

MND NEWS

March/April

2020

The newsletter of the
Motor Neurone Disease
Association of Victoria

**Until there's a cure,
there's care.**



MND
AWARENESS
WEEK

MAY 3-9

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Instagram: www.instagram.com/mnd_vic

ABN 44-113-484-160
Reg. Assoc. No. A7518

SUPPORT GROUPS

MND Victoria Support Groups provide opportunities for people living with MND, their carers and interested members of the public to come together on a regular basis. For information about Support Groups contact MND Victoria, phone: 1800 806 632 or info@mnd.asn.au Support Group Meetings:

Western Metro: Last Monday of each month at 12.30 in Footscray.
Coordinator – Christine Robson

Barwon Region: First Monday every second month at 12 noon
Coordinator – Ian Parton

Ballarat Region: Last Friday of each month at 1pm
Coordinator – Bev Phillips

Hoppers Crossing Area: Meet every 4 weeks on Thursday at 1pm
Coordinator – Leanne Dewhurst

Bendigo Area: Meet once a month on a Thursday from 11.30am to 3pm.
Coordinator – Carolyn Hutchinson-Kane

STAFF

Chief Executive Officer: Kate Johnson

Manager Finance & Administration: Megan Crellin

Administration Assistants: Isabelle Lloyd, Rebecca Moussa

Manager Supporter Development: Kathy Nightingale

Supporter Development Officer: Daniel Woodrow

Supporter Development Officer Digital: Steph Cross

Communications Officer: Beryl Chen

Manager Support Services: Jo Whitehouse

Coordinator MND Advisor Service: Janette McDonald

Team Leader MND Advisor/Support Coordinators:

Elizabeth Crask, Eric Kelly

MND Advisors/Support Coordinators:

Ruth McEvoy	Jenny Waites	Lauryn Matheson
Trish Duffy	Sam Mitchell	Michelle Sharples
Fran Hurst	Julie Wilson	Jenny Fuller (Hobart)
Lesley Burcher	David Cox	Emma Wilkinson-Reed (Launceston)
Alex Talvy	Sarah Barratt	

Coordinator Operations: Eric Kuncoro

Coordinator Equipment Service: David Harkin

Equipment Officers: Kathy Walker, Sandra Nicholls

Coordinator Volunteer Programs: Deb Olive

Coordinator Information & Resourcing: Alison Jones

Information & Resourcing Officer: Vacant

FROM THE CEO



The year has certainly taken an unexpected turn with the implications and impacts of COVID-19 unfolding rapidly, and the information and advice changing on an almost daily basis. At MND Victoria, we are closely watching this advice and changing the ways that we work to ensure that we are still able to provide the high-quality care and support needed by our clients, whilst keeping clients, families, volunteers and staff as safe as possible.

The changes we have made to date include:

- Suspension of all face to face visits
- Reduction of the number of staff in the office at any one time, through working at home arrangements
- Delivery of advisory, support coordination, information and volunteer services by video, phone or other remote methods

It is fortunate that, in the last month, we upgraded all of our IT systems, moving to cloud storage/systems. This has enabled our staff to access all IT systems remotely, meaning that they are now easily able to work away from the office. We have also increased our access to, and expertise in, video conferencing systems to ensure that staff has easy access to support clients.

The NDIS have put measures in place to ensure participants can access supports, including:

- The ability to extend plans by up to 24 months, to ensure continuity of support, and to direct planning resources to urgently required plan reviews
- Planning to be done by telephone meetings where possible
- More flexibility in the use of capacity building funds (shifting these to core where necessary)
- An 'action plan' to ensure NDIS participants and families continue to receive the essential disability supports they need

Additional supports are also available to NDIS providers to support their sustainability and ongoing cashflow.

There is more detail about the ways in which we will continue to support our clients in Jo Whitehouse's article inside this newsletter. We look forward to implementing innovative ways to remain engaged and deliver our volunteer and group programs remotely – and to keep things running as normally as possible.

We will continue to provide the latest updates through our website and social media, as information and advice changes.

Please rest assured that we have the needs and safety of our clients and their families at the forefront of all our decision making and will continue to provide high quality services throughout this crisis.

Keep calm, keep well and do get in touch if there is anything further we can support you with.

Until there's a cure, there's care.

Kate



SUPPORT SERVICES



Welcome to autumn! What a challenging time this has become with, dare I mention it, COVID-19 becoming part of our lives.

As with all organisations, we have had to review how we deliver services on an almost daily basis. The health and welfare of our clients, their families and friends, staff and volunteers is paramount, and we have decided to restrict face to face visits for the time being. This means that our advisors and volunteers are unable to visit clients at home or in clinics.

We will still be offering supports and services, but these will be provided remotely either by phone, video conference or email. We know this is not ideal, but think that we will still be able to support clients with most things until life returns to the “new normal”!

For example, we can set up 3 or 4 (or more!) way phone conversations, so that we can all still participate in meetings such as NDIS plan review meetings or Clinic appointments together. If clients have access to a computer, tablet or mobile phone, we can also set up video teleconferences. As planned meetings come up, we will be in touch with clients to find out what is the preferred way that they would like the meeting to take place. We also have instructions available on how to access free videoconferencing facilities. Our staff are up-skilling in working in this way and we are happy to assist any of our clients who may need training/support to use remote technology. Please ask! I know remote contact is not everyone’s cup of tea, but for the time being it is going to become our new best friend!

