

February 2012

From the Executive Officer's Desk

Hello everyone,

My name is Mathew Brown and I am the new Executive Officer for the Association. This is my first report from the EO desk and I look forward to sharing with you many more.

Firstly I would like to express my thanks to the Board of Management for this opportunity to work for the Association, a cause close to my heart which I have a great deal of passion for. I come to the Association with extensive personal experience of Motor Neurone Disease, with my father Stephen Brown having lived with the disease for most of my life. This has instilled with me an understanding of what living with MND entails and an appreciation of the strength required by those who experience it, be that the individual, family or friends.

I've experienced the amazing services provided by the Association first hand and look forward to now working on the other side, helping its services grow and develop to satisfy what is needed by our members.

Currently I am in the process of familiarising myself with the position and recruiting a couple of new members to the team. My thanks go out to the Care Advisors and Soraya who have often covered other duties while these positions have been vacant. I would also like to thank them for being very welcoming and assisting me in joining the team.

I look forward to meeting you all.

Mathew.



New Care Advisor

It is a pleasure to be able to introduce myself Carly Davies, in the first MNDWA newsletter of 2012. Happy New Year!

I started with the organisation on 2nd January and with great support and advice from all the team at the association, I am settling into my role very nicely.

I am a new comer to Australia having moved here with my partner Gareth in July 2011 from Wales, UK. I have spent my working career within the health care sector, gaining several qualifications in Health and Social Care between 2004 and 2010. For 5 years I worked alongside health professionals to provide a solid, common based goal of support and guidance to people who are blind and partially sighted. I later

changed positions and became a Care Coordinator in community care where I was responsible for managing and coordinating care packages for clients suffering with MND, MS, Dementia and ME.

I became familiar with MND in my late teens; my late Uncle was diagnosed with the disease which affected both his upper and lower neurones. Initially, we were all unfamiliar with the disease but we soon established how great the support network is for someone with MND. We came to rely upon those significant supports at every progressive step. My family, late uncle and I were all very grateful for the emotional, physical and practical support that was provided and as a result I became very passionate and dedicated to

supporting others in a similar way.

I am extremely excited about working with MNDWA and look forward to my adventure with you all.

Best Regards,

Carly.



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Motor Neurone Disease Association of WA Inc

Contact Details

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 Phone: 9346 7355
 Fax: 9346 7332
 Email: admin@mndawa.asn.au
 Web: www.mndawa.asn.au

Office Hours

9:00 am - 4:30 pm Mon-Fri
 For after hours, call **0412 749 971**

Emergency

If you have an urgent matter please contact Sir Charles Gairdner Hospital on **(08) 9346 7391** or your nearest Emergency Department

Membership

MNDAWA is a member of MND Australia, with a delegate on the Board. It also has strong links with other MND Associations around Australia and internationally, and the MND Research Institute of Australia.

Staff

Executive Officer..... Mathew Brown
 Administration Officer..... Soraya Kumail
 Senior Care Advisor..... Rose Gibbins
 Senior Care Advisor..... Cherylyn Vickery
 Care Advisor..... Jude Humphreys
 Care Advisor..... Carly Davies
 Accountant..... Ling Lee

Regional Contacts

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Care Foundation Trustees

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 Marie Macdonald
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 Member..... Mrs Marylin MacLennan

March Newsletter

Readers are encouraged to send us stories of their holiday adventures, achievements, life in general or a joke to evoke a smile. We would love to hear from you!

Please send any items for the March newsletter to admin@mndawa.asn.au by **Friday 23 February 2012**

Ride for someone with MND

Sunday 15 April 2012

Rise to the Be Active Dams Challenge and ride for someone with MND. All you have to do is create an Everyday Hero page and Fundraise for MND! This ultimate two person team event for serious riders in WA will see riders visit the dams in the Perth Hills before returning to the starting point.

Riders will need to complete either the 3 dam 146km ride, or the 234km 5 dam course within the 12 hour time limit which will take them through Mundaring Weir, Churchman Brook, Wungong Dam, Canning Dam and Serpentine Dam before descending from the foothills and returning to the city.

Grab a riding buddy, start training and ride for someone with MND!

Registrations are now open.

Contact the MNDAWA Office on (08) 9346 7355 if you are interested in participating.

