AUTUMN/WINTER 2020

myeloma Matters



Spotlight On
Treatment choice

My life with myeloma
Steve Hardy

Research Focus
CRISPR

My myeloma story
Dannielle Collis

MyelomaUK

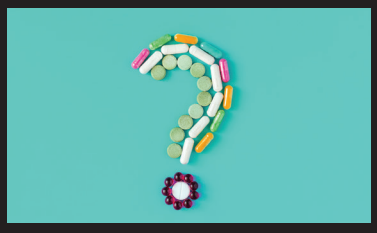
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Alice Baron



Sandra Quinn

DEAR READER

Alice Baron
Myeloma Matters Co-Editor

Welcome to the Autumn/Winter edition of Myeloma Matters.

After a very challenging year, it can be encouraging to look back and think about the people who have made a difference during this difficult time. I'd like to highlight our Myeloma Stars Christmas Appeal, which provides the opportunity to celebrate those people who made a difference. This appeal allows you to dedicate a virtual star in honour of the special people in your life or to commemorate the lives of those who have passed away. Whoever it is that stands out to you, you can dedicate a star to them on our website and spread light and love this Christmas. You can find out more and visit our night sky at myelomastars.com.

Although COVID-19 has dominated the year, 2020 was also the year that the Nobel Prize for Chemistry was won by two women for the first time. In recognition of this achievement, this edition features an article on CRISPR, the scientific breakthrough for which the award was given to Dr Emmanuelle Charpentier and Dr Jennifer Doudna, and outlines its potential applications in myeloma.

In our Supporter Stories, Andy Hamilton shares a wonderful testament to his late friend Barbara Stonehouse, and Steve Hardy and Dannielle Collis share how their lives are affected by myeloma.

There's also information on how Myeloma UK are supporting GPs in diagnosing myeloma and how you can get involved in shaping our work.

Finally, a huge thank you goes to everyone who has supported us this year. Your support enables us to continue working for all myeloma patients, their families and friends, at a time where help and support has been more vital than ever.

We wish you a lovely festive period and a happy new year.

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MYELOMA RESEARCH NEWS FROM AROUND THE WORLD

CAR-T cell therapy could be a reality for myeloma patients

A new treatment, Idecabtagene vicluecel (ide-cel), previously known as bb2121, is set to become the first CAR-T cell therapy licensed for the treatment of relapsed and refractory myeloma.

The manufacturers, Bristol Myers Squibb and Bluebird Bio, have submitted applications to the Food and Drug Association (FDA) and the European Medicines Association (EMA) to market the treatment in the US and Europe.

Following the submission to the EMA, the National Institute of Health and Care Excellence (NICE) initiated a technology appraisal to assess whether the treatment would be made available through the NHS if the treatment is licenced for use in Europe.

As part of the submission, the health approval bodies will review the results from the phase II KarMMa clinical trial which looked at the safety and effectiveness of ide-cel in 128 relapsed and refractory myeloma patients who had received at least three lines of treatment. The results showed that ide-cel was effective with 73% of patients responding to the treatment. The median progression-free survival (the length of time following treatment before myeloma starts to come back) was 8.6 months. The side effects were considered manageable. Reductions of blood cells and cytokine release syndrome were the most common side effects.

New clinical trial aiming to improve outcomes for older, less fit myeloma patients opens in the UK

A new phase III clinical trial (Myeloma XVI: FiTNEss) aiming to recruit 740 newly diagnosed myeloma patients from around 90 UK hospitals has opened for recruitment in the UK. The trial aims to improve the remission time and life expectancy of older, less fit, newly diagnosed myeloma patients who are not eligible for high-dose therapy and stem cell transplantation.

It will evaluate the effectiveness of a new triplet combination, ixazomib (Ninlaro®), lenalidomide (Revlimid®) and dexamethasone, and will explore the use of tailored dosing based on the overall fitness and general health of the patients. It is hoped this will enable researchers to identify the patients who are more likely to stop treatment early due to side effects so they can have their treatment adjusted in advance.

Do myeloma patients diagnosed through A&E have more aggressive myeloma?

UK researchers working on a project to prevent severe complications and early mortality in myeloma have discovered that the high level of symptoms and complications (disease severity) in patients diagnosed through emergency routes (e.g. A&E) may be associated with more aggressive forms of myeloma rather than a delayed diagnosis.

The study, which included data from 915 patients, is the most comprehensive analysis of diagnostic routes in myeloma to date. It looked at the relationship between the route to diagnosis, the disease severity and time to diagnosis.

The researchers found that, whilst patients diagnosed through emergency routes tended to have poorer overall health and higher levels of organ damage, there was no difference in the overall length of time to diagnosis compared to those diagnosed by GP referral to haematology.

This data suggests that a multi-faceted approach is required to improve myeloma diagnosis with programmes investing in both screening methodologies and symptom awareness.

Knowledge sharing improves myeloma patient access to whole-body MRI

In 2016, the National Institute of Health and Care Excellence (NICE) identified whole body MRI (WB-MRI) as the preferred imaging method for all patients with suspected myeloma. However, a survey of UK myeloma treatment centres revealed that skeletal survey was the most used imaging method for patients with suspected myeloma. One of the main challenges to WB MRI access was radiologist training. To resolve this, a team of clinicians from the Royal Marsden, Surrey, initiated a programme of knowledge sharing to increase patient access to WB-MRI. The team has provided several training sessions and shared their knowledge and expertise via international journals and conferences. Their work has seen the number of radiographers offering a WB-MRI service rise from 52% to 64%.

MY LIFE WITH **MYELOMA**

NAME: Steve Hardy

LOCATION: Swansea

AGE: 70

Like most people of a certain age, I will always remember where I was when JFK was assassinated. I was 13 years old and an angelic choir boy at the time (well, maybe not so angelic) and had just returned home from choir practice. Like that 13 year old boy, I will always remember where I was when I was told that there may be a 'problem' with my blood test results.

It was January 2015 and I was driving home from a meeting in Derby and was just approaching Monmouth when my phone went off (hands free of course). A voice said, "Hello, Mr Hardy? I'd like to book you an appointment to see me please, as I have a slight concern about your latest blood test results." On pressing her, she elaborated and said "your paraprotein levels are rather high, which might suggest a blood cancer called multiple myeloma".

> **My GP referred me to the Haematology Department at Singleton Hospital where my cancer diagnosis was confirmed.**

Without really thinking about what she was actually saying I replied, "Oh, OK". It wasn't until the call ended that I began to take it in. I stopped at the next service station and started to think about the consequences of this possible diagnosis: Am I going to die? What about my wife and family? What do I tell them? What will the treatment be? I'm sure these questions will be familiar to those of you who have received the same news. On calling my wife, she was reassuring and said "we'll deal with it"; that was just what I needed to hear. In a state of shock, I travelled the remaining 70 miles or so back to Swansea and thought about all the other questions that needed answers.

My GP referred me to the Haematology Department at Singleton Hospital where my cancer diagnosis was confirmed. I have to say that the time between my GP's first suspicions and the start of my treatment was phenomenally short; I started my chemotherapy in the Spring. As I worked next door to the hospital, I naively planned to pop out from work for my weekly injections and then return to work. After all, it was only a ten minute walk from my office to the ward. Unfortunately, that thought was very short lived as I quickly lost my energy levels during treatment. I was able to work from home for a few months but went off on sick leave late Summer 2015 and finally retired in Spring the following year.

