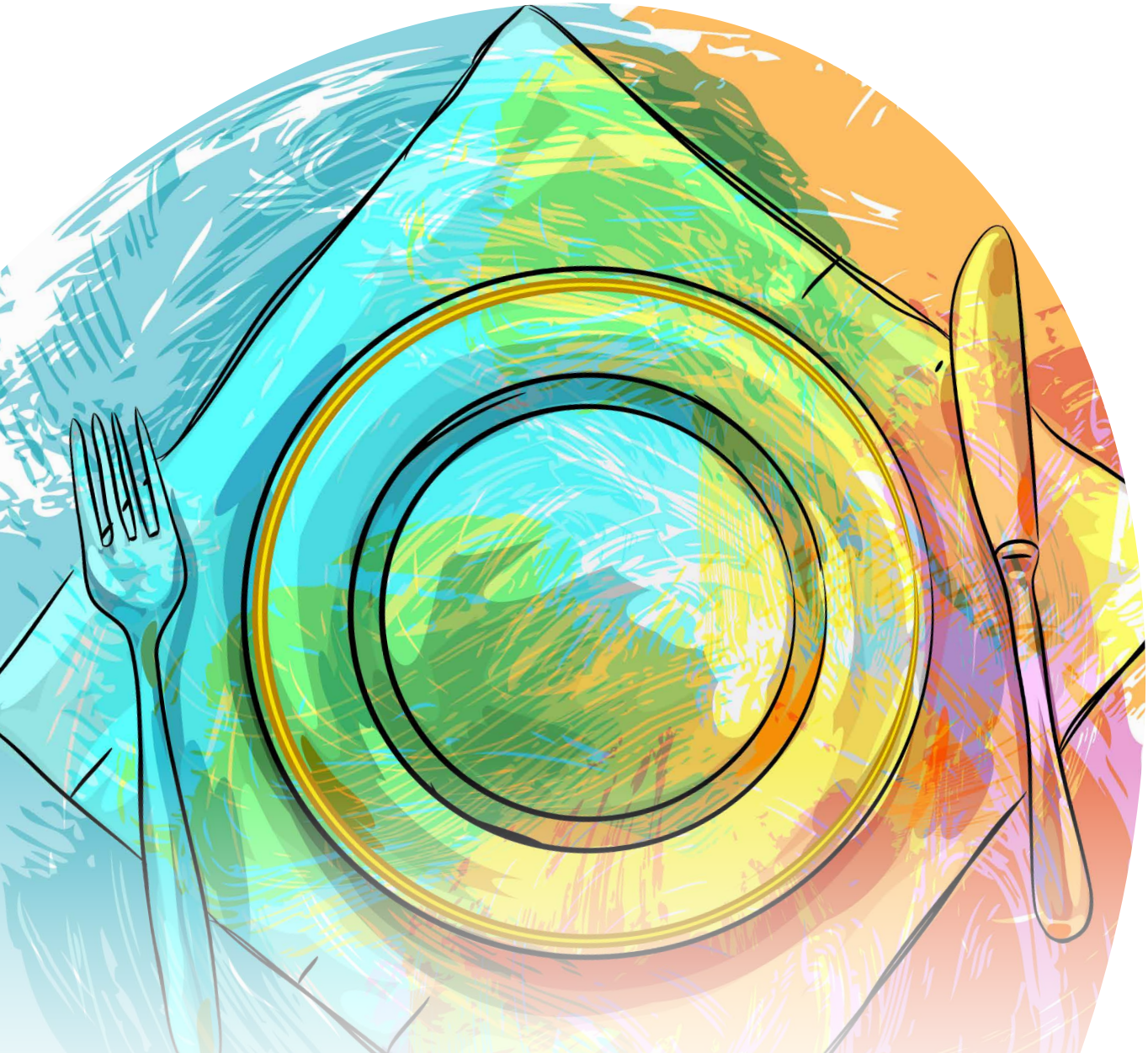
AUTUMN/WINTER 2019

myeloma Matters



Spotlight On
Diet

My life with myeloma
Mark Scott

Medical Focus
Palliative care

My myeloma story
Fran Laws

MyelomaUK

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Alice Baron



Sandra Quinn

DEAR READER

Sandra Quinn
Myeloma Matters Co-Editor

Welcome to the Autumn/Winter edition of Myeloma Matters.

In the final edition of 2019, we'd like to start by thanking all our readers for subscribing and supporting the magazine this year. We have enjoyed hearing all your feedback and suggestions.

As usual, we have two experiences, the first from Mark Scott who shares his experience of living with myeloma over the last 18 months, and the second from Fran Laws who explains her role in supporting her husband since his diagnosis in 2006. In our 'Supporter Stories' section, Denis Cairns talks about his experience of living with myeloma and his efforts to fundraise for Myeloma UK by abseiling off the Forth Rail Bridge.

We know that, for many patients, taste and appetite changes have a huge impact on their day to day life and diet is always a popular topic on our Infoline and at our Infodays. In this edition's 'Spotlight on', Laura Nunn, Specialist Haematology/ Oncology Dietitian, gives plenty of practical advice for patients who are experiencing these changes.

Our 'Medical Focus' is from Consultant in Palliative Care Dr Ahamed, who explains the vital role that palliative care plays in the treatment of myeloma. This is often a misrepresented area of medicine, so we hope that this article is informative and helps patients in need of more supportive care to access it.

I hope you enjoy this edition and please don't hesitate to get in touch with feedback and suggestions. From everyone at Myeloma UK, we wish you a wonderful festive season and a happy new year.

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MYELOMA RESEARCH NEWS FROM AROUND THE WORLD

New research helps differentiate between MGUS and myeloma patients

Researchers from the UK have been developing a new methodology to differentiate between monoclonal gammopathy of undetermined significance (MGUS) and myeloma using paraprotein and serum free light chain (sFLC) blood test results.

Currently, determining whether a person has MGUS or myeloma from blood test results can be challenging. Both myeloma and MGUS patients present with paraprotein and/or free light chains in the blood. However, unlike myeloma, MGUS is a non-cancerous condition and usually only requires monitoring.

To improve diagnosis, the team analysed blood test results from historic patient records and defined new ranges and thresholds that can exclude a myeloma diagnosis. This enables healthcare teams to distinguish quickly between MGUS patients and those with suspected myeloma who can then be referred for urgent assessment. It is thought that the use of this new methodology in general practice for any patient with suspected myeloma could speed up diagnosis and prevent unnecessary referrals to haematology.

Daratumumab triplet receives positive opinion from European advisory group

The Committee for Medicinal Products for Human Use (CHMP) have recommended the approval of daratumumab (Darzalex®), lenalidomide (Revlimid®) and dexamethasone (DRd) for previously untreated myeloma patients who are not eligible for high-dose therapy and stem cell transplantation (HDT-SCT) in Europe. The decision was made based on results from the Phase III MAIA trial which demonstrated that DRd was more effective than lenalidomide and dexamethasone (Rd) alone in newly diagnosed, HDT-SCT eligible myeloma patients. Overall, the DRd triplet led to deeper responses, a three-fold higher MRD negativity rate, and tolerable safety profile. If this recommendation is approved by the European Medicines Agency (EMA) it will mean that daratumumab will be available in Europe to newly diagnosed patients for the first time. Daratumumab is currently approved for use on the NHS as a monotherapy at fourth line and with bortezomib (Velcade®) and dexamethasone at second line.

Information should be tailored to patient preferences

New research from the Netherlands highlights the importance of tailoring the information patients receive to match the level of information they prefer. The research team evaluated the benefit of tailored information to patient preference for limited or extensive information using two different video consultations. One consultation had extensive information and the second limited information. The team found that the patient satisfaction of the consultation did not change when tailoring information to patient preference. However, not tailoring the information to patient preference affected recall and recognition. This suggests information preferences should be assessed in clinical practice to prevent overwhelming patients who prefer limited information.