For event information visit the event website: <http://www.bwa.org.au/events/110/>



Disclaimer: The articles provided in this newsletter sometimes contain personal opinions that may not reflect board policy. Research articles are selected from reliable sources, we do our best to ensure currency and accuracy.

MNDAWA Platinum Partners

Halls Head Cricket Club
 Jim Kidd Sports
 Australian Manufacturing Workers Union

Maritime Union of Australia
 Apache Energy
 Stadium Snappers

MND Upcoming Events Diary

	Event	Date	Time	Venue
F e b r u a r	Craft Group	Thurs 09 Feb 2012	10am-2pm	The Niche - Passmore Room
	Carers Lunch MND Volunteers Meeting	Tuesday 21 Feb 2012	11.30am-1pm 10:30-11:30am	The Niche - Passmore Room
	Past Carers Group	Thursday 23 Feb 2012	2.00pm	The Place of Reflection" in King's Park
	Pamper Day	Sat 25 Feb 2012	11:30am-2.30pm	The Niche - Conference room RSVP attendance to (08) 9346 7355 or admin@mndawa.asn.au
M a r c h	<i>Labour Day Public Holiday</i>	<i>Mon 5 Mar 2012</i>	<i>MND Office will be closed</i>	
	Craft Group	Thurs 08 Mar 2012	10am-2pm	The Niche - Passmore Room
	MND Volunteers Meeting	Tuesday 20 Mar 2012	10:30-11:30am	The Niche - Passmore Room
	Carers Lunch	Tues 20 Mar 2012	11:30am-1pm	The Niche - Passmore Room
	Past Carers Group	Thursday 29 Mar 2012	2pm	Residence of Heather Joppek, contact on 0418929672
A p r i l	Craft Group	Thurs 12 Apr 2012	10am-2pm	The Niche - Passmore Room
	MND Volunteers Meeting	Tuesday 17 Apr 2012	10:30-11:30am	The Niche - Passmore Room
	Carers Lunch	Tues 17 Apr 2012	11:30am-1pm	The Niche - Passmore Room
	<i>Easter and Anzac Day Public Holiday</i>	<i>Fri 22 – Tues 26 Apr 2011</i>	<i>MND Office will be closed</i>	
	Past Carers Group	Thurs 29 Apr 2012	2pm	TBA

Notice Board

MND Pamper Day

Saturday 25 February 2012

11:30am-2.30pm

The Niche Conference Room

Cnr Aberdare Rd and Hospital Avenue, Nedlands 6009

Please **RSVP** your attendance by **20 February** on (08) 9346 7355
or at admin@mndawa.asn.au

Contact person: Jude Humphreys



Carine Fair

The Rotary Club of Hillarys – Carine Community Fair will be on Sunday 18th March 2012.

We will be having a Craft Stall and day Raffle. All are welcome!

Any queries contact Lois on 9409 6076.

Past Carers February Function

The "The Place of Reflection" in King's Park is the venue for the 23rd February at 2pm for our get together.

The location of the Place of Reflection is on Forrest Drive which comes off Lovekin Drive beside the Pioneer Women's Memorial. Continue past the Roe Memorial and you will find us on the left side of the road. I will put out one of the MND signs to make it easier.

You will need to bring a chair, thermos or cool drink and a plate (as usual). We will be under shelter out of the sun (or rain) as the case maybe. Phone me on 93143863 or 0418 929672 if you need further information regarding the day.

I look forward to seeing you there.

Heather Joppek

Care Advisor's Corner - February 2012

I was fortunate enough to attend the ALS/MND International Symposium in Sydney in early December along with my colleagues. It was great to meet our peers striving for the same goals all over the world and to hear of ongoing developments in research, and inspiring to meet people living with MND who had travelled to Sydney to the "Ask The Experts" forum. I hope as many of you as possible took advantage of the live streaming. Don't we live in a wonderful technological age!

Carers WA

I would encourage you to join this carer organisation as they are a great resource – membership is free (ask your Care Advisor). The "Young Carer Team" provides information and activities specifically for people under 26 who look after a family member who needs extra support at home. The Young Carers website is www.youngcarerswa.asn.au. MNDWA has information for talking with children and grandchildren about MND. Ask your Care Advisor.