I started to feel sharp pains in my feet mid-way through the chemotherapy. The peripheral neuropathy I was experiencing changed from pain to a general sensitivity in my feet.

At every visit to the hospital the same question was asked "do you have difficulty buttoning up your shirt?" For a long time I was able to say "not really", but this changed as my peripheral neuropathy extended to my fingers. I still have peripheral neuropathy, but it is managed with tablets.

In September 2015, after six months of daily thalidomide capsules and weekly injections, I went to the University of Wales Hospital in Cardiff to have my stem cells harvested.

I'm sure many of you will know that you have to sit perfectly still for what seems like an eternity. The nurse in charge of the dialysis told me that if I needed to go to the loo she would help me. Since both my hands were hooked up to the dialysis machine and could not be moved, I didn't drink all day to avoid the embarrassment.

> **I found the whole experience extremely harrowing.**

I moved into one of two isolation rooms at Singleton Hospital for my stem cell transplant in late October 2015; this was preceded by a dose of chemotherapy. Until this time, my hair had not been affected, but it fell out two to three days after this dose, which just goes to show how large it was and the poisonous effect it had on my body.



I found the whole experience extremely harrowing. Please don't get me wrong, all the staff were amazing and very supportive, but it was a very small room with a noisy extractor fan. I lost my appetite and had great difficulty eating or drinking anything, which clearly didn't aid my recovery. I had regular bouts of sickness and diarrhoea, which didn't help either.

> **"In spite of feeling very poorly, it was generally rewarding to keep in touch with the outside world."**

However, I know that every patient is different and I don't want to put anyone off. The important thing is that I soon began to recover and felt much stronger by Spring 2016.

Several things kept me going whilst in isolation. Top of the list was the daily visits from my wife, although I regret to say I wasn't always good company. Although I know how stressful and tiring it must have been for her to visit me in hospital every day and, at the same time, organise her life around those visits, she was always cheerful. It was also nice to see my dog in the car park from my window. I say "my dog", but he's actually a mummy's boy. My three children also visited me in hospital and although I wasn't very talkative, it was uplifting. I also tried to keep in touch with close friends and colleagues through emails and texts. In spite of feeling very poorly, it was generally rewarding to keep in touch with the outside world.

The recovery process was quite long. Eating continued to be a problem and the taste of metal cutlery didn't help. One useful bit of advice I received was to use plastic cutlery. My hair began to grow back curly. Previously, my hair had always been totally straight and this new style provided a good talking point. In fact, someone commented that I resembled Roger Daltrey to which I replied "Who?". Unfortunately, my curls were gone after my next haircut.

I relapsed almost three years to the day that my first treatment started. Naturally, I was disappointed, but who wouldn't be? It followed exactly the same path as before with a second HDT-SCT in late October 2018. However, I am now on a clinical trial and so far the results are very good. My myeloma has been in remission since and I remain positive.

I've always led a fairly active life but I can only work for so long before I need to rest as I become physically, mentally and emotionally fatigued. I also experience 'chemo brain' and difficulties with short-term memory that hasn't improved over time; much to the annoyance of the people around me. I would blame it on old age, but I know it is more than that. It is really frustrating forgetting people's names, what I need to buy at the shops or get from another room. Let's not forget the leg cramps too. I'm not sure what causes it but it really is a painful experience, which happens on average once or twice a week and generally during the night. The only way to shift it is to get up and move around; trying not to wake up my wife in the process.

As far as work is concerned, I felt cheated out of my retirement plans as I wasn't ready to to do so.



Before the diagnosis, I was making plans to work two days a week but that decision was taken away from me. There wasn't time to adjust and being at home 24/7 is not easy. I regularly get under my wife's feet and it puts a strain on any relationship. One relies heavily on their partner for care and support and that can be very demanding on them. It also makes me feel frustrated and sometimes inadequate. I also feel angry at times.

There is no doubt that having myeloma has changed me. In many ways, I am a very different person. My behaviours are very similar to those that my Mum showed when she developed dementia. Like her, I don't always recognise them and it has to be pointed out to me. I know I am not that easy to live with and that must be difficult for my wife and family. At first, I didn't want to meet people and became very self-conscious and anxious about a number of things. Having to explain that my physical appearance was not representative of how I felt inside was such a mountain that it was easier to avoid contact. I invariably stayed in the car on our supermarket excursions. I did think that one solution might be to carry a sign saying 'please don't talk to me', but staying in the car was the easier option.

> **"There is no doubt that having myeloma has changed me. In many ways, I am a very different person."**

I recently saw a sign outside our local Baptist church that said 'Google can't satisfy every search'. Yes, there is always that question 'when will my cancer return?' in the back of your mind, but even Alexa can't tell me when that will be.

I do believe that faith is important. I am not afraid of dying because I believe that death is not the absolute end.



There is something beyond death, but I don't know what to expect. At the same time, it is essential to enjoy life to the best of one's ability and not dwell on such things. It is important to remember that it is the people who are left behind that are most affected, and try as much as possible to leave them with good memories.

However, for those of you affected by myeloma, new treatments are appearing all the time and I remain very positive that they can keep this condition under control.

I can't finish my story without acknowledging the tremendous help and support that I received along the way. Firstly, my wife and family have been a great support and although it has not always been easy for them I know I couldn't have done it without them. The staff in the Haematology Department and the Isolation Unit at Singleton Hospital have been amazing. I cannot thank the teams enough for the care and dedication they have shown me. I have also had tremendous support from the Macmillan Cancer Support Team, Maggie's, the Ty Olwyn Pain Relief Team and the Cancer Information Support Services. I feel that I am very lucky to have all of this support, which is freely available for those 'living with cancer' and the people around them. I am also lucky to have a number of close friends who have supported me during this difficult time. From the bottom of my heart, thank you to everyone.

SPOTLIGHT
ON TREATMENT CHOICE

“I want the best possible treatment to lengthen my life but I do believe quality of life has to be taken into consideration, not just for myself but for my husband and family.”



INTRODUCTION
TREATMENT CHOICE



"Which treatment should I have?" is a common question on our Myeloma Infoline. Questions around clinical trial results and drug effectiveness are asked alongside practical considerations like trips to the hospital and potential side effects.

It can seem like an overwhelming decision to make, with added factors to consider during the COVID-19 pandemic.

Although the pandemic has added to the list of considerations, it's still vital when choosing which treatment to have to think about your preferences and needs. These needs are balanced with risks and benefits of the options.

Crucially, you should discuss your options with your healthcare team, and communicating with them openly and honestly is essential. They are there to support you and offer advice and guidance, but it's important for patients to be involved in these decisions. Ultimately, it's your health and your healthcare team want you to feel empowered and confident in the decisions made. Shared decision making is a key part of NHS care and aims to put you at the centre of your health and care.

During these discussions, your healthcare team will be thinking about you holistically and will try to understand what your priorities are. They'll consider how much support you have at home, whether or not you can get to hospital frequently, if you can cope with pain or nausea, and all the other factors that go along with treatment. Letting them know what you prefer, what's important to you and what you are more flexible on can help you both to choose the treatment that's right for you.

In this edition's Spotlight on, we consider both the patient's and the doctor's perspective when it comes to choosing treatment. On page 12 Dr Jaimal Kothari takes us through the various factors doctors consider when recommending treatments and on page 13 Dr Charlotte Pawlyn explains the role clinical trial data plays in practice.

