

YOU, ME & MND - CLIENT NEWS

UNTIL THERE'S A CURE THERE'S CARE

FOR SOUTH AUSTRALIANS WITH MOTOR NEURONE DISEASE



On Thursday 17th of November 2016 MND SA's You, Me and MND Session was held at the Hilton Hotel.



We had an amazing turn out this time – our best yet! The increasing group sizes have reinforced the importance of these sessions to our community. We still encourage anyone and everyone to attend these sessions - clients, their families, friends and community members. All are welcome to attend to learn more about MND, network, discuss and socialise.

The large group sizes have made MND SA consider the future of these gatherings in 2017. We are looking to move these meetings to a more suitable location nearby that is capable of accommodating larger groups. We of course will keep you updated on this, but if you have any concerns, please do not hesitate to contact MND SA to discuss.

Julia Grieg from the Repatriation Hospital presented an amazing and detailed session titled 'MND and Speech Pathology 1' where she discussed the process of swallowing and how MND can affect this. She also described the role a Speech Pathologist plays in caring for someone with MND. This presentation was very detailed, but due to time constraints only covered a small aspect of



Speech Pathology and Julia has agreed to return in the new year to complete her presentation in 'Speech Pathology 2'.

Julia Grieg is a highly skilled and experienced Speech Pathologist based at the Repatriation Hospital. She works closely with many people with special needs including MND. Julia assists people with swallowing, speech issues, assessment, symptom management, treatment and diet modification etc.



Items covered in the session:

- Explained that MND management must include complete holistic care, encompassing every aspect of the person. Although an important aspect – Speech Pathology is only one aspect of care, but a very important aspect of support for those with MND.
- Discussed the goals for swallowing management.
- Julia discussed the normal and abnormal swallowing processes using diagrams and videos.

Oral Phase:

- What happens in the mouth
- This phase is under the persons control
- The airway closes off when the swallow occurs.

Pharyngeal Phase:

- This phase is a reflex action
- The phase lasts for only approximately one second
- The breathing stops during this phase.

Investigations used in Speech Pathology:

- Modified Barium Swallow (MBS)
- Fibroscopic Endoscopic Evaluation of Swallow (FEES)
- Explanation of Aspiration and residue.



Julia also detailed what would display if issues in either the Oral or Pharyngeal phases were present and the management of these symptoms.

Early Stages of Dysphagia (Swallowing issues), including:

- Management of Dysphagia
- Lip seal strategies
- Tongue strategies
- Tips for effective swallowing
- Management of fatigue
- Management of choking
- Food modification and textures
- Fluid consistencies/thickness
- Discussion about Percutaneous Endoscopic Gastrostomy (PEG) placement
- There was a great interactive discussion about PEG insertion and management with the group
- SA Ambulance Service (SAAS) may be able to re-insert PEG tube if accidentally removed
- Julia suggested to have a catheter and gel as a backup if the tube is accidentally removed this will ensure that the hole for the tube does not close up prior to reinsertion.

Julia also discussed case studies of patient/clients experiences with PEG insertion and management.

Which covered:

- Excess saliva
- Thick secretions
- Oral hygiene
- Coughing attacks
- Weak cough
- Goals of Speech Pathology.

Julia indicated that a potential location to source modified fluid consistencies privately is:

Atlas McNeil Health Products

35 Magill Road, Stepney, S.A. 5069

Ph: 1300 741 085 Em: info@atlasmcneil.com.au

MND SA ARE HERE TO HELP

We understand that there will be times where you may have questions or need assistance outside of scheduled appointments with Pamela or Jerry.

Please do not hesitate contact us if you need anything.

We are available Monday - Thursday 8:30am - 4:30pm.

Please leave a message if the phone is unattended and we will get back to you as soon as we can.

PLEASE RSVP ASAP FOR THURSDAY 15 DECEMBER!

Please remember that our next You, Me and MND Session will be located at the Adelaide Sailing Club, *not at the Hilton Hotel!*

We have had a fantastic response for our December You, Me & MND Session followed by the Xmas Lunch.

You can join us for the session only or just the lunch, however we would love you to attend both!

Places are limited so please let us know by Monday 5th December if you would like to attend.

At 11am Viythia Katharesan, PhD Candidate/Associate Lecture, University of Adelaide, Motoneurone Research Group will present for our information session followed by the Xmas lunch at 12pm.



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!

SACARE IMAGINATION HOUSEBOAT

We are delighted to announce that SACARE have donated 7 nights' accommodation on their Imagination houseboat as first prize for the 2017 Walk to D'Feet Raffle. More details to come...

Imagination is the only fully equipped wheelchair friendly houseboat on the River Murray. Imagination is perfect for any individuals seeking a holiday or respite option.

If you would like to take part in a complimentary cruise on this incredible houseboat you are welcome at SACARE's event, For International Day of Disability, Thursday 1 December.



Please join us on the
SACARE Imagination Houseboat
For International Day of People with Disability
Thursday December 1st
AM Cruise 10:30am - 11:30am
12 Noon Sausage Sizzle
PM Cruise 2pm - 3pm
Please RSVP 28th November
rsvp@sacare.com.au



COMING SOON IN 2017...

MND SA will run a 'Know your MND Health Professional' series, which will include personal bio's of various MND health professionals and service providers state wide and what drives them to do the amazing work they do.

Thursday the 16th of March 2017 is a client led discussion group – we are still looking for more people willing to present or discuss topics close to their heart. Please contact us to discuss. Any topics are up for discussion so please contact us with your ideas.

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

UPCOMING YOU, ME & MND SESSIONS

Thursday 19 January	11am	Marianna from Physio Neuromoves
Thursday 16 February	11am	Mary-Louise Rogers from Flinders University – local SA based research update
Thursday 16 March	11am	Client Led Discussions – 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 20 April	11am	Public Trustee – Wills, Power of Attorney and Advance Care Directives

You, Me and MND: It is always our goal to provide an open and welcoming environment for all participants that is full of important information, along with an opportunity to share experiences and socialise.

These sessions are so important to the South Australian community affected by MND and all are welcome to attend.

The meetings 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.

Join us for a cuppa and a chat and stay for lunch!

YOUR MND SA TEAM

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