Tips on Gardening/Sewing/Reading – Thanks to Barbara and Ian

- Its easy to install a raised garden beds so those with green thumbs can tend to plants.
- A magnet glued to the end of a bamboo stake can easily retrieve dropped needles or pins from the floor.
- The dimples on a rubber thimble provide friction to help turn the pages of a book or magazine.
- The "Housebound Readers Service" delivers books, magazines, talking books, music CDs, and DVDs to your home. Phone Perth Library Service on 9461 3587 for more information or ask your Care Advisor.

Mouth Care

If swallowing is an issue sometimes keeping the mouth fresh and clean can be more problematic. For dry mouth, sipping water with a slice of lemon or lemon teas can be refreshing if it's safe to do so. Wiping the mouth with lemony swabs or plain water icy poles are a good alternative.

If there is thickened saliva, dark grape juice either sipped or frozen into icy poles and sucked or wiped over the mouth may thin down saliva. A low foam toothpaste can be useful, such as Biotene or Pearl Drops.

Cherylyn Vickery

Bequests to MNDWA

Wills are a convenient means for making charitable gifts to the people and causes you hold dear. Making a bequest to MNDWA will help ensure our continued efforts in making a difference to the lives of people living with MND continue into the future.

Lotterywest Grant Update

The grant for a new, more advanced photocopier machine has been approved by Lotterywest.

A big thank you from all of MNDWA.



A Little Humour...

A new teacher was trying to make use of her psychology courses. She started her class by saying, "Everyone who thinks you're stupid, stand up!" After a few seconds, Little Johnny stood up. The teacher said, "Do you think you're stupid, Little Johnny?" "No, ma'am, but I hate to see you standing there all by yourself!"



Clayton Binns Is The Winner Of 2011 Young Carer Award

Thirteen year old Maddington teenager, Mr. Clayton Binns, has been awarded the 'Young Carer Award' as part of the 2011 Young People Who Care Awards, which is co-hosted by Silver Chain, Carers WA and Woodside Energy Limited.

Clayton is the eldest of three boys and he is the main carer of his father Paul. Paul is a single parent and had previously worked and supported his family until his diagnosis of Motor Neurone Disease (MND). Motor Neurone Disease is a terminal condition there is no effective treatment for this rapidly degenerative neurological condition.

Ms Karlene Jordan, Neurological Community Nurse to Clayton's father Paul, notes that Clayton is an inspirational young man. "For the past three years, I have had the pleasure of working with people with rapidly degenerative conditions such as MND, and I have never met two brothers who care for their father the way some adults will not. Their love for Paul is unconditional and Clayton is an amazing young man," said Ms Jordan.

Mr Chris McGowan, Silver Chain's Chief Executive Officer, noted that the Young People Who Care Awards is an opportunity to recognize exceptional Western Australians aged 10 to 18 years, who provide voluntary care to in our community. "There are many young people who provide voluntary care to others and it's important that we recognize the special role that they play. Clayton and his brother Jake are wonderful examples to both their peers and the community and we wish them much success for the future. Congratulations Clayton," says Mr. McGowan.

A Big Thank You for Our Annual Sausage Sizzle 2011

A big thankyou to all our Volunteers and Members for donating their time and money for Raffle prizes, pass the parcel and lovely food for our Annual Sausage Sizzle.

Also thankyou to Reggie our Elf – Father Christmas, Fairy Robyn, Ian for cooking the sausages and onions which were "yummy", not forgetting Classic Meats, IGA, Bakers Delite both from Kingsley and Lolly man Ron.

It was fun and laughter day with the temperature about 23c... Perfect! We raised \$ 328.00 with the raffle and the Sizzle.

Many thanks once again.

Lois Peck.



ASPIRI Piara Waters Charity Golf Day

The Rotary Clubs of Fremantle and Attadale present a Charity Golf Day with all proceeds raised going to the Fremantle Hospital Medical Research Foundation and the Motor Neurone Disease Association of WA.

Get together a team of four (\$400 per team) for an 18-hole round of golf with a sausage sizzle, drinks, and after game finger food on Friday 2nd March, 2012 at the Royal Fremantle Golf Club from 11:30am until 8:00pm.

