

MyeNews

Winter 2021 Issue no 58

Myeloma
Australia



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From the President

We live in a very lucky country, what with COVID-19 still causing havoc all over the world. At least Australia has been able to limit its direct effects. Our new normal is very different from the normal of 2020.

My wife and I have only just started to go out and be a little more relaxed, though always alert. At the time of writing this, we have just celebrated our eldest grandson's 21st birthday with a family party. The first time our extended family had all been together in the one place since March 2021. Also, we have both just had the COVID vaccine with very little side effects other than a sore arm for two days. I feel very strongly that everyone should have a discussion with their specialist or GP to decide whether they should have it. As we have seen in various states there have been very small breakouts of the virus which luckily have been quickly limited, though we must all be very careful.

May was Myeloma Awareness month and our team developed the 38mate campaign to help spread the awareness through the whole community. I have bought some of the caps for my family and we will be looking at ways to take some selfies and put them onto social media to spread the word. Please join me in this project. More information is enclosed in this edition and on our website.

During May we held a series of webinars which were shown live, with recordings made available on our website to watch at your leisure. I made a short cameo appearance on the first, telling a little about the history of Myeloma Australia. It is interesting that when reviewing some of the things we did in the early years, things have not changed very much. Sure, we are now utilising the internet for our webinars and social media to spread the word, but our core is still the same. We are using myeloma nurses to educate everyone, and we are still communicating through this magazine and information sheets. We have just grown from one nurse in Melbourne to having 16 spread all over the country.

We still believe that we all have the resilience to get through the treatments with the hope for the eventual cure.

Brian Rosenporter



Myeloma Support Line

Monday – Friday 9am – 5pm (AEST)

1800 MYELOMA (1800 693 566)

A confidential service providing those living with myeloma, their family and friends and health professionals access to specialist myeloma nurses. Open to anyone with a question about myeloma or just to have a chat.

COVID-19 vaccination

for people with myeloma

Now that COVID-19 vaccines are available in Australia, many people in the myeloma community have questions and some people might have hesitations about being vaccinated.

Through our support groups and Telephone Support Line, our Myeloma Support Nurses have received questions about how well the vaccines work in people with myeloma, if the vaccines can be safe after being developed so quickly, and the possible risk of developing blood clots after the AstraZeneca vaccine.

We understand that these are important questions and that you need reliable, evidence-based information. We also understand that there is some misinformation about the vaccines – and it can be difficult to tell this apart from the facts. That's why we have reviewed current literature and guidelines to answer your questions.

The information in this article can help you to make a more informed decision about COVID-19 vaccination, but please remember that your doctor is always your best source of information about all medicines and vaccines that are best suited to your needs.

Does the COVID-19 vaccine work in people with myeloma?

As at May 2021, one research paper has been published that looks at whether people with myeloma are able to mount an immune response to COVID-19 vaccines.

Early data published after people had received one of the two planned vaccine doses shows that 7 out of 10 people in the myeloma group had an increase in their total immune response, while nearly all the people in the control group had an increase in their total immune response.

While this shows that the response to the vaccine is lower in people with myeloma than in the general population, there is still good evidence of benefit.

Because people with myeloma are at higher risk for COVID-19 infection and also at higher risk of serious outcomes that may need them to be admitted to hospital or intensive care, protecting against COVID-19 infection is especially important.

As well as protecting through vaccination, this means that it is still vital for people with myeloma to keep taking extra precautions to protect themselves against COVID-19 infection – including handwashing, physical distancing and wearing a mask where necessary. It also means that it is very important for your family and close contacts to be vaccinated to help create a protective circle around you.

Research into the effectiveness of COVID-19 vaccines in people with myeloma is continuing, and this will guide ongoing medical advice. We will keep you updated on new developments.



You can also read more about the current research in *Medical Corner* on page 21.

Were COVID-19 vaccines developed too quickly to be safe?

Research into how to respond to a pandemic started long before COVID-19. Information from other coronavirus outbreaks, such as Severe Acute Respiratory Syndrome (SARS CoV) in 2002 and Middle East Respiratory Syndrome (MERS) in 2012, gave researchers a head start on how to develop vaccines against COVID-19.

The COVID-19 vaccines were able to be developed faster than previous vaccines because of the unique collaboration between scientists, manufacturers and distributors, along with a level of global funding that has never been seen before. This allowed the development and implementation planning phases for the vaccines to be run side-by-side, instead of one after the other.

In Australia, the Therapeutic Goods Administration (TGA) has been rigorously assessing all potential COVID-19 vaccines for safety, quality and effectiveness. The TGA will continue to do this with future vaccines before they are approved and made available in Australia.

Once approved, each vaccine batch is checked to make sure it meets the same quality standards.

What is the risk of developing blood clots after having the AstraZeneca (AZ) vaccine?

A very small number of people who have received the AstraZeneca (AZ) vaccine worldwide have developed an extremely rare immune response that causes blood clots and low levels of blood platelets. This is called thrombosis with thrombocytopenia syndrome (TTS) and is similar to a very rare reaction to heparin treatment called heparin-induced thrombocytopenia (or HIT).

The overall rate of TTS is estimated to be about six cases per million people vaccinated in all age groups – or 20-40 cases per million in people under 60 years.

It is important and helpful for you to know that the way that this rare blood clotting side effect develops after the AZ vaccine is different from the way that clots develop when they cause deep vein thrombosis (DVT) or pulmonary embolism (PE) associated with active myeloma or its treatments.

In Australia, the Australian Technical Advisory Group on Immunisation (ATAGI) now recommends that the Pfizer COVID-19 vaccine is the preferred vaccine for adults aged under 60 years.



The AZ vaccine is recommended for most people with myeloma who are aged 50 years or over.

However, your GP may want to confirm this with your haematologist. If you have myeloma and a

history of blood clotting problems, please talk with your haematologist about the best approach to COVID-19 vaccination for you.

What are the possible symptoms of a blood clotting problem after having the az vaccine?

In Australia, people who have developed symptoms of TTS experienced these 4-26 days after receiving their first dose of the AZ vaccine.

If you have had your first dose of the AZ vaccine, please seek urgent medical attention if you experience any of the following symptoms:

- shortness of breath
- chest pain
- swelling in your leg
- persistent abdominal (tummy) pain
- neurological symptoms, including severe and persistent headaches or blurred vision
- tiny blood spots under your skin beyond the injection site

What are the commonly reported side effects of COVID-19 vaccines?

Like many other vaccines, common side effects with any of the COVID-19 vaccines may include:

- tenderness, pain and swelling at the injection site
- tiredness
- headache
- muscle and joint pain
- chills
- fever.

Most side effects are mild and will go away within 1-2 days.

If you have had a COVID-19 vaccination and think you may be experiencing side effects, you can check how severe they

might be with this online tool: <https://www.healthdirect.gov.au/COVID-19-19-vaccine-side-effect-checker>

Why do vaccines cause side effects?

Common side effects from vaccines, such as fever and tiredness, are often a good sign that your immune system has been activated and is learning how to fight the disease.

Making your decision to get vaccinated

Deciding if you will have the COVID-19 vaccine is very similar to deciding whether you want to have any medicine to treat myeloma and its effects, or to treat any other health problem. It really comes down to answering the question “Is the benefit of taking this medicine worth the risk of experiencing a potential side effect?”

Most people with myeloma do experience some side effects from their treatment, but they are usually manageable and are outweighed by the benefit of having their condition under good control.

COVID-19 can cause serious illness, ongoing health problems, and sometimes death. People with myeloma are at higher risk of COVID-19 infection and also at higher risk of serious outcomes that may need them to be admitted to hospital or intensive care.

The vaccines are designed to ensure that, even if you do catch COVID-19, you do not get seriously ill and reduce your risk of being admitted to hospital or intensive care.

Getting vaccinated is the best way you can protect yourself, your loved ones, and our community.

For the vast majority of people with myeloma, the benefits of being vaccinated against COVID-19 outweigh any risks. Ask your doctor when will be the best time for you to be vaccinated depending on your current myeloma treatment plan.

For a list of references used to develop this article, please email nurses@myeloma.org.au



Email communications

Are you receiving our email communications, such as our monthly newsletter The Myeloma Muster?

If not, please make sure we have your current email address, and your email security settings are allowing emails from the domain myeloma.org.au. Our emails may end up in your spam folder so please check this. If you need to update your email address or would like to receive our email communications, please email support@myeloma.org.au



Ray back home after his SCT in 2016

Ray Pereira who has been living with myeloma since 2016, recently received an Order of Australia Medal (OAM) for services to the Performing Arts as a percussionist, performer and composer.

Ray has established a reputation as one of the leading percussionists in Australia and is a recognised leader in his field of Afro Cuban and African drumming and percussion. He has performed and recorded with several of our top artists including Paul Kelly, Kate Ceberano, Renee Geyer, leading indigenous artists Yothu Yindi, Archie Roach, Christine Anu and jazz musicians Vince Jones, Paul Grabowsky and Barney McAll among many others. Ray has performed extensively in Australia and has also played concerts in North America, Europe, Japan, South America and Africa. He has performed on several television shows backing many international and Australian singers, has been a member of the Logies Band for several years, having also performed on television as a featured artist.

