MND NEWS

July/August
2020

The newsletter of the
Motor Neurone Disease
Association of Victoria

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

DELIVERING CARE

PAST, NOW AND ALWAYS

mnd Victoria

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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

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Education and Client Support Team Leader: Vacant

Education and Client Support Administration Officer: Vacant

FROM THE CEO

As winter sets in, we are still adapting to the changing requirements and limitations that the COVID-19 pandemic brings. In a time when we are all socially isolating (I prefer to call it physically isolating) it is more important than ever to focus on how we stay connected with our family, friends, networks and supports. In this edition of MND News we are focusing on **care**. The ways in which we care and show that we care are even more important at the moment than in "normal" times. At MND Victoria we have been working hard to ensure that the care and support we provide is maintained and that we can find new ways to stay connected with the people we support.

We are working to ensure that people have access to the technology that will best support them to stay in touch with us and with their broader support networks.

We have also ensured that the other ways that we connect with the MND Community have continued via online/video to ensure we stay in touch. One of the newer online events we have initiated is "Zooming with Dan" where our Supporter Development Officer, Daniel, chats to different members of the MND community live on Facebook. I had the opportunity to "Zoom with Dan" on Sunday 21st June – Global MND/ALS Awareness Day. This is an important day in the MND community calendar, where we recognize and raise awareness of the **2100 people in Australia** and the **420,000 people worldwide living with MND**. It is a time to come together as an international community to raise awareness of the impacts of MND, the work of the organisations across the world providing support to people living with MND, and the work of researchers internationally in the search for the causes, treatments and ultimately a cure for MND. Global Day is acknowledged on the solstice, representing hope for a turning point in the search for answers that will lead to **a world free of MND**.

Finally, I would like to acknowledge the amazing support we have received from our fundraisers and donors across the last few months, our Australia Moves for MND virtual campaign, our Tax Appeal and our general donations. We have seen support such as one of our volunteers Joe Mantella walking 2100kms in 50 days for AM4MND, two families recently donating the proceeds of sale of wheelchair accessible vehicles and another family donating the proceeds of the sale of their vintage WWII Airforce Rescue boat. Your support is critical to our work and we are just so grateful for your generous support.

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

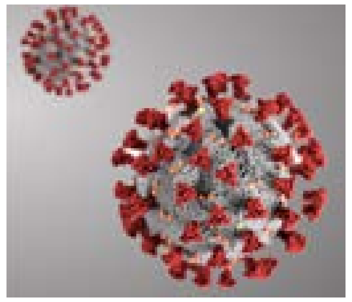
Kate

We are interested to get your feedback on MND News – what do you like? What don't you read? What kinds of articles and information would be of interest and value to you? Please complete our survey www.surveymonkey.com/r/MNDNews

Support Services

COVID-19

Sorry, I have to mention this again! – I am looking forward to the day when our staff and volunteers can recommence meeting our members, colleagues and each other in person! In the meantime, I would again like to thank all our members, MND families and volunteers for their patience and understanding about MND Victoria needing to change how we do things in these challenging COVID-19 times.



National Disability Insurance Scheme (NDIS) and MND!

It is 4 years since the NDIS commenced rolling out across Australia and it is constantly evolving, changing and (mostly!) improving.

Following significant consultation over the last 18 months, the National Disability Insurance Agency (NDIA) has set up a new team called the Complex Needs Team. This national team has been given the jurisdiction to do "the planning" for people diagnosed with MND (under 65 years of age). The NDIA has identified planners from this team to become SME's (Subject Matter Experts – the NDIA love a good acronym!) in MND.

On the 16th June, Elizabeth Crask and Trish Duffy, two of our very experienced MND advisor team, ran a training session for 17 of these SMEs!! They did a session about MND the disease; talking about symptoms and how they can impact on the life of a person with MND, and the importance of having equipment and care supports in place quickly.

Photo Left: Elizabeth Crask Photo Right: Trish Duffy

The second session was about "how to write a good NDIA plan for someone with MND" and the planners asked loads of great questions.

In the afternoon, our whole team of advisors joined the training with the planners which was led by the NDIA, and discussed topics such as:

- Importance of flexibility being built into a plan – needs can change so rapidly for some people and having to do an unscheduled NDIA review can be frustrating
- Familiarising planners with the "MND Practice Guide" – this is a "secret" document, accessible only to planners on their internal intranet - but written with advice from the MND State Associations. It includes some pertinent information about what types of supports should/could be included in a plan
- Funds that should be included for equipment needs – is it for an equipment bundle or individual hire/purchase of equipment?
- Specialist Disability Accommodation - this is very hard to access in a timely manner, so often is not considered for people with MND as they may need to move into accessible accommodation with relevant supports very quickly and the SDA process is very l-o-n-g winded. Discussed the need to simplify this process
- Residential Aged Care for people under 65. MND Victoria is currently supporting 8 people who are under 65 who are living in Aged Care in Victoria or Tasmania. No young person should be living in Aged Care however, until there are more suitable alternatives available, it is the only option for some people. We are pleased that the NDIA has increased the flexibility and level of support that can be provided for a person who is living in a nursing home.

