

MNDnews

The newsletter of the Motor Neurone Disease Association of Victoria

40 YEARS OF CARE AND SUPPORT



Until there's a cure, there's care

MESSAGE FROM THE CEO



Welcome to 2021 and our first newsletter for the year which, as you can tell, has had a slight refresh! It's incredible to think that we are already a quarter of the way through 2021. This time last year we were adapting to so many changes in such a quick timeframe. Fast forward 12 months and I am so proud of our team at MND Victoria – both our paid staff and our volunteers – and the ways in which they adapted to working virtually and remotely. The innovations we have implemented across our support services and our supporter development have shown us new ways of working that we will take the best of and carry through into the future.

It's been very pleasing to welcome back staff to our Canterbury office during the first 3 months of the year. Some changes have been made around the office to accommodate a COVID-safe environment for our team to work in. There is no doubt everyone missed the camaraderie of working in the same building and working together in person instead of the very regular Zoom meetings from their own homes.

At MND Victoria, our focus is always on providing the best possible care and support to people living with MND to ensure that they can live as well as possible for as long as possible. This has been in the forefront of our minds as we planned, adapted to, and implemented new ways of delivering services throughout the pandemic. Advisor home visits to those they are supporting was the thing that we missed most during the various levels of restrictions, but I am so glad technology was embraced by all during these difficult times to ensure the vital support our team provides was still delivered. Home visits have slowly commenced again at the time of writing and we certainly hope they become as 'normal' as they were before the pandemic began.

2021 marks MND Victoria's 40th Anniversary. From small beginnings in 1981, where a small group of volunteers who had been impacted by the disease formed what was then known as the 'MND Society of Victoria', to today, where we employ 34 staff who are all dedicated and passionate in working to provide the best possible care and support for the 450 people currently living with MND in Victoria. I'm very excited to have the opportunity this year to look back and recognise the incredible contributions by so many within the Victorian MND community. We can only do what we do today due to the work of many before us and the very generous contributions by all our donors, fundraisers, and volunteers. Throughout the year, there will be many opportunities to acknowledge our 40 years of service and I encourage as many people as possible to keep an eye out and engage with our 40th Anniversary activities.

Like everyone, I'm looking forward to a much more positive 2021, and remember – until there's a cure, there's care.

Kate Johnson
CEO, MND Victoria

MND VICTORIA SAYS THANK YOU

Rosebud Walk

In late November 2020, the Rosebud Walk took place within the huge community of The Village Glen. This was the first in-person fundraising event for MND Victoria in 7 months.

It was a cold and miserable day, but that didn't deter many locals from coming out for a walk around the picturesque golf club in support of all those who have passed away from MND and those who are living with the disease today.

The event has been running for 6 years and was created in honour of a local favourite, Ken McKenzie, who passed away from MND a few years ago. Just over \$10,000 was raised this year thanks to the hard work of the organisers and the generosity of so many within the Village. The overall total for the Rosebud Walk is now well in excess of \$70,000!



MND Victoria Volunteers

At MND Victoria, we are very aware of how fortunate we are to have had the continued support of our amazing volunteers over the past twelve months.

We could not do the work we do without their dedication to help provide people living with MND with the care and support they need to live better for longer.

In line with safety precautions and COVID-19 restrictions, we paused a number of our regular volunteer roles in 2020. We are now very excited to be recommencing the return of some volunteer roles. This is a gradual process and as restrictions ease, we will continue to liaise with our volunteers and clients as we are able to recommence more roles.



Geelong Softball Association

In mid-December 2020, the Geelong Softball Association ran an MND Awareness - Fundraiser Event in honour of their beloved Janine Jewell, who has recently been diagnosed with MND. Their goal was to raise \$1,000 and sell 100 pairs of our Walk to D'Feet MND socks.

Through the selling of merchandise, raffle tickets and donations, they smashed both of their goals – they raised over \$6,000 and sold 231 pairs of socks!!! A massive congratulations and thank you to Raeleene and her team for organising such a wonderful and successful event. We especially love the creativity in your milk bottle top cornflowers and blue softball display.



Heathcote Bowls

The 'Never Give Up' Group and the Heathcote Bowls Club have once again outdone themselves with another magnificent fundraising event for MND Victoria.