As an educator Ray conducts master classes at universities and tertiary institutions around the country, teaches African drumming at his local primary school and runs his own

workshops. He also runs annual study tours to Ghana and Sri Lanka where his Australian and international students accompany him to study drumming and dance styles from these countries.

We asked Ray about his career and his experiences living with Myeloma.

How did you first find out that you had multiple myeloma?

Firstly, I'd like to thank you for giving me this opportunity to talk to you. I actually feel very lucky, as I was diagnosed quite early, before I had any obvious symptoms. Follow up tests for a prior surgical procedure found a small lesion on my hip. Further testing including a bone marrow biopsy led to my myeloma diagnosis in 2016.

How did you react to this news?

I have to admit, my myeloma diagnosis came as a bit of a shock. Having had friends who had undergone cancer treatment, I had often wondered how I would have handled it if it had been me. I must say even though the news came as a shock, I didn't react as badly as I had thought I would. The positive attitude of my wife to this news also helped me in this regard.

I remember feeling rather stressed and apprehensive sitting in the doctor's surgery at Peter Mac in June 2016 waiting for my test results. My wife, who was with me, looked relatively relaxed however, and in fact was on her phone, organising meetings and other matters related to her busy career. Her relaxed attitude helped me reduce my anxiety. The specialist then walked in to give us the news of the test results and I knew by the grave look on his face that this wasn't going to be good news.

He said, "The news is not good but it's not the worst news either. You've got a blood cancer called multiple myeloma, but we think you are in the lower risk category and we think we should be able to manage it with treatment". My wife then tapped me on the knee, "Don't worry love. I don't think this is going to kill you. Someone else will", she said laughing. "Very funny" I said, although I must say this did relieve my anxiety, injected a bit of humour into the situation and helped me to come to terms with the news.

Would you like to tell us how you have handled your subsequent treatment?

I responded well to the initial three-month course of Velcade, dexamethasone and cyclophosphamide and my paraprotein levels came down significantly over this period. My specialist then suggested I bring forward my stem cell transplant which I had at the new Peter MacCallum Centre in November 2016. I must say that the new Peter Mac is such a fabulously well designed and welcoming building that strange as it may seem, I look forward to my appointments and having a coffee in the cafés.

When I was first shown the room where I was to spend the next three weeks or so during my SCT, I was pleasantly



surprised to find the room was bright and airy. It looked more like a good hotel room than one in a hospital. My always supportive wife who had been on some of my music tours with me commented, "What a great room. It looks just like your rooms when you are on tour. Television, remote control, room service. The only thing you don't have is a bar fridge and no gig in the evening." "The view is great too" she said, looking out of the window. She was right.

The next few weeks, while not pleasant, certainly wasn't as bad as I had imagined. I got through the process reasonably well without any complications. The nursing staff were great. No request was too much trouble. I had all the information I needed and overall, I must say I quite enjoyed the time off and the enforced rest. I felt extremely lucky not to feel worse and three weeks later, I was at home recuperating.

I felt a bit tired but otherwise alright. After a month at home, I was back playing music. I have since been on a combination of maintenance treatments both with and without dexamethasone and cyclophosphamide and after initially experiencing some neuropathy on thalidomide, I was taken off it and have now been on Revlimid for just over a year after two years in-between without any treatment, as my levels were low and stable.

Overall, I am handling the Revlimid pretty well and apart from having some issues with my knees which were affected by the steroids and having to push through

fatigue on some days, I feel fine and continue my work as a musician. Although I am not able to travel to Ghana any more on my annual tour, as I'm not able to have the Yellow Fever vaccination after my stem cell transplant due to risk associated with having live vaccines. I am also a very strong believer in exercising and even when I was on the chemotherapy/dex regime, I continued to exercise regularly, pushing through mentally when I was experiencing some fatigue. I believe that you need to be strong mentally and sometimes force yourself to push through and to do the right thing. Easier said than done I know.

You have just received an OAM. What was the award for?

I was pleased to receive this award as I see it as an appreciation of my work by the community and a recognition by my peers of my contribution to music in Australia.

The nomination did come as a surprise however, as the process is confidential. In fact, when I first received the email from the Governor General's office asking me whether I wanted to accept the award, I thought it was a scam and almost deleted the email. I was amused that some scammer would think that I would be foolish enough to click on the accept button. My son, who knew I had been nominated, convinced me that it may indeed be genuine and so I went ahead with the process of accepting the nomination.

I was nominated by one of my long-term drumming students who was an ex-principal at a primary school. She decided that she wanted to nominate me for the award as a result of both my teaching and fundraising work and also my work as performer. As part of my music career, I also run my own drumming and percussion teaching business where I teach adult students drumming styles from Africa, Cuba and Sri Lanka. I also organise cultural study tours to Ghana and Sri Lanka and have been doing so for many years. Through these tours I have established good community connections in these countries and together with my students we try and help the local communities with their educational and medical needs by organising fundraising concerts where all my students perform. The person who nominated me, later told me she did so because she thought that I should be recognised for this work and, also for my work as performer. She then approached the more high-profile musicians I have worked with to act as referees to support my nomination. Some of these musicians were already recipients of the Order of Australia, so I guess this carried some weight.

Is there anything else you would like to say?

The doctors, my nursing team and all the other staff at Peter Mac have provided me with incredible support right through my treatment. I feel it is an absolute privilege to be able to pick up the phone at any time and get expert advice from my nursing team. I can't speak any more highly of the quality of treatment and care that I have received. So, I'd like to sincerely thank everyone at Peter Mac who have looked after me and given me the confidence to truly believe that I will survive and beat this disease.

Upcoming PBAC meeting July 2021

In the myeloma space, there are six submissions on the agenda for the July 2021 Pharmaceutical Benefits Advisory Committee (PBAC) meeting. The submissions relate primarily to four anti-myeloma medications namely elotuzumab, selinexor, daratumumab and bortezomib.

Elotuzumab (Empliciti®)

Elotuzumab is a monoclonal antibody targeting the SLAMF7 receptor on myeloma cells. Following an unsuccessful submission in the November 2020 meeting, this is a re-submission for elotuzumab in combination with lenalidomide and dexamethasone for those whose myeloma has come back.

Selinexor (Xpovio®) – 2 listings

Selinexor has a different mechanism of action to the other myeloma treatments available, it inhibits the nuclear export compound XPO1 in myeloma cells. There are two submissions relating to selinexor, one in combination with bortezomib and dexamethasone for treatment of those whose myeloma has returned and secondly in combination with dexamethasone in a select group of people who have received at least four prior therapies.

Daratumumab (Darzalex®)

Daratumumab is a monoclonal antibody targeting the CD38 receptor on myeloma cells, it is currently available for those at first relapse as an intravenous infusion in combination with bortezomib and dexamethasone. This submission is for approval of a new subcutaneous dosing regime in the same combination and indication as already approved.

Bortezomib (Velcade®) – 2 listings

Bortezomib is a proteasome inhibitor that has been available for many years for people with myeloma. Both listings are for new brands of bortezomib, there is no change to the current indications or combinations available.

The PBAC makes recommendations to the government about which myeloma treatments (and in which combination) will be reimbursed by the Pharmaceutical Benefits Scheme (PBS) and available to Australians with myeloma, both present and future. It is therefore vitally important that we at Myeloma Australia, our Medical and Scientific Advisory Group (MSAG) and the myeloma community make comment as to how important it is that these additions and changes be made. Thank you to all who provided feedback and comments, we will keep you updated with the outcomes when available.

Daratumumab (Darzalex®) Treatment

We have been receiving lots of questions from people who are about to start treatment with daratumumab.

Our Myeloma Support Nurses are ready and waiting to provide you with information and support.



Please contact us via our Telephone Support Line – 1800 693 566 or email – nurses@myeloma.org.au to learn more.

Jess Church Occupational Therapist



My name is Jess Church and I am an occupational therapist (OT) working at Max Healthcare Equipment in Adelaide.

I recently had the pleasure of speaking at the Myeloma SA Support Group about how an occupational therapist and home care equipment, can increase the quality of life and safety for a person with

myeloma. I met some great people and had some important and valuable discussions that I would like to share.

I have been working as an OT for 20 years in Australia and overseas and with a variety of client groups. My passion is working with clients in their own homes where I can make a real difference to their lives, which is why working at Max Healthcare is so rewarding.

The role of occupational therapy is "to facilitate and enable an individual patient to achieve maximum functional performance, both physically and psychologically, in everyday living skills."

Due to the uniqueness and complexity of human occupation, each individual diagnosed with an illness will experience different challenges in his or her various activities and roles. Myeloma and its treatment can cause fatigue, pain, weakness, fractures and changes in self-esteem. These side effects or changes also cause interruptions in daily routines affecting how individuals perform their self-care, work, leisure, or social activities.