It was fabulous to meet the planners, (albeit "virtually" due to COVID-19) and we anticipate this work will have a direct and positive effect on the plans that people with MND receive. Having a name and a phone number of an NDIA planner is like winning the jackpot!

Commonwealth Home Support Program and MND!

We have been successful in receiving an Emergency COVID-19 grant for the next year to help us provide more support for people with MND who are over 65. This will be used to employ an additional advisor for 3 days a week to increase our responsiveness to the needs of people who are over 65.

More iPads!

The grant also included funding for a new batch of iPads which will be loaned to people with MND – please speak to your advisor about our iPad loan program if you are interested. We hope these will be available from the end of July.

As an Association, we continue to advocate for ALL people with MND to receive the care and support they need, regardless of age. We would like to see much faster access to high level Aged Care packages and additional funding for assistive technology.

Changes in our Information Team

We are changing the focus of our information provision to increase the amount and type of education and information resources we provide. We are recruiting an experienced health professional to the team to assist us with this.

Watch this space!

As always, please do not hesitate to contact me if you have any feedback about any of our Support Services.

Jo Whitehouse, Manager Support Services

jwhitehouse@mnd.asn.au

0402 183 140

YOUR STORY

Dallas Hanson's Story

Making the most during COVID-19 times

At Kingston Beach – our beach of choice as it has the best public changing facilities, clear water and interesting shells and fish to keep our minds off the cold.

Dallas was diagnosed with MND on February 16. We had just returned from three weeks of swimming and body surfing in Port Macquarie.

As we both enjoy swimming, we started going to the open pool in Glenorchy, Tasmania, every second day. We used to walk three or four times a week but that has become impossible. Swimming is a form of exercise which Dallas can still enjoy. We knew the pool would be closing at the end of March, as it did every year. But this year the coronavirus closed it even earlier.

We decided to start swimming in the sea. The water was fresh but after the first ten or twenty seconds, once our bodies acclimatised, the experience was lovely. We both just loved being back in the sea and so we continued to go swimming every second day. Of course, in the process we have acquired a lot of cold-water swimming gear. Dallas loves gear, particularly gear with 5-star reviews. Dallas now has a watch with a thermometer - so that he can measure the temperature every time we swim. This has fast become one of his favourite activities. So far, the coldest we have swum in is 12.1 degrees. It will get colder. We swim for around 20 minutes. If we swim for longer, our feet and hands turn numb and it becomes exhausting.

A good wetsuit and hat, and gloves, and boots are essential in cold water. There's a huge variety of wetsuits now because of the popularity of triathlons (where the swimming component is often the hardest). Dallas bought an Orca wetsuit - one called '3.8' that supports the legs and torso with some fancy air bubble product. But he is now aspiring to a 'Blueseventy thermal reaction' that is designed for very cold water, and that has furry pink stuff as lining. Dallas figures he can still swim, sort of, when/if the legs totally collapse. The hat of choice is 3mm thick and is called 'flash bomb'. He now also has new booties that are 5mm - very thick- and, so far, they keep his feet really warm.

Our friend Annie now joins us. As do Dallas' son, Jamie, his partner, Gabrielle, and their 4-month old son, Wulfy. Dallas, Annie and I swim first, then we look after Wulfy while Jamie and Gabrielle have their swim.

Post swim, the key is to change into dry, warm clothes as quickly as possible. Then we hang around just a little bit longer to have cups of hot tea from a thermos and unlimited chocolate biscuits. Swimming is now one of the highlights of our week. Of course, it is easier to love when it is a still, sunny day, as it was when the photo above of Dallas and me was taken. But we love our cold water swims no matter what the weather is, and we hope to continue with them for as long as we can. I have said that 10 degrees might be my limit... but we will see.

TRAIN-ALS PROJECT RESEARCH UPDATE

By Dr. Alessandra Ferri

Can people with MND exercise and can exercise improve their quality of life? If so, how much should they exercise? What are the effects of exercise on muscle health and physical function in individuals with MND?

These are all questions that Dr. Alessandra Ferri, from the Institute for Health and Sport (iHeS) at Victoria University, is trying to answer, thanks to the TRAIN-ALS project she is leading. Dr. Ferri is passionate about the idea of "Exercise is Medicine"; her preliminary findings indicate exercise can counteract the negative effect of inactivity and disuse and improve physical independence and quality of life in individuals with MND. The hypothesis of her research is that exercise, as with any medicine, needs to be precisely prescribed based on the specific needs of each individual with MND.

The TRAIN-ALS project received ethics approval and it is now mid-way to its conclusion. Individuals with MND who participated in the study reported a desire to continue exercise when the 12-week study concluded because they felt better and stronger. Here is an example of two messages from participants involved in this research.

"Your exercise program has been the best thing we have been involved in. What you are doing is important and I suspect will have longer term benefits… so please be encouraged to know that we appreciate having been part of the research program and your continuing research." (Russell Creek)

"Thank you for all your support over the past 14 weeks. It has given me courage and confidence to achieve more in life!!"