The support shown by the Heathcote Club and the wider lawn bowls community for the annual Australia Day fundraising event over the past 6 years has been truly amazing. This year, the club was able to host their first COVID-safe event for nearly 10 months. A fun day of bowls, food, drinks, raffles and plenty of banter was had by many. It was an honour to have the CEO of Bowls Australia, Neil Dalrymple, attend the day and give his support to MND Victoria. Once all was said and done, the fundraising total was approximately \$10,000, bringing the overall contribution from this annual event to a whopping \$80,000! An incredible effort by this amazing community.

Blackbird Preview Screening

We recently hosted our first fundraising event for 2021 – a special preview screening of the film, 'Blackbird'.

Starring Susan Sarandon, Sam Neill, Kate Winslet, Mia Wasikowska and Rainn Wilson, Blackbird is a moving film about a family affected by MND who come together over a weekend at their country home to be with their terminally ill mother for the last time. It is a heart-warming and emotional drama that focusses on celebrating life and living it to the fullest.

Thank you to everyone who supported the event – over \$2,400 was raised to help us provide the best possible care and support to all 450 Victorians currently living with MND. We love that Blackbird is bringing awareness of the impact MND has on people living with the disease.



Reconciliation Action Plan

A group of MND Victoria team members and State Council representatives have commenced drafting our first Reconciliation Action Plan (RAP).

We hope to start the journey of MND Victoria contributing to the National Reconciliation Movement, and ensure all of our services and supports are accessible to anyone who identifies as Aboriginal or Torres Strait Islander.

We are excited to collaborate with anyone in the community who may have experience and knowledge to share with us. Please contact us at info@mnd.asn.au or 1800 806 632 if you are interested in being involved.

PERSONAL STORY

For many, the MND journey can be a rollercoaster and, for Peter Chambers, his journey was no different. Pete had symptoms for around 18 months leading into his diagnosis in December 2019. And, as he explains, no stone was left unturned when investigating the cause of his symptoms.

"There were three or four things the neurologists were looking at and had to exclude. MND was always in the background, but it was never the likely diagnosis during that 18 month period," he says. "When it was finally diagnosed as MND, there were tears, but it didn't come as a complete and utter shock. I was kind of prepared for it, but when you hear those words, it's not what you want to hear".

Not wanting his diagnosis to define him, Pete has used it as the catalyst for his positive mindset and desire to help others.

"I wanted a legacy that is not negative. There's no way I want people to look at me and remember me as being someone who couldn't cope with this.

I looked at my kids and my wife, and I wanted the legacy of 'this is how you battle a disease such as this. This is how you face and cope with adversity'. I was driven by that really early on to say I know what the end result will be, but it's not going to get me. It's not going to define me."

MND Victoria have been with Pete every step of the way since his diagnosis, providing him and his family with care and support.

"We didn't know MND Victoria existed so, to find it really quickly, to make a phone call, and to receive a phone call back in a matter of hours, and then for Fran [his MND Advisor/Support Coordinator] to be on our doorstep 48 hours later, 3 days before Christmas back in 2019, was extraordinary. To know that you've gone from finding something that you didn't know existed to all this physical support really quickly is fantastic."

Pete has now started what he calls his 'MND Career'. He is using his voice to create a platform to advocate for others living with motor neurone disease.

"It means everything to me, that I can help others with my platform," he says. "You see all the positive responses come in and it's great to know people are thinking of you, but it also reinforces that what I'm doing is being seen by people, and people are seeing it as a really positive thing for the community in general."

"I want to make a commitment to give back for what I'm receiving. To be able to contribute in any way is not only an extension of what I'm doing, it's an extension of what's driving me to be an advocate for the work of MND Victoria and the recognition of the disease itself."

Part of his MND Career has included a recent appearance on Nick Bracks' podcast, "Move Your Mind", to discuss 'Dealing with Adversity'. Throughout the episode, Pete shares the life lessons that have come from learning to live with MND and focusing on the important things in life. "It was a tough gig at the time, but it's incredible how the mind works", he says. "I have my down times of course, but you've got support around you. MND Victoria look after me - I've got an Advisor, OT's, Physio and a support network of carers who do a wonderful job of taking the stress out of my life. It means I can get on with things and lead as normal a life as I can."