Our information sessions will be held remotely for the foreseeable future – we are currently looking to set up our information sessions via a remote platform called Zoom. The positive thing about this is that all people from all over the state will be able to join. Please see our website for details as things are constantly changing!

Our Equipment Service is still operating as usual. Our third party providers who deliver and collect equipment are practicing the most up to date infection control procedures. When delivering equipment, they will be asking clients the standard questions recommended by the Chief Health Officer, i.e.

- Has anyone living in the house been asked to practice social isolation?
- Has anyone living in the house got flu like symptoms?
- Has anyone living in the house been overseas in the last 14 days, or had close contact with anyone who has been overseas?
- Has anyone in the house been in contact with someone who has a confirmed case of COVID-19?

If the answer to any of the questions is YES, the equipment will be left in a safe place outside the home and we hope that the client, carer or family member will be able to bring the item(s) inside.

We are also liaising with the key allied health professional staff who prescribe, set up and train people in using equipment, to ensure that we can continue to supply equipment to people who have motor neurone disease.

If you have access to social media, updates on any change to how our services will be delivered as a result of government advice will be put up on Facebook and Instagram, in addition to our website. We also encourage anyone to contact us with any concerns at all in relation to COVID-19 and what the Association is doing to minimise the impact for our clients.

Staff updates

Welcome to Alex Talvy who joined the team at the end of January as an MND Advisor and Support Coordinator working in the Metro Outer East area of Melbourne. Alex has a background as a speech pathologist and prior to joining MND Victoria was working as a support

coordinator. He has been settling into the role and has been making direct contact with our clients who live in the LGA's of Yarra Ranges, Maroondah and Knox.



We will soon be recruiting for the vacant Information Officer role created when Sarah Barratt (nee Wilkie) was appointed as an MND Advisor.

The Support Services team has grown in the last year to a team of 25 staff! – who all work in our MND Advisor and Support Coordinator, Information, Equipment and Volunteering Services.

OTHER SUPPORT SERVICE SNIPPETS!

Living Well Program



Living Well Program, Participant Creighton Parker

I am thrilled to be reporting that our Living Well Program which provides support to people diagnosed with MND and their carers, recommenced in February.

This six-week program includes topics such as Reaction to an MND Diagnosis, Taking Charge of your Health and Living Day to Day. More than anything else, it has proven to be a great forum for people with MND and their carers to get together and share experiences, tips

and to support each other. The first 5 group sessions were held “face to face” at our Canterbury Road office; the last session was successfully run via teleconference as we had moved to “no face to face contact” by this time and had to rapidly change how we ran the group. We plan to run more of these sessions later in the year.

Audit

We successfully completed stage two (and the final stage!) of our required NDIS and ISO audits on the 17th and 18th of February.

Thank you to the 13 MND Victoria clients who the auditors spoke to by either phone, email or text during the two days of our audit. The auditors reported that “Participants interviewed spoke very positively of the sensitive approach MND (Victoria staff) take to providing them with information” and that there is evidence that “MND Support Coordinators are responsive to participants' changing needs and act on them in a timely fashion.”

Assistive Technology for All (ATFA) Campaign

A new campaign has recently been launched asking the Australian Government for a National Assistive Technology Program for people of all ages who are not eligible for the NDIS.

Our experience is that people over 65 do not have the same access to assistive technology as those who are under 65 who are able to access equipment through the NDIS. We feel that this is unfair and support the ATFA campaign. For more information or to sign the petition, please check out the ATFA website -

www.assistivetechforall.org.au

As always, please don't hesitate to contact me if you have any feedback about any of our Support Services.

Jo Whitehouse, Manager Support Services

Email: jwhitehouse@mnd.asn.au

Mobile: 0402 183 140

By Shelley McKean

Like all mums, my mum was the most amazing woman. She lived a selfless and compassionate life, spending most of her life caring for others.

Two weeks before her 21st birthday, her mother unexpectedly passed away. This was of course a shock for the whole family, and the event that changed the course of her life forever. Instantly, her family looked at her and expected her to take over her mother's role. Her father and brother looked to her to run the household, cooking, cleaning, etc.

Her grandmother also looked to mum for help and support. She would be running around for everyone else with no complaints or regards to herself.

As a kid growing up, I remember mum raising my brother and I and dragging us from our home in Croydon to my great-grandmother's house in North Melbourne every Thursday so that she could tend to her needs. She would need to take her to the bank to cash her pension cheque and take her grocery shopping. Once back, she would then need to clean the apartment and get her washing done then get the week's meal preparation done. In addition to our Thursday visits, she would also need to run my great-grandmother around to all her medical appointments as needed.

She did this for about 25 years, all while raising her own family and working part time.

Not long after my nanna passed away, my grandfather's health started to deteriorate. While by now my brother and I were independent, she was now needing to help her stepmother care for her father, running from Wantirna to Pascoe Vale every other day to help with his needs. This went on for about ten years.

Finally, mum thought that it was now time for herself and dad, but that was not to be. At the age of 52, my dad had his first big heart attack. This started a chain of health issues that my dad never fully recovered from. After multiple heart attacks, 3 angioplasties and open-heart surgery, dad's health deteriorated to the point of

needing full time care and supervision. Eventually, Dad was then diagnosed with lung cancer. After 10 years of ill health, dad passed away at the age of 62.

Finally, mum was free of caring for others and was ready to live her life for herself. Her big bucket list must, was to visit Canada and Alaska. In September 2017, her first big dream came true. Mum, my brother, nephew, myself and some close family friends made the one month trip. It was the trip of her life and I'm so glad that I was able to be there to help her fulfil the first of her many dreams.