Initial results indicate that individuals who exercised 3 times/week for 12 weeks, strictly monitored by experienced exercise physiologists, presented an increase in lower-limb strength, which translated to an improved physical function. These results are only preliminary and we need a larger number of participants to confirm them.

For further information about the TRAIN-ALS project, and/or if you are interested to be part of this study, and to help the scientific and medical community to understand the role of exercise in the management and treatment of individuals with MND, please contact Dr. Alessandra Ferri **alessandra.ferri@vu.edu.au** Ph: **(03) 9919 4756**

The study will recommence as soon as it is safe to do so.

VOLUNTEER NEWS!

MND Victoria volunteers care! It is just what they do!

Over the past few months – though face to face volunteer roles have been placed on hold, our volunteers have remained active in many roles and have taken on new ways of working to continue to provide care and support for people living with MND.

MND Victoria **Life Stories Volunteers** work with people living with MND to record stories from their life that they want to create into a book to share with their family and friends. Throughout this pandemic period, many of our Life Stories Volunteers have been able to continue to work with members – holding their regular meetings "online" rather than in person. Moving to working online has meant that we have been able to match members living in remoter areas of the state with volunteers to complete their Life Stories. This is something we will continue to do even once physical distancing restrictions are eased. For people who are not able to work online, our Life Stories Volunteers will commence face to face visits when it is safe to do so.

MND Victoria volunteers have stepped up to support people living with MND who are feeling isolated. Our new role of **Social Chat Volunteers** commenced after physical distancing began. Social Chat Volunteers are available to make regular calls to members and carers - with the time to listen, our volunteers are making a difference to their day.

MND Victoria **Bereavement Call Volunteers** illustrate the care that underpins volunteer involvement at MND Victoria. Every month, a small team of volunteers make phone calls to family members who have recently lost a loved one to MND. For family members who ask for a call, it can make a real difference to know that someone who has some understanding of what they are dealing with is available to listen and care.

Volunteer Stories

Recently we introduced our **Story Catcher Volunteer** role. Our Story Catcher Volunteers talk with and record the stories of our volunteers – what brought them to volunteering with MND Victoria, what volunteering looks like, and what volunteering means for them.

Last issue we introduced **Amanda**. This issue we introduce **Marilyn**, the second member of our "Story Catcher" team.

Marilyn volunteers with MND Victoria, as a result of the passing of her husband from MND. Bearing witness to the courage he showed while living with MND, Marilyn contacted MND Victoria to enquire about the Life Story Volunteer role.

As a retired teacher/librarian, Marilyn is fascinated by stories. As people listened to her story, Marilyn saw the opportunity to give back to others by listening to theirs.

The Life Story Volunteer role called to her initially, now she is also excited to be part of the Story Catcher team. Both roles suit her flexibility and mean she can continue to volunteer remotely at present.

'Volunteering is not something that you can be told to do. You need to choose to do it. It's not something you have to do but know that when you do, you are contributing to others.' (Marilyn Martyn, 2020)

Upon reflection, Marilyn noted through volunteering with MND Victoria and listening to the stories of others, that she has become more empathic, is a better listener, and more sociable in her interactions with friends and family. Somewhat surprisingly, Marilyn feels as though she has softened and become a nicer individual due to her volunteering experience.

In recent months, Marilyn has joined the University of the Third Age. Here she has made new friends, joining groups to speak about areas of interest.

She is looking forward to sharing the stories of MND Victoria volunteers.

Marilyn Martyn, MND Victoria Volunteer

Volunteering with us

If you would you like to volunteer with us later in 2020 please contact **volunteer@mnd.asn.au** or call **03 9830 2122**

Deb Olive

COOK BOOKS

FOR A RANGE OF DIETARY AND SWALLOWING NEEDS

Hammond Care have a range of cook books that provide nutritious meal ideas that cater to an array of dietary or swallowing needs. The books were written in collaboration with a chef, speech pathologist and palliative care specialist and aim to provide practical advice so food can remain a pleasure and a comfort. '***It's all about the food not the fork***!' tackles meal ideas for people with swallowing difficulties and '***Lobster for Josino***', provides advice and tips about preparing food for loved ones nearing end of life.

MND Victoria will also have copies available for loan – contact **info@mnd.asn.au** or speak to your advisor.

If you would like to purchase a copy, Hammond Care is providing a 25% discount to MND Association members by using the code **MNDAUST** at checkout. Visit the Hammond Care shop here:

www.hammond.com.au/shop/food-culture

YOUR STORY

By Matt Moran

George was born in 1944, he grew up in Eltham and his parents ran the Post Office/General Store. He studied PE at Coburg Teachers College under a scholarship, after which he taught in several schools including Essendon Grammar School, Port Melbourne Primary School, and Carey Baptist Grammar. He was married to the love of his life in 1969, just 2 days after finishing a theological degree of divinity. George and Betty brought their 3 kids to Central Victoria where George and his growing family started the first of 10 Christian Schools, 4 of which are still in operation today. He supported and influenced many more schools across the country. In 1982 he started a teacher's college in the family home, which for the next 5 years trained and influenced a powerful group of passionate teachers.