An occupational therapist can address these challenges and limitations through assessment and intervention aimed at achieving a maximum level of independence and quality of life through home exercise programs, modifying activities and teaching energy conservation or modifying the environment with equipment, aids and home modifications.

Home Care Equipment and Assistive Technology (as it's called under the NDIS) plays a significant role in all of the above. Enabling independence, increasing safety and providing comfort.

These are some of the key items of equipment that we have at Max Healthcare Equipment that meet the Occupational Therapy Principles in treating myeloma for falls prevention, pain relief, comfort, safety and independence:

- Shower chairs/stools and bath-boards to use for sitting instead of standing for safety and to conserve energy, Example Shower stool
- Long handled aids including pick up sticks, long handled shoehorns, long handled sponges or even a toe wiper that reduce bending. Examples shown: Pick up stick and toe wiper



- 4 wheeled walkers with a seat which are ideal to increase balance and provide a seat for rest when out walking or at the shops. Example shown: Days 4 Wheeled Walker 8-inch wheels
- Wheelchairs, scooters and electric wheelchairs can aid mobility when walking can be tiring.

Example shown: Merits Fendi Scooter



- Electric Recliner Lift Chairs can alleviate pain on the spine and can enable custom seating positions. Recliners come in single and dual motors and a range of styles and fabrics. Example shown: Care Quip Monarch Dual Motor Lift Chair



- Electric Beds offer the ability to move the bed from the floor to hip height as well as adjusting the back rest knee break and tilt which can alleviate pain and provide comfortable positioning. Example shown: Icare i333 Home Care Upholstered Bed.



- Foam and air mattresses and cushions may also assist in pressure and pain management and can be used on chairs, in the car and on any beds.

Accessing Equipment

There are different options for how people might access the equipment that I have discussed above:

- If you have a Home Care Package you can talk to your coordinator about purchasing the equipment with the available funds, or you may require an occupational therapist or physiotherapist to conduct an assessment to determine the best equipment for you.
- If you have Commonwealth Home Support Program (CHSP) funding, which means you are waiting for a HCP, you may be able to access equipment codes that enable you to source some items of approved equipment.
- If you have an NDIS plan, Max Healthcare Equipment can provide quotes and trials of equipment as a registered NDIS equipment provider.

If you do not have any of the above, you can still buy or hire this equipment from us at Max Healthcare Equipment. I can assess you at our showroom or come to your home to complete an assessment of your needs and recommendations on strategies and equipment that may improve your independence and enjoyment in life.

Editors note: There are equivalent healthcare equipment providers all around Australia. If you need help locating one, please reach out to your local treating team or contact our Myeloma Support Nurses: e | nurses@myeloma.org.au t | 1800 693 566 (Monday – Friday, 9am – 5pm AEST).

Staff Profiles



Diana Yun
Myeloma Support Nurse
New South Wales

Hi everyone in the myeloma community, my name is Diana Yun and I will be joining the Myeloma Australia Team in NSW.

I first worked on the inpatient haematology ward at Royal Prince Alfred Hospital in 2018 as a new graduate nurse and have been unable to part from the specialty. In September 2020 I joined the Apheresis Unit at Royal Prince Alfred Hospital in a part-time position and further specialised in stem cell & CAR-T cell collection and infusions as well as performing therapeutic plasma/red cell/extra-corporeal photopheresis procedures for patients with different haematological diseases and disorders. I applied for the Myeloma Australia support nurse role because I want to be able to reach out to people in the myeloma community and be able to play a part on their myeloma journey. I want them to know confidently that we have support for them no matter where they are. I am enthusiastic and passionate, and I hope I can connect everyone to the latest myeloma treatment and bring a sense of hope to the myeloma community and their loved ones.

My main hobbies are sewing and knitting – I love making bags and scarfs throughout the year. I am a huge fan of Taylor Swift and I love playing her songs on guitar in my spare time. Recently I have started to learn roller skating to increase my fitness level, however, I am still a major hazard to anyone who comes near me.

I look forward to working with the Myeloma Australia staff in coordinating support groups and connecting with our myeloma community in the next few months.



Emma Huybens
Myeloma Support Nurse
Victoria

Hi everyone, my name is Emma, and I am so excited to be joining the Myeloma Australia team as a Myeloma Support Nurse covering Laura whilst she is on maternity leave (congratulations!). I have been working as a nurse in haematology with myeloma patients for seven years now at the Peter MacCallum Cancer Centre in Melbourne. During this time, I have completed my Post Graduate Certificate in Cancer and Palliative care at Melbourne University and have also worked as an Associate Nurse Unit Manager.

My real passion is patient education which is what drew me to apply to be a Myeloma Support Nurse. I believe that one of the most important aspects of my role as a nurse is ensuring patients and their loved ones are well informed about their disease and treatment, enabling them to make educated decisions and help improve their overall quality of life. I am also leading a chemotherapy education improvement project on the haematology ward at Peter Mac.

On my days off I try to spend as much time outside as possible (when Melbourne weather permits) and enjoy hiking, camping and lazing in the park with my pug 'Libby' and Briard 'Romero'. I love to travel and spent a year travelling and living in Europe in 2016/17 where one of my most memorable experiences was skydiving from a helicopter over the Swiss Alps – the views were incredible.

Unfortunately, like everyone else I have not been able to enjoy much travel in the last year, fingers crossed for some time soon! I am also a bit of a 'foodie' (more the eating part and not so much the cooking) so luckily for me my partner is a chef, and I am spoilt with delicious food every day! During lockdown last year I decided I would take up a bit of gardening and planted multiple pot plants on my balcony. To sum up my success, my brother calls my balcony 'the graveyard' and thinks I should stick to taking care of people and not plants. However, I am not one to give up easily, so I am open to any tips and tricks any of you may have.

I am looking forward to meeting and supporting everyone in Victoria in the face-to-face support groups and the rest of you online in our various seminars and online events.

Supporters in the Spotlight

In this edition, we put the spotlight on two of our major donors – Robin Fogarty and David Orford. Robin, from South Australia, has been living with myeloma for 16 years. David is from Victoria and cared for his brother with myeloma.



Robin Fogarty



David Orford

Q: How were you diagnosed with myeloma?

A: In 2005, I fell and grazed my knee. The recovery didn't go smoothly, and I ended up in hospital. I was then told there was a possibility it was myeloma. I was shocked to receive this news about something I had never heard of. The specialist told me the average life expectancy was seven years – this was very confronting. I replied that I was not Mrs. Average, and I set a goal right then to be around for my granddaughter's 18th birthday. She's now 23. Now I need a new challenge!

Q: As a donor of Myeloma Australia, what makes you passionate about the cause?

A: After my initial diagnosis, my mother-in-law started making an annual donation to Myeloma Australia. She always had that hope that a cure would be found. When she passed away, we decided to match her gift every year.

Q: Which Myeloma Australia services have you utilised?

A: We have attended the seminars held in Adelaide. We were very impressed with the high standard of information provided, the quality and dedication of the speakers, and their research which provided new therapies to allow patients to live longer. Myeloma Australia has grown into a very professional organisation, advocating on behalf of patients and keeping us informed of the latest information. All of this inspired us to help by donating.

Q: What keeps you busy?

A: I come from a large, very close family and we spend a lot of time together. We are members of our local church community who provide much support. My husband Brian is my carer, and we find holidays that I can enjoy as I am unable to walk very far. We love going for drives and eating out. I like gardening – it's a great way to exercise.

Q: What message would you send to people who are living with myeloma?

A: I remember my specialist telling me this is my journey, and it will be different to anyone else's. When things go wrong, it's important to have confidence in our doctors, and not to compare ourselves to others. We must stay fit and strong in our outlook, to keep calm (yoga and meditation help) and have belief in yourself. This can be difficult but keep trying. I have my faith to call on to help me through the tough times. One last thing – don't Google, it only makes you more anxious.

Q: How did you first hear about myeloma?

A: When my brother rang me to say that he had been diagnosed with it. He had spent one week in hospital with pneumonia and had struggled with some pain in his legs and very cold hands before that. I'd never heard of myeloma before then.

Q: As a donor of Myeloma Australia, what makes you passionate about the cause?

A: Finding a cure, or at least ways to increase the life expectancy for those living with myeloma, requires research, which requires money. I believe these advancements will come in time, and I'm glad to feel a part of that via my contributions.

Q: What keeps you busy?

A: I'm the Managing Director at Optimum Pensions, so I'm currently trying to persuade Australian retirees to purchase longevity protection when they retire. I love to travel and spend time with my family. I love walking along the beach and flying kites. I also help mentor two small start-up businesses. I like donating to causes that will make the world a better place.

Q: What message would you send to people who are living with myeloma?

A: Enjoy your life as best as you can. Learn as much about myeloma as possible, then follow the guidelines and your doctors' advice. Participate in research projects and trials. Never give up – on anything – every one of us has a reason to be here.

