mnd matters

Issue 3 | Sept to Dec 2022

40 Years of Hoping and Helping

Accessible Comfort Away from Home

Local Patronage – Hannah Beazley MLA

Staff

Chief Executive Officer	**Courtney D'Mello**
Fundraising and Events Manager	**Sarah Wiley**
Accountant	**Ling Lee**
Administration and Accounts Receivable	**Anne Northall**
Administration and Events Coordinator	**Anita Nici**
Marketing Coordinator	**Jasmin Woodhall**
MND Advisors	**Joan Ellis, Emma Evans (South West region), Jade Arnott and Oonagh Vereker**
Respiratory Physiotherapist	**Vivienne Travlos**
Occupational Therapists	**Sophie Nunn and Terrie Simpson**
Coordinators of Support	**Jodie Nicks and Shanaz Lambat**
Allied Health Assistant / Equipment Coordinator	**Tuti Clift**

Motor Neurone Disease Association of Western Australia

ABN **49 312 430 982**

Unit 1/184 Raleigh Street
Carlisle WA 6101

- **(08) 6186 4133**
- **admin@mndawa.asn.au**
- **www.mndawa.asn.au**

In the spirit of reconciliation, MNDAWA acknowledges the Traditional Custodians of country throughout Australia and their connections to land, sea and community. We pay our respect to their Elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples today.

Board of Management

President	**Prof Samar Aoun**
Vice President	**Maureen Bathgate**
Treasurer	**Helen Kraus**
Secretary	**Maeve Egan**
Members	**Drew Bathgate Lachlan Haughey Melissa Cashman Prof Anthony Akkari Paul Rogers Guy Marchesani Dr Tom Jenkins**

Patron

Hannah Beazley MLA

Ambassadors

Kirsten Whitby
Narelda Jacobs

Auditor

Tony Silipo

REGISTERED CHARITY
acnc.gov.au/charityregister

Inside this Issue

MNDAWA Awards, October 2022

MESSAGE FROM THE CHIEF EXECUTIVE OFFICER

Dear members and friends,

Welcome to 2023! For many of us, 2022 was a whirlwind of ups and downs with the pandemic continuing to take hold and many world events making the headlines and leaving us wondering what was coming next. On behalf of the team at MNDAWA, we are proud to have provided a constant support for the families in our community.

I think we could all agree that navigating our way through the past few years has taught us all to be more resilient and adaptable – or perhaps highlighted how resilient we already were!

I would like to give special recognition to the volunteers who contribute so greatly to the Association. Over the 2021-22 financial year, our volunteers donated over 800 hours of time – the equivalent of over $47,000. Many of our events and initiatives rely on these volunteers and we are sincerely grateful for their dedication.

The MNDAWA Awards were presented in October, acknowledging the significant contributions of businesses and individuals who have supported the Association through the 2021-22 financial year. It was an honour to have the opportunity to personally thank these supporters as without them we could not achieve what we do. Special congratulations to Denise Fox, MNDAWA Volunteer of the Year. Denise not only volunteers in the Association's office weekly, but also took part in the 'Dive for Dollars' event in November.

Dive for Dollars demonstrates quite literally the lengths some individuals will go to show their support. Congratulations to the participants who all thoroughly enjoyed the experience and together raised over $14,000.

At the Annual General Meeting in November, Prof Samar Aoun was re-elected as President of the Association. I look forward to working with Samar, along with the Board members as we continue to progress the Association's objectives.

At the end of 2022 we ran our Christmas appeal, calling on Western Australians to show their support of the Association and help us raise funds to continue providing our vital services. We have been humbled by the response to this campaign and are extremely grateful for the support received.

This year we have a new adventure lined up for the thrill-seeking supporters. Soar to Support will be held in March – climbing the Matagarup Bridge over the Swan River and either climbing or zip-lining down. If this appeals to you, please visit the website and sign up. It will be a great afternoon and a unique way to fundraise.

Courtney D'Mello

Chief Executive Officer

MESSAGE FROM THE PRESIDENT

Dear MND community,

Welcome to the New Year – a time for fresh beginnings! I do hope you have been energised by the holiday season and shared valuable time with your family and friends.

I am honoured to carry on as President of MNDAWA and look forward to continuing to lead the Association in best practice, providing a high standard of support for our clients and family carers, with the support of our wonderful Board members and dedicated staff. At the AGM in November we farewelled Dr Robert Edis, who has been an integral contributor to the wellbeing of the MND community since 1984 and on the MNDAWA Board for the last four years. Dr Edis was honoured with a Life Membership and I look forward to his continued involvement, albeit in a different capacity. I extend my thanks also to Meredith Corr who departed from her role on the Board. I trust Meredith will continue her involvement with the Association.

We have welcomed new Board members Maeve Egan and Dr Tom Jenkins and I would like to congratulate consumer representative Maureen Bathgate who has been nominated as Vice President. Consumer input is essential to drive improvements and without it the Association would lack relevance.

In the area of advocacy, we will be working with our Patron, Hannah Beazley MLA to progress the 'Parliamentary Friends of MND' group. This will facilitate communication and enable representation at State Parliament level. We continue also to collaborate with the other state and territory associations, as well as MND Australia to advocate for the needs of those living with MND, with particular focus on the provision of disability supports and services including NDIS and Aged Care support.

It is with mixed feelings that we recognise that 2023 is the 40th anniversary of the Association. While we are proud of the services and support provided over this time, we look forward to the day that there is a cure for MND, and the Association is no longer needed. In this publication and throughout the year we will be looking back at the 40 years of service and acknowledging some key stakeholders.

Lastly, I would like to thank those who have reached out to congratulate me for my recent award as 2023 WA Australian of the Year. This acknowledgement is an honour and I believe it will give us a platform to strengthen our advocacy around palliative care and compassionate communities that are vital to enhancing the supportive networks needed for the MND community.

Professor Samar Aoun
President

Board of Management

The Annual General Meeting, held on Tuesday 29 November included the election of the Board of Management. We would like to congratulate and welcome our Board members:

President:
Prof Samar Aoun

Treasurer:
Mrs Helen Kraus

Vice President:
Mrs Maureen Bathgate

Secretary:
Mrs Maeve Egan

BOARD MEMBERS

Board Member:
Mr Drew Bathgate

Board Member:
Mr Guy Marchesani

Board Member:
Mr Lachlan Haughey

Board Member:
Prof Anthony Akkari

Board Member:
Mr Paul Rogers

Board Member:
Tom Jenkins

Board Member:
Ms Melissa Cashman

We would like to thank outgoing Board members Dr Rob Edis and Mrs Meredith Corr for their service to the Association.

Local Patronage

Hannah Beazley MLA became the Patron for the Motor Neurone Disease Association of WA in 2022. For a charitable, not-for-profit association, the role of the Patron involves lending their name and using their profile to support a worthy cause, adding credibility and integrity. We spoke to Hannah about her involvement and her plans to help advocate for those living with MND.

Q. Before becoming Patron of the Association, what was your awareness of Motor Neurone Disease?

I didn't know as much as I should have.
I think like many in our community, I knew that Motor Neurone Disease was extremely serious and always fatal. I knew that it involved the progressive loss of function to body parts. I considered it a disease that is viewed with a lot of fear.

Q. And what would you say about the importance of community awareness, and how we could increase this?

One of the things that has struck me since working with MNDAWA is that MND doesn't just affect the person with the disease, it deeply affects their families and loved ones, who become caregivers for someone with an often confronting and high-needs illness. It's really crystalised to me that we need to spread awareness of the needs of families with a loved one who has MND and make sure that we are providing those families with support through their journey.