He then went on to work as a teacher, principal, and pioneer at Hillcrest Christian College for the next 7 years. During this time, he also Pastored a Church in Croydon, bringing vision and direction not only to the church community but the broader Maroondah area.

A pioneer at heart, George has been a great influencer of leaders both in the education sector and within the Church. George's great passion was to see everyone around him grow to their fullest potential.

One of his outstanding achievements was with the Chin people in Burma and Australia; for over 10 years George invested in schools, leadership development, refugee support, and theological training colleges helping to re-establish struggling, war-torn communities. It was when working with the Chin people that George first noticed some symptoms that were beginning to affect his work. Stumbling, a husky voice, reduced fine motor skills all led to a diagnosis of 'BULBAR MOTOR NEURONE DISEASE.' Whilst devastated by the news, George always remained resilient, courageous, and grateful for God's gifts in his life! His faith had sustained him through many adventures and now it would become his foundation to face his greatest challenge yet.

The last 4 and a half years were filled with visits to the phenomenal staff at Calvary Health Care Bethlehem in Caufield, along with many wonderful home care assistants. The progression of MND was surprisingly slow. Because of his love of sport and running, this caused George to have many falls, some requiring hospitalisation. Learning to become a spectator rather than a participant was difficult and the persistent decline of George's abilities meant that he was consistently adapting to his new circumstances. MND Victoria was an incredible support providing many assistive technologies that enabled George to live at home with Betty in Chirnside Park through it all.

In September 2019, George moved into Regis Blackburn and was welcomed as family. Embracing the curated activities, social interaction, and sincere care provided by the team at Regis Blackburn, his days were full indeed! The lifestyle team were big fans of George and his approach to life. Sharing the final days with his wife Betty, also at Regis, and an endless stream of family and friends, George remained thankful until the end.

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.

The next program is scheduled to commence in **August**. Please contact MND Victoria either by phone or email to register your interest and you will be notified when the starting date 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: 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: 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 phone (02) 8877 0902

Support services for carers of people with MND

Carers Victoria— 1800 514 845

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

EXPLORTECH PROJECT

You are invited to take part in the EXPLORTECH 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!

A SPOTLIGHT ON COMMUNICATION

By Sam Mitchell, MND Victoria Advisor

People living with MND can experience communication changes in a variety of ways, including slurred speech, reduced vocal volume and strength, or a person may only be able to speak in single words or short phrases. Fatigue may also impact speech quality – there may be changes to clarity the more someone talks or as the day progresses. These changes may be related to muscle changes around a person's mouth, throat, or neck, or because of respiratory changes. When communication difficulties are experienced, people often become frustrated and find talking takes a lot of effort and energy.

There are several strategies that can be useful to assist with speech clarity when communicating with others. These include:

- **Slowing down, even just slightly**
- **Over emphasising sounds and words**
- **Break-up long words into syllables**
- **Reduce background noise – turn off TV/radio and other appliances during conversations**
- **Face the person you are speaking with**
- **Be in the same room when talking**
- **Outline topic of conversation; context can help others know what you are trying to say**

Use of these strategies will hopefully lead to less frustration for both the person living with MND, as well as any conversation partners.

When vocal volume drops off, a voice amplifier is an option that may be considered. A voice amplifier is a personalised microphone and speaker system that allows you to increase the volume of your voice but will not change the clarity of your speech. The microphone may be attached to your ear or head, clothing, or worn around your neck. This last option can be used with an NIV mask and allow a person to speak single words or short words without needing to remove the mask, which can compromise respiratory function and comfort.

As communication symptoms develop or change further, alternative methods of communication need to be considered so that people living with MND can continue to get their messages out effectively. Speech generating devices allow a person to get messages out in a different way. There are multiple apps and software options available on phones or tablets that allow a person to type in a message and the device will speak this out loud. How a person accesses these programs also needs to be considered, based upon an individual's physical function and where people may be using the communication devices. Options may include a head-mounted mouse, a switch positioned next to a body part people may have some movement in such as a foot, or via eye-gaze. Eye function is not generally impacted in MND and eye-gaze software allows someone to scan letters, phrases, or pictures to get their message out and communicate effectively with others. It is important that where a person is using this device is also considered – be it inside the home, out in the community, in bed, electric recliner, a wheelchair or other options relevant to a client. Allied Health professionals, including Speech Pathologists, Occupational Therapists and Physiotherapists, will often work together in the assessment and decision-making process.

Many of these speech generating devices can incorporate personalised voices, known as either Message Banking or Voice Banking. Message Banking involves the process of recording words, phrases, or sentences which, when used, will sound exactly as they were recorded. Voice Banking enables a person to record a sample of words and phrases, which can then be used to create a synthesised voice. These recordings can be used to create new phrases and sentences to customise the needs of the device user. The voices can be incorporated into the relevant software of communication devices.