Immune function predicts treatment-free survival after HDT-SCT

Measuring how and when immune function is restored after high-dose therapy and stem cell transplantation (HDT-SCT) could help identify myeloma patients at high risk of early relapse. A recent study investigated the relationship between levels of different immune cells and treatment-free survival in myeloma patients who had received HDT-SCT. The results indicate that low lymphocytes, low neutrophils, and low immunoglobulins levels were predictive of poor treatment-free survival. This research highlights the role immune function might play in delivering stratified medicine by helping identify patients at risk of early progression.

New drug selinexor effective for treatment of heavily pre-treated myeloma patients.

Results from a Phase II trial evaluating selinexor (Xpovio®) and dexamethasone for the treatment of relapsed/refractory myeloma showed that the combination of selinexor and dexamethasone was effective with 26% or patients achieving partial response or better. The most common adverse events were low platelets, fatigue, nausea and anaemia. These trial results supported the approval of selinexor and dexamethasone by the Food and Drug Administration (FDA) in July for the treatment of myeloma patients who were refractory to at least five anti-myeloma drugs.

MY LIFE WITH **MYELOMA**

NAME: Mark Scott

LIVES: Wigan

AGE: 46

My myeloma journey started on Friday 3 August 2018 at about 9pm; very specific, I know. The hilarity of the situation I found myself in will always stay with me.

Picture the scene. I'm strapped to a stretcher listening to my (very Wigan) ambulance drivers having a somewhat heated discussion with a beleaguered nurse in Ward 38 at Manchester Royal Infirmary. The conversation went something like this.

"Sorry, there's no bed for him. The bed manager said he's got to go back to Wigan," said the nurse.

"That's not going to happen. He's in agony (I was), and there's no way we're taking him back," said the ambulance driver.

"Well, unfortunately there's no bed or a doctor to book him in and the bed manager left hours ago," said the nurse.

"Well, we're leaving him here. It's our last job of the night and we need to get back to Wigan. Bye Mark, nice to meet you!" said the ambulance driver before they left the building.

I'm on the stretcher listening to this conversation, whilst, ironically, lying next to an empty bed, wondering what on earth was going on. Thankfully, the very calm, collected, competent and composed nurse gave a heavy sigh and sorted me out.

After finally being put into a bed, I lay there thinking, "Right son-shine, how are we going beat this beast?"

I'm getting ahead of myself a bit because there was a significant amount of build up to this cherished moment.

It all started in January 2018 when I, Mark Scott, history teacher, husband to the beautiful Emma, father to the (very teenage) Molly and William, and lapsed runner and cyclist, went to the doctor with nagging back pain. I was in the midst of a midlife crisis and, at 45, had decided to buy myself an expensive road bike and some outrageously tight and somewhat inappropriate lycra. I was finding it increasingly difficult to exercise, as I was experiencing a lot of back and hip pain.

> **"There's no way myeloma was going to define me, and I decided there and then that I would 'out positive' my myeloma until it was as dormant as it could possibly be."**

What followed was several months of physiotherapy, trips to the chiropractor and the osteopath, but all to no avail. I was still going to school, despite my worsening health, and it was a matter of some mirth to the students that "Sir" was constantly limping, moaning and groaning like an old man (as they were fond of calling me).

My body gave out in May 2018 and I was off work with, what was still considered, back pain. Doctors and physios were united in their belief that I had a bad back, and despite copious amounts of opiates, I was in increasing amounts of pain.

By late July, I was bed bound and in a bad way. Blood tests and an agonising MRI had come back inconclusive and both Emma and I were beginning to despair as to what was wrong with me. As they say, not all heroes wear capes and my own superhero, Emma, marched, well drove to be honest, down to the GP surgery and demanded a home visit. The doctor took one look at me and organised an ambulance and with that my myeloma journey began in earnest.

Before being moved to Manchester, I spent 4 days in Royal Albert in Wigan. I must be honest, the conversation when the doctor revealed that my bad back was in fact myeloma was of immense relief. I'd have hugged him if I wasn't bedbound and suffering with several fractured and collapsed vertebrae! Just to have certainty of knowing what I had and how it would be treated was a relief.

Once the treatment plan was explained I felt a surge of determination. As I lay there thinking about how I would break the news to my family, I thought, "Right you bugger, you don't know what's going to hit you!"

There's no way myeloma was going to define me, and I decided there and then that I would 'out positive' my myeloma until it was as dormant as it could possibly be.



This mindset was shared with Emma. Her steely determination to help me beat this matched my own. It is testament to her strength of character that she juggled family, work, dog, rabbits, fish and moody husband so successfully during the Autumn of 2018. Without her relentless positivity, my journey would have been all the harder.

I cannot understate the power of family and friends rallying round to help me get through my stay in hospital. Hats off to my brother Neil! Whether it was pushing me like the Body Coach to do those 10 extra steps or sneaking me in a cheeky Maccies cheeseburger, Neil was ceaselessly positive in acting as my own Mr Motivator to get me through. He was (and still is) a great source of comfort. Not forgetting the fantastic friends and colleagues from school that made daily visits. They even organised a rota for staff to visit me so I didn't get down and it was with great surprise and delight that the Head turned up one day for a visit! The students were also a source of inspiration and the constant cards, cakes and chocolate were very much appreciated. In fact, over the course of the school year, the little blighters raised over £5,000 for cancer charities.

I responded well to aggressive treatment; dexamethasone, thalidomide and Velcade over a period of 6 months. Perversely, I quite enjoyed my energetic dex days and didn't suffer unduly with side effects. I was under the care of the awesome Dr Rocci, my amazing consultant, and was on the mend after a few cycles of chemo.

Unfortunately, I was still stuck in hospital as 10 weeks of being bedbound had left me too weak to stand, let alone walk, and I'll be forever grateful to the rehabilitation team who got me from bed to running marathons. Ok not quite, but enough to be allowed to go home with my Zimmer frame in tow.

What helped sustain me during this testing period was my 'small wins' philosophy. I was determined that every day I would have a victory, however small, to sustain me and keep me positive. This could be as simple as beating my ongoing constipation and 'enjoying' a significant bowel movement, to managing to sit in my bedside chair for half an hour. It didn't matter what it was. Each of these moments were cherished and held on to as a sign of my slowly improving health.

Thoughts now turned to a stem cell transplant. The dangers were discussed, and I can empathise and understand why people are reluctant to go ahead. It certainly wasn't wine and roses. In fact, it was more ice cream and water!

I struggled through it; manfully complaining and being miserable about my sickness. However, I've always been a bit of a mardy pants when it comes to feeling poorly. The trick was to keep my eyes on the prize; the longest and deepest remission available. To be honest, I'd rather be chucking up and feeling awful than putting my remission at risk; no pain, no gain as they say.

By April 2019, after 8 months of treatment, I was done. Bald (didn't like this) and 2 stone lighter (very happy with this) my first battle with myeloma was over and in July 2019 Dr Rocci confirmed I was in complete remission. Now it was time to get my life back.

Being home presented a whole new set of issues. In the words of Spock, "It's life Jim, but not as we know it." I slept downstairs as climbing the stairs was beyond me at that time. However, bed baths from Emma were an unexpected perk! Simple tasks were frustratingly difficult, and I lacked the patience to deal with them and was constantly grumpy; although Emma denies this.

Probably my biggest frustration was the physical weakness. This has been an ongoing battle. At times, I get breathless getting dressed in the morning, but I need to take baby steps as I work towards a level of fitness that will allow me to go back to the activities I used to love and return to school.