Unfortunately, that was all she was able to do for herself before she passed away.

In June 2018, she noticed some weakness and muscle wastage in her right hand. Not thinking too much about it, she eventually got around to visiting her GP. From there, she was given a referral to a neurologist to have her carpal tunnel looked at. Within the hour, we were shocked to learn that mum had MND.

As anyone who has been touched by this disease, we felt like we had been hit in the face by a Mack truck and the future we were facing was very daunting.

After a life of caring for others, this was a nightmare coming true for her. We always spoke openly about any end of life needs with each other. Even as a kid, I remember mum saying on multiple occasions that if she ever was in a situation that required 'us kids to wipe her arse, I give you permission to pull the pin'. All of a sudden, it was the future she was facing.

Mum's MND journey was very quick. By October, she was no longer able to drive and was using a ventilator at night. In January 2019, I went to part time work so that I could be home with her more and by March, I had resigned completely to care for her full time. She hated this, she never wanted anyone to put their life on hold for her.

She was a proud woman who even qualified to compete in the Mexico City Olympics as a butterfly swimmer and was now needing full time care.

We were fortunate enough to do one last family trip to Phuket in April. It was a trip we had booked before she was diagnosed with MND, and I know that mum dug very deep within herself to make that trip, our last family memory.

By May, she was ventilator dependant full time, was unable to move on her own and was starting to choke



on water. She was looking down the tunnel of being a 'prisoner in her own body' as she would say.

With euthanasia becoming legal in Victoria on 19 June, she asked me to help look into end of life options for her. This was the hardest thing for me to do. She was my mum, I didn't want her to die, but I also knew what the future held for her and understood that it was a life she didn't want, not just for herself, but for my brother and I as well. So we started her end of life journey together.

With euthanasia, as this was new and doctors weren't sure on what was involved, the hoops and red tape were too much for mum. It was going to take too long. Fortunately for her, she had another choice. As she was now ventilator dependant full time, she made the decision to stop any medical treatment that was prolonging her life. This meant switching off her ventilator. After meeting with all her medical team and the staff at the VRSS, a date was set. Of course, the doctors wanted to be sure she understood what she was asking. Mum's response was that this is the easiest decision she has ever made in her whole life. She had no doubt that this was the right decision for her.

She was given the choice to go through the process at home or in the hospital. As my brother and I had to continue living in the house after her passing, she

wanted to go through this at the hospital.

So, on 25 June, she was admitted to hospital. That night, I stayed with her. We watched some movies and shared the last of her time together. I have always loved travelling, it was my work and life. My bucket list was to step foot on every continent at least once in my life and mum knew that. She made me promise her that I would get to Antarctica, the last continent. She told me that it's ok to be selfish and do things for yourself. While you should always be there for those you love, don't waste your life on others. So, I promised her that I would and get to Antarctica.

She passed away the next day, with her stepmother, son, nephew and me by her side.

That was it, rather than going back to work, I made the 'selfish' decision to fulfill my bedside promise to mum and go to Antarctica. I ended up planning a three month trip through Central America and ending with a two week trip to Antarctica.

Six months after I made my promise to mum, I boarded the plane to start my journey.

I know mum was with me for my whole trip, and I know that she is proud of me.

I'm sure she is now yelling at me to make a new bucket list!

VOLUNTEER NEWS!



MND Victoria is fortunate to have the support of our dedicated volunteers.

While the current situation is challenging and has changed the way many of our volunteers are working, we will continue to do everything we can to engage and support our volunteers to maintain services for people living with MND in our community.

Volunteers working to support people living with MND typically work in the community providing services such as Social Visiting, Hand and Foot Massage, Life Stories, Hairdressing and Bereavement Calls.

In response to COVID-19, MND Victoria has suspended personal visits by volunteers to clients. This is to protect the health and safety of our clients, their families, our volunteers, and is in line with community guidelines.

We are working to develop ways for volunteers to stay connected with clients through phone calls and the use of online technology wherever possible.

MND Victoria volunteers are also essential to community events raising funds and awareness of MND. Recently our volunteers completed another successful Sausage Sizzle at Bunnings Box Hill. While walks and community events have had to be postponed, we are confident that once the current threat is past we will

be busy again with the support of our volunteers.

Of course our volunteers who are usually actively working at the Canterbury office are currently on hold. Impacted volunteer roles include in Reception, Merchandise, Equipment Services and Information and Resources.

We do have a number of volunteers working on specific projects who are able to continue to complete their work remotely.

It is incredible to have such a dedicated and diverse volunteer workforce supporting everything MND Victoria does.

Management of this workforce is a significant commitment of the organisation. Did you know that every person who wants to volunteer goes through a comprehensive process of application, interview and screening to ensure we find a role that suits them and that they are the right person for the role?

This process can take some time but is essential to ensure we meet our Duty of Care to people we are working with in the community and to each of our volunteers. It provides an opportunity for us to get to know each volunteer, their interests, skills and what they offer to share with the organisation. It provides volunteers with opportunity to reflect on what they want and need to get out of their volunteer involvement. This is essential to making successful volunteer matches and to developing strong relationships within our programs.

National Volunteer Week 2020

National Volunteer Week (NVW) is the annual celebration to acknowledge the generous contribution of our nation's **volunteers**. This year, National Volunteer Week will run from Monday 18 May – Sunday 24 May **2020** and will include celebration and recognition events within organisations involving

volunteers across the country. MND Victoria will take time to acknowledge and celebrate the work of our volunteers across the state. The current situation gives us opportunities to look to new and creative ways to recognise and celebrate our volunteers.