There will be times when high-tech devices are not appropriate – such as in wet environments, if technical issues are experienced, or in emergency care situations. It is important that there are alternative options available; these may be picture or alphabet boards, key messages, or a communication book. Your Speech Pathologist or caregiver can assist you in developing these.

For someone who is in the early stages of an MND diagnosis, it can be overwhelming and difficult to comprehend the need for communication devices, particularly if bulbar symptoms may not be present. These options are discussed early, so that device trials can be arranged (the process of this can take some months depending on the waitlists of suppliers) and allow reports required for funding to be completed. The process of voice and message banking can also take some time, and it is recommended it be started early if people are interested in exploring this option before any communication changes start or deteriorate further.

For any questions or concerns you may have regarding communication and the changes you may be experiencing, discussing these with your Speech Pathologist is recommended. If you do not have a Speech Pathologist, your MND advisor can help in arranging a referral.

MND Victoria has a number of iPads available to registered members; these can assist people to communicate and connect with family, friends and health professionals. Equipment requests can be made via your treating Speech Pathologist.

PEOPLE-POWERED HEALTH IN MND

By Nicole Jackson

For people living with MND, communication and social connection can be significant challenges that impact on daily life.

During 2019, Nicole Jackson, an Allied Health Manager from Calvary Health Care Bethlehem, undertook a research project in conjunction with La Trobe University's School of Public Health, titled '***Photovoice impact on communication and social participation for improved quality of life in motor neurone disease***'. People with MND and their partners/primary carers were recruited to the study via CHCB and MND Vic. All participants attended a fully developed and piloted 4-week 'photovoice' communication group which is run by the Speech Pathology team at CHCB. The objective of the research was to investigate how an action research approach using photovoice can improve the quality of life for families living with MND.

'Photovoice' is a type of participatory action research in which people use photos to depict their lives and experiences in order to express their thoughts and opinions. The goals of photovoice are:

- **To provide a voice for communities which are marginalized in some way**
- **To instill critical consciousness.**
- **To stimulate social change or to influence policy.**

You know the saying, "***A picture speaks a thousand words***". Over 300 photos were shared by the research participants, so that would be equivalent to 300,000 words! These photos formed the basis of critical discussions, providing rich qualitative 'evidence' about the lived experience of MND for families.

Key research findings:

1. **Self-care**

A thematic analysis revealed particular behaviours were critical to emotional wellbeing and self-care: keeping passions and hobbies alive, the power of positivity and nurturing the emotional connections in your life, particularly family and pet dogs. The sense of inclusion and belonging afforded by supporting a football team was another very strong facilitator of connecting with others.

2. **Expanding modes of communication is the key to maintaining social participation.**

Photo-sharing contributed significantly because of the augmentative impact on communication / reduced speech burden, as well as adding a creative element to self-expression. The use of social media for photo-sharing enabled new, renewed and strengthened social connections with family and friends. The ability to trial new modes of communication, including social media and high-tech alternative communication options in a safe social setting was critical to success.

3. **Taking Action**

It is widely acknowledged that effective communication, having a voice, is one of the key social determinants of health. This desire for participants to be active citizens and take action on things that mattered to them has been the most significant outcome from this research.

Actions triggered by the photovoice program participants continue to stimulate social change by educating whole organisations. Critical to creating 'health' for those living with MND is to increase community knowledge about MND, in order to change individual attitudes and reduce the discrimination frequently experienced by those living with a disability. One example of a collective action using photovoice to raise awareness and achieve change for the MND community included:

- **The Melbourne Airport Hidden Disability program** which is an initiative launched in 2019 to develop the knowledge and understanding of airport staff so that they are able to provide additional assistance and care to customers with hidden disabilities in order to make the actual travel journey less daunting.

Families living with MND still love to travel, the many travel photos shared were evidence of this! Following the photovoice participants' sharing of photovoice narratives with the Hidden Disability program staff, an MND case study has now been included in the staff training package to build awareness around the impact of communication disability in adults, highlighting the hidden disability that is frequently experienced by those with speech loss due to bulbar MND. Sadly, COVID-19 travel restrictions came into place shortly after a photo shoot was conducted at Melbourne airport earlier this year but watch out for it when travel resumes!

Examples of actions from previous photovoice programs conducted at CHCB are testament to the sustainability of this intervention and the benefits that such action bring to the wider MND community.

- **Victoria Police** – An MND case study using participant photo narratives is utilised in recruit training to illustrate the importance of footpath access for wheelchair users.
- **Commonwealth Serum Laboratories (CSL)** introduced a liquid form of riluzole medication for those with swallowing difficulties. This important development was triggered by a participant photovoice letter targeted at the pharmaceutical industry.

100% of research participants responded that the photovoice process and outcomes improved their quality of life. Actionable, participant driven initiatives for individual or collective change were of most importance to participants because they reflected what mattered to them. This people-powered approach to 'health' is vital for organisations involved in delivery of quality, person-centred MND care.

Thank you to MND Victoria for hosting one of the research groups at Canterbury and a huge thank you to all the participants in the research study.