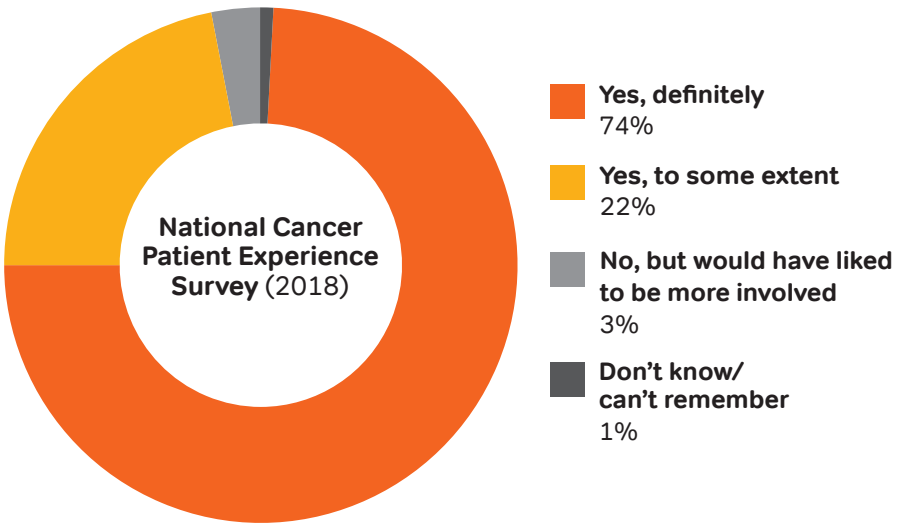
THE PATIENT **VIEW**

DID YOU **KNOW?**

In a study conducted by Myeloma UK, average survival, risk of severe side effects and treatment administration were considered the most important attributes to patients. However, the data indicated that patients value the attributes differently, and researchers identified two distinct patient groups. Group 1 focused on average survival and mild to moderate side effects, whilst group 2 placed more importance on out of pocket costs and the mode and frequency of treatment. Those living with others and those diagnosed in the last five years were more likely to be in group 1. Patients who had been on treatment for longer were more likely to be in group 2.

Myeloma is a relatively rare and complex cancer and choosing the right treatment can sometimes be challenging for doctors as well as patients. Patients can ask for a second opinion if they want to be sure their treatment plan is appropriate for their situation and that all other options have been considered. Doctors are usually happy to arrange this; however, you may find it easier to approach your GP about it.

Were you involved as much as you wanted to be in decisions about your care and treatment?



Top 5 factors to consider

1 Mode of treatment

2 Frequency of treatment

3 Side effects

4 Support needs

5 Out of pocket costs

THE DOCTOR **VIEW**

By Dr Jaimal Kothari, Consultant Haematologist,
Oxford University Hospitals NHS Trust

Before deciding what treatment to start you on, your healthcare team will look at some key factors.

The type of myeloma you have

We have learnt that myeloma does not behave in a uniform way. Although the average length of time that someone lives from starting treatment is 5–7 years, every patient is unique and can have different responses to treatment, and 30–40% of all patients will live for more than 10 years.

The underlying genetics of your myeloma partly determine how it behaves and how difficult it is to control. Your consultant may decide to recommend a particular class of chemotherapy as a result of the genetics. It may also determine whether you are treated with a three drug combination or a two drug combination.

Your age and fitness

In all healthcare decisions, health and fitness are crucial cogs. Myeloma is generally a disease of the elderly, and most of our patients will have at least one or two other concurrent medical conditions. These have to be taken into account as it has been shown over many years that treatment is tolerated less well by the older and the infirm – they tend to get more side effects from treatment, and therefore have more interruptions. This often means that the treatment is not as effective. There are also specific combinations of drugs that are used for patients who are suitable and are likely to proceed to autologous stem cell transplant (ASCT). To be suitable for ASCT, patients are generally under 70-75 years old and in good physical health.

Negotiating the NHS algorithm

The increasing number of effective treatments that have become available over the last few years has been fantastic to see, but it has made decision making more complex. Certain drugs and combinations are only available at certain time points – e.g. can be used for second line treatment only, if certain pre-requisites are met. This means that clinicians are often having to think ahead, what gives me the best options for this patient at various time points in their illness. This is a complex and inexact science for a number of reasons – each year options change and other factors may impact your health meaning that a proposed future treatment becomes unviable. However, what your team will always strive to do is keep as many options open for you at each time point, without compromising the actual treatment that you may be due to start imminently.

> **“It can often be a delicate balancing act”**

Clinical trials

The potential availability of clinical trials in your hospital will be a crucial factor in determining what treatment is recommended for you. It may well be that an open trial for your myeloma (e.g. a new combination of drugs, where a fourth newer drug is added to an existing well-known combination of three drugs) allows you to potentially gain the benefit of a combination that may not become routinely available for years. However, trials have risks as well as potential benefits, and sometimes new drugs can cause problems that are not known of before. The key thing is, whenever you are due to start a new line of treatment, ask your consultant if there is a clinical trial available for you either in your home hospital or a bigger hospital nearby.

Each trial will have detailed information for you to read so that before you decide to consent and take part you have a good understanding of the pros and cons.

What happens at relapse

At different points in your journey with myeloma, newer/alternative treatments may become available, as has happened with regularity over the last few years. These newer treatments all have overlapping toxicities (side effects) and these need to be taken into consideration when planning subsequent treatments. Unfortunately, in some circumstances, people pick up cumulative toxicities from prior treatments (e.g. neuropathy) and they may also get affected by other health concerns. This may make it more complex in planning and delivering treatment, and this will require careful discussion with your treating team. Later treatments (e.g. 3rd, 4th, 5th line) tend to work less well than earlier ones, and for that reason trying to maintain and maximise quality of life becomes even more important.

Patient preference

No one factor will take priority – it can often be a delicate balancing act, and can often require changing chemotherapy doses as cycles go on, and reviewing treatment goals as the weeks and months move on. What is absolutely crucial is that as a patient, your views and needs take centre stage when making

these decisions. It may well be that a particular type of treatment is recommended, but, for example, if you were very keen on having oral treatment only, that could be an option, but it may not be as effective (or it could be equally). You would hopefully have time to discuss the pros and cons of different options with your consultant.

The impact of COVID-19

It has been an enormously difficult year for patients and families. Decision making during the pandemic has been fraught with many uncertainties and has required trying to balance disease related factors (can we hold off treatment for now to reduce the risk of serious COVID-19 illness), treatment related factors (can we maintain disease control, but change/reduce doses) and patient related factors (are there additional non-myeloma reasons that a patient might be at increased risk of COVID-19). Then there has been shielding and the marked geographical differences in spread of COVID-19. As we move into 2021, the hope of further treatments and vaccines provide some cautious optimism, however, COVID-19 is having a significant impact on how patients are treated. Only over time will we better understand the impact of these COVID-19 related treatment decisions, but clinicians everywhere are trying to use the most up-to-date data to allow optimal treatment decisions, while minimising risk.

Summary

The landscape for myeloma treatments continues to evolve. Decision making is an inexact science and disease factors, patient factors and availability of treatments all interact. The aim is to provide the best, bespoke treatment for you at any point in time, and we hope that you get the time to discuss all of this with your treating team when you need to – as you, the patient should always be at the heart of the decision-making process.

What role does trial data play in practice?