Looking back over the last 18 months, I can now reflect on my journey so far. Treatment-wise, I've been left with the spine of a 90 year old woman (my spine consultant's words, not mine) and several minor physical ailments; a touch of neuropathy, 6 inches of height loss and several aches and pains. To be honest, I don't mind these at all as they're a constant reminder that I'm doing well now and it's better I have a sore back than be 6 foot under!

What balances out the physical ailments is the mental change that has come over me, my 'cancer perks' as I call them. I'm thankful to myeloma for allowing me to re-evaluate my life and help change my mindset. When you become a sufferer you quickly realise how much more loved and respected you are, how strong you are and how resilient you are in the face of a difficult and painful fight. Trust me, you've got this. I'm grateful for that and found the whole thing quite life affirming.

I'm now closer to Emma and the kids than ever before and we cherish every moment together. We've made a conscious decision to do more together as a family and not let little things affect us, as I've realised, they don't really matter in the grand scheme of things.

"I'm now closer to Emma and the kids than ever before and we cherish every moment together."

Myeloma has created a 'new normal' for us all. Things are different but this certainly hasn't been a negative. Living life in high definition, with clarity and a clear sense of purpose has been liberating. I won't be the same teacher, husband, or father that I once was and I'll be better. For that, myeloma, I thank you. Make no mistake though, I'm still coming for you and I'll be fighting you until we get a cure for this beast.

SPOTLIGHT ON DIET

"Experiment with food as taste changes."



INTRODUCTION
DIET



Whether you are a food lover or someone who eats out of necessity, a disrupted appetite can have a big effect on a person's life.

Myeloma can affect a person's diet through many ways, such as loss of appetite, pain, fatigue and treatment side effects.

Many people, therefore, need safe and reliable information about diet and we live in an age where information is available at the click of a button. However, the internet is not always the best or safest place to seek dietary advice. There is a lot of poor information available that makes dramatic claims to grab attention; claims that are not supported by evidence. For example, there is no evidence to support the idea that diet can 'cure' cancers once you've already been diagnosed, and to date, there is no scientific evidence to support a single diet to help with myeloma. Many of these diets can be dangerously low in energy, protein and nutrients that are vital for supporting your body through treatment.

To help you navigate changes to your diet and find quality information, myeloma patients have access to specialist nurses or dietitians who specialise in dealing with the problems you may face and can offer dietary advice to help you through them.

The title 'dietitian' is protected by law and a code of conduct, ensuring that only degree-qualified professionals are able to practice under the title. They provide practical, evidence-based and individualised dietary advice to patients in hospitals, clinics, public health and many other areas. For people with myeloma, a dietitian can help if you are losing weight, struggling to eat because of treatment side effects, support rehabilitation goals and offer support with unwanted weight gain during treatment.

In this 'Spotlight on', Specialist Haematology/Oncology Dietitian Laura Nunn covers some of the common nutritional problems myeloma patients face and shares advice she gives in daily practice.

Top 5 benefits of keeping well nourished

1 Maintain muscle strength

2 Decrease fatigue

3 Maintain independence

4 Improve mental wellbeing

5 Improve ability to fight infection

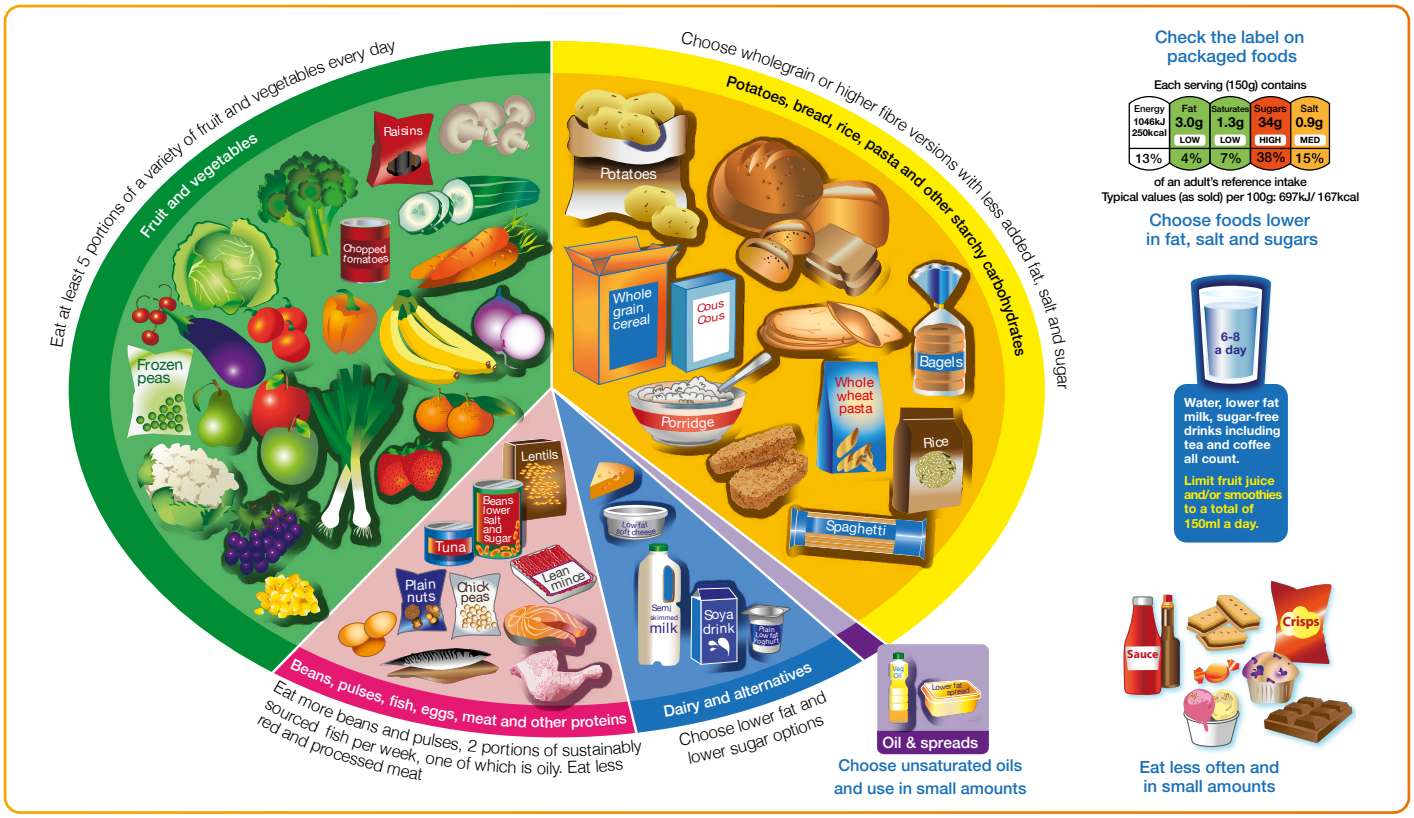
WHAT IS A 'HEALTHY DIET'?

The Eatwell Guide below shows what is currently considered a healthy and well-balanced diet comprised of five food groups: starchy carbohydrates, such as potatoes, rice and pasta; fruit and vegetables; proteins from a range of sources including meats, fish and pulses; dairy and alternatives; oils and spreads. Foods high in fat, salt and sugar are suggested less often and in small amounts.

When you are feeling well with your myeloma, you should follow this guide to keep you healthy and reduce the risk of other health conditions.

However, if you become more unwell or eating is a struggle, you may need to adapt your diet to take your needs into consideration to help you maintain a healthy weight.