Please contact Rodney Rate (Vice President of Rotary Club Attadale) on 94304848 or the MNDWA office for more information.

Book your team in now!!!



Have you renewed your MNDWA Membership?

Alphabet Soup!



Alphabet soup is a metaphor for an abundance of abbreviations or acronyms... let's continue digesting.

AHP – Allied Health Professional (1)

They work in health care teams to make the health care system function by providing a range of diagnostic, technical, therapeutic and direct patient care and support services that are critical to the other health professionals they work with and the patients they serve.

AHD – Advanced Health Directive (2)

This form deals with your future health care. The time may come when you cannot speak for yourself. By completing this form, you can give directions about your medical treatment at such a time.

OT – Occupational Therapist (3)

The role of an occupational therapist is to work with a client to help them achieve a fulfilled and satisfied state in life through the use of "purposeful activity or interventions designed to achieve functional outcomes which promote health, prevent injury or disability and which develop, improve, sustain or restore the highest possible level of independence."

Neuro Physio – Neurological Physiotherapist (4)

Neurological physiotherapists work with many different people at different ages and stages of life, in public or private health systems. Neurological impairment, disability and handicap can result from trauma (such as brain or spinal cord injuries), from disease processes (such as Parkinson's disease, multiple sclerosis, motor neurone disease and muscular dystrophy) or from cerebrovascular events such as stroke, to name just a few. There is increasing evidence that even though some neurological diseases may be considered degenerative, physiotherapy intervention, in the form of training and exercises, can improve or maintain function and enhance quality of life, particularly by preventing falls, maintaining independence, health and fitness.

RN – Registered Nurse (5)

Has three years study/training at University and Health Facility to achieve a Bachelor Degree in Health Science (Nursing) or Bachelor Degree in Nursing. High level of accountability and more responsibility than EN or AIN Regulated by the Nurses and Midwives Board. Roles may include administration, team leader or unit manager duties, medication administration, assessment and management of the client including complex nursing care, specialised nursing care or undertaking research. An RN is a person with appropriate educational preparation and competence for practice, who is registered and licensed under the appropriate Nursing Act to practise nursing in Australia. The national competency standards give certain responsibilities exclusively to RNs and midwives, giving them more autonomy in their practice decisions than other nurses. RNs and midwives are then responsible for ensuring the quality of the work through their involvement in teaching, competence assessment, supervision and the evaluation of clients' outcomes.

CRN –Community Registered Nurse

A registered nurse that works in the community.

PCN – Palliative Care Nurse (6)

Palliative care nursing is a key component in the multidisciplinary approach to care necessary to meet the complex needs of individuals and their families/carers facing life threatening illnesses. Care is directed towards easing the symptoms associated with end stage illnesses and the fears, anxieties, grief and concerns of both clients and their families/carers. The central concerns for nurses in care of individuals in the palliative care phase of an illness are the improvement of quality of life, the promotion of comfort and the preservation of dignity and choice.

References

1. http://en.wikipedia.org/wiki/Allied_health_professional
2. Advanced Health Directive Q'ld
3. http://en.wikipedia.org/wiki/Occupational_therapist
4. <http://synapse.org.au/Services/neurological-physiotherapy-fact-sheet>
5. http://en.wikipedia.org/wiki/Registered_nurse
6. Royal College of Nursing Australia-role of the nurse in palliative care.pdf

The above information was compiled by :

Jude Humphreys, Care Advisor MNDWA.

Ray White Western
Australia is proud to be
associated with
MNDWA, supporting
those living with Motor
Neurone Disease

Ray White.

Online Donations

You can now access three online options for donating to MNDAWA from our website home page using:



Click on the link at www.mndawa.asn.au and you will be guided through the donation process

Interested in doing some simple and easy fundraising for MND?

Place a **Blue Cornflower box** on your countertop at work, or ask your local pharmacy if they will put one up. You could also add a **Change4Change Tin** in the office or at home and encourage everyone to donate any spare change.

Call the MND Office on (08) 9346 7355 to start fundraising!



In Remembrance

Remembering a gentle and caring soul who is Phillip Walsh... You will be missed and thought of everyday....

By your loving family.



