Thanks to our Skydiving Fundraising Heroes
Letter from CEO 3 MND SA Skydiving 21
Jerry Packer 4 - 5 You, Me & MND February 22 - 23
Media Spokesperson 6 SA Ambulance Fact Sheet 24
Aged Care - have your say 7 MND Staff Matters 25 - 26
Research - Copper ATSM update 8 Fundraising Heroes 27
Talking about MND with Children 9 Community Support Program 28
NDIA 10 Come Walking, Get Talking 29
Article of Interest 11 - 13 Family Information Evening 30
Vps4 Protein Study 14 - 15 Living Well with MND 31
NDIS Update 15 MND Massage Workshop 32
Accessible Telecoms 16 - 17 Thank you 33 - 34
National Advance Planning Week 18 Sausage Sizzle Fundraising dates 35
MND SA Business Focus 19 Glitz & Glamour Gala Evening 35
MND SA Media happenings 20 Walk to D-Feet 2019 36

Motor Neurone Disease Association of SA
302 South Road Hilton SA 5033
Ph 08 88234 8448
Email: admin@mndsa.org.au

BOARD MEMBERS
Chairperson
Geoff Thomas
Vice - Chairperson
Meredith Waterhouse
Treasurer
Daniella Di Girolamo
Secretary
Dr Peter Allcroft
Members
Kristine Colliver
Sarah Annicchiarico
Mary-Louise Rogers
Grant Law

STAFF
CEO
Karen Percival
Support Services Manager
Jerry Packer RN
MND Advisor
Ash Dolman
MND OT
Carlye Thompson
Support Services Administrator
Sarah Del Fante
Marketing, Communications & Fundraising Officer
Narelle Kaimins
Administration Officer
Carol Armstrong
Welcome to our first newsletter of 2019.

Here at MNDSA we can’t believe how we are already in to March. Lots of planning has been undertaken for client services for 2019 in order to meet the current increasing demand.

In order to meet the needs of our community we have reviewed our staffing and increased staff hours across the board, including the addition of a new office based member of support services, Sarah. You can read about Sarah later in the newsletter and we are delighted to have her on board.

What comes with this increase in resources is the need to continue our fundraising efforts in earnest, whilst continuing to lobby for state government support. Over two thirds of our clients are not eligible for NDIS services and we are trying to support them through fundraising and donations, in an environment that is getting more challenging.

Our inaugural skydive event was held on Sunday 24th February where we saw some amazing supporters and staff go above and beyond, jumping to raise funds for MNDSA. We had a few people deferred to jump at a future date due to unsuitable weather conditions and concerns for safety, so more to report on this one. We had a $50,000 fundraising target for this event and are currently at $39,011, so are hoping we can still make target. You can support Carlye and Ash who have still to jump if you would like to help us.

Unfortunately our Occupational Therapist, Carleye had an accident and as a result has been unable to drive for a number of weeks. A call out for a volunteer driver to assist was met with amazing support from our community, for which we are truly grateful.

We have also had changes in our Board, with Grant Law, of Grant Law Public Relations being appointed to compliment our current skill set around the Board Table. Recruitment for a new Treasurer is also well underway.

Don’t forget the Walk to D-Feet MND 2019, we would really like all the support we can get to make it our biggest yet. We have provisions for 2,000 people to register but would love more. If only half that target raise $100 each, we will smash our $100,000 fundraising target. We need these funds to survive - this is our flagship remembrance and fundraising event to pay it forward and means so much to so many. Hope to see you there!
MND SA are a small organisation looking at achieving big things. We have several items that we are working towards and hope to achieve each one of them before the conclusion of 2019. We can only achieve these goals with your help, so please support us in any way you can help us help you.

We hope to achieve the following:

- A new permanent residence for MND SA to live
- A new vehicle, so all of the Support Service staff can attend visits at the same time.
- Government funding for continued and improved services over 2019
- A significant increase in our equipment pool
- A further increase in staffing and hours to better support our community
- A new agreement with an equipment provider to assist with storage, delivery and maintenance of our existing and growing equipment pool.