By Dr Charlotte Pawlyn, Haematology Consultant, The Royal Marsden Hosptial NHS Foundation Trust

Clinical trials are essential for the evaluation of new treatments or new combinations of existing treatments to treat myeloma. Trial data is used by regulatory bodies such as the European Medicine Agency (EMA) to decide whether to license a treatment and by bodies such as The National Institute for Health and Care Excellence (NICE) who analyse the cost-effectiveness leading to funding decisions. Haematologists also use trial data to help advise patients on the most appropriate treatment at a given point in their disease.

Randomised trials (comparing one medicine or combination to another decided by the toss of a coin) are the only way to get a completely unbiased comparison of treatments in a large group of patients. However, the interpretation of trial results for an individual patient in the clinic is more challenging. This is for a number of reasons.

The choices of treatment available may not have been directly compared in a clinical trial. Sometimes inferences can be drawn between different trials but this is less reliable than a direct comparison.

Strict patient selection criteria are used in some clinical trials which can limit the applicability of the results to a broader range of patients. These criteria are often in place for good reasons, such as to ensure the safety of patients taking part but can lead to a relatively homogenous group of patients being treated within the trial. In the 'real-world' patients are all different and may have other illnesses or individual circumstances that make them somewhat different to the trial population. Data-sets of patient outcomes collected from the 'real-world' (outside of a clinical trial) can be used to compare treatments administered without patients having to have met trial entry criteria, but these analyses are limited by the lack of randomisation which leaves interpretation open to bias.

Trials usually measure disease remission times and overall survival as their outcomes. This may not always be the most important outcome for an individual patient who may be more concerned about the way in which a treatment is delivered or the possible side effects that may be encountered. The increasing use of patient reported outcome measures in clinical trials is going some way to address this by improving our understanding of the symptom and treatment burden experienced by patients in addition to the remission and survival times.

Outcome measures are often quoted as a 'median' value. This is the outcome that lies in the middle of all the outcomes experienced by patients in the trial. This means that there is an equal probability of an individual having a better or worse outcome than this median value. Predicting where an individual patient may lie on the spectrum of possible outcomes if they take the treatment is very difficult.

Optimal treatment decision making for a patient involves using trial information alongside clinical experience and individual patient factors in a collaborative discussion between patient and doctor. Trials remain essential, however, to identify new treatments and combinations for patients and often have the added benefit of giving patients access to new treatments before they are available more widely or funded by the NHS.

RESEARCH FOCUS

CRISPR: The key to a cure?

BY CAROLINE DONOGHUE

Senior Scientific Knowledge and Communications Officer, Myeloma UK



This year, the Nobel Prize for Chemistry was awarded to Emmanuelle Charpentier, Director of the Max Planck Unit for the Science of Pathogens, and Jennifer A Doudna, Professor of Biochemistry, Biophysics and Structural Biology at Berkley, for discovering a new way to modify DNA, known as CRISPR.

Since its discovery, CRISPR has generated a lot of excitement in both the research world and the media. It has been called a technological revolution and the greatest scientific development of our time. There have been claims of reviving extinct animals like dinosaurs and mammoths, eradicating mosquitos and even curing cancer. However, the actual potential of CRISPR is unknown with much of the research into its applications still at a very early stage.

What is CRISPR?

CRISPR, more formally known as CRISPR-Cas-9, is not a drug or treatment. Instead, it is a technique used by scientists and researchers to make very precise changes to DNA.

It is made from an enzyme that can cut and make changes to DNA and a guide molecule designed to recognise a distinct pattern or section of DNA.

Its discovery means scientists can make very precise changes to DNA cheaper and faster than ever before.

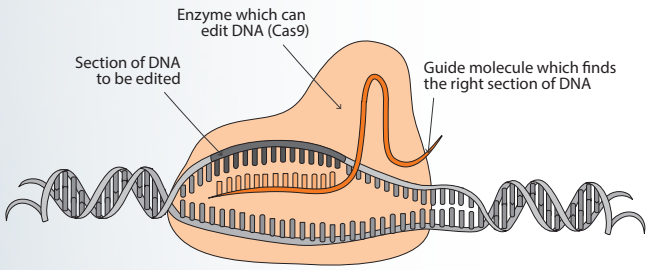


Figure 1. CRISPR is a technique that uses a guiding molecule and an enzyme to alter DNA

Therefore, CRISPR has the potential to fix faulty cells, change the way cells work and fully understand why some cells become dysfunctional and cause diseases like cancer.

DNA is the blueprint for life

DNA contains the biological instructions (genetic code) an organism needs to grow, live and reproduce. It is found in every cell and contains many different sections, known as genes, which control how the cell works. This is because each gene contains the genetic code to make a particular protein that has a specific function within the body.

There are many different types of protein (e.g. enzyme or antibody) with a variety of important roles in the body's cells, tissues and organs. Proteins can provide structure and support to a cell, control cell growth, act as a messenger or help to protect the body from viruses and bacteria. Therefore, by changing or editing genes in a cell, you can change how the cell functions.

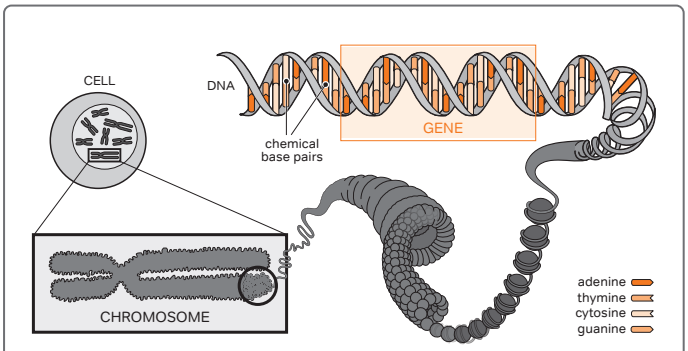


Figure 2. Genes are made up of DNA which is coiled up into chromosomes within cells

Could CRISPR cure cancer?

Many scientists believe that DNA holds the key to curing cancer. This is because cancer is caused by mutations in our DNA that make cells start growing and multiplying uncontrollably.

However, finding a cure for cancer is a very complex challenge. Cancer is not a single disease, so there is no one size fits all solution. Furthermore, cancers are typically caused by an accumulation of lots of DNA mutations inside cells, rather than a single, correctable fault.

Therefore, it is unlikely that CRISPR could be used to simply edit out the faulty gene or correct a cancer-causing mutation to prevent or cure cancer.

CRISPR, however, does have the potential to find new ways to treat cancer and even make new targeted treatments.

Changing our understanding of cancer

Working out which mutations or faulty genes are essential to cancer cell growth and survival is critical to understanding cancer and how to treat it. Although several cancer-causing mutations have been identified, there is still a lot we don't know.

CRISPR is helping researchers find out more about cancer cell biology by uncovering the relationship between specific mutations or faulty genes and the development of cancer.

Researchers are using the technique to change or delete mutations or faulty genes in cancer cells. By replacing faulty genes with the normal form of a gene, researchers can then identify whether the faulty gene is essential for the development of cancer and why. This means that treatments can be designed and tailored to block the action of the faulty gene and kill cancer cells.

Changing the world of immunotherapy

The most promising idea so far is to use CRISPR to make new immunotherapies (treatments that work with the patient's own immune system) like CAR-T cells.

CAR-T cells are made from a patients' own T cells (a type of immune cell). The T cells are taken from the patient and genetically modified (DNA edited), using CRISPR, so that they can identify and kill the cancer cells when given back to the patient.

By using CRISPR, researchers can not only make the required changes more quickly, they can also make multiple edits at the same time. This means they can add several new functions to the T cell at the same time.