Maintaining a healthy weight through your myeloma treatment is important, as this can help to avoid malnutrition or excess weight gain. Malnutrition does not just affect those with a low body weight; it concerns anyone who is losing weight unintentionally.



COPING WITH TREATMENT SIDE EFFECTS

There are many side effects of anti-cancer treatments that can make eating and drinking more difficult. Here are some examples of these, along with some tips to make eating and drinking more tolerable. With any side effects, make sure to tell your doctor or nurse as there is usually something they can do to help.



Sore mouth (mucositis)

- Softer foods with extra sauce may be more comfortable and easier to chew and swallow, whereas rough foods like crusty bread may hurt more
- Avoid extremes of heat or cold
- Cold foods and drinks can be soothing e.g. yoghurts, milky drinks
- Avoid spicy or acidic foods as these may irritate the mouth further



Dry mouth

- Take sips of fluid with meals or add extra sauce or gravy to meals
- Try sucking on boiled sweets to stimulate saliva
- Fruit such as pineapple can help stimulate saliva



Fatigue

- Batch cooking and freezing meals when you do feel well can help for the days when you're not able to cook a meal
- Ready meals or meals-on-wheels services are a good alternative when home cooked meals aren't an option
- Have easy ready-to-eat snacks or nourishing drinks available for a quick and easy energy fix



Diarrhoea

- Drink plenty to replace losses
- Limit alcohol, coffee, fatty foods and spicy foods as these can worsen symptoms
- Reduce foods high in fibre (raw fruit and vegetables, wholegrain cereals, pasta or bread)
- Diarrhoea is a common temporary side effect of treatments such as chemotherapy or antibiotics. However, it can be severe at times and will require more than dietary management to solve. Seek help from your medical team if:
  - Symptoms are severe (more than 4-6 episodes a day)
  - Symptoms persist for more than a few days
  - Symptoms are impacting on your quality of life
  - There's blood in your stool



Nausea

- If possible stay away from food while it's being prepared as cooking smells can be a trigger
- Cold foods may be easier to manage as these smell less than a cooked meal, for example sandwiches or cereal
- Try dry crackers or toast
- Some people find ginger (tea, biscuits) or peppermint (tea, sweets) helps reduce feelings of nausea
- If you are vomiting and struggling to keep down fluids or medications, seek advice from your medical team



Taste changes

- Avoid the foods you no longer enjoy the taste of
- Try new foods or foods you may not have previously liked
- Extra salt, sugar, spices or herbs, lemon or vinegar can help bring out flavours or make foods more palatable
- Strong tasting pickles, sauces or marinades can make meats taste better
- Citrus fruit, juice or sweets can be refreshing
- Brushing your teeth after eating can help prevent flavours from lingering

COPING WITH WEIGHT LOSS AND LACK OF APPETITE

1. Try to eat something, no matter how small. The less you eat the more used to it your body gets, decreasing your appetite further
2. Serve smaller portions at mealtimes – having a smaller target can be less daunting and mean you eat more
3. Eat little and often – small regular snacks or nourishing drinks can be easier than regular meals
4. Fortify your foods – adding butter/oil or cream to cooking, cheese on top of meals, or extra cream/ice cream on puddings adds extra calories without adding much volume
5. Choose high energy snacks – full-fat products, full-fat milk and non-'diet' products will have more calories meaning you get more out of a small amount of food
6. Choose high protein snacks – full-fat yoghurt, custard, rice pudding, nuts or cocktail sausages
7. Try nourishing drinks – drinks can be easier to manage when you have a poor appetite. Good choices include milk, milkshakes, milky coffee/tea, Horlicks, hot chocolate, fruit juice and smoothies

COPING WITH WEIGHT GAIN

For some people with myeloma, weight gain is more of an issue than weight loss. Treatments such as steroids can increase appetite and lead to weight gain.

Tiredness can make you less able to exercise, or fractures may reduce your ability to mobilise. Food can be a source of comfort in times of stress, which can contribute to weight gain. If you have gained weight through your treatment and you didn't want to, try not to be hard on yourself – you are not alone. If you want to lose weight, speak to your medical team first – weight loss is very individual and having the support of your doctor, nurse or dietitian can help you achieve your goals.

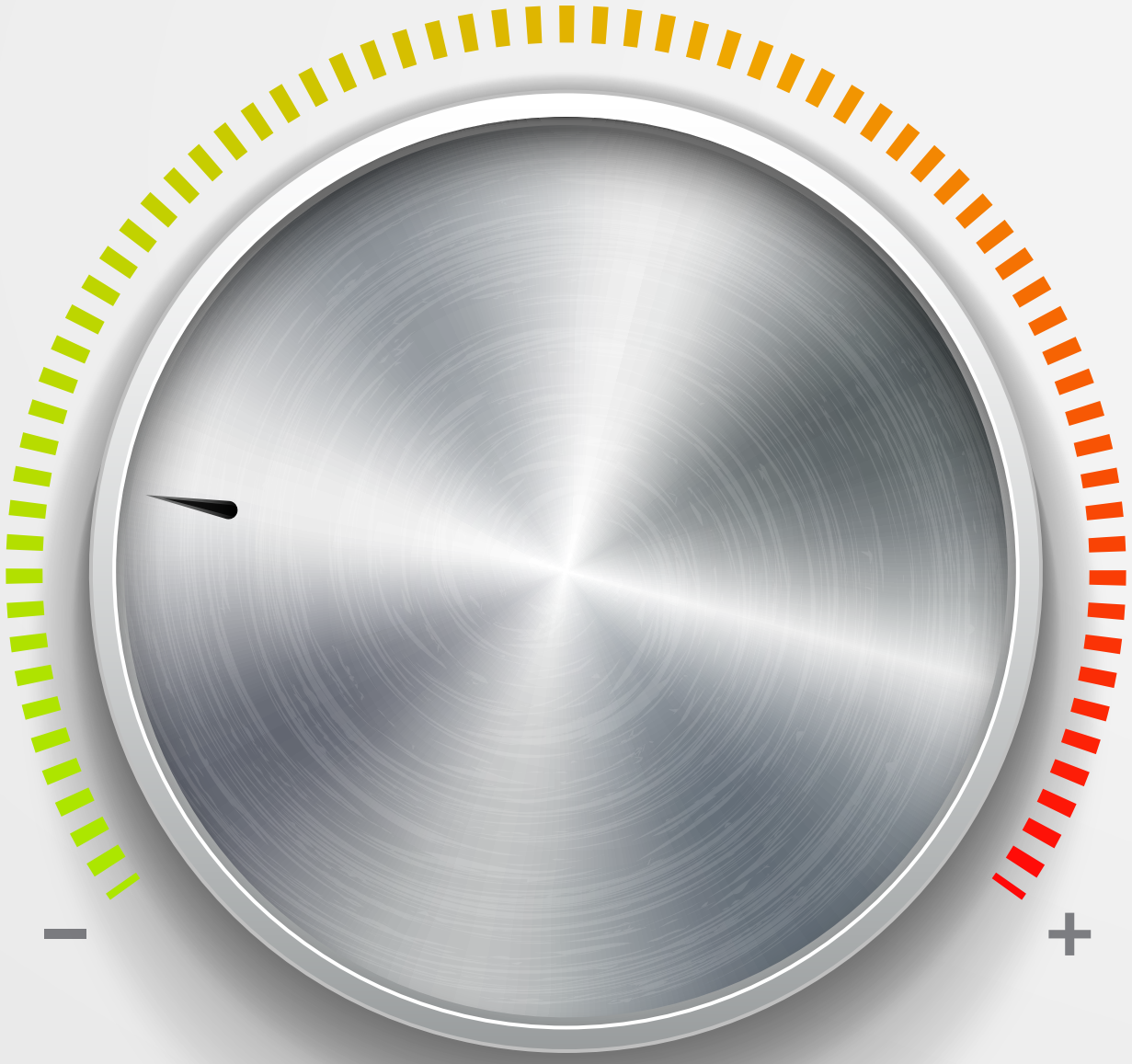
1. Set small goals – these will be more realistic and easier to reach
2. Have a breakfast – this will help keep your energy levels up and make you less likely to snack later
3. Eat more fruit and vegetables – they are low in calories and full of fibre and nutrients
4. Don't weigh yourself more than once a week
5. Have a protein source at each meal – this will help keep you fuller for longer and reduce muscle loss. Healthy protein sources are 'lean' red meats, poultry, fish, dairy produce, eggs and pulses. Limit processed meats like sausages, bacon, burgers and pies
6. Limit alcohol – alcoholic drinks are high in calories
7. Check food labels – many have traffic light labelling

