

YOU, ME & MND - CLIENT NEWS

UNTIL THERE'S A CURE THERE'S CARE

FOR SOUTH AUSTRALIANS WITH MOTOR NEURONE DISEASE



Our first You, Me and MND Session for 2017 was held on Thursday the 19th of January at our new location. The West Adelaide Football Club.



This month the event was a great success. The location is much improved in comfort and size from our 2016 location. Also the consensus of those that attended was that the meals are wonderful and very affordable. The club management and kitchen staff are keen to support our clients in any way they can – they will modify or swap items on plates to better suit dietary needs, all you need to do is ask. Anyone wishing to socialise and to learn more about services, equipment and research pertaining to MND are encouraged to attend these sessions and everyone is welcome to attend. The club also has disabled toilets, complimentary tea and coffee.

We have started a new game each month in 2017. It is called lucky squares. Those in attendance can try their luck at winning a free lunch at the club at the end of each session for just \$2. We will announce the winner each month. No winner was drawn this month, due to a small group size. It was decided by the group to wait until our February 16th session. So bring your luck at a \$2 coin (or two) with you in February!

MNDSA would like to personally thank everyone who fundraised, donated money, volunteered or just plain helped us out throughout 2016. It was by far our most successful year to date and we can't do what we do without your help. Because of the amazing efforts of our supporters, we have improved support services, bought on new staff, improved our physical information resources, increased our equipment pool and commenced educational workshops etc. It has been a great year, but we are planning on making 2017 even better!

For those of you who attended our end of year Christmas lunch at the Adelaide Sailing Club in December 2016, we introduced Connie – our new Support Services Assistant. Connie commenced at MNDSA towards the end of last year. Her role is to support the work of the MND Advisors who are often out on the road visiting clients. Connie is office based, encouraging socialisation and support of our clients through regular phone calls and emails. So please be prepared, she will be calling you soon for a good ol' chat, if she hasn't already!



We are also very excited to announce that through the amazing generosity of the QBE Foundation Trust we have secured a \$10,000 grant to employ an Occupational Therapist (OT) for one day per week for the next 12 months. Therefore, as of 2nd February 2017, MNDSA will have our very own OT, Carlye Thompson who will be working for us on Thursdays.

Rebecca Hayes, Jenny Bax, Karen Percival, Jodi Mastrangelo

This will enable MNDSA to support our clients with quicker and cheaper assessments for equipment provision. We are also working on increasing our equipment pool to coincide with this increased service capability. We are very excited about this improvement to our services and envision it helping reduce the waiting times of our clients for an OT.

This all came about when Karen Percival our Executive Director was invited by Jodi Mastrangelo Senior Account Executive from Marsh Pty Ltd to attend an event held by The Australian Institute of Conveyancers. At that event Karen met Jenny Bax, Regional Manager from QBE and when she heard about what we do here at MNDSA, asked if there was any way they could help. The outcome was the successful application and award of the \$10,000 grant.

Jenny Bax, Jodi Mastrangelo and Rebecca Hayes (CEO of the Australian Institute of Conveyancers SA Division) all came along to our You, Me and MND session to present a very large cheque to Karen.



Carlye Thompson, Jenny Bax, Karen Percival

MNDSA would like to say a huge thank you to everyone at the QBE Foundation for the approval of this wonderful grant. You have enabled MNDSA to considerably improve our services for 2017.

MND AND CARERS

We had Stewart Pope from SA Care, who has many years experience as a Registered Nurse in community and disability nursing, come and present to our group. He spoke at length about the services SA Care provide to the MND Community, including care worker support, respite services and specialised accommodation.

SA Care is a NDIS funded provider, but is it an unfunded provider only via the My Aged Care system. This means that their services are not fully subsidised for the over 65 years of age group.

SA Care's strength has always been person centered individualised care. Other service providers use predetermined generalised formats to care for their clients, whereas SA Care has earned the name of one of SA's best providers of care workers because of their ability to provide individualised care for each person. This is an important aspect of care, when related to someone with MND. This group of people do not fall into any one category. People with MND utilise the services of acute, community, surgical, chronic and palliative care service categories, which makes caring for them very difficult to manage and achieve effectively.

SA Care have an agreement with RDNS, who train their care workers to support complex health procedures with competency based training. This helps to support the care of complex medical areas including ventilation, stoma, Gastrostomy (PEG) and tracheostomy care etc.

SA Care workers can assist with:

- Showering
- Dressing
- Getting in and out of bed
- Meal preparation
- House cleaning
- Social interaction and respite services

Once services are initiated a detailed care plan is drawn up and then is reviewed every 12 months, or more frequently if required, to ensure appropriate support of the client.