Achieving these goals will ensure improved and continued services and support to all people in SA affected by MND.

It has been a busy start to 2019 and I am happy to admit that we have already made some leeway on several of these items. I am excited to announce the addition of a new staff member at MND SA. Her name is Sarah Del Fante and will be assuming the role of Support Services Administrator. Sarah will be predominantly office based supporting Jerry, Ash and Carleye while they are out visiting clients etc. The addition of Sarah is a trial for 6 months and we hope that it is successful, because it is our intent to have improved outcomes and shortened timeframes with all of our activities using Sarah’s support in the office. Sarah already has an extensive history and knowledge base around Disability and MND in particular. I would like to formally welcome Sarah to the team. Some of you may already know Sarah, but everyone please make her welcome to our wonderful MND community.

While the MND Association provide funds towards finding a cure for MND, the bulk of our work is directed towards supporting our MND community to get the care and equipment they need.

Sometimes this means advocating at the highest levels in the Government to ensure that the decision makers properly understand MND and its unique support requirements.
Other times it means finding the right care providers who not only understand MND and its progression but are flexible in the way in which they are prepared to support people living with MND.

With so much emphasis in the media of late around advances in research, I thought it important to also highlight the need to continue to support people who are living with the impact of MND here and now. While we all look hopelessly to a future cure, the reality is that people living with MND need support and services today.

What is Support Services? It is comprised of several program areas. A brief overview of this service includes:

- **MND Advisor and Support Coordination**
  - Case Management and information sourcing
  - We are the go-to people for MND information and we will assist you to get the services, supports and equipment you need to live a better life
  - Bereavement support service

- **Occupational Therapy support**
  - Assessments, prescription and provision of needed equipment to live better at home and accessing the community

- **Community Support Program**
  - Support Groups, including: Come Walking, Get Talking Carers Group; You, Me and MND; Client Christmas Lunch
  - Educational Workshops, including: NDIS Updates; Falls Prevention; Living Well with MND; Family Information Evening; MND Massage

- **Equipment**
  - Extensive equipment pool of difficult to access and specialised equipment for supporting people with MND at home and in the community

- **Volunteers**
  - Community Visitor Program (CVP); Support Service Assistant (SSA); MND Spokesperson and Community MND Educators

We hope you enjoy our first issue of MND Matters for 2019 and remember, your input is always welcome!
At times, the media contact us to identify a person with MND to provide comment on an issue. Usually that will be about research, as it was recently with the announcement of the Cu(atsm) phase 1 trial.

But it might be other things! It could be there is an issue for people over 65 accessing services or a completely different issue.

We are looking to have available a list of people diagnosed with MND who are willing, at relatively short notice, to be a spokesperson for people with MND. The media want to hear from real people affected by MND.

If you would like to be a “spokesperson”, we need you to:

- Have an email address - so that we can contact you and provide background material
- Have a mobile phone so that we can text message you when something is very urgent and is a backup to email
- Indicate if you communicate with speech, speech synthesizer or by text
- Tell us how available you are.

We will maintain a list and contact people as appropriate when required. We will keep that list confidential with MND SA, and we will seek your permission before providing any details. If you prefer, we will give you the contact details of the media and you can call or email them.

We will make sure that you have background information on the issue at hand in as much detail as possible.

If you would like to be a spokesperson, please email Narelle at: nkaimins@mndsa.org.au to commence conversations. It would be fantastic if we could have five or six people ready, willing and able to be our MND spokesperson and to be able to put the human face of MND in the media!
For many people living with MND, appropriate aged care and support which can and should be delivered within a person’s own home, is completely unavailable to them. Many more are struggling to even achieve a fundamental level of support. This is unacceptable.

The current Royal Commission into Aged Care in Australia has primarily focused on the experience of older Australians in residential settings. This only represents part of the substandard care older people are experiencing through our aged care system. Depriving someone of the right to remain living in their own home, simply because of an unavailability of in-home packages is also substandard care.