Q: What message would you send to other people who are considering becoming donors of Myeloma Australia?

A: The cause of myeloma is not yet known and there is still no cure. There ought to be more support available for those living with myeloma, and far more research into myeloma causes, treatment and a cure. Your investment in myeloma might be one of the best investments that you've ever made.

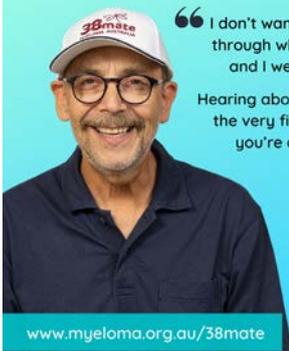


Article written by Olivia Myeza,
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Myeloma Australia is a registered not-for-profit organisation and all donations made are tax-deductible.

Meet Henry

Henry became a 38mate in 2015



“ I don't want others to go through what my family and I went through. Hearing about myeloma for the very first time when you're diagnosed. ”

www.myeloma.org.au/38mate



Meet Linda

Linda has been caring for a 38mate since 2004



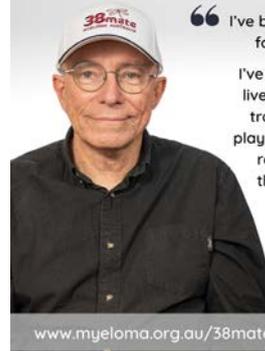
“ In the beginning my carer's role was immediate, intense and prolonged for approximately 6 months. Then life went back to normal, albeit with the shadow of myeloma. ”

www.myeloma.org.au/38mate



Meet Peter

Peter became a 38mate in 2004



“ I've been relatively stable for five years now. I've been able to retire, live a pretty good life, travel, and continue playing in a professional rock band despite the side effects of treatment. ”

www.myeloma.org.au/38mate



Meet Natalie

Natalie became a 38mate in 2016



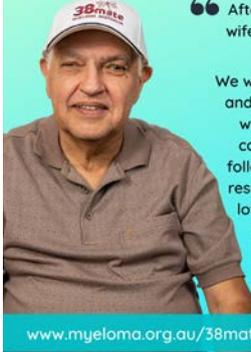
“ Being a mum of two young boys I was really overwhelmed and scared. I knew if this was going to be my life I needed to focus on all the good stuff I already had as a base. ”

www.myeloma.org.au/38mate



Meet Nimo

Nimo has been caring for a 38mate since 2006



“ After investigations, my wife was diagnosed with myeloma. We were in complete shock and were confused as to what this unheard of cancer was. This was followed by denial, fear, researching, anger, and lots of scary feelings, finally accepting. ”

www.myeloma.org.au/38mate



Meet Pana

Pana's dad became a 38mate in 2014



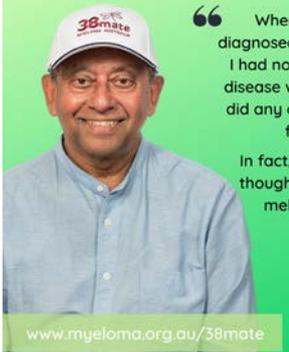
“ While Dad stayed positive and fought to the final hour through his 4 year journey with myeloma; his battle, pain and passing will be a scar that is felt forever by me, my family and all those who met him. ”

www.myeloma.org.au/38mate



Meet Ray

Ray became a 38mate in 2016



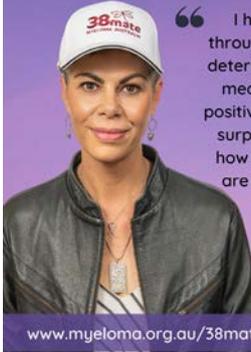
“ When I was first diagnosed with myeloma, I had no idea what this disease was and neither did any of my family or friends. In fact, most people thought that I had a melanoma. ”

www.myeloma.org.au/38mate



Meet Kiri

Kiri became a 38mate in 2019



“ I have learnt that through sheer strength, determination, amazing medicine and a very positive mindset you can surprise yourself with how strong you really are when faced with adversity! ”

www.myeloma.org.au/38mate



We would like to acknowledge and thank our myeloma advocates Henry, Linda, Peter, Natalie, Nimo, Pana, Ray and Kiri for taking the time to share their stories. We would also like to thank CVP Events, Film and Television and Mars Photography for helping us bring it all together.

Inaugural myeloma awareness campaign

38 Australians are diagnosed with myeloma every week. Despite this, many people have never heard about myeloma until they or a loved one are diagnosed with it. This May, as part of National Myeloma Awareness Month, Myeloma Australia set out to change this by launching the inaugural 38mate awareness campaign. The campaign aimed to raise awareness about myeloma and show solidarity and support to the 20,000 Australians currently living with myeloma.

The 38mate campaign had two components – a series of short videos and a 38mate cap.

The video series shone a light on myeloma and told some of the stories behind the statistics of 38 new diagnoses each week. During May we shared the videos across social media, on our website, during myeloma information and support groups and seminars as well as in Rotary Club meetings.

The main 38mate video was released on 1st May in conjunction with the first day of National Myeloma Awareness Month. So far, this video has been viewed over 24,000 times, a number we could have never imagined when we first considered this initiative. Throughout the month of May, we continued to release a series of eight short videos. Each of these videos tells the story of someone who is living with or who is affected by myeloma. These videos give a rare and personal insight into the lives of people affected by myeloma. Our 38mate advocates shared their stories openly in the hope of raising awareness, as in each case they had not heard about myeloma until they or a loved one were diagnosed.

In addition to the series of videos, a 38mate cap was – and still is – available to purchase from our webstore. The cap was designed to be a conversation starter about myeloma, both in the real world and on socials. Again, we could have never imagined just how supportive and excited our community would be. So far, we have sold 1,000 caps*!

We are grateful to be a part of an initiative that not only builds awareness, but also gives a voice to those living with myeloma. Throughout May we have heard some beautiful stories and seen some wonderful photos of people proudly wearing their cap out in their community. Many ripple effects of impact have been created by this campaign, too many to count or mention here.

Myeloma Awareness Month wrapped up at the end of May, but the 38mate initiative does not end there. Myeloma Australia will continue to advocate for and share the stories of those affected by myeloma in the hopes that awareness grows in our community and that the first time a person learns about myeloma isn't when they or a loved one is diagnosed.

We will continue to sell 38mate caps so that you, our supporters and advocates, can start conversations about myeloma whilst out in your community. Continue to use the hashtag #38mate on your socials to keep the conversations going.

If you would like to throw your weight behind 38mate, you can still buy a cap and share the videos on your socials.

Visit our 38mate page to learn more
www.myeloma.org.au/38mate

38mate introduction video has reached 24,000 people via socials

Series of short videos have reached 14,000 people via socials

1,000 caps sold so far!

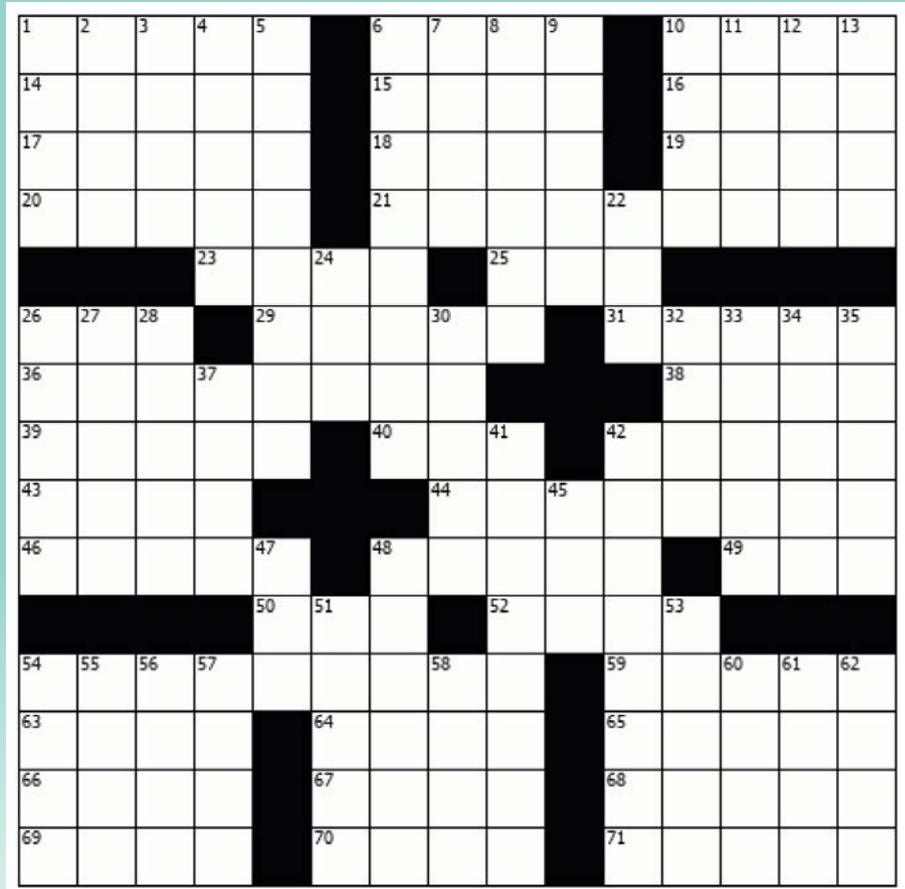
** At the time of printing*



Exercising the Brain



One of the most common effects of myeloma and associated treatments on the body is impaired cognition, otherwise known as chemo brain or brain fog. This can present as difficulty concentrating, short term memory loss, impaired ability to find words in conversation, difficulty learning new skills and mood swings. These symptoms can be even further compounded by the fatigue that is also caused by both myeloma and its treatment. Some strategies to improve cognition include daily gentle exercise, adequate food and fluid intake and exercising the brain with puzzles, craft projects or learning a new hobby. If cognitive impairment is having a significant impact on the ability to function, a psychologist can help by way of cognitive rehabilitation.