One of the other reason why community awareness is critical is research. The MNDRA undertakes critical research every year into Motor Neurone Disease, and donations and other streams of funding are essential if we are to find a cure or an effective treatment.

Q. What advice or perspective would you offer our community who are navigating the NDIS or perhaps the Aged Care Assessment?

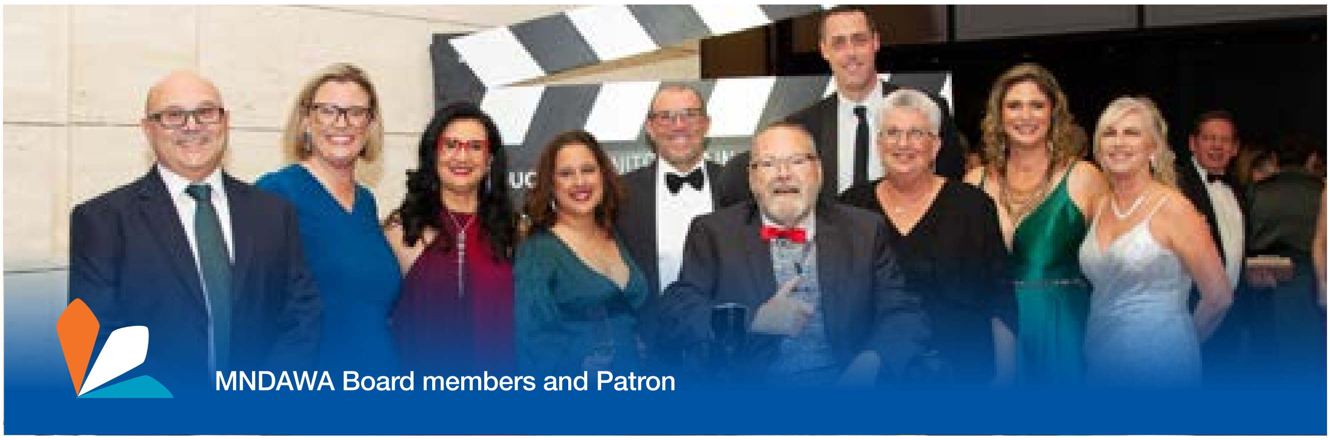
As a mother of a son with extra needs who is on the NDIS, I've experienced first-hand the challenges of navigating the NDIS system and can empathise with those who find it frustrating. But I'm also aware of the extraordinary benefits the NDIS can have on the lives of those who desperately need its assistance. I've seen first-hand the benefits NDIS-supported therapies have had on my son's well-being.

My advice would be to contact your Local NDIS Area Coordinator before you even begin your application – in my Victoria Park electorate, this is Mission Australia. Your NDIS Local Area Coordinator will be able to guide you through the application process.

I also encourage you to gain as much evidence as possible and ensure that you note in your application that your disease is fully treated and permanent. If in doubt – reach out to your local Federal Member of Parliament, as they may be able to help.

Q. Earlier this year you joined us at the Unite Against MND Charity Ball. You spoke there about the prospect of developing a Parliamentary Friends of Motor Neurone Disease Group. Can you provide any updates on this?

Parliamentary Friendship Groups are a useful way to raise awareness of, or increase liaison between parliamentarians and policy makers



MNDAWA Board members and Patron

with, a particular group, organisation, or issue. I am very passionate about our new Parliamentary Friends of Motor Neurone Disease. The inaugural Parliamentary Members of this group will be myself, Margaret Quirk MLA, Member for Landsdale and Hon. Pierre Yang MLC, Member for North Metropolitan Region. I look forward to the group's official launch event in our next Parliamentary sittings in the new year.

We have Parliamentary Friendship groups for palliative care; for people with rare and undiagnosed diseases; for the deaf, deaf blind and the hard of hearing – which I am also a co-convener of – as well as many others. These groups help raise the profile of each respective issue or struggle within the community and gives Members of Parliament an opportunity to learn about the needs of those living with challenges such as MND.

Q. In March 2023 you will be joining us for the inaugural Soar to Support event – where you will climb the Matagarup Bridge in East Perth and zipline down. How are you feeling about this adventure and what made you decide to take part?

Very nervous! As someone who has a very large fear of heights, this is going to be a big challenge for me. But if I've learnt anything from my time as Patron of MNDAWA, it's that those who live with MND wake up every day and face the kinds of challenges that those who don't live with MND could not understand, which is why I think raising the profile of MND in the community is so important. The more people who are aware of the disease, the more we have on our side to help, one day, discover a cure. So I am very nervous, and I urge you all to support me and my ziplining adventure for MNDAWA!

Visit **www.mndawa.asn.au/soartosupport** for more details.

Hannah Beazley was elected to the Parliament of Western Australia as the Member for Victoria Park at the March 2021 State Election. Hannah is the first woman elected to represent the Victoria Park community in the State Parliament.

Hannah brings to Parliament over 20 years of extensive professional experience having held senior positions across the education and private sectors. She was also a Senior Policy Advisor and Speechwriter to two Premiers, Dr Geoff Gallop and Mark McGowan.

In December 2022, Hannah was sworn in as the Parliamentary Secretary to the Minister for Emergency Services; Innovation and the Digital Economy; Medical Research and Volunteering.

Accessible Comfort Away from Home

Whether you are visiting family, ticking-off a bucket list adventure or travelling to attend a medical appointment – your accommodation selection is crucial.

For those living with limited mobility, there are several factors to consider when finding a place to stay. Accessibility means so many different things to different people, so when a property is listed as 'accessible' – how can you be confident that it will meet your needs?

> That's where the Accessible Accommodation website and rating system comes in.

Kerry and Grant Williams are the people behind Accessible Accommodation. They understand the importance of good information for people with disabilities, from the perspective of people needing accessible accommodation and for people owning and managing accommodation that may or may not be accessible.

Seven years ago, they built an accessible holiday rental. They discovered just how different everyone's needs are, that there simply isn't a 'one size fits all'. They have spent considerable time researching and talking to guests who require varying levels of accessibility. They understand the needs of people with disabilities and now share this knowledge with other property owners.

Each of the eight members of the Accessible Accommodation team has lived experience, either living with a disability themselves or caring for a family member living with a disability. So when they speak to prospective clients, they have a level of understanding and compassion that not many booking clerks can offer. This makes it that much easier when you need to discuss the space required around the toilet to turn a wheelchair around, the type of shower chair needed or the height of the sink.

The three categories by which they rate an accessible property is now the benchmark for Accessible Tourism. Accommodation providers are offered peace of mind by ensuring their property will meet their clients' expectations. Once their rating is confirmed, they can promote this on their front door and via listings.

Most importantly, holiday-goers can avoid the risk of checking in to a property, only to find that an essential facility isn't suitable for their needs.

The accommodation listings cover extensive detail. Property owners are asked 50 questions regarding accessibility and are asked to provide a video tour as well as information on accessible activities nearby.

Visit the website
www.accessibleaccommodation.com
to subcribe for the latest accommodation offers and listings.