Now is the time to add our voices to the discussion and provide a very clear message to the investigators and the decision makers that people living with MND want, need and expect to access their care, their way in their own homes. You can make a submission or have your voice heard at a hearing.

To make a submission, please go here:

or subscribe to:
Royal Commission updates to receive more information about 2019 hearings:

Join the MND Australia campaign to MAKE AGED CARE FAIR
mndaction.org.au
Clinical outcomes for copper-ATSM as a treatment for MND have very recently been reported in the media, with some of the reports describing exciting results for efficacy.

We all desperately hope for the day when any person diagnosed with MND can be prescribed a drug that will stop the disease in its tracks. Copper-ATSM may one day prove to be that drug, but we’re not there yet. Here, we provide a brief update on Copper-ATSM.

The development of Copper-ATSM as a treatment option for MND started around 15 years ago when it and related compounds were tested in animal models of neurodegenerative disease. Over the years, the laboratory based evidences supportive of Copper-ATSM being an effective treatment accumulated to the extent where clinical testing in MND patients became a legitimate possibility. It was given to MND patients as a therapeutic for the first time in 2016 when the phase 1 testing commenced. In December 2018, outcomes from the phase 1 trial were announced at the International ALS/MND Symposium in Glasgow and in January 2019 the same information was circulated as a press release from the company supporting the clinical testing, Collaborative Medicinal Development.

First and foremost, the phase 1 trial was a success. The primary objective, as per any phase 1 trial, was to assess safety and tolerability of the drug and, if possible, identify a dose that could be taken to the next round of testing. By assessing the drug at a number of different doses the trial successfully identified a safe and recommended dose for phase 2 testing. Many potential drugs that show promise in the research laboratory ultimately fail to get through phase 1 testing, so for Copper-ATSM to get past this important milestone is an excellent achievement.

In addition to confirming that the drug is safe, reporting on the phase 1 trial also included descriptions of efficacy, such as improved respiratory function and a slowing of disease progression as assessed by the ALSFRS-R scoring system. These are very exciting indications that Copper-ATSM may prove to be an effective drug for MND. However, the number of patients included in phase 1 testing (for any drug) is kept small by necessity and phase 1 trials are not designed to demonstrate efficacy. For example: all patients in the phase 1 trial knowingly receive the drug and there is no placebo control group for direct comparison. So, while the phase 1 results for Copper-ATSM are very encouraging and are good cause for excitement, there is still a considerable amount of work to do before it can be confirmed that Copper-ATSM is an effective treatment for MND.

It is therefore very welcome news to hear that planning for Copper-ATSM to enter phase 2 testing is already underway. Phase 2 trials are specifically designed to assess efficacy. It is reported that the phase 2 testing will start in the second half of 2019 and that the trial will include 80 MND patients. Details of the phase 2 trial, including the participating clinics and the patient recruitment criteria, are yet to be announced.

Upon completion of the phase 2 testing we all hope that the promising indications from the phase 1 trial are confirmed as a reality.

By Dr Peter Crouch, University of Melbourne
Talking about MND with Children

There is no easy way to inform your children that you have been diagnosed with MND. It is an extremely difficult conversation to have and one that needs consideration prior to broaching the subject.

When and how to tell your children is a question we often get asked and one we always struggle to answer, as there is no ‘right way’.

How you tell your children is a very personal decision and each family will have their own way of dealing with it. There are a few thoughts that will be shared throughout this article that will hopefully assist you with your conversation or provide some conversational tools with which to work with. It has been said that if you can arrange for your doctor to share the information with your children it takes the pressure off you and allows you to be there to comfort and support your children. If, however, that is not possible it is best to tell them in a location where they don’t feel confronted; somewhere that allows you to have a ‘side by side’ conversation, walking on the beach or in a park.

Some parents find it useful to broach the subject by finding out firstly what their children already know about MND. For example you could say, ‘what do you understand about Mum’s legs getting tired?’ Then discuss any essential information they don’t already know. Ensure you check in on how they are feeling, give them a hug and reinforce how important it is to talk about feelings.

MND SA have some very useful information regarding this difficult issue and provides ideas that may help with information sharing and managing the situation on a day to day basis.