MEDICAL FOCUS

Palliative Care: Symptom Control Experts

BY DR ASHIQUE AHAMED

Consultant in Palliative Care,
Manchester Royal Infirmary



Based on his talk at our Manchester Myeloma + Me event, Dr Ashique Ahamed discusses the role palliative care plays in the treatment of myeloma and dispels some of the misperceptions around this speciality.

What is palliative care?

Patients can experience a huge variety of symptoms during their myeloma journey. Pain, fatigue, confusion and bowel symptoms are just some of the most common symptoms. As well as the physical side of things, some of you may well be aware there's an added psychological and psychosocial distress that goes along with a diagnosis, which can worsen your symptoms.

So, what can we do about it? As the Supportive and Palliative Care Team, this is right up our street. We are symptom control experts. This is our bread and butter. This is what we do day in, day out.

Our aim is to improve your quality of life by proving symptom control and holistic care. We believe in giving individualised care to each person with myeloma. It's tailored to your condition, the extent of your myeloma, your symptoms and your psychosocial situation.

We're there to improve quality of life, not just by supporting you as a patient, but by supporting carers as well. Carers are part of the journey, you go through a huge range of emotional issues as well.

Complementing speciality

We work very closely with the haematology team and are part of the multi-disciplinary team, forming part of the discussion before and during treatment. As our main aim is to improve your quality of life, we work with the haematology team to complement each other. While they deal with the treatment side of things, we deal with the symptom side of things.

> **"We are symptom control experts. This is our bread and butter. This is what we do day in, day out."**

In Manchester, we have inpatient care and three outpatient clinics a week. We work across the whole of the adult Trust, and a significant part of our work is with haematology patients, but we also work with patients with solid advanced cancers, advanced heart failure, emphysema and so on.

A big part of our job is training staff around symptom control and palliative care as well.

Misperceptions about palliative care

You must be thinking that it's a no brainer; if you have a lot of symptoms then why not refer to the palliative care team? But occasionally, there are some barriers to referral, and that may be to do with the stigma associated with palliative care. When someone hears palliative care, it is often synonymous with end of life care, and while we are involved with patients who are in the last months and weeks of life, that is only a small cohort of patients. The reason we are involved with end of life is because patients who are approaching end of life may have more or more severe symptoms. They may suffer from more pain, or from problems like nausea and vomiting. As we are symptom control specialists, we're there to help them with that.

A big proportion of our work aims to help patients who have a relatively good prognosis but at the same time have symptoms that may actually be stopping them from getting on with treatment.

> **"We've seen that the better symptoms are controlled, the more compliance to treatment there is."**

Sometimes there's a misperception that our involvement means a patient should stop all active treatments, that your doctor has given up on you, or that if you're given morphine we are trying to hasten death. I can assure you, that's definitely not the case. Nothing could be further from the truth.

Involving the palliative care team does not mean stopping all active treatments. It does not just focus on dying, nor does it aim to shorten life. As previously said, we work very closely with our haematology colleagues and we are fully aware there are a lot of symptoms that you as a myeloma patient will experience with your myeloma.

We are also very aware that those symptoms can affect treatment and affect care. We've seen that the better symptoms are controlled, the more compliance to treatment there

is, which means better recovery. Therefore, we can actually improve your prognosis. Lengthen your life, not shorten your life.

Pain management

Unfortunately, pain is a very common symptom in myeloma patients; about 70-80% of patients who have myeloma will suffer from moderate to severe pain at some point in their diagnosis. This could be due to the myeloma itself or it could be due to treatment.

Some of you may have had peripheral neuropathy (damage to the feet and hands) which can be even more debilitating than the condition itself. We can help with that. I've had patients say, "My myeloma is under control but I can't get out of my house, because my feet are burning all the time or feel numb. I can't sleep, I can't sit still, and it's having a massive impact on me." This is where we can make a difference.

"We have an individualised, holistic approach when we treat symptoms."

We tailor treatment to the individual. We use a variety of painkillers that may include opioids, like morphine, nerve pain medicines (neuropathic agents like pregabapentin), and occasionally anti-inflammatory medicines (based on how well the kidneys are working). The key thing is that we monitor your pain, we titrate the dosages depending on how well your condition is controlled and how well the current regime works for you.

Occasionally, we use other interventional techniques. For example, you may have a substantial fracture in the spine which does not subside with pain management. We can refer you for radiotherapy, bisphosphonates or surgical intervention to help with the pain.

Opioids

There are some myths around opioids. People can be concerned that they are only used in end of life care, that they're addictive or that there'll be no alternative when the pain gets really bad. Opioids are used to control severe pain in a variety of settings (and not just at end of life). They are very good painkillers for the short term so we use them over a shorter period of time in myeloma and in monitored, controlled doses, which does not cause dependence.

"Any opioid painkillers given by the palliative care team will be regulated and you'll be monitored."

Dependence only occurs when a drug is used for a purpose it shouldn't be. Any drug given inappropriately can cause harm. It's about how, when and why the drug is administered. Any opioid painkillers given by the palliative care team will be regulated and you'll be monitored.

When the pain gets worse or if it's not managed by opioids, we have other options we can use. We can tweak doses and use a multimodal approach to pain management in myeloma. We use a wide variety of painkillers to help with your pain, not just opioids.

Other symptoms

As well as pain management, the palliative care team can help you with gastrointestinal issues like nausea, vomiting or constipation. We also help with people who are experiencing confusion, which could be due to infection, electrolyte (salt) imbalance or hypercalcaemia (higher than normal levels of calcium in the blood).

Holistic care

In palliative care, we are aware of a concept we call "total pain". This refers to not just the physical aspects of pain, but the psychosocial distress as well.

This psychosocial element is as equally important as the physical in palliative care. Many of you might be thinking:

- Why me?
- Will the treatment work?
- How is it going to affect my career?
- How will it affect my relationships?

All these questions can be distressing and can manifest as physical symptoms which is why we have an individualised, holistic approach when we treat symptoms.

We're there to help; we can facilitate open discussions and signpost you to the right people. I would thoroughly encourage you to ask if you have any questions or concerns about your treatment. You may also have access to a psychologist who can help. In certain cases, if you are depressed and finding it really hard to cope with the situation, you can consider anti-depressants to help.

Summary

I hope I've been able to dispel some of the misperceptions about palliative care. Patients shouldn't feel concerned about being referred to their palliative care team. They work closely with your haematology team, with the aim of improving your quality of life at whatever point in your myeloma journey you are.

Speak to your doctor or nurse if you are having symptoms or side effects so they can help and refer you to your palliative care team if necessary.