However, as promising as this sounds, there is a lot of research that needs to be done before CRISPR-made treatments become a reality.

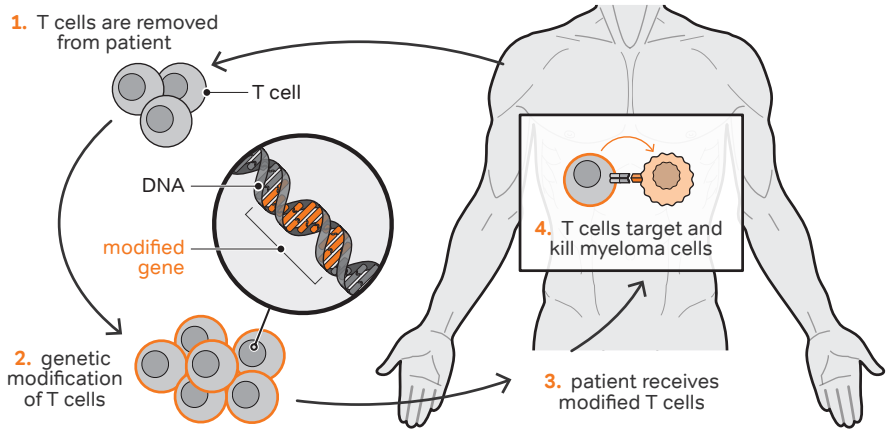


Figure 3. CAR-T cell treatment process

First, researchers need to make sure the correct edits are being made. Although more accurate than other gene editing techniques, CRISPR only knows where to cut by recognising specific patterns in our DNA. Our DNA contains so much information there is a chance the pattern appears more than once, so CRISPR could edit genes it isn't supposed to. If CRISPR makes unplanned edits the treatment won't work the way it was supposed to. This could mean the treatment isn't effective or has unwanted side effects. The edits also need to be reproducible so T cells that are edited in the same place in equal quantities every time.

Then they need to make sure the treatment is safe and effective. Every treatment needs to be tested in clinical trials. This is same for CRISPR made immunotherapies.

To date, there have only been a few, very small clinical trials testing CRISPR edited T cells for the treatment of cancer. One trial involved myeloma and sarcoma patients. The modified T cells used in the trial had been edited in two ways: to remove a protein receptor from the T cell so it doesn't get tricked into thinking cancer cells are healthy cells; to add a protein receptor to the T cells surface so it can identify cancer cells more easily.

The treatment was given to two myeloma patients and one sarcoma patient. The early results indicated that the toxic effects were manageable and that the modified cells were detected in the blood. No details of the effectiveness and/or side effect profile have been reported.

Conclusion

CRISPR is, undoubtably, an exciting discovery and could be the beginning of a new wave of cancer research and treatment. But, there is a long way to go before we find out if CRISPR will live up to the hype and deliver all that has been promised.

DID YOU KNOW?

CRISPR technology originates from bacteria

Some types of bacteria use the DNA editing enzymes as part of their 'immune system' helping to stop an invasion from viruses or other foreign organisms.

POLICY BRIEFING

UPDATE ON POTENTIAL NEW MYELOMA TREATMENTS

BY DANIEL CAIRNS

The year so far has been particularly busy for the myeloma access pipeline with five new myeloma treatments being appraised by both drug approval bodies, the National Institute for Healthcare Excellence (NICE) and the Scottish Medicines Consortium (SMC).

Isatuximab (Sarclisa®), pomalidomide (Imnovid®) and dexamethasone

The combination of isatuximab, pomalidomide and dexamethasone has been approved use through the NHS in England and Wales through the Cancer Drugs Fund. This treatment combination is available for myeloma patients who have received at least three previous lines of treatment including lenalidomide (Revlimid®) and a proteasome inhibitor (bortezomib (Velcade®), carfilzomib (Kyprolis®) or ixazomib (Ninlaro®)). Isatuximab has also been scheduled for appraisal at the SMC with Myeloma UK invited to submit a Patient Group Evidence Submission in November 2020. The Patient and Clinician Engagement (PACE) meeting and SMC committee meeting are still be scheduled.

Lenalidomide maintenance

Lenalidomide maintenance is currently being assessed for the treatment of newly diagnosed patients following high-dose therapy and stem cell transplantation (HDT-SCT). Many patients in the UK will have taken part in the Myeloma XI clinical trial for lenalidomide maintenance and we have been expecting this HTA for some time.

To help support our evidence submission to both NICE and the SMC, Myeloma UK conducted a patient treatment survey asking for patients' views on lenalidomide maintenance. There has been a fantastic response to this survey, which highlighted the positive benefits of lenalidomide maintenance and helped to inform our evidence submission. Unfortunately, NICE have issued a draft no recommendation for lenalidomide maintenance. The committee highlighted the clinical benefits of the maintenance treatment; however, uncertainty remained around the long-term economic projections for the treatment. Myeloma UK is currently working with NICE, NHS England and the pharmaceutical company, Celgene BMS, to resolve the issues and change this 'draft no' into an approval. For patient based in Scotland, lenalidomide maintenance has been approved by the SMC for use through NHS Scotland. It is available for patients who are eligible for HDT-SCT.

Carfilzomib, lenalidomide and dexamethasone

The combination of carfilzomib, lenalidomide and dexamethasone is being considered for patients who have received at least one previous treatment. Unfortunately, NICE have issued a draft no recommendation for carfilzomib, lenalidomide and dexamethasone. The committee agreed that this treatment delivered clinical benefit compared to current standard treatments. However, NICE considered that uncertainty remained about the long-term impact of this benefit, making cost effectiveness estimates uncertain. Myeloma UK is currently working with NICE, NHS England and the pharmaceutical company, AMGEN, to resolve the issues and change this 'draft no' into an approval. For patient based in Scotland, this carfilzomib combination has been approved by the SMC for use through the NHS. It is available for patients who have had one prior treatment.

Daratumumab (Darzalex®), bortezomib, thalidomide and dexamethasone

The quadruplet combination of daratumumab, bortezomib, thalidomide and dexamethasone is being considered as an induction treatment for newly diagnosed myeloma patients who are eligible for HDT-SCT. Myeloma UK submitted evidence for this appraisal in September 2020 with the NICE committee scheduled to take place in March 2021. Myeloma UK have also submitted evidence to the SMC in October 2020, with the PACE meeting scheduled for November 2020 and the SMC committee meeting still be to be scheduled.

Summary

The active HTA schedule is a welcome sign of the continuing advances in treatment in myeloma. We will continue to work with patients, their families and carers, and with clinicians to make the case for the approval of effective new myeloma treatments.

MYELOMA

HOT TOPICS



MAKING YOUR VOICE HEARD

Many patients and family members ask us how they can get involved with activities at Myeloma UK. As well as the vital role you can play in fundraising and supporting our work financially, you can help us shape our work by volunteering for our panels, which ensure the patient and carer voice is at the heart of all we do at Myeloma UK.

Patient and Carer Information Panel

The Patient and Carer Information Panel plays a vital role in shaping the information we produce for patients and carers. Members offer their perspective on our information resources and help us to make sure it fits the needs of patients and carers.

What do members do?

Activities that members may be involved with include:

- Reviewing resources and publications
- Answering surveys about information needs
- Helping with information planning
- User testing digital resources

Members can get involved in a flexible way, volunteering as much or as little as you like, from filling in a few short surveys to reviewing a new publication. Activities can all be done remotely and the panel operates by email.

How do I join?

