproteins started to rise to around 40 in 2008. This resulted in a diagnosis of smouldering myeloma. Up to that point, our boys were only aware that their dad had a blood illness. However, we decided to spell out the illness in detail to our boys. Murray is a very private man, but this illness had changed him and after the boys had the full picture, he was very happy to talk openly and honestly. His positive attitude remains amazing and admired by all who meet him. I am sure this has helped us all to cope with his illness.

> **His positive attitude remains amazing and admired by all who meet him.**

By July 2009, Murray's paraprotein level had risen to 52 and although his other indices were all acceptable, he continued to feel tired. Inevitably, Murray started induction therapy prior to a stem cell transplant.

This was a difficult time for us. The gruelling treatments included a three-week cycle of 500mg cyclophosphamide weekly, 100mg thalidomide daily and 40mg dexamethasone (days 1–4 and 12–15).

Thankfully, the specialist nurse explained everything so we knew what to expect and when things would happen.

The days after the steroids stopped were the worst as he felt very ill and had to stay off work. However, we tried to carry on with our lives and even had a brief holiday in Scotland.

On the night we returned home he had a rigor which terrified Murray, but I immediately recognised it and calmed him. The following day he was diagnosed with pneumonia. His chemotherapy was suspended so that the team could treat the infection.

The six cycles of CTD were completed by December and with

a paraprotein of eight, we looked forward to some respite before the stem cell transplant took place. However, he developed swine flu and spent Christmas in bed.

> **During this agonising nine-day period, we saw each other through windows and had to talk via mobiles.**

The next steps required numerous hospital visits. I was fortunate to have locum insurance which meant I could accompany Murray on these visits. Being able to go with Murray was vitally important as I could get the chance to understand what would happen next and ask the many questions that worried me as a professional. In response to my questions, the briefing the specialist nurse provided was excellent.

Murray was admitted to one of the new isolation rooms on the haematology ward in March 2010 for a stem cell transplant. I was unable to visit him due to an outbreak of *C. difficile* in the hospital. During this agonising nine-day period, we saw each other through windows and had to talk via mobiles. This was the hardest thing for me as I knew how ill he was and I could potentially lose him.

Thankfully, his treatment was a success and he came home after 14 nights in isolation. The staff were most impressed by his positivity and determination, how he kept to a routine of showering and dressing each day and did not hang about in nightwear. I was very proud of him.

Whilst neutropenic, he was on numerous antibiotics and I worried about that and the many other aspects of his treatment, but was always reassured by the caring medical team who understood my anxiety in light of my medical knowledge.

The extreme weakness he experienced on discharge gradually improved and he was well enough to drive himself to the hospital to have his Hickman line removed. On returning home from work that same evening, I found him unwell. For the first time I felt panicked as this change was unexpected. Whilst, the course of his treatment had been fully explained, this complication was not! After a few more days in hospital and more antibiotics he was better and we never looked back.

The high-dose therapy and stem cell transplantation (HDT-SCT) gave him five years remission and during that time we both retired and travelled far and wide. Our younger son moved to San Francisco and we took the opportunity to have a holiday in the United States and also did Route 66, in part, on a Harley Davidson. We also visited Canada, South Africa and Australia and had numerous breaks in Europe and the UK.

Murray did an abseil off the Forth Rail Bridge and raised over £2,000 for Myeloma UK in 2011. This was amazing and we were very proud that he was able to undertake this on behalf of the charity.

Unfortunately, his paraprotein started to rise and in December 2014 we prepared for HDT-SCT. I found this particularly hard to accept as Murray appeared well, but his bloods and PET-CT scan told a different story.

The doses of the treatment were much lower this time and the side effects were less troublesome for Murray. However, the stem cell transplantation was delayed because the medical team needed to check his lung and cardiac function.