This year the theme of National Volunteer Week is "Changing Communities: Changing Lives." During National Volunteer Week we will invite you to let our



volunteers know how their commitment changes communities and changes lives through contributions and posts to our MND Victoria Facebook page.

Volunteer Opportunities

MND Victoria continues to accept expressions of interest from people interested in volunteering with the organisation.

Contact Deb Olive to find out more

phone: (03) 9830 2122 or

email: volunteer@mnd.asn.au

YOUR
STORY



By Maureen Fordyce, Volunteer Receptionist

Well here we are living in the days of unknown

And our normal lives out the window have flown.

No more going shopping just for the day

Or taking the kids to a park to play.

We have to keep our distance so things don't go wrong

It's times like this I wish my arms were long!!!

But we will get through this and when it all ends

We will be very grateful for the support of our friends.

So as we all adjust to spending more time indoors

I send my very best wishes to you and yours.

And when the light at the end of the tunnel we can see

I will be very happy to come back to the office in Canterbury.

Living with MND during the COVID-19 pandemic

What you should do

- Stay home except to get medical care that cannot be provided via telehealth
- Wash your hands regularly with soap and warm water for 20 to 30 seconds
- Clean all surfaces that you and others in your household touch regularly throughout the day
- Keep 30 days of medical supplies and medication on hand if possible
- If you have appointments to see your GP, neurologist or MND clinic ring ahead to arrange a telehealth appointment instead of a face to face consultation if possible
- Talk with your MND Association, NDIS or home care package providers to communicate your needs and expectations about the precautions needed to keep you and your carer safe when providing services to support you at home.

About COVID-19 and living with MND

To help keep the MND community informed a [COVID-19 page](#) has been developed on the MND Australia website with links to trusted and up to date information. The International Alliance of ALS/MND Associations has collated COVID-19 information from associations internationally and has started a [webinar series](#) to answer questions from the global ALS/MND community.

People living with MND often have a harder time with swallowing, breathing and coughing due to muscle weakness and are therefore at risk of developing serious complications if they become infected with the COVID-19 virus, regardless of their age. Every precaution should therefore be taken to prevent you and the people in your household from becoming infected with COVID-19.

If you are sick or think you have COVID-19

For people living with MND it is important that if you, or anyone in your household, develops a fever or flu like symptoms such as coughing, sore throat, fever or increased fatigue you should isolate yourselves and seek medical advice as soon as possible. If you are concerned that you may have symptoms or may have been exposed to COVID-19 you can call the National Coronavirus Health Information Line on 1800 020 080 or use the [healthdirect symptom checker tool](#). You should let your home care team and neurologist or MND Clinic coordinator know of your concerns as soon as possible.

People living with MND may already have some difficulty with breathing so if you experience any increased difficulties or sudden onset of breathing difficulties call 000 for urgent help.

What you should know about breathing and MND

- Over time MND causes the muscles that support your breathing to weaken. The respiratory muscles include the diaphragm and intercostal muscles. Problems with the respiratory muscles can occur at any stage of disease progression, and lead to symptoms such as fatigue, difficulty sleeping and shortness of breath.
- Positioning, adjusting air flow in the room, physiotherapy, breathing exercises, assisted coughing techniques, staying away from people with colds, influenza or respiratory tract infections and saving your energy are just some of the simple techniques you can use to manage mild respiratory symptoms.
- Getting advice about respiratory management soon after your diagnosis with MND can help you live better for longer. Let your doctor or clinic know if you notice changes to your breathing.
- Other strategies for managing breathing with MND include medically supervised use of medications such as opioids or benzodiazepines to minimise the sensation of breathlessness and reduce stress and anxiety, or supplementing breathing with non-invasive ventilation (for more information see the MND Australia [Evidence Based fact sheets](#) on breathing)

If you use a ventilator, non-invasive ventilation or cough assist device

- Speak to your health care provider or respiratory doctor or nurse about the precautions you, your carer and home care team should take in your home
- Clean your equipment and replace filters regularly as per your device manual
- Ensure you have an adequate supply of filters and tubing
- In case you develop symptoms of COVID -19 and require admission to hospital, ask your health care provider or respiratory doctor or nurse to give you a one page list outlining your respiratory management and machine settings to take with you
 - Include in the list information about use of oxygen as opposed to natural air flow for people with MND. Oxygen should be used with caution and will require appropriate monitoring.
 - You might also want to ensure that you have a copy of an up to date advance care plan to take with you to ensure your wishes are respected.

What should you do if you do not currently use any of these devices but think your respiratory muscles are weakening

In response to COVID-19, the Federal Government has introduced a much-expanded '[Medicare at Home](#)' measure which safeguards and ensures care for all those with chronic conditions such as MND. It means people living with MND can safely stay at home, and still have access to their allied health care team, GP, nurses and specialist doctors, such as neurologists and respiratory specialists via telehealth services.

If you do not have any symptoms of COVID-19 but think you may be developing symptoms of respiratory muscle weakness due to your MND, then you should contact your neurologist. Your neurologist may refer you to a respiratory specialist for an assessment of your respiratory function. There are a number of strategies that can help, as outlined in this fact sheet. Non-invasive ventilation may be prescribed to manage respiratory symptoms and improve your quality of life. Your neurologist may also advise you to consider having a gastrostomy tube inserted (PEG) to support eating and drinking should you also develop difficulties with swallowing (for more information see the MND Australia [Evidence Based fact sheets](#) on considering gastrostomy). It is safer to have this procedure before respiratory muscle weakness progresses too much.