Subscribe

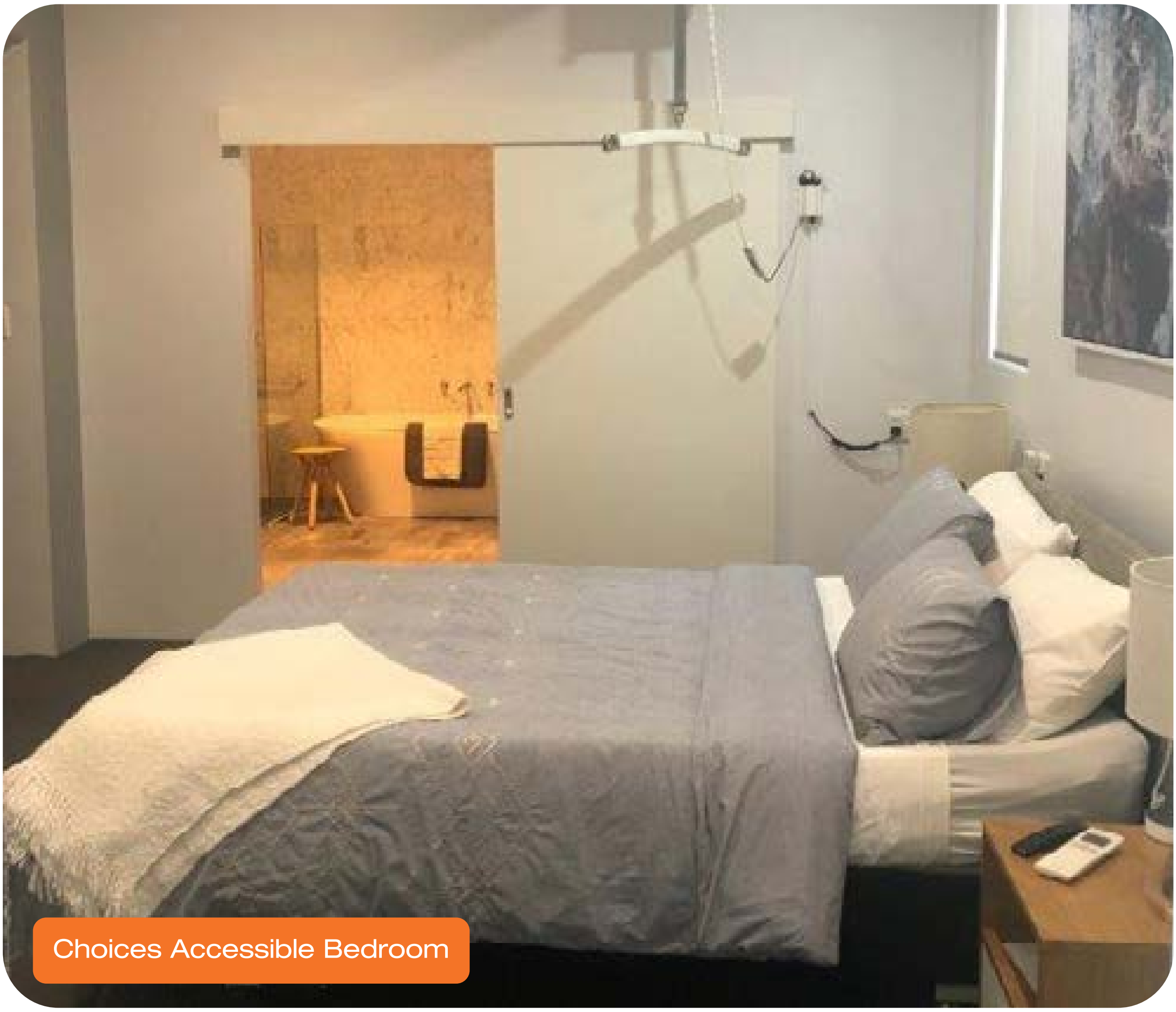
Accessible Qualified

1.

2.

3.

Quest Perth Ascot
Accessible Living


Choices Accessible Bedroom

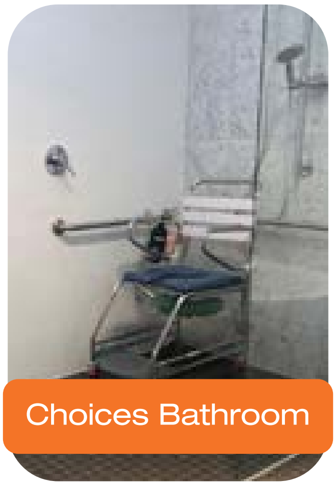
The following properties are a sample of the accommodation profiled on the website.


Choices Kitchen

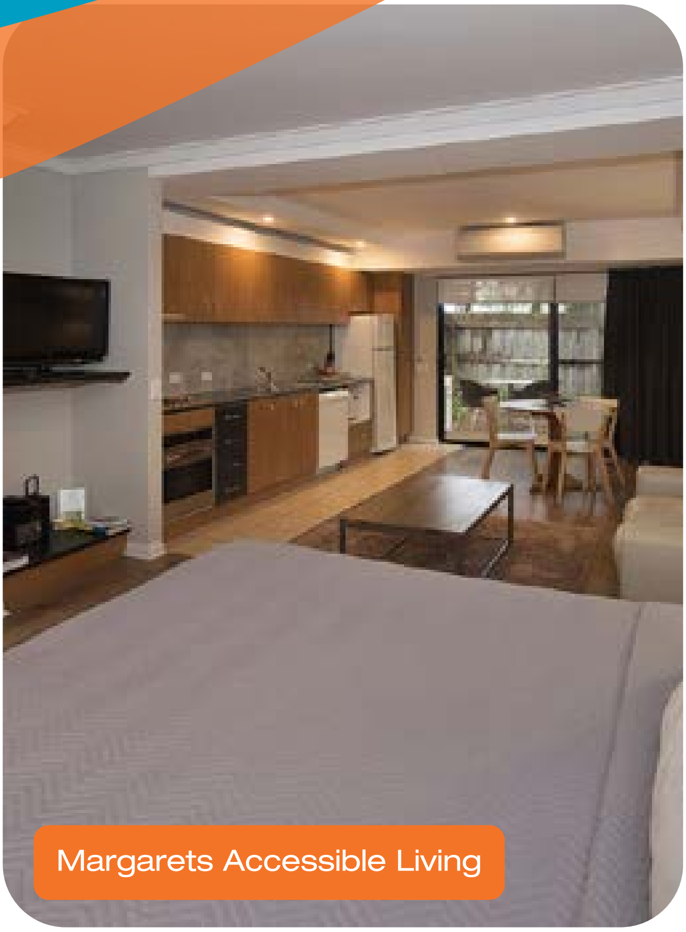
CHOICES HOUSE FLOREAT (PERTH)

Accessibility level: Assisted Wheelchair User.

Rarely found, highly desirable, SCIA (Spinal Cord Injuries Australia) offer this family retreat in Perth, situated in the lovely suburb of Floreat. Whether it be for respite with family and friends, or to take advantage of the peer support services on offer, this is the place you'll find it. Best of all, it is pet friendly, there is an accessible pool (with hoist) and a Neuromoves accessible gym!


Choices Bathroom

Quest Accessible Living

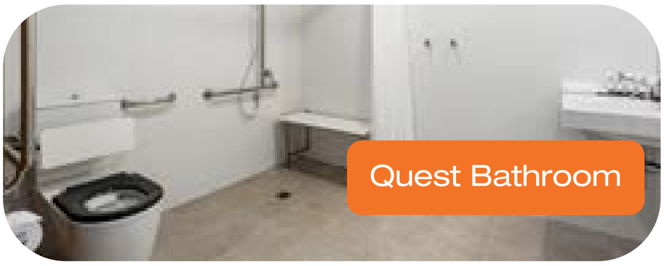


Margarets Accessible Living

QUEST PERTH ASCOT (PERTH)

Accessibility level: Independent Wheelchair User.

Quest Perth Ascot (Perth) Accessible Accommodation, bringing a stunning new accommodation experience for both the business traveller and leisure traveller. Perfectly positioned in the suburb of Ascot, located between Perth airport and the city centre, Quest Perth Ascot has 5 one-bedroom and 5 two-bedroom accessible apartments.