ACROSS

1. Hold tightly
6. Light source
10. Eye amorously
14. Heart artery
15. Double-reed instrument
16. Dry
17. Trotter's kin
18. Not theirs
19. "Newsweek" rival
20. Beginning
21. Respected leader
23. Mellow
25. Deep
26. Fitting
29. Feel 31. Wear away
36. Prime Minister Thatcher
38. Goofs
39. Japanese, e.g.

40. Carter's party (abbr.)
42. Legendary stories
43. Guess 44. Scenic view
46. Hot sauce
48. Fall flower
49. Negative vote
50. Ripken, Jr.
52. Wide-spouted pitcher
54. Motorboat feature
59. Lowest tides
63. Own
64. Change direction
65. Artist's stand
66. Cake decorator
67. Diva's song
68. Spectacle
69. Fasting time
70. Whirl
71. Be upright

DOWN

1. Guitar device
2. Bank transaction
3. Circle sections
4. Guide
5. Supporting one political group
6. Made less tight
7. Border on
8. Group spirit
9. Basil sauce
10. Horse feed
11. Bleak
12. South American capital
13. Adam's garden
22. Flock mother
24. Each
26. Stockpile
27. Macaroni, e.g.
28. Courtroom event
30. Short distances

32. Raise
33. Church instrument
34. Serious play
35. Composition
37. Yaks
41. Motherly
42. Pain
45. Never used
47. Expert
48. Attraction
51. Church feature
53. Respond
54. Dr. of TV
55. Speed contest
56. Toaster
57. Jaunty
58. Huron's neighbor
60. Not ashore
61. Actor Sean
62. Winter toy

answers on page 23

News from Australasian Leukaemia and Lymphoma Group (ALLG)

The ALLG is the only not-for-profit collaborative clinical trial group in Australia and New Zealand, delivering research projects focused on blood cancers. We are a for-purpose organisation dedicated to delivering clinical trials to achieve better treatments and better lives for patients with blood cancer.

ALLG Clinical Trials

Current Myeloma Trials

MM22 – leading doctor Professor Andrew Spencer

The FRAIL-M trial is evaluating the most appropriate treatments for patients with newly diagnosed, transplant-ineligible multiple myeloma, taking into consideration patient frailty (weakness). This is an early phase randomised study that will recruit 300 patients across Australia and New Zealand. ALLG is thankful to the Australian Government's Medical Research Future Fund for funding to run this trial.

We have recently opened a Teletrial centre for MM22 at Latrobe Regional Hospital, linked to the Alfred Hospital.

Recruiting Hospitals – VIC – Alfred, Sunshine; NSW – Calvary Mater Newcastle, Nepean Hospital, Concord Hospital, Tamworth Hospital; QLD – Princess Alexandra, Townsville Hospital, Sunshine Coast University Hospital, Toowoomba Hospital; SA – Royal Adelaide; TAS – Royal Hobart; NT – Royal Darwin.

MM23 – leading doctor Professor Hang Quach

The SeaLAND trial is a phase III randomised study evaluating a new treatment option called Selinexor in maintenance therapy, versus the standard maintenance therapy for post-autologous stem cell transplant patients. This is the only study globally assessing this new treatment option for patients with newly diagnosed multiple myeloma.



Better treatments...
Better lives.

MM23 has opened 11 sites across Australia and New Zealand in 2021, and the investigating team is excited to embark on this journey with all of the investigators and ALLG clinical trial site teams at the participating sites, working together towards improvements in therapy for multiple myeloma.

Current Recruiting Hospitals – VIC – St Vincent's Melbourne, Austin Hospital, Alfred Hospital, Geelong Hospital, Peter MacCallum Cancer Centre; NSW – Concord Hospital, Orange Health Service, Border Medical Oncology; SA – Royal Adelaide Hospital; QLD – Townsville Hospital, Princess Alexandra Hospital. More hospitals to open in coming months.

What's New

The ALLG has another new myeloma trial in development, due to open for recruitment in 2021.

MM24 – leading doctor Dr Simon Gibbs

This is an international Amyloidosis trial, in collaboration with the French Myeloma Group IFM. It will evaluate a new treatment for relapsed/refractory amyloid patients at 4 sites across Australia. ALLG is proud to bring this important international trial to Australia. We are working closely with our French colleagues and aiming to open this trial in Australia in late 2021.

For More Information

For more information about the ALLG and myeloma clinical trials, please visit <https://www.allg.org.au/clinical-trials-research/current-clinical-trials/>. You can also speak with your treating physician to find out more about ALLG trials.

News from Australasian Myeloma Research Consortium Update

Throughout Autumn, as we continue to recruit and open new sites for our existing studies, AMaRC has been making progress with our trial development activities.



Currently recruiting trials

- **FRAIL-M (MM22) study – Prof. Andrew Spencer** – This study aims to look at use of lenalidomide and/or bortezomib based on a patient frailty (weakness) score to identify optimal treatment for myeloma patients.

Recruiting hospital sites – 1 new site

- VIC – Alfred Hospital, Sunshine Hospital
 - NSW – Concord Hospital, Nepean Cancer Care Centre, Tamworth Hospital
 - QLD – Princess Alexandra Hospital, Sunshine Coast University Hospital, Townsville Hospital
 - SA – Royal Adelaide Hospital, Queen Elizabeth Hospital (new)
 - TAS – Royal Hobart Hospital
 - NT – Royal Darwin Hospital
- **I-RIL study – Prof. Hang Quach** – This study explores the addition of isatuximab in specific cases to improve treatment for patients already receiving lenalidomide and dexamethasone to treat newly-diagnosed myeloma

Recruiting hospital sites

- VIC – Alfred Hospital, St Vincent's Hospital, Epworth Freemasons
 - NSW – Calvary Mater Newcastle, Border Cancer Hospital, Concord Hospital, Nepean Cancer Care Centre
 - SA – Flinders Medical Centre
 - TAS – Royal Hobart Hospital
 - WA – Fiona Stanley Hospital
- **BelaCarD study – Prof Hang Quach** – The BelaCarD study explores a combination of belantamab, carfilzomib and dexamethasone to treat patients with relapsed/refractory myeloma.

Recruiting hospital sites

- VIC – Alfred Hospital, St Vincent's Hospital

AMaRC contact

Website: www.amarconline.org
Email: amarc@alfred.org.au
Twitter: @amarconline



News from the Myeloma and Related Diseases Registry (MRDR)

The MRDR has now reached 4,500 patients. A big thank you to all participating sites on this achievement. Special mention to Launceston General Hospital who entered the 4,500th patient. The latest site to receive local approval to participate in the registry is Griffith Hospital; it is exciting to see our regional representation increasing.