SA Care also have a range of supported accommodation. This accommodation is located in several locations throughout Adelaide – including North Adelaide, Kingswood, Magill and Hope Valley.

The accommodation usually incorporates new and old – old style rooms and buildings with newer extensions and room formats and furniture. The rooms are set up with ensuite bathrooms, large rooms, storage areas, personalised courtyards, kitchenettes and roof mounted lifting hoists. Common areas in the building include kitchen, dining areas and lounge rooms. Also included are swimming pools, gyms and overnight care worker access. Their accommodation is thought out and created with the individual in mind. To live in a supported environment with carer support as an individual, couple or participate in larger groups.



SA Care also have a disabled friendly bus for transport to different events/appointments and a disabled friendly houseboat for hire on the River Murray.



They have kindly donated a weeks houseboat experience worth over \$3,500 as first prize in this years Walk to D'Feet raffle.



For more information on services and accommodation of SA Care, please call Stewart Pope – Client Services Manager on 1300 145 636 / 0412 669 740 or alternatively you can email him on stewart.pope@sacare.com.au

YOU could win 7 nights' accommodation on SA CARE's luxury house boat when you purchase a \$5 Walk to D'Feet raffle ticket.

\$5 for a holiday of a lifetime...Tickets are selling fast! Call 8234 8448 and find out how to get yours! The raffle will be drawn at the event, Sunday 7 May.

Other fantastic prizes include:

- 2 day getaway package at The McCracken Country Club valued at \$600 (Conditions Apply)
- A Motoring Package including a service at Blackwood Dyno Tune & Service
- Dinner for two at Ambrosini's up to the value of \$150
- Two Gold Class tickets at Event Cinemas.

UPCOMING YOU, ME & MND SESSIONS

- Thursday 16th February 11am Mary-Louise Rogers from Flinders University – local SA based research update
- Thursday 16th March 11am Catherine Hansen – Trial Coordinator – Sleep Health Service RGH
- Thursday 20th April 11am John D’Amico - Public Trustee – Wills, Power of Attorney and Advance Care Directives
- Thursday 18th May 11am Client Led Group Discussion
This is your time to get involved. This session will be open for topics and discussion pieces that interest you. If you would like to get involved and talk about a specific topic – please let us know.
- Thursday 15th June 11am Ann Buchan – Neuro-physiotherapy

Client Led Discussion Group update: We would like to apologise, we have moved the client led discussion group session from March to May to make room for a great talk from Catherine Hansen regarding new international research and therapy from the 25th International MND Symposium in Dublin December 2016.

LIVING WELL WITH MND

An information day about living well with MND for people with MND.



Who should attend?

Living well with MND is a day seminar that extensively covers various topics important for people affected by MND. Various guest speakers will discuss topics that directly impact people with MND. This is an opportunity for all interested people to gain an in depth understanding of various topics as well as meeting others in the MND SA community.

WEDNESDAY 29TH MARCH 2017

City Mazda Stadium
57 Milner Road, Richmond SA 5033
10am – 4 pm

By the end of the day you will know more about:

- Motor Neurone Disease
- Living independently at home
- Eating well with MND
- Equipment that can assist
- Communication and MND
- Managing breathlessness and fatigue
- Finding services and support

Have your questions answered by a range of local health care professionals with expertise in MND.

Registration

There is no charge for you to attend this program, but you will need to reserve your place. RSVP to admin@mndsa.org.au or phone (08) 8234 8448 or freecall 1800 777 175.

Please note Living Well with MND will be offered on Wednesday 26th July & Wednesday 29th November 2017.

MND SA FAMILY INFORMATION EVENING

MND SA warmly invites you, your family and friends to an information evening specifically designed to educate and support those affected by a loved one's diagnosis of MND.

Who should attend?

MND SA's Family Session is an opportunity for people to learn about MND and the sources of help available when you are a member of the MND SA community. Information will assist friends and family of a person who is diagnosed with MND to have a greater understanding of the disease, and how they can assist.

The session will include:

- An overview of MND
- Living well with MND
- How MND SA supports its members and families
- How to access support services
- Opportunities for people to discuss individual needs and concerns with MND Advisors.

WEDNESDAY 22ND FEBRUARY 2017

City Mazda Stadium, 57 Milner Road, Richmond, SA 5033

Parking is available at the rear of the club.

6:30pm-8:30pm (please arrive 10 minutes early)

Tea and coffee supplied. A set menu at a discounted rate will be available for evening meal. More details to come.

Registration

There is no charge for you to attend this program, but you will need to reserve your place. RSVP to admin@mndsa.org.au or phone (08) 8234 8448 or freecall 1800 777 175

UPCOMING INFORMATION SESSIONS:

If you would like to volunteer at a You, Me & MND session please let give us a call! You would assist with the set-up of the event and make coffee/tea for guests.