Pete has created his own campaign, Pete's Legacy, where you can follow along with his journey. Visit: www.mnd.org.au/campaign/2/petes-legacy

Like all other Australians living with MND, Pete receives services from his local MND Association. Please contact your local State Association for more details on the services they provide.



LIVING BETTER

Toilet Talk

One of the key areas that people express concerns about is their ability to use the toilet safely and independently. Using the toilet is typically a very private and personal affair; so when someone experiences problems with toileting, it can be stressful and impacts on confidence and dignity.

In this article, I would like to highlight some of the most frequently requested assistive technologies and other strategies that can be used to overcome practical difficulties and enhance safety and independence.

Issues with mobility and fatigue can interfere with a person's ability to:

- * get to and from the toilet
- * sit down and stand up from the toilet
- * maintain a stable sitting position
- * manage lower-body clothing
- * manage personal hygiene tasks



Grab rails: If you find yourself grabbing at furniture or fixtures to assist with getting on and off the toilet, then this is an indication you may need grab rails. Rails come in a range of shapes, materials and sizes and are used to provide assistance with lowering and standing. Drop down rails can be stored upright when not in use. Rails should be installed by a qualified tradesperson. An occupational therapist can advise on the type and positioning of rails to optimise their effectiveness.



Toilet surround: This is a height-adjustable frame that fits around most standard toilets. It provides armrests to grasp for assistance with lowering and standing. This can be a handy alternative to installing permanent rails.



Over toilet frame (OTF): Like the toilet surround, this provides armrests to assist with transferring. An OTF also has an in-built toilet seat which sits higher than a standard toilet seat.



Toilet seat raiser: As the name suggests, this raises the height for sitting. Some models have cutouts at the front and rear of the seat to enable easier access for cleaning. If raising the height of the toilet seat, ensure your feet are still able to reach the floor as this provides greater stability than if your feet are floating.



Toilet seat raiser with arms: This piece of equipment combines the use of a raised toilet seat with armrests to assist with transfers. The armrests can swing up out of the way if you need to transfer onto the toilet from the side. What I like about this item is that it keeps the floor clear of clutter.



Commode: Commodes can offer a higher level of support and come with a wide range of features to suit different needs. For wheelchair users, if there is not sufficient space to transfer between wheelchair and toilet, it can be more effective to transfer onto a commode and then wheel into position over the toilet. Commodes can also be used to sit on during showering. Dual-purpose items such as a commode can help reduce the amount of equipment required within the bathroom.



Urinal bottle: Urinal bottles are a portable option and come in styles for men and women. Some prefer to use urinal bottles overnight to avoid the disturbance of getting out of bed and to the toilet. These can be convenient for their reduced energy expenditure requirement.



Bidet: Bidets are becoming increasingly popular for automated cleaning and drying. They direct a gentle stream of water to assist with cleaning and can be operated with a control. These are particularly helpful for people with limited use of their arms and hands. Electric bidets require a power source and different models have particular installation requirements that should be considered before purchasing.

Other ideas:

- * **Flushing controls:** For someone with hand weakness, a lever may be easier to use than a button, or alternative controls can be integrated.
- * **Adapted clothing:** If managing your clothing is difficult, consider wearing clothing that is easy to remove and adjust (e.g. loose-fitting fabric, elasticated waistband, magnetic closures).
- * **Door:** If the toilet is located in a small space, consider changing the swing of the door so that it opens outwards, or switch to a sliding door if possible. This increases the circulation space available in the room and enables a helper to access the room if you were to have a fall behind the door.
- * **Remove trip hazards:** Ensure you have a clear path to get to the toilet. Avoid having a pedestal toilet mat as these can present a trip hazard.
- * **Lighting:** Ensure you have adequate lighting to guide you to the toilet. A night light or sensor light can be handy if you tend to get up in the middle of the night to use the toilet.
- * **Carers:** If you require a carer to assist with toileting tasks, it is important that you are afforded as much choice and control as possible. Carer assessment and education can be helpful to guide caregivers on dignified ways to support you to participate with as much independence as possible.