Gifts and Donations

In Loving Memory of

Stephen Brown

Anne Tidmarsh

Allan Conroy

Margaret McCarthy

Joy Vause

Kenneth Vause

Tim Firth

Ed Kreenwy

Warren Sagasser

Leonie Lorian

Libby Neglic

Mark Humbie

George Shedraw

Peter & Nicole Dywer

Nicole Willers

Kellie Agar

Rob Towers

Lyn Tagliaferri

Peter & Michal Lennon

Natalie Tagliaferri

Dave Smith

Michelle Davis

Martinelli

Lesley Reece

The Dead Parrots

Natasha Oke

Tim Firth cont.

Tim Smith

Judy Thompson

P Maths

Kristina Pye

Megan McCorry

Anonymous

Cornflower Box Donations

Alanda Cafe



Your change can make a positive change for people living with Motor Neurone Disease.

TAB Agency

TAB Booragoon

DONATION FORM

If you wish to make a donation to support the work of the MND Association of Western Australia, please complete this form and post or fax it to the Association (address details on page 2 of this newsletter).

All donations over \$2 are tax deductible.

Name:
Address:
Post-code:
Phone:

Please tell us the reason for your donation:

Donation amount: \$.....			
<table border="1"> <tr> <td>MasterCard <input type="checkbox"/></td> <td>VISA <input type="checkbox"/></td> <td>Cash/Cheque/Money Order <input type="checkbox"/></td> </tr> </table>	MasterCard <input type="checkbox"/>	VISA <input type="checkbox"/>	Cash/Cheque/Money Order <input type="checkbox"/>
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Card No.

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Card expiry date: __ / __

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PAST EVENTS



Community Spirit is Alive and Well in Mundaring!

On behalf of the Motor Neuron Disease Association of Western Australia, I would like to say a huge thank you to Gloria, The Book Club Ladies, who, with the generous time given by volunteers organised a book sale at the community centre known as *The Hub* in the peaceful hills of Mundaring. 100% of the proceeds donated to MNDAWA.

It was a wonderful morning and I was honoured to be their guest speaker. I did not expect such a turnout with over 60 people attending from various groups, including; The Book Club Ladies, Mundaring Walking Group, Prime Movers Mundaring, Tuesday Morning Tea Patrons, Mundaring Men's Shed, the Indoor Bowls Club and members of the local community. I will forever remember the feeling of togetherness that was in that room.

The volunteers put on a delectable morning tea! Thankyou ladies!

I recommend this event as the selection of books was outstanding.

Jude Humphreys, Care Advisor.

KEITH POTGER – THE ENTERTAINER

Saturday 26th November 2011 was a balmy evening and perfect for Vicki and Rod Bone's annual Xmas themed fundraising dinner held at their Thornlie home.

This was the eighth dinner held in memory of Vicki's father, Fred Dyer who suffered from Motor Neurone Disease, and the dinners are Vicki's major fundraiser for MNDAWA.

Vicki and her friend Helen cooked a delicious three course meal with all the accompaniments. They had an amazing team of helpers including their granddaughters Rebecca and Chloe to enable the evening to run smoothly for the 68 guests.

The special entertainer this year was Keith Potger who was fabulous and had everyone singing and dancing in the aisles. Keith not only donated his time but also a 4 pack of his solo CDs and a DVD which he signed for the lucky winner. CDs were also available for sale from which Keith donated half of the profit towards the fundraising. Keith always supports MNDAWA when he can and we always look forward to his music. A big thank you to Keith – you are amazing.

We all had a fabulously festive evening – so thank you Vicki, Rod and all your helpers for such a fun way of raising \$2,752 for MNDAWA. Congratulations to all the raffle winners and to the winner of the "Lucky Door" prize. Yes it really was a door.

Chloe, Vicki and Rod's 14 year old granddaughter, has promised (in writing – on the tablecloth!!) to carry on the dinners when she is old enough so this means we can look forward to many more dinner in years to come.



Find the Motor Neurone Disease Association Of WA on Facebook and 'Like' us. Encourage your friends to 'Like' us too! It's the best way to keep up to date with others within the WA MND Community!



Support the Companies That Support Us

If you no longer wish to receive MNDAWA Newsletters or if you would prefer to receive newsletters by email, please contact us on (08) 9346 7355 or via admin@mndawa.asn.au



Thank you for helping us conserve our resources.