For further information about these research findings or to participate in a photovoice communication group program, please contact Nicki Jackson ph **9595 3474** or **Nicole.jackson@calvarycare.org.au**

REGIONAL FOCUS

David mainly works with members in the City of Casey and the Mornington Peninsula but also a few in other regions.

David has been using a lot of phone calls, emails and Zoom meetings to deliver support services.

IN THE LAST 8 MONTHS, DAVID PROVIDED 612 HOURS OF SUPPORT TO PEOPLE WITH MND.

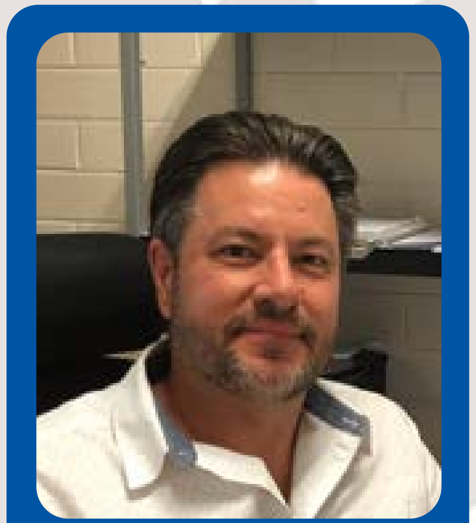
MND Victoria volunteers are active on the Mornington Peninsula and they are available to support people living with MND with services including **Life Stories** and **Hand and Foot Massage**.

Volunteers also travel from the Peninsula to participate in fundraising and other events, to assist with **Reception** and roles at head office including sending out **MND News**.

We look forward to getting together with our Peninsula volunteers when we are able.

Most people with motor neurone disease 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.

**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 **



DAVID - MND ADVISOR +SUPPORT COORDINATOR

David personally works with **36** people with MND.

Almost half of David's members were born overseas.

David has been an MND Advisor and Support Coordinator with MND Victoria since November 2019.

13 members access the NDIS.

21 members are in the Commonwealth Home Support Programme (CHSP).

2 members are pre-participants (neither NDIS nor CHSP).

'My Aged Care' system fails to meet the needs of people with MND. Please join the campaign to make Aged Care fair: **www.mndaction.org.au**

ROSEBUD WALK TO D'FEET MND

In 2015 the Rosebud Walk for MND was born. At the time, a group from The Village Glen Golf Club were looking for a charity to support for a fundraising event at their beloved club. It wasn't a hard decision as a favourite resident from the village, Ken McKenzie was diagnosed with motor neurone disease early in the year. Ken's MND was very aggressive causing him rapid decline in function throughout the year. Gwen Phillips and her team from the golf club decided to organize a walk around the beautiful golf course to help raise funds and awareness for MND Victoria, the organisation which directly helps people like Ken and all other Victorians living with MND by providing critical care, support and assistive equipment to help them stay safe, independent and engaged with their community for as long as possible.

In the first year, the event was purely a golf club event with 50 walkers taking part. Over the next couple of years, the golf club was the host venue, however the invitation was sent to all Village Glen residents. This saw an increase in participants who walked the figure eight course, collecting a stamp on their sheet of paper for every 1km lap they completed. In 2018 and 2019, the event became public and many families from all over the Mornington Peninsula and surrounding areas, who had been impacted by MND in one way or another, registered to take part in this annual event. Over 200 walkers took part last year which was incredible! Gwen has been the driving force since the beginning. She spends many hours in the months leading up to the event collecting donations from local businesses and residents in the village. The vibe on event day has never changed. It's such a happy day to be a part of. The volunteers are always so cheery and helpful, the raffle is fantastic and the weather is always great (mostly). Everyone is there to have a good time whilst doing their bit for the organisation that has played a big role in the life of one of their own. In the 5 years since the event began, $57,000 has been raised!

Ken was absolutely delighted to see all the work that was put into the inaugural event. He waited around just long enough to see the event that was created in his honour before passing away that night.

We don't know how the 2020 event will shape up because of the current Covid-19 situation, however we know this is an event that will continue on the first Sunday in November for many years to come!

How Can I Help MND research

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

To Participate or Not to Participate in Research: Challenging the Myth

Despite international guidelines emphasizing consumer-directed care and autonomous decisions in research participation, there is a common myth held by health professionals that research can be an additional and unwanted burden on patients and their family carers. However, evidence demonstrates that patients and their family carers wish to decide for themselves whether to contribute to studies and that they experience benefits by so doing.

In Western Australia (2015), 322 primary family carers of people with life-limiting illnesses participated in a trial to implement a systematic approach to assessing the support needs of carers. At the end of the study, they were asked about their experience and the impact of research on them: 87% perceived positive aspects and 83% rated their involvement as very, or extremely, beneficial. Many derived comfort from feeling valued and cared for, a sense of validation and self-worth in their role as a family carer. The research prompted the carers to reflect on the issues at hand and they developed a greater insight into both their own need for support and the services available to them. Being involved in research offered them the opportunity to share their experiences and feelings thus giving them a voice, and therefore they felt less isolated and more connected to others. The altruism of participants was evident as they wanted to make a difference and improve support for others in their situation. Participants expected that much of this perceived future benefit would be achieved through service improvement: "I am happy to do whatever I can to help if it makes a difference for others. Unless the government knows the details of what we need they can't make a difference"; "without research you can't have change, evidence is needed for funding".