Quest Bathroom

MARGARETS FOREST-MARGARET RIVER ACCESSIBLE ACCOMMODATION

Accessibility level: Independent Wheelchair User.

This property offers two separate ground floor, accessible spa studio apartments at the property. Free, non-designated private parking is generously available onsite. Furthermore, the accessible rooms also offer their own parking in front of the apartment. The rooms come with a King bed, that can be split into 2 Singles if desired. Therefore, it is recommended for couples or someone travelling with an abled carer. The bathroom is equipped with a toilet and handrails, a walk-in shower (shower chair provided) and hand shower. There is also a twin non-accessible spa bath.

MNDAWA President Awarded WA Australian of the Year 2023

Prof Samar Aoun

Prof Samar Aoun is the Perron Institute Research Chair in Palliative Care at the University of Western Australia. She is an internationally recognised leader in the advocacy of public health approaches to palliative care. Samar volunteers her time as the MNDAWA President, leveraging her networks and knowledge to advocate on behalf of the MND community.

Samar is the co-founder and chair of the South West Compassionate Communities Network. The program is a volunteer-led initiative designed to enhance the social networks of families living with chronic or life-limiting illnesses.

Her work focuses on 'under-served' groups, or those that may not have access to adequate medical and support care, including people with Motor Neurone Disease and dementia, terminally-ill people who live alone, and family carers.

Congratulations to Samar on this outstanding recognition.

MND Life Membership Awarded to Dr Rob Edis

Dr Rob Edis

Dr Rob Edis retired from the MNDAWA Board in 2022. Dr Edis has been recognised as an outstanding practitioner within the field of neurology and neurology rehabilitation and has contributed greatly to many MNDAWA projects.

Rob had this to say on reflection of his involvement:

> *"The best highlight of being associated with the MNDAWA (since 1984!) has been the professionals I have known, working as part of and leading dedicated and committed multidisciplinary MND Clinic teams, delivering coordinated specialist best care for people living with MND from our hospital base [in my case RPH and then SCGH -Perron Institute] out into the community since 1994; but more specifically from 2008 when the three NMHS/SMHS/EMHS based MDT MND Clinics were established.*
>
> *Going on the 2019-2020 MDT MND Educational Seminars Tour with MNDAWA President Samar and others to present in Bunbury, Albany and Geraldton was another fulfilling worthwhile experience. Doing social research with (but led by Samar) into the effects of 'Telling of the Diagnosis of MND' on the neurologists but also the families was also groundbreaking.*
>
> *And finally, the privilege of sharing with people living with MND and their families, their stories and trust; and marvelling at their bravery and resilience in response to losses during the progressive course of the disease; brought so many life lessons for me. Then the privilege to be there to advocate on their behalf if needed, at their end of life, will in a number of cases, stay with me forever."*

Our congratulations to Dr Edis and on behalf of our community, thank you for your contribution over the past 39 years.

Commemorating *40 Years* of Hoping and Helping

Established as the Motor Neurone Society of Western Australia in 1983 to support people living with MND, their families and their carers, 2023 marks our 40-year anniversary.

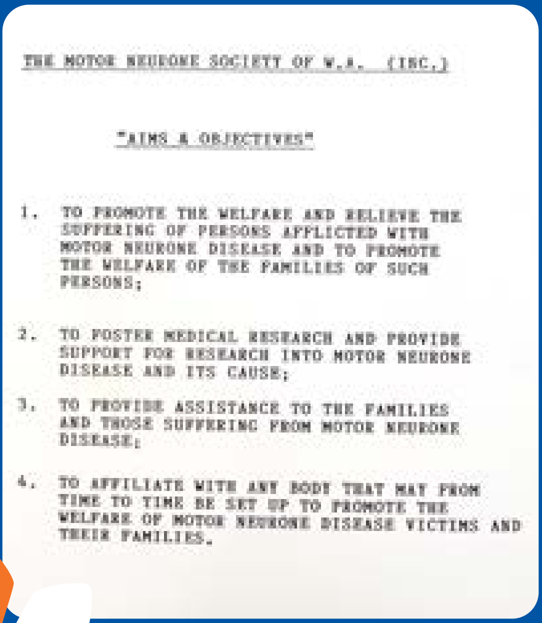
Let's be clear – the goal was never to make it to 20 years, let alone 40. The Association was established to care for those living with MND, while hoping for the major breakthrough in research that would bring a cure to stop MND in its tracks. Unfortunately, despite the ongoing, worldwide research, we aren't there yet.

However, marking the 40-year anniversary is an important milestone. A time to reflect on the support services we have provided over the years.

MNDAWA is a not-for-profit organisation, and our mission is to lead in the specialist support, enhancement of quality of life, awareness raising and promotion of research for people living with MND.

It is grounding to look back at where the 'Society' began, the aims and objectives, and to see that in 2023 we are staying true to our purpose.

1983



THE MOTOR NEURONE SOCIETY OF W.A. (INC.)

"AIMS & OBJECTIVES"

1. TO PROMOTE THE WELFARE AND RELIEVE THE SUFFERING OF PERSONS AFFLICTED WITH MOTOR NEURONE DISEASE AND TO PROMOTE THE WELFARE OF THE FAMILIES OF SUCH PERSONS;
2. TO FOSTER MEDICAL RESEARCH AND PROVIDE SUPPORT FOR RESEARCH INTO MOTOR NEURONE DISEASE AND ITS CAUSE;
3. TO PROVIDE ASSISTANCE TO THE FAMILIES AND THOSE SUFFERING FROM MOTOR NEURONE DISEASE;
4. TO AFFILIATE WITH ANY BODY THAT MAY FROM TIME TO TIME BE SET UP TO PROMOTE THE WELFARE OF MOTOR NEURONE DISEASE VICTIMS AND THEIR FAMILIES.

2023

The objects of the Association are

a) To support people in Western Australia with MND, their carers and their families, and assist them to gain access to appropriate physical, emotional and advocacy services.

b) To promote awareness of MND and the care needs of people living with the disease among health professionals, care providers and the general public.

c) To promote research into all aspects of MND.

d) To raise funds for use by the Association in pursuit of its objects.

Recent Events

DIVE FOR DOLLARS - our thrill-seekers' fundraising event – was held in November. Participants were flown 14,000ft over Rottnest Island, before skydiving over some of the most beautiful beaches in WA.

MNDAWA AWARDS 2022 - Presented in October, the awards recognise the individuals, groups and businesses which have supported us throughout the year. For a list of award recipients please visit the website.

MND HERO HIKE - On 1 October the inaugural MND Hero Hike saw fundraising heroes set off for various distance walks. Four inspirational supporters took on a challenge of walking 100km. The support of over 70 participants joining them for the commencement of their walk set them up for a great start.

PAMPER DAY - MNDAWA hosts Pamper days throughout the year – a chance for those living with MND as well as their carers to take time away from the daily routine and be pampered with massages, treatments and relaxation activities.

CHRISTMAS LUNCH - To end the year, staff, clients and carers get together to enjoy an informal lunch, reflect on the year and share experiences. Thank you to everyone who joined us and to Developmental Disability WA for their support of the event.

Community Champions

The MND Association of WA is sincerely grateful for the many supporters who donate their time to raise awareness and funds. These individuals and community groups help us to make a real difference for people living with MND.

The Dongara High Tea in November raised $17,012 – and guests had a great time doing so!