You can record your symptoms and side effects in the Myeloma UK Patient diary. Get yours at **myeloma.org.uk**



PATIENT INVOLVEMENT

BY AMY CAPPER

How patients can help shape our advocacy work

In the policy team, our approach is evidence-based and patient- and family-led. To achieve this, we ensure that our policy making is supported by our patient insight and data work, and that we work closely with patients and families to inform them about our advocacy approach and priorities.

Our current work is focused on improving diagnosis and reducing inequalities; access to treatment; the pricing of medicines; NHS cancer strategies and commissioning; the myeloma research environment; and "real world" data from treatments and results.

What does the current policy landscape look like for myeloma?

The current health and policy landscape is complex and highly visible in all four nations of the UK. Improving outcomes for cancer patients remains an important priority for the UK Government and for the devolved administrations. This is reflected in significant policy drivers including the NHS England Long Term Plan, the new Branded Medicines Pricing and Access Scheme (VPAS) and the current health technology assessment (HTA) landscape.

The NHS England Long Term Plan was published in January 2019 and includes 35 specific recommendations for cancer across a number of areas. While some of the measures outlined in the plan relate directly to blood cancer, many are much more directly relevant for solid tumours. The plan will be the biggest influence on the development of cancer programmes in the coming years and it will be very difficult to engage decision makers on any issue which is not related to or aligned with targets and actions set out in the plan.

The new voluntary scheme for branded medicines and pricing access is an agreement between the Department of Health and Social Care (DHSC) (acting on behalf of the UK Government and the Governments of Scotland, Wales and Northern Ireland), NHS England and the Association of the British Pharmaceutical Industry (ABPI). It sets out a range of measures to improve innovation and outcomes through improved access. The new scheme is a vital part of the access infrastructure, and patient organisations, including Myeloma UK, now have a better opportunity to engage with these issues.

In 2018, the National Institute for Health and Care Excellence (NICE) reviewed its methods to introduce a new technical engagement step which will give patient organisations the opportunity to input earlier on the value of a treatment. This has the potential to strengthen the patient voice in the process.

How can I become involved in shaping the advocacy work at Myeloma UK?

We will soon be launching our Advocacy Patient Partner Programme and encourage anyone with a personal experience of myeloma to apply.

The programme will enable Myeloma UK to work with a network of appointed patients, carers, family and friends to help shape our advocacy work with external stakeholders, like politicians, senior figures in the NHS, drug approval bodies and industry.

Our appointed partners will make a valuable difference by influencing and shaping our advocacy work; helping us to make key decisions and inspiring decision-makers to listen to the needs of myeloma patients. They will also be able to share insight, views and experiences on important issues in myeloma.

Our partners will have many opportunities including:

- Contributing to the development of Myeloma UK's advocacy work
- Working with Myeloma UK in engaging with external stakeholders such as parliamentary groups and provide feedback to Myeloma UK and other partners
- Contributing to Myeloma UK engagement with drug approval bodies by speaking from a patient experience perspective
- Sharing personal experiences of myeloma and services for media opportunities

If you would like to get involved look out for the launch of our Advocacy Patient Partner Programme on our website and social media pages very soon.

MYELOMA

HOT TOPICS



EYE COMPLICATIONS IN MYELOMA

BY JILL WILLIAMS

Although they are fairly unusual, eye complications can sometimes occur in myeloma. Most often, they are related to drugs used to treat myeloma, but occasionally they may be a direct effect of the myeloma itself. It is good to be aware of the potential complications that can arise, and to get any eye symptoms you may be having checked out.

Effects of treatment

Several anti-myeloma drugs can sometimes cause side effects on the eyes. This includes the commonly used bortezomib (Velcade®) and lenalidomide (Revlimid®). Although uncommon, side effects can include blurred vision, dry eyes, eye swelling, and conjunctivitis (inflammation of the lining of the eyes). Bortezomib and other similar drugs can also increase the risk of cataracts.

High-dose therapy and stem cell transplantation (HDT-SCT) can have after-effects such as dry eyes, glaucoma (raised pressure in the eye) and increased risk of cataracts. However, this is more likely with allogeneic (donor) SCT, which is less commonly done in myeloma than autologous (using a patient's own stem cells).

High dose steroids can also affect the eyes as they can increase the risk of glaucoma.

Eye infections

Both myeloma itself, and the drugs used to treat it, can increase the risk of infections. This can include infections in the eyes. This is because they can both reduce the number of white blood cells that are important in fighting infections.

Bortezomib, lenalidomide and similar drugs can also increase the risk of a form of herpes zoster (the virus that also causes shingles) affecting the eyes. The effects of this are redness and pain in and around the eyes. Myeloma patients are not vaccinated against shingles (herpes zoster) because the vaccine used is "live", and should not be used when a patient's immune system is weakened. However, it is important for close contacts of myeloma patients to be vaccinated against shingles. To minimise any risk of infection being picked up from the live vaccine, any blisters forming at the vaccination site should be covered up.

Direct effects of myeloma on the eyes

In some cases, myeloma itself can cause changes in vision due to an increased thickness of the blood supplying the eye. This is known as hyperviscosity and is due to paraprotein in the blood. However, this is only likely to happen when paraprotein levels are extremely high and myeloma is active. In rare cases, the paraprotein can deposit in the eye itself and cause symptoms.

Other co-existing medical issues

You may have other medical issues that increase the risk of eye problems, alongside your myeloma. This could include diabetes, high blood pressure and thyroid issues, or cataracts.

If you have any of these medical issues, you may be at greater risk of eye complications caused by myeloma and its treatment.

What should myeloma patients do?

Although eye complications in myeloma are rare, they can occur, so it's important not to neglect any eye symptoms you notice and get them checked out by your healthcare team (haematologist or clinical nurse specialist). You should make sure you are getting regular checks at the optician, and that they are aware that you have myeloma. Your healthcare team may want to refer you to an ophthalmologist (hospital eye specialist) if you have specific eye problems.

If you have any co-existing eye problems such as cataracts or diabetic retinopathy, you should make sure these are being checked regularly as well, as your myeloma or its treatment may worsen them.

To find out more:

Speak to your **healthcare team** who can advise you on your individual situation

Read **information** from Myeloma UK, including Treatment Guides covering the different drugs used to treat myeloma, and Infosheets on Vaccines in myeloma and Infections in myeloma

Call the **Myeloma Infoline** on 0800 980 3332

DRUG ADMINISTRATION

BY CAROLINE DONOGHUE

Patients are often on a multitude of different drugs for their myeloma treatment, which can leave them wondering why some drugs are given a certain way and why others aren't. Here, we look at the answer to this and uncover why the way drugs are given makes such a difference and how this can change.

What is drug administration?

Drug administration refers to the instructions for how a drug is given to patients. This includes the size of the dose, method of administration and dosing schedule (e.g. daily, weekly).

These specific instructions are shaped by the results of the clinical research carried out during drug development. They are also influenced by the chemistry of the drug itself and our biology.

What can be affected by drug administration?

The way in which drugs are administered affects a variety of factors.

Drug efficacy

For a drug to be effective it needs to enter the bloodstream in sufficient amounts to have an effect and kill cancer cells. How a drug is administered will affect whether it is able to do this. For example, some drugs are broken down by stomach acid, thereby losing their activity, while others pass straight through the digestive system and aren't absorbed into the blood. In these cases, the drugs cannot be given orally. Other drugs don't last very long in our bloodstream so need to be given more regularly to be effective.

Number of side effects

High doses of drugs are more likely to cause side effects than low doses. Giving a lower dose more regularly or administering a drug over a longer time can deliver the same effect but reduce side effects.

Patient experience and quality of life

Having a drug which is given frequently in clinic means multiple hospital visits for patients with increased transport costs and a greater impact on everyday life. Therefore, changes to scheduling or the administration method can improve the quality of life of patients and family members.