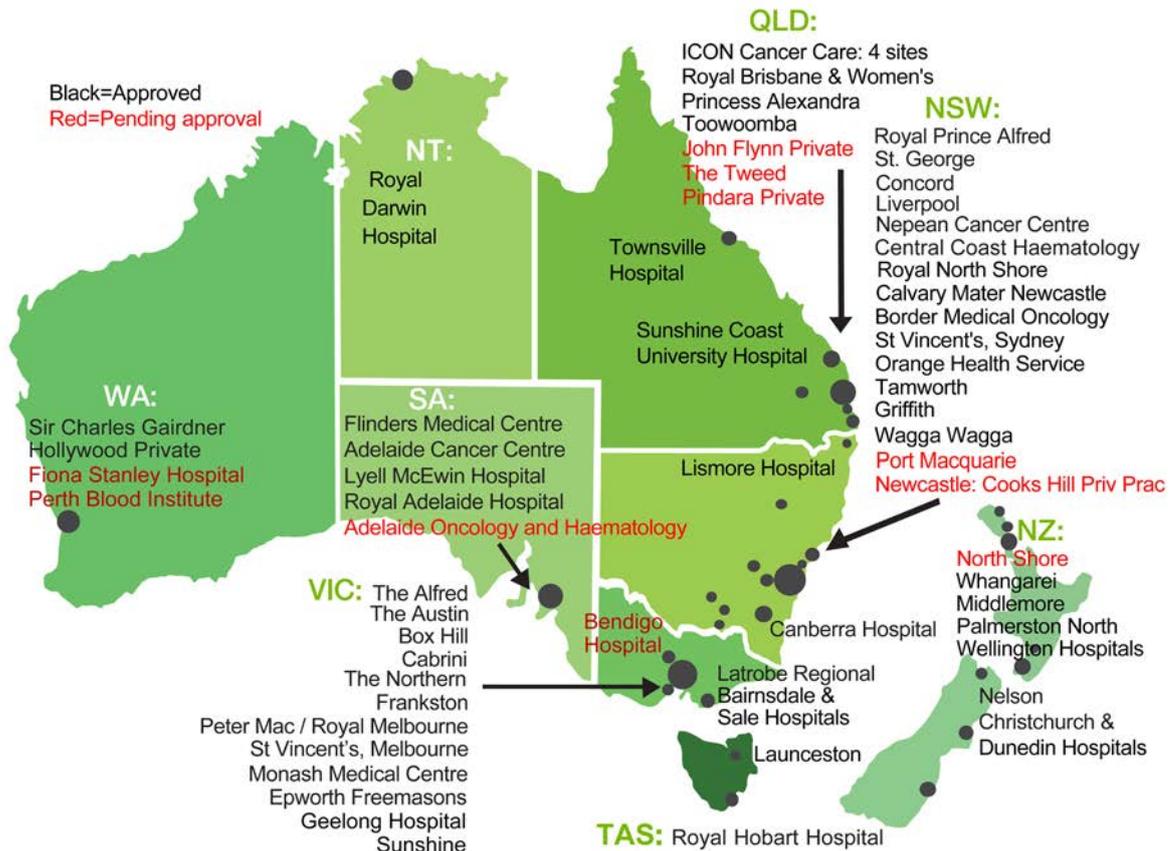
We are pleased to report that another journal article using registry data has been published, "The Myeloma Landscape in Australia and New Zealand (ANZ): The First Eight Years of the Myeloma and Related Diseases Registry (MRDR)" by Dr Krystal Bergin and colleagues. This is a great example of how the registry data can be used. Access the paper via this link: [10.1016/j.clml.2021.01.016](https://doi.org/10.1016/j.clml.2021.01.016)

The MRDR team are looking forward to the Blood 2021 conference in Adelaide. Four proposals for presentation at the conference have been submitted using registry data on a diverse and interesting range of topics. Topics

explored include the impact of quality of life on outcomes in multiple myeloma (MM), the use of tandem autologous/ allogeneic stem cell transplants in selected patients with relapsed MM, causes of death in multiple myeloma, and the impact of the addition of biomarkers to the criteria for MM diagnosis (introduced in 2014). Submitting authors range from members of the steering committee to a student who has worked with the MRDR team. We are pleased to put this valuable data to work!

If you are interested in participating in the registry, ask your treating specialist if your hospital contributes data to the MRDR and if you are eligible to participate. If so, you will receive a patient information sheet about the registry including how to opt out if you change your mind.

To contact the MRDR phone: 1800 811 326 or email: sphpm-myeloma@monash.edu. Website: mrdr.net.au



What's Happening

Community Engagement & Fundraising

I am pleased to introduce to the members of the NSW myeloma community Robert O'Brien, our NSW Community Engagement & Fundraising Executive. Robert can be emailed at: robert.obrien@myeloma.org.au A full bio about Rob will appear in the next edition of MyeNews.

Despite the cancellation of the Perth HBF community walk/run event in May, we are pleased that Team Myeloma will have the opportunity to gather at the following events:

Sunday 25th July: Run Melbourne, Melbourne
Sunday 19th September: city2bay, Adelaide
Sunday 17th October: city2surf, Sydney

If you are keen to be a part of Team Myeloma at one of these events please get in touch with me and I will happily send you the appropriate details. If you have thoughts as to possible Team Myeloma events in your town, city or region, do please let me know. Team Myeloma events do not have to be limited to running events; many of you will remember the cover of *MyeNews* from June 2019 that featured the spectacular picture of a Team Myeloma group at Everest Basecamp!

** Event dates subject to change, please check relevant websites for further details.*



In late July our latest Myeloma Australia/Charity TV Global Ambassadors will be heading off on their Adventure of a lifetime – to a location which will only be revealed to them on the first morning of their adventure.

We are currently planning our third adventure, which will take place in the latter stages of 2022. If you're interested in learning a little more about this opportunity please let me know.

There have been several community fundraising events that have been held in the early part of 2021 – these have included marathon runs, jam making, a month of 'no junk' eating and head-shaves. As you can see from this small sample, fundraising concepts need only be limited by one's own imagination! After such a challenging 2020 it is so very encouraging to see the myeloma community continuing to support the work of Myeloma Australia. Thank you to you all.

And as always, do please reach out to me (and now to Rob if you're in NSW) with your community engagement & fundraising ideas. We are here to help and love helping you establish successful events.



Matt Maudlin
Community Engagement & Fundraising Manager
M: 0407 891 052
E: matt.maudlin@myeloma.org.au



good2give

Did you know that you can donate to us through your pay? It's easy and quick, tax benefits are immediate and there's no need to organise receipts at the end of June. It even has the possibility to double your donation to us!

We're listed on the Good2Give workplace giving platform. Scroll to the bottom of www.good2give.ngo and see if your employer is one of the 150 companies in the scroll bar. If your company isn't yet on Good2Give, direct your corporate responsibility or payroll teams to www.good2give.ngo and suggest they request a demo.

Workplace giving streamlines our financial management of corporate donations and reduces our administration. Ninety nine per cent of all donations reach charities on the Platform, and 70 per cent of the companies match their employee donations!

You can even fundraise for us if your employer is listed on Good2Give, and channel your donations through workplace giving, again, potentially doubling your result!



Any questions? Please contact Matt at Myeloma Australia: matt.maudlin@myeloma.org.au

What's Happening



New South Wales

It has been an exciting few months for team NSW as we welcome two new staff members to our Sydney office.

Diana Yun joins us as a new Myeloma Support Nurse. She will be working Thursday and Friday from our Sydney office and she looks forward to speaking with you via the support line or meeting you at one of our support groups soon!

We are also fortunate to have had Robert O'Brien join us as our NSW executive for Community Engagement and Fundraising. Robert brings a wealth of knowledge and experience to this role and is a welcome addition to our team. If you have any ideas or want to be involved in any volunteer or local fundraising activities, please get in touch with him.

May has been busy as we acknowledged National Myeloma Awareness Month! It was wonderful to join with our colleagues and friends around the country to present the online seminars. We also enjoyed some smaller local events during the month – a morning tea in Newcastle, an afternoon tea on the Central Coast and our Q&A session with Dr Sylvia Ling in Sydney.

Our information and support groups continue around the state and it has been so wonderful to be able to meet in person again for many of them. We have enjoyed both informative sessions like our Q&A session with Dr Wojt Janowski in Newcastle in April, as well as more informal 'Cuppa and Chats' fostering community connection and offering the chance to catch up with others living with myeloma.

We are looking forward to starting new support groups in the Nepean/Blue Mountains and Port Macquarie areas, as well as re-establishing our face-to-face groups in regional areas like Tamworth and Orange. Some of our groups are still running via Zoom online platform or as a 'fusion' of both Zoom and face-to-face. Please check the Myeloma Australia website events calendar for details of upcoming groups or contact one of our NSW Myeloma Support Nurses for more information.

Myeloma Support Nurses – Jacqui Keogh, Juliet Hill, Catherine Bowley and Diana Yun!



Queensland

May is a big month for our Myeloma nurses and Tash and Megan have been representing Myeloma Australia at several events this past month.

We were lucky enough in April to chair a national educational meeting for health professionals for the launch of Darzalex hosted by Janssen here in Brisbane. This was a fantastic evening for health professionals to learn about Daratumumab and its applications in clinical practice now that it is funded by the PBS in 1st relapse of myeloma.

May 8th was also the bi-annual Amyloidosis Patient Workshop where we had many wonderful volunteers from patients, doctors, nurses and a few kids all pitching in to help this day be as successful and as informative as possible. Myeloma Australia sincerely thanks Dr Peter Mollee of our MSAG committee, Dr Emad Abro, Carmel Woodrow and Pat Kneely for passionately advocating for those living with both amyloidosis and myeloma.

On May 22nd we held our National Myeloma Awareness Month event in the beautiful space at Walkabout Creek Function Centre. We had guest appearances from Dr Jason Butler, haematologist and Dr Tina Skinner, exercise physiologist as well as our 38mate awareness campaign presentation. We enjoyed a relaxed morning together with a joint cause, to dispel fear and spread awareness about myeloma.