Wanneroo Golf Club Event raised $5,030

Ardath Tennis Club hosted the annual Colin Smith Memorial Day, which raised $410

Vicki's 'I Can Walk' Event raised $1,215

MND Ambassador Kirsten Whitby (Darren's Ride), organised a Spring Fashion Show in Busselton, which raised $1,418

North Metropolitan Health Services, Workforce & Integrity directorates hosted a bake-off which raised $82.50

Trudy Renshaw and The Body Transformation Studio hosted Stand Up For MND, raising $1,152

Red Dot stores across WA invited customers to donate in-store and raised $12,162

Staffordshire Bull Terrier Club of Western Australia Inc. raised $130

The 'Playing Through for MND' golf day raised $9,446

$10,000 was donated as part of the CommBank Staff Foundation Community Grant. photo

Cindy Dean's 'A Celebration of Olivia Newton-John' raised approximately $1,500

The Old Boys Business Club hosted a lunch in November and donated $5,000.

MND Charity Matches raised $6,789. Ivan Pobrica's family hosted MND charity soccer matches. A special thank you to everyone who donated on the website or attended/participated in the event. They also acknowledged these supporters:

Bindoon Mitre 10

ERCEG Aviation

Del Basso small goods

Indigenous Emerging Business Forum

Infinity Designed

Cina Ghiassi - C Realty

Lynford Ford

Can you help?

MNDAWA relies heavily on the generosity and support of the community to continue our vital care and support services.

If you would like to fundraise for MNDAWA or discuss ways in which you may be able to support us please contact 6186 4133 or email admin@mndawa.asn.au.

If you have organised a fundraiser and would like your story shared in the newsletter please let us know.

Family Carers' Perspective

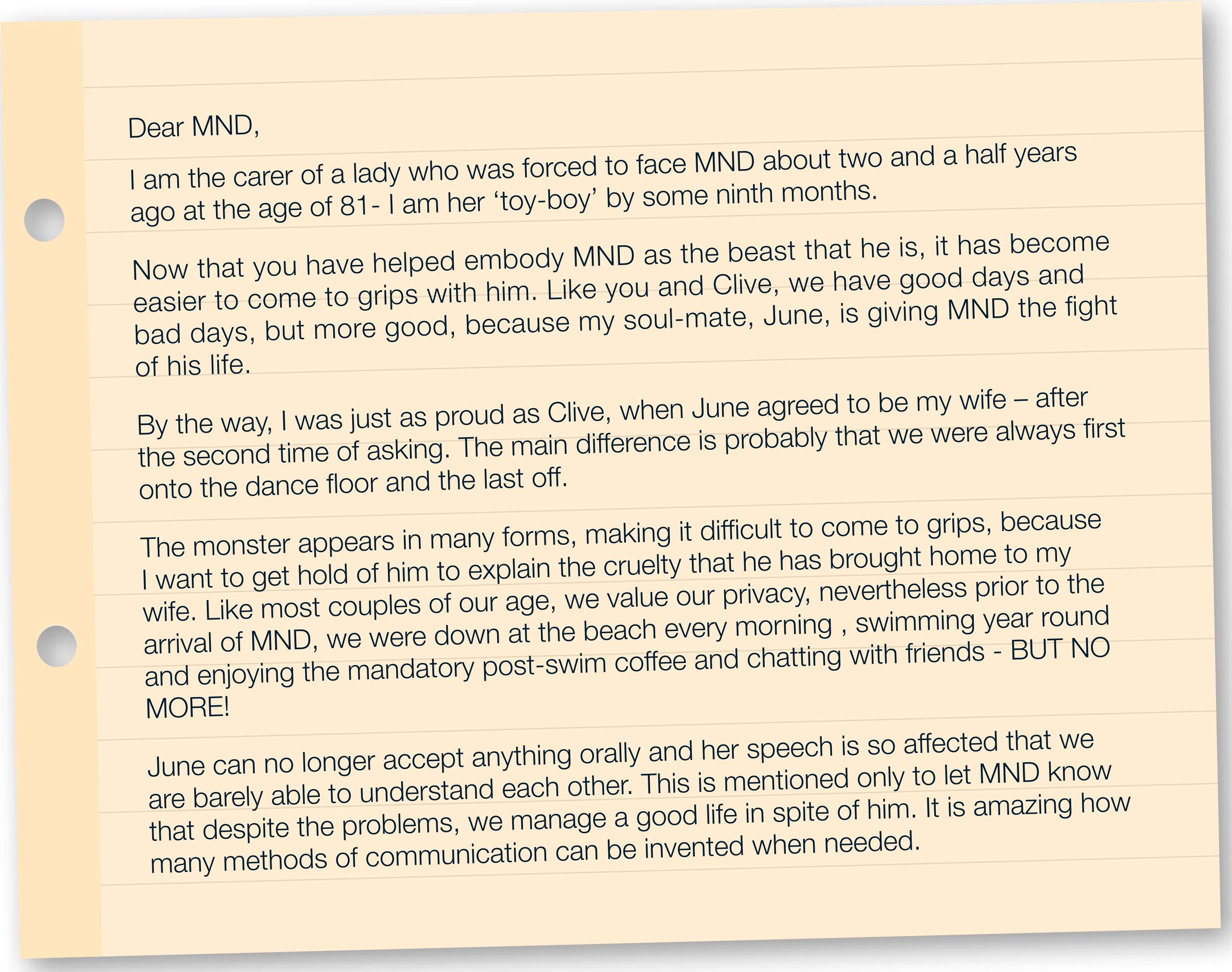
A large part of the Association's work is to understand the role and the needs of the carers. After all, they often spend every day with a loved one who is living with MND. Here we share an article written by, or of interest to, our community of carers.

In the last edition of MND Matters we shared a letter by Jacqui, written to MND, as though it were a person. Jacqui used this to direct her feelings in response to watching her husband Clive battle this illness. This letter captured the emotions of many carers as well as those living with MND.

Martin wrote in:

> *"Dear Jacqui, your heartfelt letter was an inspiration to read. Not only that, it encouraged me to try to catch up with MND myself and give him a blood-nose, and maybe, a black eye."*

This is the message from Martin to MND.



Dear MND,

I am the carer of a lady who was forced to face MND about two and a half years ago at the age of 81- I am her 'toy-boy' by some ninth months.

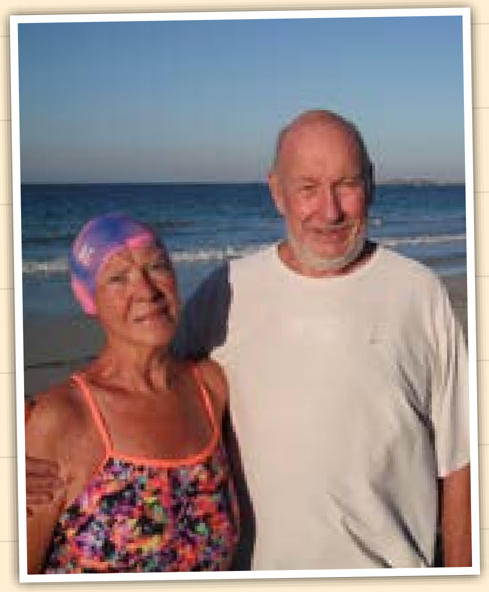
Now that you have helped embody MND as the beast that he is, it has become easier to come to grips with him. Like you and Clive, we have good days and bad days, but more good, because my soul-mate, June, is giving MND the fight of his life.

By the way, I was just as proud as Clive, when June agreed to be my wife – after the second time of asking. The main difference is probably that we were always first onto the dance floor and the last off.