Healthcare services

Some drugs can only be administered by healthcare professionals in a clinic and some take longer to administer than others. This can mean the method of administration and dosing schedule can have an impact on hospital resources.

How can drugs be administered?



Intravenous infusion
(Into a vein)

Pros	Delivery directly into the blood stream
Cons	Takes a long time to administer
	Has to be given in a hospital
	Risk of infection at the entry point



Subcutaneous injection
(Under the skin)

Pros	Faster administration
	Could be administered at home
Cons	Risk of infection at the entry point



Oral
(By mouth)

Pros	Can be administered at home
Cons	Not all drugs suitable for oral dosing
	Relies on patient adherence



Changes in drug administration and anti-myeloma treatments

After a drug is approved for use, drug manufacturers don't stop developing it. Research teams are continually looking for ways to improve the action and safety of drugs. One way to do this is by making changes to drug administration.

For a change in administration to be adopted into use, it has to be researched thoroughly and investigated in a clinical trial before being evaluated by the appropriate appraisal bodies.

Several anti-myeloma drugs have either had a change in drug administration or are in the process of changing drug administration.

Bortezomib (Velcade®)

Reduced side effects

Bortezomib was the first myeloma drug to benefit from a change to administration. When it was approved for use in 2007, it was administered by intravenous (into the vein) injection. However, today it is typically administered by subcutaneous (under the skin) injection. The change was made after research evidence showed subcutaneous injection reduced the frequency and severity of peripheral neuropathy, whilst remaining as effective against myeloma as intravenous injections.

This change in administration route has also opened up the possibility of home administration, with preliminary research into home administration showing promising results.

Carfilzomib (Kyprolis®)

Improved efficacy

This year, a new once-weekly dosing option for carfilzomib was approved by the Food and Drug Administration (FDA) in the US.

The approval was based on the results from clinical research which compared once-weekly carfilzomib to the standard twice-weekly carfilzomib. The results showed that the new once-weekly dosing schedule improved overall response rate and progression-free survival (the length of time following treatment before the myeloma starts to come back) compared to the standard dosing.

The researchers also found that even although the administration time for the once-weekly dosing schedule was longer than the twice-weekly dosing schedule it had higher scores for patient satisfaction and convenience.

This dosing schedule is currently under consideration in Europe.

Daratumumab (Darzalex®)

Better patient experience

Daratumumab based treatments have shown efficacy for myeloma, but the drug can take between three and seven hours to administer. To lessen the treatment burden on patients, a new subcutaneous version of daratumumab has been developed with the aim of shortening administration time from hours to minutes.

Clinical research has shown that the new subcutaneous daratumumab is faster to administer with similar efficacy to the standard intravenous daratumumab. Patients receiving the subcutaneous daratumumab also had fewer side effects, fewer infusion-related reactions and higher patient satisfaction scores.

This new administration route is currently under consideration in the US and Europe.

Summary

Making changes to how and when a drug is given can result in reduced side effects, higher patient satisfaction and even improved effectiveness. It is encouraging to know that research continues to look for ways to improve available drugs to deliver the best results for patients.

My myeloma story



Fran Laws is 68 years old, lives in Sheffield and is married to John. John was initially diagnosed in 2006 with plasmacytomas in his spine that progressed to myeloma. He had a stem cell transplant in 2008 and has been treatment free for the last 11 and a half years. This is Fran's story.

Before diagnosis, John suffered from severe back pain. We saw an orthopaedic surgeon who I worked with before his diagnosis. At the appointment, I completely went to pieces when we were told he had myeloma. A nurse took me into another room and told me I needed to be strong for my husband. John remained very calm and said to the surgeon, "Well, what are you going to do about it?"

When I returned to the room, we were given the chance to hear what would happen next. I felt as if my stomach had dropped and I thought I was going to be sick. Shock does not help you understand what you are being told. Afterwards, you try to replay the conversation back, but recalling information is hard, plus you are hearing medical terms that are unfamiliar.

Plasmacytoma was diagnosed after the first of two major operations and we were told this would eventually progress to myeloma.

It takes time to come to terms with this new knowledge and take onboard what is happening. To be honest, I did find it overwhelming and rather scary at first. As time has passed, the harsh edges around the diagnosis have become smoother. I feel calmer now and more able to try and carry on with a "normal" lifestyle.

After John was discharged from hospital, I was off work for nine



weeks. He was unable do anything for himself, especially the everyday things (i.e. dressing, washing, etc). He still can't lift or carry heavy items, the shopping or suitcases due to permanent nerve damage. Consequently, I do all the moving and handling. However, he has slowly got better over time.

"As time has passed, the harsh edges around the diagnosis have become smoother."

We moved into an apartment five years ago, so everything is now on one level and smaller than the three bedroom detached house we once lived in. Before retiring in 2011, I was working full time and doing all the cleaning and gardening. We had the bath removed in the apartment, as John could not get out of the bath. By replacing this with a walk-in shower and fitting grab handles, we have made life easier for us both.

We exchanged the car for an automatic, as John found it difficult to change the gears and use the clutch due to his nerve damage. We chose a higher ride level car as getting in and out of the car had also become difficult for John.

I do see myself as a carer but try to let John be as independent as possible. I always walk on his right side to prevent people bumping into him. I am constantly watching him when we are out socially, and we often leave early as sitting for long periods is uncomfortable for him.



John always knows how I feel about his illness. Lately, I am the one who gets upset when we get blood results from the hospital that show the myeloma slowly returning. I try to put it to the back of my mind and carry on as normal as possible. At difficult times, I try hard to be positive and keep upbeat. John has always had a very positive attitude and refuses to let it get him down.

I'm sure most carers feel the situation has got to them at some point. We have all had a few tears in the shower or some quiet corner. Having a sense of humour and sometimes being sarcastic carries us through those bumpy patches.

Talking together about the future is difficult but necessary, especially if you are going back into treatment. I think being honest is the best policy. Pretending everything is fine, when it is obviously not, will not help either of us. The good thing is that we are not usually in a negative frame of mind at the same time. We lift each other into a more positive place.

One of the hardest things to deal with is how our future has changed. We planned to retire at the same time and do lots of travelling. Air travel is difficult and not an option now as the flights are uncomfortable and cramped and all the time spent at the airport is hard for us both. On one occasion, I had to get cases off the belt and pull them by myself. I thought maybe people were looking at us and thinking, "Why is your husband not helping you?"

> **"Talking together about the future is difficult but necessary, especially if you are going back into treatment."**

Our social life has suffered too. We do more things during the day as John feels better first thing. Theatres and cinemas (unless they have large comfy seats) are all out of the question. In the evening, I spend a good deal of time on my own. As the day progresses, John's pain increases, and bed becomes the only solution.

I feel I have lost a companion for cosy TV evenings and visits to the theatre with a nice meal and glass of wine. We still make the very best of a life, even though it has completely changed since his diagnosis.

I have a few close friends that I can talk to when I find it hard to cope. Family are also aware of the situation. I find that some of them handle it much better than others. Some like to be kept in the loop, whilst others, for whatever reason, seem to shut it out.

I realised I needed to keep myself as fit and healthy as possible, to ensure I could carry on looking after John. I took over the gardening and with John's guidance some of the smaller DIY jobs; he is a very good teacher. Having joined Slimming World, I have lost three stone in weight and attend a keep fit class weekly. I am a health walk leader at a local walking group that I joined when I retired. In the last year, I have taken up yoga (I am not very good at it) and enjoy the classes.

We have attended two Myeloma UK Infodays that were full of useful information. It is always helpful to meet up with other carers and the people they look after.