Although health professionals might seek to protect those they see as vulnerable, denying patients and their family members the opportunity to decide for themselves whether to participate in research, violates the ethical principle of respect for autonomy. Participation is always entirely voluntary and one can withdraw at any time if they change their mind. It is apparent in this study that the ability of family carers to participate in research has been empowering and respectful of their autonomy. Without the perspectives of patients and their family carers, it is difficult to understand their needs and develop interventions to meet these needs. International guidelines have called for the need for "autonomous decisions of patients and caregivers regarding their participation in research to avoid limiting their participation through inappropriate gatekeeping and paternalistic attitudes."

Reference for further reading: Aoun, S., Slatyer, S., Deas, K., & Nekolaichuk, C. (2017). Family caregiver participation in palliative care research: Challenging the myth. Journal of Pain and Symptom Management. 53 (5) 851-860. www.dx.doi.org/10.1016/j.jpainsymman.2016.12.327

Professor Samar Aoun

President MNDAWA

Professor Palliative Care Research

Perron Institute and La Trobe University

FUNDRAISING

"Obstacles don't have to stop you. If you run into a wall, don't turn around and give up. Figure out how to climb it, go through it, or work around it."– Michael Jordan

It's with a lot of sadness that I write this article, my final one, as I've decided that, after ten amazing years in the role of Manager Supporter Development (previously Fundraising), it's time for me to ease into retirement! I have met many, many incredible people who have inspired me to "never give up" and to find a way to get over that wall, because raising awareness and funds for people living with MND is the most rewarding and challenging activity I could ever do. This is also an exciting time – for me personally and, also, for MND Victoria - because I'm delighted to say that Daniel Woodrow will be taking over as the Manager Supporter Development and Communication. Many of you know Daniel already and I'm confident that under his leadership and with your support, MND Victoria's fundraising will grow even stronger.

This past six months have been the most tumultuous, and exciting, since I joined. COVID-19 certainly brought many challenges and resulted in the postponement of several Walk to D'Feet MND events, and the cancellation of community run events. This negatively impacted our March fundraising income and we were concerned how the rest of the financial year would be impacted. But we shouldn't have been concerned! We should have known that our dedicated supporters would not let us down. The financial support we've received as a result of our first national virtual fundraising event – Australia Moves for MND – has been amazing. In addition, when we shared Shelley's story about her mum Sandra's MND diagnosis and progression, our supporters once again showed us their overwhelming commitment to ensuring that MND Victoria can continue to deliver care and support to people living with MND. Thank you to all who participated or supported our AM4MND Campaign and those who donated to our 2020 Tax Appeal.

Although we are still operating in uncertain times with restrictions on gatherings still in effect, it is our plan to commence our Walk to D'Feet events in November. We will let you know as soon as we open registrations.

Thank you to all the dedicated supporters, donors, management team, staff, state council and volunteers who have made the last ten years the best in my professional career. I will miss everyone, but I am looking forward to spending a bit more time in my garden, quilting and catching up with friends.

Kathy Nightingale

Manager, Supporter Development

AUSTRALIA MOVES FOR MND (AM4MND)

What an amazing result - $219,322 ! This was the first time all the state MND Associations joined together for a fundraising event to support the 2,100 Australians living with MND.

AM4MND had been in the planning stages for a couple of months so we were in the great position to be able to launch this soon after the COVID-19 restrictions started to come into force. AM4MND was designed to be a fun way to move while in lockdown and, at the same time, raise funds. The campaign was planned as a virtual event to raise awareness and funds from the start of MND Week, 3 May, through Global MND Day, 21 June. As each state faced a significant decrease in fundraising resulting from all Walk to D'Feet MND events being postponed or cancelled, it was very important that AM4MND be successful. It was a great opportunity for State MND Associations to collaborate and, because of this, we saw a very early uptake of interest and fund raising.

MND Victoria's very own merchandise volunteer, Joe Mantella's super-human effort to walk 2,100 kms saw him raise $29,192 making him, and us, the number one fundraiser!

WHY BEQUESTS MATTER

We know that families who have been impacted by MND face physical and emotional stress on a daily basis. In addition, many families face financial hardship as well due to loss of employment for the person with MND or their carer and sometimes both. For those aged over 65 when diagnosed, the lack of appropriate financial support through MyAged Care leaves many struggling to provide the level of care and support their loved one needs.

Thankfully, MND Victoria has dedicated donors who support us financially through participating in a variety of fundraising events, as well as donating to our Appeals. This ensures that all Victorians can access care and support from MND Victoria regardless of age or where they live.

But what if you can't donate to our Appeals or fundraising campaigns but are passionate about supporting people living with MND because you've seen first-hand the caring support MND Victoria provides every day? How can you help when your own expenses already stretch your finances to the limit?