The monster appears in many forms, making it difficult to come to grips, because I want to get hold of him to explain the cruelty that he has brought home to my wife. Like most couples of our age, we value our privacy, nevertheless prior to the arrival of MND, we were down at the beach every morning , swimming year round and enjoying the mandatory post-swim coffee and chatting with friends - BUT NO MORE!

June can no longer accept anything orally and her speech is so affected that we are barely able to understand each other. This is mentioned only to let MND know that despite the problems, we manage a good life in spite of him. It is amazing how many methods of communication can be invented when needed.

As Jacqui indicated, support for those affected and carers alike is so important and for us the support is there in many forms. Not only from family, but also provided by the MND Association, Professor Needham's so dedicated MND team at Fiona Stanley Hospital and the many caring and conscientious advisors and professionals that we see regularly are wonderful.



The fight against its dreadful consequences is ongoing at the moment, but NOT endless. A great many resourceful scientists the world over are sharing the results of the numerous surveys that they are carrying out and if we, given the chance, are willing to take even the smallest part in those, then little by little, the hope of prevention or cure is there, and, as Jacqui said, "Your days will be numbered MND".

Martin

Carer

We invite clients and carers to write a "Letter to MND".

This might be an open, uncensored letter that will never be sent, or you may wish to share your letter with other readers. Either way, the process can be beneficial in allowing you to express and clarify your own thoughts and feelings.

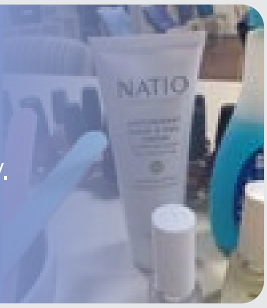
Please email admin@mndawa.asn.au if you would like to share.

Upcoming Events

Registration is essential for all events.
Please contact us for further details and to register
www.mndawa.asn.au/events

Pamper Day 2023

Clients, carers and close family members are invited to enjoy a complimentary Pamper Day. A variety of treatments are offered and light refreshments are served.



25 Mar
16 Sep

Victoria Park

Clients and carers/family only.

Carers' Lunch

Current and past carers are invited to enjoy a meal together in a supportive environment. This gives carers an opportunity to share experiences and ideas around caring for someone with MND.

12 Jan	**Mullaloo**
15 Feb	**Mandurah**
10 Mar	**Applecross**
19 Apr	**South Perth**

Clients' family carers only.

Hollywood Musical Bingo

150 of the greatest classic songs in the best movies of all time. Come dressed as a Hollywood star or character or get your table to dress to a movie theme.

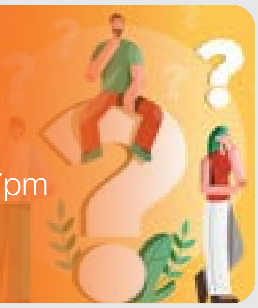
1 Apr

Dianella

General public participation is encouraged.

Let's get Quizzical for MND 2023

Who will be crowned MNDAWA Quiz Night Champions 2023? Doors open at 6pm for a 7pm start. Cheap bar and BYO snacks.



22 Apr

Gary Holland Community Centre, Kent Street, Rockingham

General public participation is encouraged.

Soar to Support

What better way to support the MND Association of Western Australia than to climb one of the state's most iconic bridges and soar down the zipline over the Swan River! Gather your friends and family to join us for this inaugural event and make a difference to the lives of those with MND.

11 Mar

Perth

General public participation is encouraged.

Walk to D'Feet MND

This annual community event brings plenty of atmosphere as we walk together to raise awareness and raise funds for those living with MND.

7 May **Perth**
28 May **Bunbury**

General public participation is encouraged.

Unite Against MND at Carnival

Join us at our annual charity ball and enjoy the colour, passion and flair of Carnival. Bring along your friends, family or colleagues and raise money to support the vital work of MNDAWA. Tickets include a three-course meal, five-hour drinks package and entertainment all night.

29 Jul

Crown Perth

General public participation is encouraged.

Back to Basics – What is MND

WHAT IS MOTOR NEURONE DISEASE?

Motor Neurone Disease (MND) is a term used to describe a group of diseases that affect nerve cells called "motor neurones".

Motor neurones normally carry messages from the brain to the muscles via the spinal cord. The messages allow people to make voluntary movements like walking, swallowing, talking and breathing. With MND, however, the nerves become damaged and start to die so muscles gradually get weaker and waste away. Currently, there is no cure for MND and it is life shortening.

> The speed at which MND progresses and survival times vary for each person.

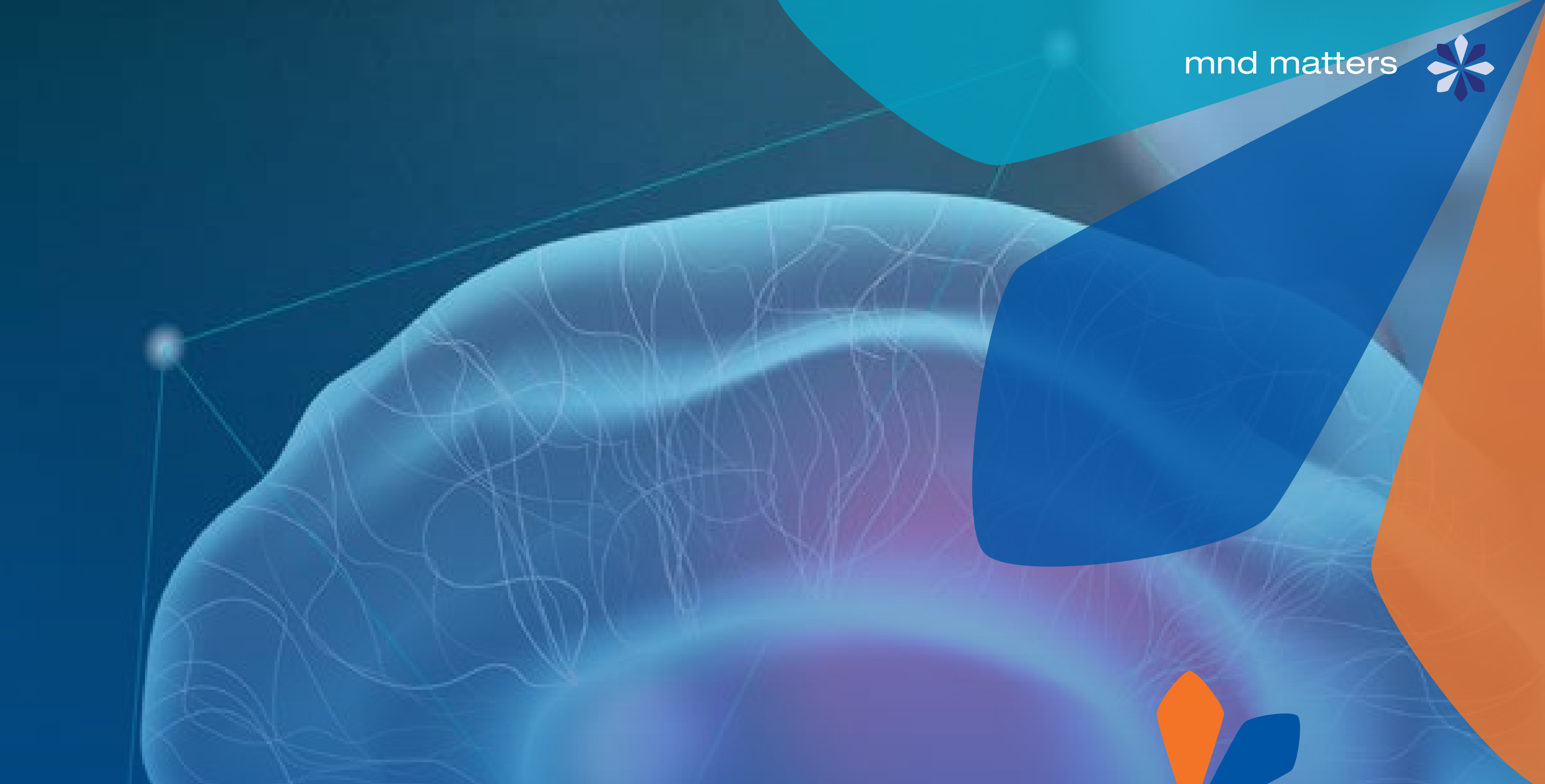
Talking with a neurologist is a good place to start learning more about what to expect with MND. Neurologists and MND clinic staff can also help in talking about treatments and support available to help quality of life. While MND is life shortening, research has shown that a team-based approach and timely treatments can help people with MND live better for longer.