To relax, I read a lot. I enjoy cooking and entertaining and putting on get-togethers with our neighbours. They all understand John's condition, so the atmosphere is very relaxed and if John needs to go to bed, no one is worried.

ASK THE NURSE

Ellen Watters, Kim Dolman and Sarah Dempsey **Myeloma Information Specialists, Myeloma UK**

In our first Myeloma UK Facebook Live on 15 October, our Myeloma Information Specialists discussed how myeloma can affect your working life. Here, we follow up with a few of the questions they were asked. Watch the full video on our Facebook page to find out more.

How do I know if I'm physically ready to return to work?

Returning to work after an extended period of time can be quite daunting for anyone, especially after extensive anti-myeloma treatment. Everyone will be different; some patients will be quite keen to get back to work whilst others will still be weighing up their options and deciding what is best for them and their families.

As a myeloma patient, even during periods of remission or stable disease, you will be more susceptible to infections than the general population. This is especially so after high-dose therapy and stem cell transplantation. Therefore, patients need to take this into consideration when deciding when to return to work. Often patients find it helpful to speak to their doctor (haematologist) or clinical nurse specialist about their desire to return to work, as your healthcare team will be able to provide specific insight into your health at that time.

Should I talk to my employer?

When making the decision to return to work, an in-depth conversation with your employer about how you are feeling both physically and emotionally can be the best place to start. You could talk to your line manager, human resources (HR) department or occupational health department. This can help you get the support you need at work.

If you feel nervous, you could take someone with you for support. It may also help to make a list of the things you want to talk about and keep notes of the discussions for reference. Being informed about your myeloma and its management can help to support your discussions, and having regular contact/meetings with your manager can keep them up to date and aware of your situation.

You are protected by law under the Equality Act, so employers must make reasonable adjustments to support your return to work. This may include things like a phased return, changes to your working pattern, adjustments to your role or responsibilities, practical adjustments to your work space, time off for hospital appointments, or introducing flexible working arrangements.

Should I tell my colleagues about my diagnosis?

It is entirely your choice whether you tell your colleagues about your diagnosis, but often they can be supportive and offer a listening ear.

You may wish to confide in one or two of your colleagues, particularly as they may notice changes in your behaviour or appearance, for example if you are feeling particularly anxious or if you have changed weight or height.

It will also help them understand why there will be times when you need to take particular care in avoiding those with obvious signs of coughs and colds if your immune system is particularly low, especially when on treatment.

Whether or not you decide to confide in any of your colleagues, HR and occupational health will maintain confidentiality.

SOME PRACTICAL ADVICE ABOUT RETURNING TO WORK:

- Be prepared to be flexible
- Actively engage in good communication with your employer
- Build up your physical and emotional wellbeing and give yourself time to rest and recover
- Seek further support and advise about your situation – from your medial team, Macmillan, the Government Access to Work programme

If you would like to find out more, visit our Facebook page, call the **Myeloma Infoline** on **0800 980 3332** or email **askthenurse@myeloma.org.uk**

SUPPORTER STORIES

My name is Denis Cairns, I'm 66 years old and I abseiled off the Forth Rail Bridge for Myeloma UK.

I retired from teaching in 2013 having spent my entire career (37 years!) at Pitlochry High School. My wife, Euna, and I have just celebrated our 43rd wedding anniversary and we live in Birnam, Dunkeld. Our son, Dan, lives in Japan with his wife, Yuri.

I was diagnosed with myeloma in September 2015 and underwent a stem cell transplant in May the following year. The care I received in Ninewells Hospital in Dundee was exceptional and the transplant was a success. I even managed to win the gents doubles at my tennis club less than three months after I was discharged!

Following my diagnosis, as is the case for everyone with myeloma, I was a little bit shocked. However, the Haematology Department and Ward 34 helped put my mind at rest and discussed the possible treatment options with me. I also looked on the internet and came across the Myeloma UK website; this was a great source of information. I found the video clips particularly useful as they managed to cover all the areas of concern that new patients experience. It was also very reassuring for my son to look at these resources, as he, like the rest of us, had no idea about myeloma.

I became aware of a local Support Group through a friend who had been diagnosed several years earlier. She helps to run the Perth Myeloma Support Group. To be honest, I was initially hesitant to attend meetings as I saw my condition as a very private affair. However, I soon discovered how supportive the Group was. They provided the space to chat with fellow sufferers and opportunities to hear from a range of visiting speakers. I would recommend that anyone with a recent diagnosis go along to their local Support Group. It is incredibly reassuring to know that you're not the only one facing this disease.

At one such meeting in 2018, the perennial issue of fundraising came up. Various possibilities were put forward and my friend Linda mentioned that her daughter and son-in-law had abseiled off the Forth Rail Bridge in the previous year for Myeloma UK. I didn't say anything at the time, but I thought to myself, 'I'm well enough', and fortunately, though not an adrenalin junkie, heights don't seem to bother me. I decided to run it past my wife and GP just in case either of them freaked out, but they were both very supportive. However, they agreed that they thought I was nuts!

Once registered for the abseil, I set about fundraising. The level of support I received from friends and family was truly touching. Being of a certain age, I don't do social media, but my son put it out and soon donations were pouring in from all directions.

> **"The level of support I received from friends and family was truly touching."**

My former colleagues and pupils from Pitlochry were fantastic and I mercilessly hounded the members of the tennis club. I must mention two donations in particular. The Fairtrade Committee at Pitlochry High School presented me with a significant donation, on top of individual staff contributions. The other demonstration of the wonderful generosity I received came from my friend Michelle whose 60th birthday



was fast approaching before the abseil. Rather than guests bringing gifts to her big party, she asked them to donate to my JustGiving page instead.

When I first set up my JustGiving page, I had set a rather tentative target of £500. By the end of August, I had managed to pass the £3,000 mark. A huge thank you goes out to everyone for their generosity and support.

The abseil itself was an absolute blast and I would do it again in a heartbeat. It's only a pity that my wife hadn't figured out how to work the video on her phone before I started!

The organisation and professionalism of the staff on the day was fantastic, and I would recommend it to anyone. Not only are you perfectly safe at all times, you also have bragging rights for the foreseeable future.

While stepping off a bridge into a drop of 165 feet may not be to everybody's taste, you'd be surprised what you are capable of. Having survived a transplant, anything else is a breeze.

Whatever activity you choose as a fundraiser for Myeloma UK, I would suggest that you open a JustGiving page. If in doubt, get help to set it up. Thankfully, it tends to look after itself thereafter.

Personally, I will probably have to leave it for a couple of years before I start going around again looking for sponsors. Maybe a tandem parachute jump? I think my wife and GP will need some persuading for that one!

Festive Fundraising

We'd love for you to organise or take part in an event to help raise vital funds for Myeloma UK this festive season.



You could organise a Christmas jumper day, cake or craft sale, concert or a festive collection. Or why not take part in a Santa Run or Boxing Day Dip?

Remember when you're Christmas shopping, don't forget to sign up for Give As You Live before shopping online: **myeloma.org.uk/giveasyoulive**

Tell us about your event and request your fundraising pack at myeloma.org.uk/fundraisingevent or call 0131 557 3332

Myeloma Stars Christmas Appeal

Who's your star?

This festive season we offer you a sparkling opportunity to celebrate someone special in your life and help support the vital work of Myeloma UK.

Visit our stunning new webpage, make a donation and dedicate a star to someone who means a lot to you in our glittering night sky. Leave a special message and upload a photograph in recognition of this brilliant person.

Share your dedication with family and friends to spread the love and help raise awareness.

Dedicate your star now!

Visit **MyelomaStars.com**

MyelomaUK

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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