When assessing toileting skills, the main goal is always to respect a person's right to **dignity** and to optimise **privacy, safety and independence**. There are many factors to consider when selecting equipment, so it is recommended that you get in touch with a physiotherapist or occupational therapist who can provide assessment and advice on strategies and technologies to suit your individual needs.

Sophie Nunn,
Occupational Therapist,
MND WA

MND RESEARCH

CHCB Neck Weakness Research

Neck weakness is a symptom of MND that can have a big impact on the quality of life of the person living with MND. However, there is a lack of good quality research about the characteristics of neck weakness in MND or the best evidence-based strategies to help support the head and neck.

The Physiotherapy Department at Calvary Health Care Bethlehem (CHCB) in Victoria want to change this and have teamed up with MND Victoria to commit to further research into this subject.

What has been done so far?

At the 2019 Allied Professionals Forum in Perth, the Physiotherapy team presented about their experiences in helping people to manage neck weakness and head drop.

To help guide their research, they then conducted a survey with 33 of their patients who have developed neck weakness. They found that neck weakness occurs across all types of MND and typically results in the head dropping forwards, or a combination of forwards and to the side. The most common strategies these patients used were:

- * Postural support from their recliner chair or wheelchair
- * A neck collar (79% of the patients used some form of collar) – a soft collar or Aspen Vista collar were the most commonly used
- * For 43% of the patients who use a neck collar, the team had made custom modifications to their collars to improve comfort and tolerance.

Other strategies currently used were:

- * Pillows, cushions and rolled up towels
- * Specialist headrests for wheelchairs
- * Various forehead supports or straps

So.....what's next?

The team are now collaborating with MND Victoria in a new research study to look at:

- * How common it is to develop neck weakness in MND
- * At what time period neck weakness symptoms usually develop
- * How head support strategies may change over time
- * The relationship between neck weakness and respiratory function
- * The relationship between neck weakness and walking

All this research aims to develop evidence-based guidelines/framework to help people with neck weakness improve their quality of life, and their therapists to improve the quality of care.

The authors for the research (questionnaire) are:

Timothy Sheehy – CHCB, Karol Connors – CHCB and Dr Christine Wools – CHCB.

For the second project, the following people are involved:

Timothy Sheehy – CHCB, Trinh Nguyen – CHCB, Rosanne Gibb – CHCB, Stephanie Zhao – CHCB, Sally Mathieson – CHCB, Anna Smith – CHCB, Dr Christine Wools – CHCB and Prof Prue Morgan - Head of Physiotherapy School of Primary and Allied Health Care, Monash University.





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ADVENTURES®

mnd 
Victoria

CHALLENGE YOURSELF TO TAKE NOT ONE, NOT TWO, BUT THREE MOUNTAIN PEAKS ON THE MND VICTORIA THREE PEAKS CHALLENGE 2021!

On this exhilarating adventure through the Alpine region, you'll raise funds towards MND Victoria's mission of providing the best possible care and support to Victorians living with MND.

Over 3 days, you'll tackle Mt Stirling, Mt Feathertop and Mt Bogong, each view from the top as impressive as the last. Stand in awe of the majestic forests of Mt. Stirling, visit iconic Craig's Hut and discover an incredible ridgeline connecting two of Victoria's highest peaks- Mt Feathertop and Mt Hotham.

The best part? Through this challenge you'll show your support for those living with motor neurone disease and help make a positive difference to their lives.



23-25 OCTOBER 2021



Quite challenging (4/5)

Fundraising target: \$2,000

Travel package: \$1,799



Excludes flights and subject to change

Registration fee: \$190

Non-refundable



Twin-share accommodation 3-4-star

For more information, contact Steph: scross@mnd.asn.au

Register online: inspiredadventures.com.au/events/mndvic-3peaks-2021/

UPCOMING EVENTS



National Walk to D'Feet MND

Help us kick start MND Week 2021 with the South East Melbourne Walk to D'Feet MND!

Scheduled for Sunday 2nd May 2021 from 12 pm, this Walk also doubles as our first-ever national Walk with each State Association hosting their own event.

Nationwide, our Walking Warriors will join forces and come together as one united MND community across Australia.