SIGNS AND SYMPTOMS

Early signs of physical problems or other symptoms of MND can be mild at first. Symptoms may include stumbling due to weakness of the leg muscles, difficulty holding objects due to weakness of the hand muscles, or slurring of speech and swallowing difficulties due to weakness of the tongue and throat muscles. Where the weakness in the body starts depends on which motor neurones are affected first.

HOW IS MND DIAGNOSED?

The diagnosis of MND by a general practitioner (GP) or other physician is often difficult. Sometimes it is necessary to check the health of a person for a period of time before a diagnosis can be confirmed. A general practitioner may suspect a problem with muscles, the brain, nervous system or other neurological issues and organise referral to a neurologist (a doctor who specialises in disorders of the brain and nervous system). Several other neurological conditions resemble MND, especially in the early stages, and need careful exclusion.



A neurologist may recommend a series of diagnostic tests which may include:

- Blood tests to look for a rise in a creatine kinase, which is produced when muscle breaks down.
- Nerve conduction studies (NCS), which involve taping electrodes over nerves and recording muscle activity when nerves are stimulated by electrical impulses.
- Electromyography (EMG), which involves inserting a needle electrode into muscles to measure their electrical activity.
- Magnetic Resonance Imagery (MRI), scans, which involve being placed in a cylinder-like machine. The machine takes images of the internal structures of the body and can show up damaged areas. An MRI scan will not diagnose Motor Neurone Disease, as the damage caused by this disease does not show up on this scan. However, it may be used to eliminate other conditions which can mimic symptoms of MND.

WHAT CAUSES MND?

In 90-95% cases of MND the cause is unknown. In the other 5-10% of cases a genetic mutation is the cause of the disease. The mutated gene is inherited from a parent. Inherited MND is also known as “familial MND”.

There are many theories about the causes of MND. Theories include exposure to environmental toxins and chemicals, infection by viral agents, immune mediated damage, premature ageing of motor neurones, loss of growth factors required to maintain motor neurone survival, ageing and genetic susceptibility. Ongoing research throughout the world is looking for causes.

WHAT REMAINS UNAFFECTED?

MND does not usually affect the senses (sight, sound, and touch) or the bladder and bowel, although diet and exercise should be carefully monitored. Some people may experience changes in thinking and behaviour but only a few will experience severe cognitive change.

Visit www.mndawa.asn.au and www.mndaustralia.org.au/mnd-connect for more information.

Friends of MNDAWA

The Friends of MNDAWA group is an opportunity for those who have been touched by MND, or who are supporters of the Association to come together for a casual workshop - everyone is welcome. The group often works on event preparation, crafts or projects which can help the Association or items which can be sold to raise funds.

The group meets fortnightly on a Wednesday at the Association's office in Carlisle. Sessions run from 10.30am – 2.30pm.

Upcoming dates:

- **22 February 2023**
- **8 March 2023**
- **22 March 2023**

- continuing thereafter on a fortnightly basis.

While these dates are set, we recommend emailing admin@mndawa.asn.au or phoning (08) 6186 4133 ahead to confirm.

Business and Services Support

MNDAWA supports approximately 200 families in Western Australia who are living with MND. We receive a range of requests for assistance and where possible, we connect clients with suitable providers. As such, we are looking to develop a database of supportive businesses.

If you have the capacity to volunteer your time and skills, or offer a discounted rate for our clients, please contact us at admin@mndawa.asn.au. Please include contact details and details of your business, service or product.

Practical Products

Increasing accessibility around the home can become an expensive task. Here we share affordable, everyday products which can double as an aid for those with reduced strength or mobility.

Automatic Soap Dispenser

This product dispenses hand wash in response to detecting motion in front of an inbuilt sensor. This contactless dispenser supports liquid soaps, hand sanitizer and other liquids of a similar consistency.

Who is this product useful for?

Automatic dispensing is particularly useful for those who have difficulties with reduced hand strength and co-ordination, as it eliminates the need to twist, pump or remove the cap from traditional hand soap dispensers. This enables the user to dispense soap or sanitizer independently, or with greater ease.

The product pictured is the ANKO Automatic Soap Dispenser, available at Kmart RRP $17.00.

Similar products are available online as either battery powered or USB rechargeable.

MNDAWA Beach Wheelchair

MNDAWA Client Kevin is pictured here with Giorgia Christos from Better Rehab.

> "Thank you so much for your hard work, effort, time and hours in making this dream come true. I honestly can't thank you enough. The chair made it a lot easier to get into the water I didn't want to get out. You have done so much amazing hard work and support to help me out every time it means so much to me, I cannot thank you enough."

- MNDAWA client, after having worked closely with MNDAWA Occupational Therapist Sophie to make this dream a reality.

- In 2022 the Association acquired this beach wheelchair which allows people to be wheeled over grass and sand to enable them to access the beach.
- The team at MNDAWA are so pleased to be able to offer these services to our clients, and receiving feedback such as the testimonial above confirms the value this can add to our clients' lives.
- This is available to be loaned to anyone living with MND - following assessment of individual suitability and determining what other supports may be required.

HIRE THE WHEELCHAIR

To hire the wheelchair or for further information, speak to your allied health physician and email **equipment@mndawa.asn.au.**

A Charitable *Legacy* for MNDAWA

By leaving a bequest to MNDAWA, you are creating a **legacy of care and compassion** for our future and for that of individuals who will be diagnosed with MND in the future.

Many donors ask what they need to do to leave a bequest to MNDAWA.

- Bequests are critical in helping us provide the best care possible.
- Bequests play an integral role in our medium and long-term funding strategy.
- Your bequest can be general to support the key priorities of the Association or it can be specific to a certain area – it's up to you.

Your options are limitless in terms of the legacy you can leave:

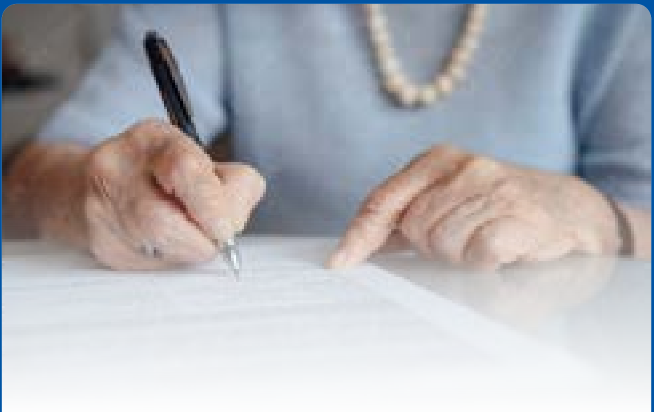
- **Whole estate**
- **Residual gift**
- **Percentage or fractional gift**
- **Specific gift**
- **Share Portfolio**

* MORE INFORMATION

Preparing a will is an important milestone for all of us. This information has been compiled by MNDAWA and is general in nature.