We're currently looking for a diverse range of patients, carers, family members and friends to join the panel so that different perspectives and needs are represented.

There are no pre-requisites, so if you're interested in joining the panel or would like to find out more, email **patientinfo@myeloma.org.uk**

Patient and Carer Research Panel

The Patient and Carer Research Panel puts patient and carers views at the heart of our research activities. Comprised of patients with myeloma and related conditions, family members, friends, and carers who volunteer their time, our panel members provide valuable input on our research activities.

What do members do?

Panel members contribute to research activities by providing their insight and experience of myeloma. The panel is an informal group that operates by email, so you can take part from anywhere. As a panel member you can get involved in many different aspects of the research that we fund and support including:

- Helping with survey design and completion
- Reviewing documents for patients in a study
- Taking part in research studies through questionnaires, interviews, or group discussions
- Joining advisory groups for specific research projects or clinical trial

Members will be emailed with opportunities and can then decide which invitations they want to take part in.

How do I join?

We are currently looking for more patients, family members, friends, and carers to join our panel. We want to ensure that the panel includes a diverse group of people so that different perspectives are represented and included in our research activities.

If you would like to find out more, or to apply to be a panel member please email **research@myeloma.org.uk**

Advocacy Partner Panel

The Advocacy Partner Panel is a collaborative group of around 15-20 appointed patients, carers, family and friends that will help shape our advocacy work. Members of the Panel will work with Myeloma UK to help make the patient voice count with decision-makers, like politicians, senior figures in the NHS, drug approval bodies and industry.

What do members do?

As a panel member you can get involved in many different aspects of our advocacy activities, including:

- Helping us shape our advocacy work
- Engaging with external stakeholders such as parliamentary groups and drug approval bodies
- Responding to requests for comment and feedback on consultation documents
- Participating in both Myeloma UK and external events and meetings

How do I join?

Appointment to the Panel is subject to a selection process, and appointments will be for an initial period of three years. Anyone with a personal (non-professional) experience of myeloma is invited to become a volunteer in our Advocacy Partner Panel. No experience in advocacy or policy is needed.
By being personally affected by myeloma as a patient, carer, family member or friend, our Partners will be experts through their experiences

If you have any questions, or you are interested in joining the Advocacy Partner Panel please get in touch by emailing **policy@myeloma.org.uk**

COPING WITH SLEEP DIFFICULTIES

BY JILL WILLIAMS

Many myeloma patients and their carers struggle to sleep well at times. Poor sleep can affect your overall wellbeing, but there are many things that may help.

What is insomnia?

Insomnia means you regularly have problems with your sleep, whether difficulty going to sleep, waking frequently, or lying awake at night. Knock-on effects can include fatigue, difficulty in concentrating, effects on mood, or worsening pain symptoms.

How can myeloma cause insomnia?

Some myeloma treatments can disrupt sleep, in particular steroids such as dexamethasone. Patients often talk about 'dex days' when they have high energy levels and can't sleep.

Stress and anxiety are also common reasons for disturbed sleep for patients and for family members. Worries about the diagnosis, treatments and the future can become more troubling during the night when there are no distractions.

Insomnia can also be caused by some of the complications of myeloma such as pain. Up to 90 percent of myeloma patients have bone pain at some point, and peripheral neuropathy is also common.

Other everyday factors may contribute to sleep problems, for example lack of physical activity during the day or using computers and mobile devices too close to bed time.

How to aid restful sleep

If symptoms such as pain or peripheral neuropathy are making sleep difficult, it is important make sure these are being addressed.

If your pain is not well controlled you can be referred to a palliative care or pain specialist.

You may find it useful to talk to a counsellor if you are finding anxiety is affecting your sleep. Your hospital or GP practice may run anxiety management groups. Maggie's Centres run workshops on stress and sleep workshops for people affected by cancer.

> **"I don't sleep a wink on [the first 'dex' nights] but once I resigned myself to this I find it is good catching up time for TV, emails etc"**

If you have high energy levels but find it difficult to sleep on steroid treatment days, it is good to plan around these days, maybe doing more chores and spending wakeful time watching TV or reading. In the same way, try to plan for more restful time on your post-steroid days if you find you lack energy on these days. You may also find changing when you take your steroid helpful, for example taking it first thing in the morning instead of later in the day.

Increasing physical activity, even just a short walk, can help with sleep by reducing anxiety, releasing 'feel-good' hormones (endorphins) and by tiring you out physically. Exercise should not be too late in the evening to allow for a relaxing 'wind-down' period before bed.

Although a nightcap can help you drift off, you should avoid having alcohol close to bedtime, because it's likely to wake you up during the night and prevent you from reaching deep sleep.

If you find yourself awake during the night, it may help to get up and use the time to do something else and try sleeping again later.

Exercise should not be too late in the evening to allow for a relaxing 'wind-down' period before bed.

Some other simple steps that may help with sleep include:

- Go to bed and get up at about the same time each day
- Keep the bedroom dark, quiet, and at a comfortable temperature. An eye mask and/or ear plugs may help
- Avoid computer and phone screens just before bed
- Listen to guided meditation tracks or apps
- Make use of lavender scented room/linen sprays
- Have a cup of mint tea or milk before bed
- Use pillows to reduce pain and pressure

> **"Exercise as often as you can. I try and do a bit every day, it makes me feel and sleep better"**

If insomnia is still persisting and affecting your daily life, it is important to talk to your healthcare team. Depending on the circumstances, they may suggest options such as relaxation techniques or cognitive behavioural therapy (CBT). In rare cases, they may prescribe sleeping tablets for a limited period.

Summary

A lot of myeloma patients and their carers suffer from insomnia at times. The causes can be varied, but there are a number of things that can help. If insomnia persists it is important to ask for help.

GP MYELOMA DIAGNOSTICS TOOL

BY HANNAH PARKIN

Myeloma patients have some of the longest delays to diagnosis of all cancer patients, with almost half visiting their GP at least three times prior to a diagnosis.

We know that a timely diagnosis, via a GP referral, results in fewer complications and a better quality of life, compared to patients who present later through A&E. Emergency admissions are often a result of severe end-organ damage such as kidney failure or spinal cord compression, which may have been prevented had myeloma been suspected sooner. At Myeloma UK, we want to give GPs the information they need to kick-start an effective and timely diagnosis process for suspected myeloma.

The average GP will only see 1 new patient every 5 years

This work forms a key part of the Myeloma UK Early Diagnosis Programme, which centres around the Myeloma UK Early Diagnosis Steering Committee. The Committee is made up of hospital specialists, laboratory scientists, GPs and guest speakers who meet throughout the year to discuss the challenges of making an early myeloma diagnosis and design projects to tackle some of these issues.

Improved symptom awareness is one way we have previously worked with GPs to keep myeloma at the front of their minds.

The average GP will only see one new myeloma patient every five years, so it is understandable that a refresh of the signs and symptoms of myeloma is necessary. Once suspected, a GP is able to start the diagnosis process if they know the correct blood tests to request. They must then be able to confidently interpret the results received from the laboratory and decide if, and how quickly, to refer a patient to a hospital specialist.



This pathway requires good communication between the GP and the laboratory. The Early Diagnosis Steering Committee identified that across the country there are inconsistencies in how effectively the laboratory and GPs communicate. This results in some GPs being unsure of which tests to request, or not receiving enough guidance to be able to confidently interpret the results they receive from the laboratory.

This is why Myeloma UK have created a new GP Diagnostic Tool to help address these issues.