During this COVID-19 crisis there is an increased and high demand from hospitals for machines to assist with breathing which may impact access to supply for the MND community. It is therefore important to stay in contact with your neurologist and/or respiratory doctor to ensure that they are able to monitor your respiratory function closely during this outbreak in case access to supply takes time.

If you experience any problems in accessing non –invasive ventilation, cough assist devices or associated equipment such as masks, talk to your [state MND Association advisor](#) who may be able to advocate on your behalf. As the national voice for the MND community, MND Australia is working with MND Clinics, the [national MND Association network](#) and members of the [International Alliance of ALS/MND Associations](#) to monitor the impact of the COVID-19 outbreak on access to services and support for people living with MND. We will work to bring any issues or impacts on the MND community that arise due to the current crisis to the attention of decision makers.

More information

Important Note

During the COVID-19 crisis having an advance care plan in place is more important than ever.

See the MND Australia Fact Sheet [Planning Ahead](#) or visit www.advancecareplanning.org.au

For more information about respiratory management contact your GP, neurologist, respiratory physician, palliative care team, MND clinic or your MND Association on 1800 777 175. MND Australia encourages people living with MND to talk to their doctor about COVID-19 to understand the implications for their unique circumstances.

To stay up to date on the COVID-19 outbreak and current advice visit the Australian Government Department of Health website [current status page](#), [healthdirect](#), the [World Health Organisation \(WHO\)](#) and the MND Australia [COVID-19 webpage](#). You can also download the [Australian Government Coronavirus \(COVID-19\) app](#).

MND Australia fact sheets

MND evidence-based interventions - an overview (EB1)
Multidisciplinary care (EB2)
Multidisciplinary care team (EB3)
Riluzole (EB4)
Breathing and motor neurone disease: an introduction (EB5)
Breathing and motor neurone disease: what you can do (EB6)
Breathing and motor neurone disease: medications and non-invasive ventilation (EB7)
Considering gastrostomy - PEG and RIG (EB8)
Planning Ahead

To find out about motor neurone disease and other fact sheets in this series contact the MND Association in your state or territory ph. 1800 777 175 or visit www.mndaustralia.org.au

YOUR STORY

By Orbst Regional Health

Orbst Regional Health's high level aged care facility, Waratah Lodge, held a very successful fund raiser for a good cause on 18th October 2019 – raising funds to find a cure and to help those living with Motor Neurone Disease (MND).

The event, Brides Revisited, saw more than 80 people in attendance, including residents, staff and members of the community. Staff and some family members looked absolutely beautiful as they modelled wedding gowns, together with the grooms who escorted them down the aisle. The girls wore their own dresses, their mothers' dresses and dresses that were loaned for the day. Some heritage dresses with their histories were on display. Each dress had a story to tell.

The cause is very close to our hearts, as one of our residents and a staff member's mother have MND. As they participated in the parade, the audience was in awe, knowing the journey they are travelling. Many a



tear was shed with the emotion of this moment.

A wonderful wedding cake was baked by a kitchen staff member and was served together with a fine array of delicious finger food. A volunteer made all the bridal bouquets, button holes, corsages and flower arrangements. It was a wonderful day with a wonderful team of helpers.

\$2,700 was raised for the MND Foundation through ticket and merchandise sales, raffle tickets and an auction of the beautiful flower arrangements. For a small rural health service, we were amazed at the generosity of staff and the community that culminated in not only a significant donation, but a wonderful occasion that brought our health service and its community together.



GROUP PROGRAMS

MND Victoria runs a 6 week **Living Well program** for people with MND and their carers. Participants have the opportunity to share knowledge and discuss topics relevant to living with MND as well as provide ideas and support for each other.

Please contact MND Victoria either by phone or email to register your interest and you will be notified when the starting date for the next program has been confirmed. Phone: **(03)9830 2122** Email: **info@mnd.asn.au**

Meeting others

Are you interested in having contact with others living with MND? MND Victoria can assist people with MND, carers, family members and friends to get in contact with others in similar circumstances via phone, email, and video conference.

Facebook support groups

MND Carers Australia: An online support group, independent of MND Victoria, for Australian MND carers to discuss issues they face. To join, go to Facebook and search for: "MND Carers Australia" or visit: <https://www.facebook.com/groups/1408400102747388>

MND Angels Australia: An online support group for people in Australia whose partners have died from MND. MND Angels is independent from MND

Victoria. To join, go to Facebook and search for: "MND Angels Australia" or visit: <https://www.facebook.com/groups/1512117609036086>

Are you an MND Genie? About 10% of people diagnosed with MND have a familial form of the disease. MND Genies is a closed and unlisted Facebook group, to join or for more information, please contact Kate Maguire, MND NSW at: mndgenies@mndnsw.asn.au or ph. 02 8877 0902

Kennedy's Disease Facebook Group: Did you know that MND Victoria also provides support for people in Victoria living with Kennedy's Disease? One of our members has shared a Facebook group for Australians with, or affected by, Kennedy's Disease:

www.facebook.com/groups/3407816342962036/

Support services for carers of people with MND

Carers Victoria— 1800 242 636

www.carersvictoria.org.au

Carer Gateway—1800 422 737

www.carergateway.gov.au

CareSearch— (08) 7221 8233 www.caresearch.com.au

BrainLink—1800 677 579 www.brainlink.org.au

MND Victoria—1800 806 632 www.mnd.asn.au

Experiencing challenges with the NDIS?