WHAT WOULD YOU LIKE TO TALK ABOUT?

We welcome your feedback, so let us know what topics you are interested in and we will plan 2017 with your ideas in mind!

Support sessions are an open informal format and provide an opportunity to:

- Gain useful information about MND and MND SA
- Network with others with MND, their Carers and families
- Socialise and share experiences
- Find out about new supports and assistive equipment
- Speak with the MND Advisors in a group setting.

SAVE THE DATE
WALK TO D-FEET MND
SUNDAY 7 MAY 2017



Tickets will be available in the coming weeks...put the date in your diary and get ready for the biggest and best event yet!

OUR NEXT MEETING
THURSDAY 16TH FEBRUARY 11AM
WEST ADELAIDE FOOTBALL CLUB,
CITY MAZDA STADIUM, 57 MILNER ROAD, RICHMOND

Mary-Louise Rogers PhD, Senior Research Fellow and Lab Head at the Motor Neurone Disease and Neurotrophic Research Laboratory, Flinders University will do a presentation about the various projects and outcomes of current research being done in SA and overseas. She is involved in both South Australian based and Worldwide MND research.

HOW FUNDRAISING MAKES A PROFOUND DIFFERENCE AT MND SA...



\$250

A CLIENT SUPPORT SESSION WITH A KEY NOTE SPEAKER FOR ATTENDEES TO LEARN ABOUT DIFFERENT SERVICES AVAILABLE IN SA FOR PEOPLE WITH MND.



\$500

TWO HOME VISITS AND A CLIENT SUPPORT PACK.



\$1000

COMMUNICATIONS EQUIPMENT (LIKE AN IPAD)

Email Bianca today about how you can host an event to raise funds for South Australian client services.

CAN YOU HELP?



D O N A T E

All funds donated remain in South Australia. We need prize items, services or experiences for MND SA to use in raffles or auctions.

S P O N S O R

Can we partner with your business?

V O L U N T E E R

We need volunteers for events, fundraising, office support and community visits.

C O N N E C T

Can you connect us to a person or business who you think can help MND SA?

SUPPORT SOUTH AUSTRALIANS WITH MOTOR NEURONE DISEASE

MAKE A DIFFERENCE TO THE LIVES OF PEOPLE WITH MND **COMMUNITY VISITORS PROGRAM**

Do you or someone you know want to contribute towards helping people with Motor Neurone Disease in SA? Have a little free time? Like to socialise? We might just have the thing for you!

Many of our clients feel isolated, because travelling from their home can get increasingly difficult. MNDSA is devoted to improve quality of life by promoting social interaction. We are commencing a new volunteer program titled the 'Community Visitor Program', where trained volunteers travel to client's homes for social interaction and support. This is not a personal carer role, but a socialisation and psychological support role. Want to meet up with likeminded people in similar situations and have a coffee and a yarn, then this might be just for you.

Please call MNDSA on (08) 8234 8448 if you are interested. We have an information meeting on Tuesday the 7th of March between 10.30am and 12pm for anyone wanting to know more about the program. We would love to see you there!

KNOW YOUR MND HEALTH PROFESSIONAL SERIES

Pamela Bartlett is a Registered Nurse (RN) who earned her Bachelor of Nursing and her Graduate Diploma in Nursing (Critical Care) from Flinders University. She has nearly 20 years of nursing experience including 10 years working in the Intensive and Critical Care Unit at Flinders Medical Centre (FMC) as a senior RN and participated in retrieval nursing. She also worked in Cardiology Research at FMC as a Clinical Trials Coordinator for many years working on clinical trials from phase I – IV.



Pamela commenced working at the Motor Neurone Disease Association of South Australia in 2014 as a Motor Neurone Disease (MND) Advisor, providing support to people with Motor Neurone Disease and their families via information and referrals, as well as providing education about MND to Aged Care Facilities and other interested groups. She has enjoyed gaining in depth knowledge in the areas of Disability, Palliative Care and Aged Care to be able to support people with MND. Last year Pamela successfully completed her Certificate IV in Training and Assessment. Pamela continues to enjoy her important work within the MND community and is looking forward to the exciting year ahead.

YOUR MND SA TEAM

Executive Director

Karen Percival kpercival@mndsa.org.au

MND Advisors

Jerry Packer jpacker@mndsa.org.au

Pamela Bartlett pbartlett@mndsa.org.au

Administration

Carol Armstrong admin@mndsa.org.au

Marketing & Fundraising

Bianka Feo fundraising@mndsa.org.au