Being clear on when and how urgently to refer patients was highlighted by both GPs and hospital doctors as an area where more guidance was needed. This referral decision is important as it identifies which patients need a hospital appointment quickly, and which require a less urgent pathway so as to not overload the hospital system. This is particularly an issue for MGUS patients, many of whom are referred urgently by GPs to the hospital haematology department, when they could actually be managed by their GP.

This is why Myeloma UK have created a new GP Diagnostic Tool to help address these issues. The new Myeloma UK GP Diagnostic Tool aims to act as a summary for GPs to help guide the diagnostic process for patients presenting with suspected myeloma. It includes a traffic light system which is used routinely by GPs to guide them on how urgently to refer patients, based on the results of initial blood tests. Ultimately, we aim to incorporate this tool into the computer reporting system of hospital laboratories, to ensure GPs receive results that include clear comments on what to do next.

This will improve consistency in decision-making, reducing the pressure on systems, and give GPs the confidence to monitor lower risk patients.

The tool is available to download from our website and a printed bookmark format is also available.

If you would like to know more about the work of the Myeloma UK Early Diagnosis Programme or have any further queries, contact **earlydiagnosis@myeloma.org.uk**

My myeloma story







Dannielle Collis is 42 years old and married to Graham (56) who was diagnosed with myeloma 5½ years ago. They have two children, Cameron (21) and Charlotte (17), and live in Greenhithe in Kent. This is Dannielle's story.

Eleven years ago, Graham had surgery on his back because he had two slipped disks. A few years later he'd been complaining about back pain and we thought it may the same thing again. Graham did a lot of heavy lifting at work so it wouldn't have surprised us if he was experiencing pain for that reason.

Unfortunately, his pain progressed and he became increasingly unwell. He attended a number of appointments at the GP surgery where they told him he had a virus and was given antibiotics. This happened a number of times before I eventually lost it in the GP surgery and told them that he's lost three and a half stone, he's not eating and sleeping all the time.

They finally agreed to do a blood test and that is when everything just exploded for us. The GP took Graham's blood at 11am and by 4pm they called us back to say an ambulance was on its way, it would arrive in a few minutes and we should put some things in a bag. As the call ended, the paramedics arrived outside. It took around an hour before we left for the hospital as they were worried Graham would have a heart attack. They said his kidneys were working at 4%, he was hypoglycemic, had sepsis and 'acute kidney injury'. They eventually took him to our local hospital, but they were concerned he wouldn't make it through the night.

I remember taking the kids to school two days after he was transferred



to Guys Hospital. Whilst I was dropping the kids off, the renal team were talking to Graham. They said they knew what was wrong with him and told him he had myeloma. Graham replied by saying 'Ok. What is myeloma?' Like so many other people he had never heard of myeloma. They told him it was cancer and there is no cure, but we can provide treatments. They then said, 'do you want to ask us anything?' He thought, what am I meant to ask? Being told you have cancer in this way was far from ideal as Graham was on his own and we really should have been told by the haematology team at the same time.

Graham sat on his own for an hour thinking about what had just happened. He asked himself whether he was going to die and was this it? He phoned me as I was walking back from the school. I tried to take in everything he said on the call and told him I was on my way to the hospital. Like Graham, I knew nothing about myeloma.

Graham's nurse Grace arrived later and provided more information. She told him that they still weren't sure if he had myeloma and they needed to do a bone marrow biopsy to confirm the diagnosis. Graham started chemotherapy soon afterwards.

Everybody goes straight to Google to find information. Doing so told us we were looking at around 90 days. That made us think we didn't have lot of time left, but clearly that wasn't true. Grace provided us with a range of information from Myeloma UK and we've stayed with that ever since. She gave us a book for our kids and one of the information packs on chemotherapy. However, she learned very quickly to give the information to me rather than Graham as he doesn't read it. Unlike Graham, I need to know everything. Having information at my fingertips via the Myeloma UK website helps me cope. With that knowledge, I can be ready for anything that comes our way and know what to look out for if Graham gets sick.

I responded to his diagnosis by getting into a routine and that helped me through the initial period. In the morning, I got the kids off to school, came home to get ready to see clients (I am a hairdresser), go off to the hospital to see Graham and then back to meet the kids from the station. In the evenings, I would sort out dinner then do some housework. That was my routine for seven and a half weeks whilst Graham was in Guys Hospital.

We didn't tell our kids about the diagnosis until Graham started his high-dose therapy and stem cell transplantation (HDT-SCT). I needed to have all the information at hand and understand everything that was going to happen before we told them. We sat the kids down, told them their dad had myeloma and what that meant. Our son Cameron has Aspergers and is really knowledgeable. He said 'dad's blood is not good'. By comparison, Charlotte responded more like I would and asked if dad was going to die? We didn't say yes or no, but told them both he had all the treatment he needed and was being well looked after by the doctors and nurses. We told them that we needed to be careful, wash our hands, and if we fell sick, we should not get too close to dad.

"We haven't had moments where we were unable to manage the situation. In fact, I know the kids were able to cope better because Graham and I managed it well together."

The thing about Graham is that he doesn't like to make a fuss or complain. He was diagnosed with prostate cancer two and a half years ago. At the appointment where he received the diagnosis, he was told that a nurse would be waiting outside to discuss anything else he wanted to know. Graham asked the doctor whether he had to talk to them. The doctor said no, but asked if he was sure he didn't want to do so. He said 'I've got myeloma, I'm probably going to die from that first'. I know that sounds very matter of fact, but the thing is he just doesn't worry about having myeloma. Aside from the shock of the diagnosis, we have tried to remain very positive. We talk openly about it as a family and that makes a real difference. We haven't had moments where we were unable to manage the situation. In fact, I know the kids were able to cope better because Graham and I managed the situation so well.

Before lockdown, I used to go to hit classes, the gym or for a run. When you've got someone shouting at you to do 50 burpies, you can't think of anything else apart from the fact that you want to kill the instructor! Graham lost six discs in his lower spine and he can't walk for too long. Instead of long walks, we drive 40 minutes to Herne Bay in Whitstable to eat some fish and chips on the beach without the need for long walks. These are the things I miss right now.

Things have been up and down this year and I've not actually worked during 2020 because Graham's chemotherapy kept being changed. We'd go up to the hospital on a Friday, find out his platelets and haemoglobin had dropped and be asked to come back on the Monday for a transfusion. I try to go to all of the appointments, but that is currently impossible - we are not grateful to COVID-19 for that outcome.

During the first 16 weeks of lockdown, the whole family didn't leave the house, but we did get on with it. Charlotte and I watched Grey's Anatomy whilst Graham and Cameron were off playing the PlayStation. We didn't step outside the door, but we did play Monopoly and the most competitive game in the world, Snakes and Ladders. The competitiveness in the room whilst we played that game was really tense.

I'm Graham's wife, not his carer. If the roles were reversed, I'm sure he'd say the same. I suffer from polycystic ovaries and endometriosis. As a result, I am not great at certain times of the month and suffer from horrendous pain. When I feel this way, Graham looks after me. He'll run me a bath, make sure I have pain killers or whatever I need. So, I don't see myself as a carer who does this and that for him.

"Things have been up and down this year and I've not actually worked throughout because Graham's chemotherapy kept being changed."