One way you can show your support and commitment is by including a gift to MND Victoria in your Will. A Gift in your Will – no matter how big or small - will enable MND Victoria to continue delivering care and support services to those who need it most. It is a very special way to show you care for Victorians impacted by MND. Your gift will be a lasting reflection of the significance you place on helping people with MND to live better for longer. It will give hope for generations to come.

If you are getting ready to write or update your Will, please think about leaving a gift to MND Victoria. If you would like more information on the wording to use please contact us at: **fundraising@mnd.asn.au** or call **1 800 806 632.**

ZOOMING WITH DAN

The past few months have been like no other. They have, however, been a time where so many of us have learnt new skills and ways to adapt to the new 'normal'. We've all learnt a lot more about the technology that's available to us incredibly quickly.

The whole team at MND Victoria became experts with Zoom and various other online meeting programs almost immediately, and transitioned seamlessly to a world that involved virtually no face to face contact. Zooming with Dan was a natural progression for the Supporter Development Team because we know how many amazing stories are out there! I have had the absolute privilege of working for the organisation for over three and a half years. In that time, it's become abundantly clear that the MND space is full of exceptional people. Whether that's people living with MND, family members and carers of people living with MND, health professionals, researchers, MND Victoria volunteers and, of course, our team of dedicated staff members.

I'm proud to work for the organisation that provides the best possible care, support and vital assistive equipment for all Victorians and Tasmanians living with MND. It's these services that help these people live as well as possible for as long as possible.

Zooming with Dan is all about highlighting the wonderful people who make up the MND community. Whether it's inspirational stories or update-to-date professional information, the guests who have appeared on our Facebook page at 7pm AEST each Thursday night have been able to connect and provide valuable insight and knowledge for the audience about many aspects of MND. Having the ability to log into a simple Zoom meeting and hitting the 'go live' button on Facebook has been a brilliant way to get the amazing personal stories and valuable knowledge and information from professionals into people's living rooms whilst overcoming the hurdle of social distancing.

I would love to hear from anyone who wants to share their story or wants to recommend someone else! Please get in touch at **dwoodrow@mnd.asn.au.** Zooming with Dan is certainly here to stay!

Daniel Woodrow, Supporter Development Officer

Walk to D'Feet MND

Event dates will be advised once confirmed.

DONATIONS RECEIVED ... THANK YOU!

In Memory

- Alan Dunscombe
- Ann Nicol
- Brenda Pilson
- Bruce Bowditch
- Christopher de Krester
- David Henderson
- Dot Dickson
- E.C Dixon
- Foong Law
- Gary Clarke
- Graeme Williams
- Jean McGregor
- Jim Bugeja
- John Dexter
- John McIntosh
- John Ryan
- John Winstanley
- Josee Finniss
- Joy Allen
- Joy Iggulden
- Lois Lockwood
- Malcolm Conlan
- Marlene Stanway
- Martin Williams
- Mary Bussau
- Mary Quinney
- Michel O'Brien
- Michelle Copeland
- Nicole Hall
- Robert Jamieson
- Ronald McCann
- Rosie Grey
- Terry Anderson
- Tim McCormack
- Tony Page
- Philip Gulle
- Malcolm Duff
- John Cannington
- Jeff Berryman
- John Wilson
- Stuart Smith
- Jane Kile
- Margaret Williams
- Max Prior
- Daniel Martinez
- Douglas Smiley
- Maggie Parsons
- Marlene Williams
- Ivan Rae
- Frank Lorichiella

Research In Memory

- Jeff Bibby
- Norm Henkel

School

- Whitehorse Primary School

Organisations

- Coles Bay Holidays
- Trevor P Weichmann & Associates

Clubs

- Rotary Club of Cranbourne

Corporations

- Ritchies IGA
- Express Insurance Brokers
- Specsavers Pty Ltd.
- McGrathNicol Melbourne

Bequests

- The Estate of Marisa Agius
- The Estate of Helen Margaret Griffin

Trusts

- The Bronsen Family Trust
- Perpetual Trustee- George & Edith Ramsay Charitable Trust
- The Kate Jones & Stephen Alomes Fund – APS Foundation
- The GW Vowell Foundation
- FightMND Care Initiatives Grant

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 2 September for the next edition, to be mailed on 15 September 2020.

GET INVOLVED IN AN EVENT VIA INTERNET!

Date:	Event:	Find out more:
Thursday 6 August 2020	Remote MND Information Session - Video Conference	Email: info@mnd.asn.au
Monday 26 October 2020	MND Victoria Annual General Meeting	Email: info@mnd.asn.au
November 2020 (TBD)	Walk to D'Feet MND, Princes Park, Carlton	Email: fundraising@mnd.asn.au
November 2020 (TBD)	Walk to D'Feet MND, Bendigo	Email: fundraising@mnd.asn.au
6-14 May 2021	National Kokoda Challenge 2021	Email: fundraising@mnd.asn.au

We are still providing vital support and care for 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.

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 | www.linkedin.com/company/mndvic