Going forward, Tash and I hope to keep spreading awareness for myeloma in person with information displays in hospital clinics. You may have spotted Megan at the Royal Brisbane Hospital or Tash at Chermside ICON. If you would like us to visit your clinic, please drop us a line.

Our support groups around southeast Queensland are back in full swing and have been wonderfully attended in the past couple of months. Please remember to check the website for updates or call Megan or Tash if there has been any covid updates close to a planned meeting.

If you have been unable to attend a group in person, we encourage you to watch our online seminars as they are so informative or join us for our regular Zoom support groups.

Myeloma Support Nurses – Megan McDowell and Natasha Clarke

Left: Megan & daughter Madeline representing Myeloma Australia at the Brisbane Amyloidosis patient Seminar.

Right: Megan and Tash chairing the Janssen Launch of Darzalex, a national education evening for health professionals.



Photos provided and used with permission



South Australia

SA has had a bumper few months with two new support groups launching in May and June as well as a local event for Myeloma Awareness Month. We were excited to launch the new Northern Adelaide support group in May at the lovely Para Hills Community Hub venue. The SA team were lucky enough to receive a grant from the Flinders Foundation and Tour de Cure charity to establish a new support group on the Fleurieu Peninsula.

Our first meeting on the 9th June will also include a Q&A session from Dr Tom Day, haematologist, who has a practice in Victor Harbor. Our regular support groups have continued in Central and Southern Adelaide, Mid-North (Kapunda) and in the South-East (Coonawarra). These have included some great topics and speakers like Jess Church, occupational therapist. For Myeloma Awareness Month at a state level, we focused on mental wellbeing with an art therapy session with Glenda Needs an art psychotherapist – it certainly gave all in the room a lot of food for thought! Jo and Alicia have also participated in two nurse education events, focusing on myeloma for nurses and Daratumumab. May also saw Jo co-host the annual amyloidosis patient seminar at SAHMRI. We look forward to connecting with even more of the myeloma community in the coming months through our expanded support group service.

Myeloma Support Nurses – Alicia Hopper & Jo Gardiner

*Left top: Amyloidosis patient day.
Left below: Daratumumab nurses evening
Right: Jess Church.*



Tasmania

In April the Southern Tasmania Support Group met at Risdon Dam for a picnic. Luckily the weather was kind, and after a catch-up with all the news, a few members enjoyed a walk by the water. In the north, Ryan Gilmour, from the North West Community Legal Centre, gave a very interesting and educational session on estate planning, to both the Burnie and Devonport groups. At the Launceston meeting, Michelle Nicholson, a senior social worker, spoke about 'Minding the Mind' while living well with chronic pain. It was an interactive presentation and well received.

Rachel, one of our Victorian support nurses, flew to Hobart to help with National Myeloma Month on May 7th at the Royal Yacht Club, Sandy Bay. Dr Nick Murphy held a relaxed Q & A session, very much appreciated by the guests. Following Nick and a lovely afternoon tea, Director Jane Hutchison, and lawyer Alex Davidson, both with the Hobart Community Legal Service, discussed wills, guardianship, and advanced care directives, increasing our knowledge with an informative talk. Rachel stayed on to help the Australian Amyloidosis Network present their workshop the following morning at the Bellerive Yacht Club.

In the upcoming months, support group topics will include exercise physiology, mindfulness, a Q&A session with Dr Usi Vithanarachchi and a presentation about the 'Get the Most out of Life' program.

Myeloma Support Nurse – Deborah Thompson



What's Happening



Victoria

Since the last MyeNews we have had so many things to celebrate. Congratulations to Laura and Sam on the birth of baby Clover. Both mum and bub are doing well, and we enjoyed their visit to Head Office. We welcome Emma Huybens into Laura's maternity leave cover for the next year. Emma comes to us with a wealth of myeloma knowledge.

Emma has a real passion for educating her patients to make informed decisions about their care. Emma hit the ground running and we were able to get out to regional Victoria and run the La Trobe area Information and Support Groups. Thank you to all the members who joined us. We stayed overnight in Metung and enjoyed getting out in the fresh air with the beautiful landscape and tasting the local delights.

May has been a very busy month preparing for all our online events whilst running our support groups. We have been overwhelmed with new members at our Mildura, Mornington Peninsula, Ringwood and Bairnsdale support groups. We are so thrilled with the response from these communities.

If you would like to join one of these new groups, please reach out to one of us and we can give you the details.



We were privileged to host the first National Myeloma Month Seminar for 2021 online. Rachel presented on supportive care in myeloma, while Emma and EJ chaired the seminar. We were joined by a great line up of speakers that being Dr Hasib Sadiqi, Brian Rosengarten, Steve Roach, Daniel, Christine and Natasha Clarke. If you were not able to attend the seminar you are able to watch a play back on our website.

We hosted our first face-to-face event on the 22nd May since November 2019, with a morning tea and Q&A session with Professors Hang Quach and Simon Harrison and joined by Kath Rutherford, a myeloma community member. This was a lovely morning enjoyed by all catching up with old friends and reconnecting. Some of the themes that arose were around clinical trials, vitamins, skin cancers and caring for oneself. Thanks to our panel Hang, Simon and Kath for offering their time and answering all the wonderful questions that were posed. It was so nice to see everyone in person.

Myeloma Support Nurses – Emma-Jane Furphy, Rachel McCann and Emma Huybens



*Above: Emma & Emma-Jane.
Left: Rachel & Emma-Jane.*



Western Australia

It's been a busy few months for the WA myeloma support team. We really enjoyed being able to host information and support groups as face-to-face events while still offering the flexibility for people from the Myeloma community to be able to attend groups virtually via Zoom.

We welcomed back face-to-face support groups in the South Metro, Perth Hills, and North Metro areas of Perth, and Narelle and Dan were very pleased to be able to take the face-to-face support on the road to the regional communities of South West WA, hosting two support groups in Busselton, 2.5hrs drive south of Perth. A diverse range of topics were discussed, Narelle presented information on new and emerging therapies in myeloma. It was great to see those challenged by the vast distances of regional WA being able to gather, interact and support one another in a very pleasant location.

In April we hosted a "Younger Persons with Myeloma" online Information & Support Group and we were able to welcome an interstate attendee joining in with the WA community. It was a fantastic session of sharing and understanding of the nuances and unique needs of the younger population with myeloma.

As part of the national Myeloma Awareness Month program, Narelle and Dan hosted a fantastically attended face-to-face event – "A Q & A with a Haematologist." Dr Brad Augustson kindly volunteered his time and expertise to listen to and answer myeloma related questions from the 45 attendees over two sessions. There was again, a diverse range of topics covered which generated some vigorous discussion and sharing of information.

The upcoming months will see us continue our Perth Metro (North, South and Perth Hills), Regional, Partners and Carers and Younger Person information and support groups, and we will be planning for health care professional events, as well as continuing to promote myeloma awareness through the 38mate initiative and through other opportunities. Event and group dates will be available as soon as we have them finalised and details will be available on the Myeloma Australia events calendar, through mail outs and by contacting Narelle or Dan.

New haematology centres are being set up regionally throughout the state of WA and we hope to extend our support and information services further, so watch this space!

Myeloma Support Nurses – Narelle Smith and Daniel Berk



Narelle & Daniel

Special COVID-19 edition – What we have learned to date about Myeloma and COVID-19

Recovery of people with myeloma from active COVID-19 infection

These papers were published in 2020 evaluating recovery of people with myeloma and subsequent recommendations for clinicians:

A tertiary centre experience of multiple myeloma patients with COVID-19: lessons learned and the path forward; Bo Wang, et al; Journal of Hematology & Oncology volume 13, Article number: 94 (2020)

Our institution has treated over 2000 COVID-19 patients during the pandemic in New York City. Mount Sinai Hospital has a large and diverse multiple myeloma (MM) population. Herein, we report the characteristics of COVID-19 infection and serological response in MM patients in a large tertiary care institution in New York.

Of 58 myeloma patients diagnosed with COVID-19, 36 were hospitalised and 22 were managed at home. In the total cohort, 14 patients (24%) died. Older age (> 70 years), male sex, cardiovascular risk, and patients not in complete remission (CR) or stringent CR were more likely to be admitted to hospital. Among those hospitalised, there was a significant association between elevated blood inflammatory markers, severe hypogammaglobulinemia (immunoparesis), non-White race, and mortality. Drug exposure and MM disease status at the time of contracting COVID-19 had no bearing on mortality. These findings pave a path to the identification of vulnerable MM patients who need early intervention to improve outcomes in future outbreaks of COVID-19.

Clinical features associated with COVID-19 outcome in multiple myeloma: first results from the International Myeloma Society data set. Ajai Chari et al; Blood (2020) 136 (26): 3033–3040.