In June 2015, Murray received the stem cell transplant and whilst he had one episode of severe breathing difficulties due to fluid overload, he pulled through. His consultant gave him a cuddle the next day. As a medic, I know if you give a patient a cuddle you're worried!

Unfortunately, the HDT-SCT was less effective and by late 2016 he was told his paraprotein levels had risen. In March 2017, a third line of treatment commenced that included ixazomib (Ninlaro®) in combination with lenalidomide (Revlimid®) and dexamethasone. Thankfully, travel has been possible for us during his treatment. He now has monthly hospital visits, a three-monthly infusion of bisphosphonates, and is currently in remission. We have therefore travelled through more of the USA and undertaken two cruises.

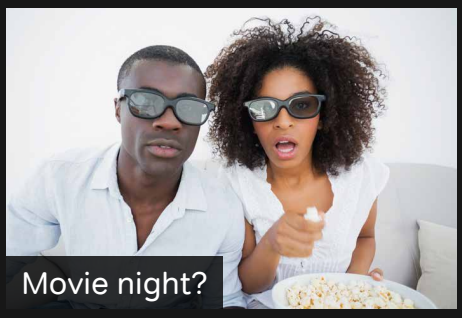
During the first week of lockdown and COVID-19, Murray was recovering from a chest infection and I had a virus so we did very little. We received the letter from the NHS with the advice on how to keep safe. Fortunately, we have a house with separate bedrooms and bathrooms and have a garden.

> **For the first time I felt panicked, as this change was unexpected.**

The bucket list of places we hoped to visit in our retirement is now on hold and may never happen. We stay at home, stay safe and look after each other and hope that we will come through this even if it is to a very different normal.

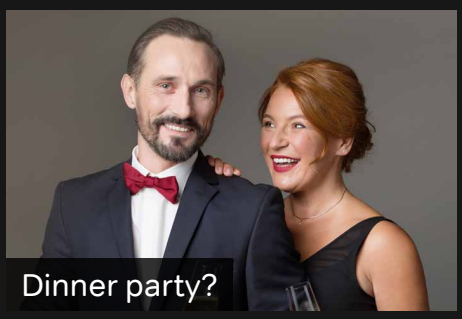
In response to COVID-19, the General Medical Council (GMC) temporarily restored my registration with a license to practice. There was a choice to opt out, but I felt I should offer my services if I could be useful. Unfortunately, as I am 70 and need to shield, I could only work remotely and as it is over five years since I did clinical medicine, I would only envisage being useful in a supportive role. So far, I have not heard from them, but who knows what is around the corner.

What does your **Big Community Night In** look like?


Movie night?

Karaoke?


Cocktail hour?


Dinner party?

BIG COMMUNITY NIGHT IN

Myeloma Awareness **Week**

21–27 June 2020


Fancy dress?

Host your own **Big Community Night In** event to fundraise with friends and family this **Myeloma Awareness Week**, and help make myeloma history.

fundraising@myeloma.org.uk

myeloma.org.uk/big-community-night-in

Register now

MyelomaUK

Given the challenges and uncertainties at this time, we have made the decision to postpone this September's **London Paris Ride.**
The safety and needs of our participants, patients and their families comes first.

The revised dates are **20–24 May 2021**.
We hope to see many of you then.

LONDON PARIS MYELOMA UK RIDE 2020

RESCHEDULED: 20–24 May 2021

Any questions please contact the Ride Team at **ride@myeloma.org.uk**
Register at **myeloma.org.uk/ride**

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 **AskTheNurse@myeloma.org.uk**

Learn about myeloma from experts and meet other patients at our **Patient and Family Myeloma Infodays.**

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 up and talk to other people face to face.

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.

Watch **Myeloma TV**, videos about myeloma presented by experts, patients and family members.

Use the **Discussion Forum** for the opportunity to share experiences and advice about living with myeloma.

Help make myeloma history by **fundraising and donating**. Email **fundraising@myeloma.org.uk** or call **0131 557 3332** to find out ways you can help.

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