If you're an NDIS **participant**, or **representative**, please take part in our research on **challenges to getting what you need from the NDIS**

Go here to participate in the mapping exercise:
tiny.cc/49otkz



UNSW
SYDNEY

REGIONAL FOCUS

Elizabeth works with clients in Boroondara, Whitehorse, parts of Knox, Yarra Ranges, Manningham and some clients in the Northern Metro area.

IN THE LAST 6 MONTHS, ELIZABETH PROVIDED 570 HOURS OF SUPPORT TO PEOPLE WITH MND.

Elizabeth has been an MND Advisor for 8 years and a team leader of metropolitan advisors for 20 months.

Elizabeth worked previously in the dementia and aged disability sectors for over 22 years.

Many clients in this region attend the Statewide Progressive Neurological Disease Service at Calvary Health Care Bethlehem. Clients also attend the Victorian Respiratory Support Service at Austin Health as well as using many local Allied Health Services.

If you live in this area (or anywhere in Victoria!) and would like to hold a fundraiser at your local sporting club, school, workplace, or with your friends and family, please contact our fundraising team for support and to get started: fundraising@mnd.asn.au

**All services and equipment needed by people with MND can be accessed in all rural areas of Victoria - please discuss your needs with your MND Advisor + Support Coordinator or Allied Health Professional **



ELIZABETH - MND ADVISOR
+ SUPPORT COORDINATOR

Elizabeth shares support services with other MND Advisors. Elizabeth personally works with **44** people with MND in this region (Eastern Metro).

26 clients in this area access the NDIS, however **18** clients are stuck with the 'My Aged Care' system which fails to meet the needs of people with MND. Please join the campaign to Make Aged Care Fair: www.mndaction.org.au

65 CLIENTS IN TOTAL IN THIS REGION AS OF TODAY.



Yarra Ranges



There are a lot of volunteers involved in this area of the state.

We currently have 7 clients matched with volunteers and in regular contact for – Hand and Foot Massage, Visiting, Life Stories, Haircuts.

Volunteers and clients, once matched, often meet on a regular basis for an extended period of time.

A number of our volunteers who provide regular support to the organisation through their work at the Canterbury Office also live in this part of the city.



Elizabeth has presented many Information Sessions and has facilitated 'Living well' programs over the years.



HOW CAN I HELP MND RESEARCH

Exercise and MND study

Researchers from the Institute for Health and Sport (Victoria University), in collaboration with neurologists at Western Health, want to better understand the role of personalised exercise training in patients with MND. Patients will participate in a supervised exercise training program in Footscray three times a week for 12 weeks. For further information about this project, please contact: Dr. Alessandra Ferri, Ph: 03 9919 4756 or email: alessandra.ferri@vu.edu.au

Familial MND research

Prof. Garth Nicholson and team based at the ANZAC Research Institute, Concord Hospital Sydney, are studying gene variations in familial MND. They are keen to obtain DNA samples from patients with familial MND. A single blood sample is required together with your consent to take part in the research and, where necessary, your permission to obtain a copy of clinical information from your treating physician. The blood sample can be taken locally and then sent to Sydney for analysis. Please phone (02) 9767 6796 or email molmed@med.usyd.edu.au for further details.

ALS Quest Survey

ALS Quest, a University of Sydney project, is an online anonymous questionnaire looking at environmental risk factors for MND: www.alsquest.org

Both people with and without MND can fill in the survey—it takes approx 90 minutes to complete.

Donate to the Tissue Bank

People with a diagnosis of MND confirmed by a neurologist are needed to donate tissue to MND research. If you are interested in donating, or if you are just interested in finding out what tissue donation involves, please contact Fairlie Hinton, Coordinator, Victorian Brain Bank: fairlie.hinton@florey.edu.au Phone: (03) 8344 1900 Mobile: 0438 530 372 or visit: www.florey.edu.au/vic-brain-bank

Join the Australian MND Registry

The Motor Neurone Disease Registry is an ambitious project to register and collect data from every person in Australia diagnosed with MND. It contains de-identified data from people with MND including information about the diagnosis, symptoms, treatment and management. This information is made available to MND researchers. The participant's neurologist will fill out a case report form detailing the treatment and health situation at the time of the visit. There are no extra tests, procedures or treatments involved. People can decline or withdraw from the study at any time.

Please contact Anna Smith: 03 9595 3355 email: anna.smith@calvarycare.org.au or visit the website: www.mndregistry.org.au

YOUR STORY

By Richard Chandler

Still going but slowing.

The March-April 2017 issue of MND News had my story about the first six years of my experience with MND PLS (Primary Lateral Sclerosis). At the time of writing in 2016 I was undergoing tests that revealed a resurgence of my prostate cancer.

Consideration of this and other problems led me to make the decision firstly to undergo a course of radiation treatment for the prostate problem, at the same time as a continuing series of mystery abdominal pains. Extended hospitalisation in mid 2017 revealed a severe gall bladder infection. What to do about this?

Having MND raises severe concerns about the advisability of undergoing a general anaesthetic; which is a requirement for the indicated surgery. After some months of consideration, following the advice of a physiotherapist, I undertook breathing exercises and following testing on my inhalation and exhalation capacity, I was judged a reasonable risk to undergo a GA to facilitate the gall bladder surgery and the repair of a rather nasty hernia. The operation was a success and I was vastly pleased with the outcome as



it improved my daily living.