Since the diagnosis, we've had to rethink our holidays in Turkey. We like to have a swim-up room in a hotel so that we can stay together as a family. Having that room means we can still feel close to one another even if Graham needs to lie down for a while. My friend lives half an hour away and his wife works in the hospital as a neonatal nurse specialist. They both speak fluent English and whilst my friend often complains about the fact I don't speak Turkish, knowing they are in the area makes me feel safe because they can translate for us if Graham needs to go to the hospital.

Two weeks before we left for our last holiday in Turkey, we were in an appointment in the hospital where Graham and I were told his myeloma was creeping up and they'd need to do a biopsy. However, as he was still in remission they said we could travel. I have to say the astronomical cost for his holiday insurance was a shock; it was £415 for two weeks. The Myeloma UK Buddy also travels with as one of our friends. We take him everywhere and have the photographs to prove it.

I think the team at Guys Hospital are amazing. They have looked after Graham and I really well and I'm grateful to them. Grace and Dr Streetly are always there for us when we need them and that is really reassuring.

ASK THE NURSE

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

Is it ok to have a couple of drinks while I'm on treatment, particularly around the festive season?

It is generally fine to drink alcohol, and having the odd glass of wine or gin and tonic is unlikely to affect you whilst you are on treatment, but this should be in moderation and within the NHS recommended limits of no more than 14 units a week. Some anti-myeloma or supportive care drugs can cause dizziness as a side effect, so if you are affected in this way it may be best to avoid alcohol as it may make any dizziness worse.

I've started my induction treatment but my high-dose therapy and stem cell transplant (HDT-SCT) has been delayed, will this affect my myeloma?

There is usually a period between finishing induction treatment and starting the HDT-SCT process (up to six weeks or so), which allows the patient to recover from induction treatment and prepare both physically and emotionally for the upcoming HDT-SCT. However, some patients may be facing a longer delay.

You will continue to be monitored in the interim period for signs of relapse. For many patients, their myeloma will remain stablefor quite some time following induction treatment. However, if there are signs that your myeloma is becoming active, your haematologist might consider starting treatment again until your HDT-SCT can go ahead. It is important to discuss these concerns with your healthcare team who will be able to reassure you and discuss your options should your myeloma progress whilst you are waiting for your HDT-SCT.

If a coronavirus vaccine is found, will I be able to have it?

There are multiple coronavirus vaccines currently in development with different ways of working, some of which may or may not be suitable for patients. In general, myeloma patients are recommended to have inactivated vaccines (e.g. the flu vaccine), and not live vaccines (e.g. the shingles vaccine), because of the risk of contracting the disease from the vaccine when you have a weakened immune system. Whether the vaccine is live, inactivated or works in a new way, it will need to be tested to ensure it is safe for people with weakened immune systems, like myeloma patients, before it can be recommended.

I've been given supportive treatment to help with my anaemia, is there anything I can change in my diet to also help with it?

Anaemia occurs when there is a reduction in the number of red blood cells or the oxygen carrying haemoglobin they contain. If you don't have enough iron, your body can't produce the necessary haemoglobin and therefore you can become anaemic. However, in myeloma, anaemia is often caused by both the myeloma itself and its treatment suppressing the production of red blood cells, rather than a lack of iron. This means that increasing the iron content of your diet won't have an effect on your anaemia. However, patients are encouraged to maintain a healthy and balanced diet because this can help with general energy and fatigue levels.

If you have a question for our Myeloma Information Specialists call the **Myeloma Infoline** on **0800 980 3332** or email **askthenurse@myeloma.org.uk**

SUPPORTER STORIES

Myeloma patient, Andy Hamilton, shares his experiences of myeloma and how his diagnosis led family friend Barbara Stonehouse to become a key supporter of Myeloma UK and leave £276,000 in a legacy to support us.

I am 59 years old and live in Edinburgh with my wife, Usa. I was diagnosed with myeloma in August 2008 after regularly visiting my GP for a year because of worsening back pain and fatigue. In the lead up to my diagnosis, a friend suggested I go for a private health check. I took their advice and had bloods taken as well as other tests. A confirmed diagnosis of myeloma followed and I started high-dose therapy and stem cell transplantation (HDT-SCT) thereafter. Over time I received a further stem cell transplant and lenalidomide.

Throughout my cancer journey, I have often turned to Myeloma UK for information and support. I have attended nine Myeloma UK Infodays that were full of supportive information and reliable advice. It is very reassuring to know that the Myeloma Information Specialists are only a phone call away if I am having problems or require information about treatments. I also attend the local Myeloma Support Group in Edinburgh, which is a good way to hear about the journeys of other myeloma patients.

From the point at which I received my diagnosis, a family friend Barbara Stonehouse took an interest in the work of Myeloma UK. Knowing that the charity started out where she lived in North Berwick really encouraged her to find out more about the organisation.

Barbara was a close friend of my mother and I got to know her well from a very young age. She lived just across the road from our family home and over time she became an increasingly close friend to us all. She gradually became a regular visitor to our house and eventually became part of the family. She also joined us on many family holidays.

Knowing that the charity started out where she lived in North Berwick really encouraged her to find out more about Myeloma UK

Barbara attended some of the Myeloma UK Infodays with me and was very impressed with the information, advice and assistance that was being presented and passed on to myeloma patients. She said I had become like an adopted son to her and she wanted to do all she could to help me and others with myeloma. As a result, Barbara started fundraising for Myeloma UK in 2010, and sent in donations a couple of times every year. She also raised funds in lieu of receiving presents for her 90th birthday and faithfully purchased Myeloma UK Christmas cards every year to help raise awareness of this cancer and the charity.

When Barbara sadly passed away in January 2019, Myeloma UK and I were amazed to discover she had left the charity a gift in her will, amounting to over £276,000. She hoped her gift would have a positive impact on my life and support the amazing research that Myeloma UK undertakes. Myeloma UK invests a lot of money in research and support, and I know this gift will be used by the charity to help many myeloma patients and their families.



In the last 10 years, the research and patient advocacy work undertaken by Myeloma UK has ensured new treatments are developed and made available to myeloma patients. Having new treatments in the pipeline helps so many patients live well and has a positive impact on lives.

I hope Barbara's legacy will assist Myeloma UK to support research into new treatments and ensure myeloma patients can access them in the future. I hope it will also help to support Myeloma UK to produce all of the Infosheets they provide, which I have found to be reliable and informative.

Jason Dyer, Director of Income Generation at Myeloma UK, reflected on her support and generosity by saying:

"We are so grateful to Barbara for the wonderful gift she has left us in her will. She has left us a fantastic legacy that we shall use to invest in helping her friend Andy and the thousands of other myeloma patients who benefit from our work on a daily basis. Myeloma UK couldn't achieve all we do without amazing supporters like Barbara."

If you would like to leave a gift in your will to Myeloma UK and help us to continue with our important work, please get in touch with our fundraising team on **0131 557 3332** or email fundraising@myeloma.org.uk

MyelomaUK

Lost in Lapland

Join us on our Festive Virtual Mission



Santa has lost Buddy the Elf, Rudolph and a sack of presents somewhere in Lapland. Can you help guide them back to Santa's Village in time for Christmas Eve?

Sign up to complete either **10km**, **50km** or **100km** distance in whatever way you like between 1-24 December.

Find out more and sign up at
www.myeloma.org.uk/lostinlapland

Myeloma UK is a registered charity, no. SC026116

Myeloma Stars Christmas Appeal

is back for 2020

Last year, supporters like you helped us raise nearly £20,000 by donating and dedicating stars to the special people in your lives on our Myeloma Stars website.

Your donations support our vital work with myeloma patients.
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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**

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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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