<https://doi.org/10.1182/blood.2020008150>

This retrospective study describes the baseline characteristics and outcome data of COVID-19 infection in 650 patients with plasma cell disorders, collected by the International Myeloma Society to understand the initial challenges faced by myeloma patients during the COVID-19 pandemic. Multivariate analysis found that only age, high-risk MM, renal disease, and suboptimal MM control remained independent predictors of adverse outcome with COVID-19 infection. The management of MM in the era of COVID-19 requires careful consideration of patient- and disease-related factors to decrease the risk of acquiring COVID-19 infection, while not compromising disease control through appropriate MM treatment. This study provides initial data to develop recommendations for the management of MM patients with COVID-19 infection.

Should myeloma treatment continue during the pandemic?

Don't Compromise Myeloma Care Due to COVID-19 Pandemic!; Nikhil C. Munshi^{1,2} and Kenneth C. Anderson¹, Blood Cancer Discov 2020;1:1–3

It has been reported that myeloma patients who are infected with COVID-19 recover better when the myeloma treatment is continued. It seems the COVID-19 is harder to treat in the face of uncontrolled myeloma, so stopping myeloma therapy is currently not recommended.

Does the vaccine work in people with myeloma?

At the time of MyeNews publication, one paper has been published looking at how effective COVID-19 vaccines are in people with myeloma. This is early data which was published after people had received the first of two planned vaccine doses.

Response to first vaccination against SARS-CoV-2 in patients with multiple myeloma; Sarah Bird, Aikaterini Panopoulou, Robyn L Shea et al; The Lancet Haematology, Published: April 19, 2021; DOI:[https://doi.org/10.1016/S2352-3026\(21\)00110-1](https://doi.org/10.1016/S2352-3026(21)00110-1)

In a cohort of 93 patients with a median age of 67 years, after their first dose of either Astra Zeneca or Pfizer vaccine, just over half the study group (56%) were able to produce IgG antibody to the COVID-19 virus. Almost three quarters (70%) had an increase in their total antibody response. There was no difference between the Pfizer (n=48) and AstraZeneca (n=45) vaccines, supporting the current advice for patients over 50 years old with multiple myeloma to receive whichever is available. Overall, the response to the vaccines in people with myeloma was lower than the control group who had almost complete response (99%). The strongest association with poor response to vaccination was having poorly controlled multiple myeloma, suggesting that active disease might play a major role in vaccine effectiveness.

Have you had treatment for myeloma?

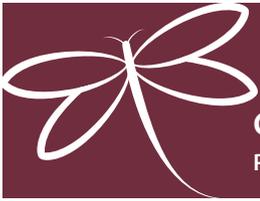
We are seeking your opinion.

Myeloma Australia is partnering with the Peter MacCallum Cancer Centre to investigate the best way to assess health-related quality of life in those living with myeloma. We want to know which aspects of quality of life are most important to you and find out if the standardised forms used to measure this actually ask the right questions.

If this sounds like something you'd like to help us learn more about, please get in touch and we'll send you more detailed information about what's involved.

Contact: Hayley Beer, Myeloma Clinical Nurse Consultant,
Peter MacCallum Cancer Centre and Manager,
Programs and Services, Myeloma Australia
e | hayley.beer@petermac.org t | 0447 332 294





Calendar of Events 2020

Groups / events are subject to change at short notice.

Please check the website for a more up to date schedule. <https://myeloma.org.au/event-calendar/>

Where possible, our Myeloma Support Nurses are working hard to put COVID-safe plans in place to allow face-to-face get-togethers with our Information and Support Groups.

We thank everyone for their patience and for embracing the online groups via Zoom. We plan to move forward making the most of both face-to-face and online gatherings to allow as many people as possible to connect with each other and our team.

Listed below are the current locations of our Information and Support Groups being held across the country. To find out specific Zoom login details for each group or if they are being held face-to-face, please go to our website.

<https://myeloma.org.au/events>

For further information or help joining a group via Zoom, please contact your state's Myeloma Support Nurses

Information and Support Groups National

- All States – Younger Persons'

For enquiries, please contact:

Myeloma Support Nurses

E: nurses@myeloma.org.au

M: 1800 693 566

Information and Support Groups ACT

- Canberra

For enquiries please contact

Jacqui Keogh

E: jacqui.keogh@myeloma.org.au

M: 0426 404 230

Information and Support Groups NSW

- Central Coast
- Forster / Taree
- Liverpool
- Lismore
- Mid North Coast Cuppa & Chat
- Newcastle
- Port Macquarie
- Orange / Mudgee / Dubbo
- Regional NSW Cuppa & Chat
- RPAH
- Tamworth
- Westmead
- Younger Persons'

For enquiries, please contact

Jacqui Keogh

E: jacqui.keogh@myeloma.org.au

M: 0426 404 230

Juliet Hill

E: juliet.hill@myeloma.org.au

M: 0433 511 554

Catherine Bowley

E: catherine.bowley@myeloma.org.au

M: 0426 404 766

Diana Yun

E: diana.yun@myeloma.org.au

M: 0452 027 765

Information and Support Groups QLD

- Friday Zoom Cuppa & Chat
- Gold Coast
- Inner North Brisbane
- Inner South Brisbane
- North Lakes
- Sunshine Coast
- Tuesday Zoom Cuppa & Catch Up

For enquiries, please contact

Tash Clarke

E: natasha.clarke@myeloma.org.au

M: 0416 019 585

Megan McDowell

E: megan.mcdowell@myeloma.org.au

M: 0416 019 022

NATIONAL TELEPHONE SUPPORT GROUP (CANCER COUNCIL NSW)



Telephone Support

2nd & 4th Monday every month

Available to those with myeloma

1.30 pm – 2.30 pm (AEST)

Cancer Council NSW with MA NSW

Cancer Council NSW

1300 755 632

E: tsg@nswcc.org.au

Information and Support Groups SA

- Partners and Carers
- Fleurieu Peninsula
- Flinders (Southern Adelaide)
- Fullarton (Central Adelaide)
- Mid-North
- Parra Hills (Northern Adelaide)
- South-East

For enquiries, please contact

Jo Gardiner

E: jo.gardiner@myeloma.org.au
M: 0447 331 165

Alicia Hopper

E: alicia.hopper@myeloma.org.au
M: 0426 716 165

Information and Support Groups TAS

- Burnie
- Devonport
- Launceston
- Southern TAS

For enquiries, please contact

Emma-Jane Furphy

E: EJ.Furphy@myeloma.org.au
M: 0426 404 233

Information and Support Groups VIC

- Albury / Wodonga
- Bairnsdale
- Ballarat
- Beaumaris
- Bendigo
- Berwick
- Coburg
- Geelong
- Horsham
- Kew
- Mildura
- Mornington Peninsula
- Ringwood
- Shepparton

...continues next column

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twitter.com/MyelomaAust_MFA



[myelomaaustralia](https://www.instagram.com/myelomaaustralia)



[Myeloma Australia](https://www.linkedin.com/company/myeloma-australia)

- Sunshine
- Traralgon
- VIC State Cuppa & Chat
- Wangaratta
- Warragul
- Warrnambool

For enquiries, please contact

Emma Huybens

E: emma.huybens@myeloma.org.au
M: 0451 404 203

Emma-Jane Furphy

E: EJ.Furphy@myeloma.org.au
M: 0426 404 233

Rachel McCann

E: rachel.mccann@myeloma.org.au
M: 0433 511 606

Information and Support Groups WA

- Cottesloe
- North Metro
- Partners & Carers
- Perth Hills
- Regional WA
- South Metro
- South West
- Younger Persons'

For enquiries, please contact

Narelle Smith

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M: 0426 404 280

Daniel Berk

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M: 0426 404 310

Answers to the crossword on page 14

C	L	A	S	P		L	A	M	P		O	G	L	E		
A	O	R	T	A		O	B	O	E		A	R	I	D		
P	A	C	E	R		O	U	R	S		T	I	M	E		
O	N	S	E	T		S	T	A	T	E	S	M	A	N		
			R	I	P	E		L	O	W						
A	P	T		S	E	N	S	E		E	R	O	D	E		
M	A	R	G	A	R	E	T				E	R	R	S		
A	S	I	A	N		D	E	M		S	A	G	A	S		
S	T	A	B					P	A	N	O	R	A	M		
S	A	L	S	A				A	S	T	E	R		N	A	Y
					C	A	L		E	W	E	R				
P	R	O	P	E	L	L	E	R			N	E	A	P	S	
H	A	V	E			T	U	R	N		E	A	S	E	L	
I	C	E	R			A	R	I	A		S	C	E	N	E	
L	E	N	T			R	E	E	L		S	T	A	N	D	

Myeloma Australia is the only myeloma specific support organisation in Australia



Call our **Myeloma Support Line** for advice, and emotional support **1800 693 566**



Learn about myeloma from experts and meet others at our **patient and family seminar workshops**



Find your nearest **myeloma support group** to meet other people



Visit **www.myeloma.org.au** to download the latest information, find support and seminar events etc

Myeloma Support Nurses are on call at

Freecall: 1800 693 566 (1800MYELOMA)

Mon – Fri 9am – 5pm AEST

E: nurses@myeloma.org.au W: www.myeloma.org.au