At the same time as we went through the surgery I also started on a course of hormone treatment for the prostate cancer. The treatment has been very successful with the PSA now at a remarkably low level.

It is now January 2020 and I am again in need of surgery for yet another hernia. Just for good measure, a routine examination revealed a melanoma amongst the thinning hair on my head. It was surgically removed and a skin graft has patched the quarry hole.

Post Script, It is now April and the arrival of Covid19, together with the pre-existing MND, has made me a poor bet for surgery so now I must wait out the cessation of the pandemic. I continue with a strenuous daily exercise regime and I am quite fit but very slow on my four wheel walker. The support that I receive from many sources is greatly appreciated.

At age 86 my outlook is still good.

EXPLORETECH PROJECT

You are invited to take part in the EXPLORETECH research project, which explores the views of participants with or without Motor Neurone Disease (MND) on the use of assistive technology.

Use of technology, such as the internet, handheld devices and computers is part of everyday life and offers ways to enhance the life of people living with disabilities. This can range from basic assistive technology, such as adapted keyboards or text to speech application, to sophisticated applications involving brain computer interface technology (BCI). In Motor Neurone Disease (MND), assistive technologies

may compensate for motor and communication impairment, facilitating social interaction. Usually this technology is developed by research and technical teams.

This research will help us to better understand what is important to end-users in their everyday life and guide the development of these technologies effectively to meet end-user needs appropriately.

This study aims to recruit up to 20 people with, and without, MND (relatives/carers). This research is initiated by Calvary Health Care Bethlehem and is funded by The University of Melbourne.

Please contact: christin.bird@unimelb.edu.au to get involved!



NEVER GIVE UP HOODIE AND OTHER MERCHANDISE

SHOP AT
bit.ly/NeverGiveUpMNDStore



FUNDRAISING



And suddenly you just know it's time to start something new and trust the magic of beginnings. Elite Daily

This year, for the first time ever, all the state MND Associations will participate in the Australia Moves for MND (AM4MND) Virtual fundraising event. The event will be launched in time for the start of MND Awareness Week, May 3, and will run through Global MND Day on June 21. This is a great opportunity for people of all ages and fitness levels to “MOVE” for MND showing their support for people with MND who no longer have the ability to move. This is your opportunity to commit to raising funds through your networks. So whether you like to run, cycle, skip, jump, swim, climb stairs, ride your horse, walk your dog or dance – you can Move it for MND in your own time and in your own area. In the next few weeks we will be contacting our fantastic supporters to let them know how they can be involved. Australia Moves for MND is even more important in the current climate where all community fundraising activities have had to be postponed, so please join us and help us support people with MND.

MND Awareness Week is an important time for the Australian MND Community. It's a time when we remember those who have already died from MND; those currently living with MND; families, friends and

work mates impacted by MND now or in the past; and those who may be impacted in the future.

It's a time when everyone who has been impacted can tell their story of how their life has been changed.

It's a time when everyone in the MND Community can raise their voices around the common theme to Make Aged Care Fair so that, regardless of age when diagnosed, everyone should have equal access to care and support to help them as their disease progresses. Although there is no cure for MND, the Association remains fixed on its mission – to promote and provide the best quality of care for people living with MND.

It's a time when we can recognise the vitally important work of the research community both here and overseas and thank them for their ongoing commitment to seeking to understand the causes, discover treatment options and, eventually, find a cure for MND.

If you would like to share your MND story, please email fundraising@mnd.asn.au and we will work with you to identify the correct media outlet in your area.

Kathy Nightingale

Manager Supporter Development



BALLARAT WALK & ROB'S RIDE

On Sunday March 1st, Ballarat hosted their first Walk to D'Feet MND along with Rob's Ride, in honour of Robert Pitman who was a very well-known local and who passed away from MND last year.

The events were a great success with approximately 200 walkers and 60 riders taking part to show their support for all Victorians living with MND. The riders set off at 7.30am for a tough 60km ride that included the climb up Mount Buninyong whilst the walkers took off at 9am for a leisurely 6km stroll around the beautiful Lake Wendouree.

All of us at MND Victoria are very thankful to the organisers who did an incredible job creating and hosting the events.

In the end, a total of \$20,150 was raised for MND Victoria. This is a brilliant result and a credit to the Ballarat community.

We are already looking forward to next year's edition!



LOOKING FOR CHALLENGES

Do you wonder how you can make a difference to others lives?

Do you need a new goal to work towards?

Do you want to experience the joys raising funds for an organisation close to you brings?

With life as we know it currently on pause, the majority of our fundraising and events have unfortunately come to a sudden halt. This doesn't mean you can't get creative or look towards the future and set your sights on a goal. Our Australia Moves 4 MND campaign is something to really get excited about. You can get creative, fitter and raise awareness and funds for those living with MND all whilst following all social distancing rules! Stay tuned to our social media and news outlets for updates.

For now, Run Melbourne at the end of July is still going ahead so if you're a runner or want to become a runner that could be an event for you. If you need a major goal to work towards, Kokoda is the perfect option! We are thrilled to head back to the iconic Kokoda Track in May 2021 for our first ever fundraising adventure trip that includes all MND State Associations.

Run Melbourne

'Run Melbourne isn't your average run. Over the last 12 years it has grown into a movement that has changed the culture of what it means to run through the city streets.'

We are absolutely thrilled to be one of ten Champion Charities in this year's event. We have an allocation of places into the event of your choice. Whether you are up for a half marathon, 10km run or 5km jog, your participation will help MND Victoria out immensely. If you commit to raising a minimum of \$1000, your entry into the event is covered and you will receive many other VIP privileges.