It should not replace formal legal advice such as that provided by a lawyer or trustee company.

We thank you for considering a bequest to MNDAWA. For more information and a confidential discussion about leaving a bequest to MNDAWA contact **08 6186 4133** or email **admin@mndawa.asn.au**



Suggested wording for your will

Based on your personal situation and preferences, the following wording may be used to make a bequest to MNDAWA.

"I give to the Motor Neurone Disease Association of WA Inc, ABN 49 312 430 982 of 1/184 Raleigh Street, Carlisle, Western Australia

- *All of my residuary estate,* ***OR***
- *_____ % of my residuary estate,* ***OR***
- *The sum of $ ____* ***OR***
- *List asset or assets* ***OR***
- *Your share portfolio of stocks or shares*

to be applied for the purposes of providing medical care, facilities, equipment or research by Motor Neurone Disease Association of WA Inc. I declare that the receipt of a Director of the Association or other authorised officer will be a sufficient discharge to my executors, who will not be bound to the application of this gift.

MND *Condolences and Loving Memory*

During the period Sep – Dec, these individuals lost their battle with MND.

We send our heartfelt condolences to the families and loved ones of:

- **Bonnie Barr**
- **Christine Flesher**
- **Jane Morris**
- **Nicholas Way**
- **Kate Rickerby**
- **Christine McDavitt**
- **Marlene Roe**
- **Beryl Mason**
- **Pauline Harper**
- **Kathleen Millward**
- **Wayne Cooke**
- **Patricia Drew**
- **Angela Cole**
- **Peter Phung**
- **Peter Gordon**
- **Neil Tuckwell**
- **Ian Tapley**
- **Mark Alekna**
- **Pamela Griffin**
- **David Poole**
- **Peter Evans**
- **Don Dixon**
- **Sam Thomson**
- **Peter Culverwell**
- **Edward Gruzdowski**
- **Alun Harries**
- **Syd Jury**
- **Vicki Sheil**

THE CORNFLOWER

The Blue Cornflower is the national symbol of hope for Motor Neurone Disease. It may have a fragile appearance, but it is hardy in nature which is representative of the remarkable strength people living with MND have. We live in hope that we will find a cure for Motor Neurone Disease.

Donations have been made in loving memory of:

- Agnes Wright
- Ron Cleasby
- Nick Way
- Pauline Harper
- Wayne Cooke
- Marlene Roe
- Pauline Hawkins
- Beryl Mason
- Christine McDavitt
- Robert Taylor
- Angela Cole
- Don Wright
- Trevor Hayes
- Mereana Turkington
- Russell Phillips
- Tom Cave
- Peter Hopps
- O'Mara & Leach Families
- Neville Healy
- Wayne Foulds
- Sandra Merendoli
- John MacDonald
- Bill Dickinson
- Frank Leahy
- Lorraine Sims
- Steve Pollock
- William Forward
- Beryl Mason
- Timothy O'Malley
- David Glenister
- Lorraine
- Sandra Cocks
- Dawn Flink Daws
- Dr Neil Tuckwell
- Andrew Nyman
- Roberta Maughan
- Heather MacGowan
- Peter Dibble
- Patricia Thomas
- George Gardiner
- Margaret Milne
- June Daniel
- Peter Wooldridge
- Tony D'Souza
- Darren Whitby
- Suzanne Tilson
- Gay Cimbaro

Donations have been made in honour of:

- Geoffrey Ball

* Information published in these listings was complete at the time of print.

More Ways to *Support* MNDAWA

Merchandise

We have a great range of merchandise available so you can show your support and help us raise awareness of MND. Visit the website to view the online store or pick something up at the next MND event.

✻ **www.mndawa.asn.au/store**

Containers For Change

Next time you drop off your used containers, you can elect to donate your refund by using our unique ID at the refund point. The 10c refund for your eligible containers will be donated to MNDAWA.

✻ **Scheme ID C10242959**

Change 4 Change Collection

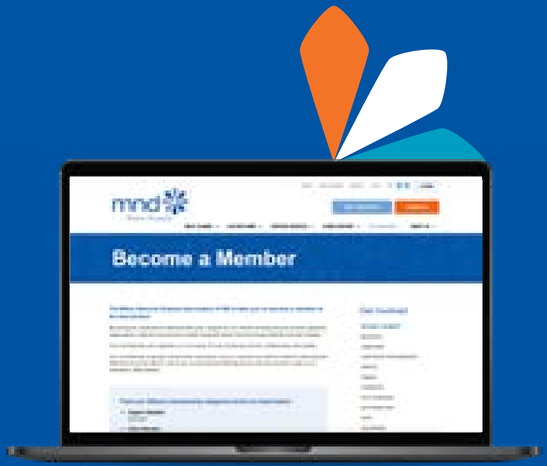
Individuals, community groups or businesses can register for a Change 4 Change collection tin or a box of MND Blue Cornflowers to sell.

✻ **Contact MNDAWA to arrange**

Become a support member

By joining MNDAWA you can demonstrate your support and have an ongoing involvement. You will be invited to special events and will be eligible to vote at our AGM. There are various membership categories. Supporter membership is $20 per year.

✻ **www.mndawa.asn.au/member**



Donations for MNDAWA

Every donation contributes towards our specialised care and support services for people living with MND, their carers and families.

I would like to make a donation to the Motor Neurone Disease Association of WA

First Name: ______________________________ Surname: __________________________________

Address: ____

Suburb: ____________________________________ State: _______________ Postcode: _________

☐ YES! I would like to make a regular donation. If you tick this box we will contact you to arrange this

Please accept my gift of:

☐ $250 ☐ $150 ☐ $100 ☐ $50 ☐ or my choice of $ ☐

☐ My cheque/money order is enclosed and made payable to MNDAWA

☐ Or please debit my credit card: ☐ Master ☐ Visa

Card Number: ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐

Expiry: ☐☐☐☐ CCV: ☐☐☐

Name of card holder: ____

Signature: _____________________________________ Date: _________________________

Motor Neurone Disease Association of Western Australia ABN **49 312 430 982**

Unit 1/184 Raleigh Street
Carlisle WA 6101

- **(08) 6186 4133**
- **admin@mndawa.asn.au**
- **www.mndawa.asn.au**

Follow us for more info & events /MNDAWesternAustralia/

mnd Western Australia

mnd Western Australia

mnd matters
Issue 3 | Sept - Dec 2022

Unite Against MND at CARNIVAL IN 2023

Join us at our annual charity ball and enjoy the colour, passion and flair of Carnival!

Saturday 29 July 2023
7pm - Midnight
Crown Perth

Bring along your friends, family or colleagues and raise money to support the vital work of the MND Association of Western Australia.

Tickets include a three-course meal, five-hour drinks package and entertainment all night.

$260 per ticket or $2500* for a table of ten.*

www.uniteagainstmnd.com.au

Unite Against MND

For event details and booking enquiries email: sarah.wiley@mndawa.asn.au

**Early bird ticket price until 30 January 2023. Tickets increase to $290/seat $2800/table on 31 January 2023*

Sponsorship Opportunities

Show your support by partnering with MNDAWA and sponsoring the event.

Sponsorship opportunities are tailored to suit each individual business. Event sponsors benefit from brand exposure as well as promotional opportunities before, during and after the event. Sponsors are also given the opportunity to host a table of clients or staff, for a team night out or networking opportunity.

Contact Jasmin for sponsorship information:
jasmin.woodhall@mndawa.asn.au