Bring your family, friends and dogs along for a fabulous day out to support people with MND. The Walk is an easy 1.3km flat walk around the Lakeside Amphitheatre in Pakenham and is wheelchair and pram friendly. Disabled parking is available for people with MND. Every registered participant will receive a free National Walk T-Shirt.



For more details and to register, visit <https://www.mnd.org.au/events/11/semelb-walk-2021>

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GIVING

\$40 For 40 Years: Join MND Victoria's Committed Community

What does \$40 mean to you? It means the absolute world to those living with MND.

For 40 years, MND Victoria has provided the best possible care and support for Victorians living with MND. The level of support, the quality of information and the access to vital assistive equipment has increased greatly since 1981 and is allowing those who are diagnosed with MND to live as well as possible for as long as possible.

Last year, MND Victoria:

- * Supported 656 people living with MND
- * Delivered 11,321 hours of service to people living with MND
- * Provided 3,002 items of equipment to people living with MND
- * Presented information sessions to 231 people



The only way the above is possible is because of our generous fundraisers and donors who contribute 70% of the funds the Association requires to deliver all its vital service.

MND Victoria is looking to establish a Committed Community of donors who wish to support the Association on a regular basis. Our \$40 for 40 years of service campaign is an opportunity for you to commit to donating \$40 per month to recognise the critical role MND Victoria plays in the lives of the 450 people currently living with this disease.

To join our Committed Community, visit: <https://www.mnd.org.au/campaign/5/40-for-40>

Why Give

Every single contribution made to MND Victoria, regardless of its size, helps make a difference in the lives of people living with MND. Because of the generosity of our community, we were recently able to purchase six brand new power wheelchairs. This equipment enables more people living with MND to stay as safe, independent and as engaged with their community for as long as possible, and our team are proud to be providing the help they need.

Our brand new website makes it even easier to show your support: <https://www.mnd.org.au/donations>



SUPPORTED
656
PEOPLE LIVING WITH MND



DELIVERED
11,321
HOURS OF SERVICE



PROVIDED
3,002
ITEMS OF EQUIPMENT



PRESENTED INFORMATION SESSIONS TO
231
PEOPLE

40 YEARS OF CARE AND SUPPORT



2021 will be a memorable year for so many people but, for us at MND Victoria, it is a very important year.

2021 is the year we acknowledge 40 years of having a significant impact on the lives of thousands of Victorians affected by motor neurone disease. Since we were founded (originally as the Motor Neurone Society) in 1981, it has been our mission to provide and promote the best possible care and support for people living with MND.

Each newsletter this year, we are going to look back on a decade in our history to reflect on the journey that has led us to where we are today. **Below are our milestones from 1981 – 1990.**



- 1981** The Motor Neurone Society was founded on 13 October by Michelle and Nandi Kaszonyi and others at a public meeting at Bethlehem Hospital.
- 1982** Eames Bishop, President of the ALS Society (now known as the ALS Association) in the USA, visited Australia in August.
- 1983** Assisted by the Oakleigh Lions Club who generously provided a lease and two years rent, the Society moved to a shop in Kangaroo Road, Oakleigh.
- 1984** The first seminar on MND was held in cooperation with Bethlehem Hospital and the MS Society.

- 1985** Our first support group was initiated with the creation of the North Central Support Group. Similar groups soon followed in Gippsland, Echuca, Birchip, and Shepparton.
- 1986** The Society moved from Kangaroo Road, Oakleigh, to 518 Kooyong Road, Caulfield South. The new house was named in honour of Ian Coates, a former VFL umpire, ex-president of the Society, and person living with MND.
- 1987** Warragul Jaycees produced the ETRAN Board, a non-electronic communication aid that is held up so that someone with MND can communicate words, letters, and numbers using eye movement.

- 1988** A part-time secretary was appointed to help with general office work for the first time.
- 1989** The first MND Awareness Week and National Conference of Australian Motor Neurone Societies was held.
- 1990** Attendance at the UK MNDA Conference established links and information sharing between the Society and other MND Associations around the world.

Our next newsletter will cover our milestones from 1991 – 2000.



MND VICTORIA

265 Canterbury Road,
Canterbury, VIC 3126 Australia

Phone: (03) 9830 2122
Freecall: 1800 806 632

- info@mnd.asn.au
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