It's been a few years since the streets of Melbourne were flooded with legends running for MND Victoria and raising funds for the care, support and equipment

for all Victorians living with MND. On July 26 this year, we can't wait to see MND Victoria well represented amongst the tens of thousands of runners taking part in the city's most popular running event!

*Due to the current COVID-19 situation there is a chance this event will be postponed or cancelled. The benefit to become a Champion Runner for MND Victoria is you are not liable to pay an entry fee. All you need to do is raise funds and train. Both of those tasks are very doable in the current climate!

National Kokoda Challenge 2021

In May next year we are embarking on the challenge of a lifetime. Conquer one of the most iconic treks for Australians and one of the toughest sea level hikes in the world. For the first time ever, we are thrilled to be taking on this challenge alongside our State Association counterparts. This challenge will allow people from all around the country who understand the impacts of MND to come together to show their support for loved ones and the 2100 Australians currently living with this horrible disease.

All participants taking on Kokoda will have their own fundraising campaign, fully supported by our fundraising team. You will also be invited to group training hikes and various other activities that allow you to form a bond with the team and work towards this incredible challenge.

Fast facts:

- 6th May - 14th May 2021
- 8 days of trekking
- 1st and last night spent in 5 star accommodation in Port Moresby

- Trip cost: \$4999 (all inclusive)

- Fundraising target: \$4000

Are you up for this ultimate adventure?

Please get in touch with Daniel with any questions and for more information about any of these major events - dwoodrow@mnd.asn.au or on 03 98302122



BECOME A CHAMPION RUNNER FOR MND VICTORIA!

IF IT'S NOT CANCELLED IN THE MEANTIME,
JOIN US ON 26 JULY AT RUN MELBOURNE 2020



Be an inspiration to many and run for ALL Victorians living with MND. Your support will enable continued services that allow those with MND to live better for longer.

Take on a personal challenge and become part of an amazing team with many VIP privileges.



To apply, please visit
<https://runmelbourne.blackbaud-sites.com/mndvic>

For more information, contact Daniel on
03 9830 2122 or at **dwoodrow@mnd.asn.au**



DONATIONS RECEIVED ... THANK YOU!

In Memory

Anastasios Filis
Andrew McMillan
Barry Baker
Beverley Sipek
Brendan Chatham
Bruce Nelson
Delfa Ljubici
Denis Gerdtz
George Butcher
Iris Lahav
Jillian Meade
Johanne Yianni
John Daurdy
Kathleen Walker
Kaye Wright
Mark Lundberg
Martin Williams
Michael Bennett
Nandor Kaszonyi
Peter Danson
Rosa Medina-Vacc
Stuart Peterkin
Thelma Henson

Tim Steadman
Trevor Penhalluriack
William Wilson
Karen Blyth
Brenda Faulkner
Warren Smith

Organisations

Cavity Bar
Mountains Sports Wodonga

Clubs

Bass Coast Lions Club
Australia Day Long Table Group
Heathcote Bowls Club
Chrysler Restorers Club of Australia
Victoria
Midlands Bowls Club
Lions Club of Bass Valley

Corporations

Arcare Malvern East
Express Insurance Brokers
Ritchies IGA

Bequests

The Estate of Isobel Caroline McLaren
The Estate of Daphne Hazel O'Hanlon
Estate of Dorothy Jean Mahler

Support Groups

Bendigo Support Group

Church

Uniting Church Pyramid Hill

Thank you so much for your support of our work and people with motor neurone disease!

MND Victoria Membership

Have you renewed your membership for 2020?

You will have received a reminder if your membership is due for renewal. Please keep up your membership—we need you.

Please phone the office on: 03 9830 2122 or email: info@mnd.asn.au for more information on MND Victoria membership.

Contributions are invited!

MND Victoria members are invited to write stories, anecdotes, letters, or 'Handy Hints' for the newsletter. We cannot guarantee that all contributions will be published as this is dependent on available space, but every effort will be made to do so.

Please email your story or article with a photo to: info@mnd.asn.au by 6 May for the next edition, to be mailed on 2 June 2020.

GET INVOLVED IN AN EVENT VIA INTERNET!

Date:	Event:	Find out more:
3-8 May, 2020	MND Week 2020	Email: fundraising@mnd.asn.au
Sunday, 3 May 2020	Day of Hope and Remembrance - Live Stream	Email: info@mnd.asn.au
Tuesday, 5 May 2020	Ask the Experts - Research Event - Live Stream	Email: info@mnd.asn.au
Tuesday, 12 May 2020	Remote MND Information Session - Video Conference	Email: info@mnd.asn.au
Sunday, 21 June 2020	Global MND Awareness Day 2020	Email: fundraising@mnd.asn.au

We are still providing vital support and care to all Victorians and Tasmanians living with Motor Neurone Disease (MND). Our MND Information Sessions are presented live via ZOOM, allowing access to everyone throughout Victoria and Tasmania.

For more information and the latest events updates, please visit our website www.mnd.asn.au/events

From all of us here at MND Victoria, we want to say a very BIG thank you to all of our donors, supporters, fundraisers and event organisers. We look forward to working with you all again in the near future, once all COVID19 gathering restrictions have been lifted.



#NEVERGIVEUP

Visit our website at: www.mnd.asn.au or follow us on:

www.instagram.com/MND_Vic | www.facebook.com/MNDVic | www.twitter.com/MNDVic