- Let your children know how they can help, that allows them to feel part of your life;
- It’s important to have an outside focus and not let MND dominate your life;
- Everyone will experience grief, let your children go through the process. Shutting it down will only prolong the grief and not allow them to ‘walk beside you’....

A couple of other great ideas when trying to read your children’s responses are:

- Make an ‘Emotion Thermometer’ and put it on the fridge. Put phrases on it like; ‘ask me what’s wrong’, ‘I need a hug,’ ‘please don’t ask me how I feel’ etc. A fridge magnet can be used to point to the ‘feelings of the day’. This is a nonconfrontational way for kids to communicate their feelings, allowing you to address them appropriately.
- Another easy way for kids to get their feeling across is to have a chart on their bedroom door with sayings such as. ‘I need a hug today’; ‘I need a bit of space today’; or ‘Great day! Let’s do something fun!’

One psychologist recommended watching Australian Story as a nice family thing to do. It provides an opportunity for kids to see how other people cope in difficult situations and manage adverse circumstances. It can also provide an opportunity to discuss tough circumstances that other people are facing and address how you as a family are coping with your situation.

Trying to stay positive will always benefit yourself and your family. If you are having a hard time, reach out to your MND Advisor. They are always there to listen and support you regardless of the situation and are also able to provide you with other resources.

Someone once stated; “MND doesn’t stop bad things happening - but it doesn’t stop us doing good things!”

If you would like to read more, here are some useful links:

- ‘When Someone Special has Motor Neurone Disease’- from the MND Association of Victoria, (About MND, Information for Kids). www.mnd.asn.au
- ‘All For Kids’– information about MND for young children, adolescents and parents – Canadian ALS Association www.als.ca/allforkids
- www.kidshealth.org/kid Lou Gehrig’s Disease (ALS) Nemours Foundation – from America
- Real Stories from people living with MND www.mndassociation.org/life_with_mnd/experiences_of_MND
- MND SA also have access to a detailed ‘Talking with Young People about MND’ pack available for those in need.
The NDIA have announced a new pricing tier for self-care, social and recreational support for participants with "very complex" support needs.

The long overdue new loading will be set at 10.3% and will be effective from February 2019. *The Australian* has reported that around 10% of participants will be funded for supports at this level.

Currently, the prices for self-care, social and recreational support fall into two tiers: standard needs and complex needs, with the high intensity rate set 5.5% higher.

This welcome price increase has come off the back of the Independent Pricing Review (IPR)'s recommendations, which found that the existing pricing levels for participants with complex needs are insufficient to hire appropriately skilled workers or the necessary ongoing training and supervision.

The second part of this recommendation, which we are sure many of you will be wondering about by now, was that the NDIA needed to be clearer on what is meant by "complexity" to ensure more consistent application of pricing tiers in participant plans.

The IPR's proposed definitions are included below, though it has not been confirmed whether these definitions will be applied.

**TABLE 3: DESCRIPTION OF PROPOSED LEVELS FOR PARTICIPANTS WITH COMPLEX NEEDS**

<table>
<thead>
<tr>
<th>Classification</th>
<th>Participants characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Standard (no price loading)</td>
<td>• No health related intervention needs (e.g. feeding through a nasogastric tube; ventilation support)</td>
</tr>
<tr>
<td></td>
<td>• None or mild behaviours of concern</td>
</tr>
<tr>
<td>Complex (5.5% price loading)</td>
<td>• Health related intervention needs (e.g. nasogastric feeding; ventilation support)</td>
</tr>
<tr>
<td></td>
<td>• Mild / moderate behaviours of concern (e.g. infrequent rapid escalation of challenging behaviour)</td>
</tr>
<tr>
<td>Very Complex (10% price loading)</td>
<td>• Combination of health related intervention needs and mild / moderate behaviours of concern</td>
</tr>
<tr>
<td></td>
<td>• Severe behaviours of concern (e.g. rapid, severe and frequent escalation of challenging behaviour)</td>
</tr>
<tr>
<td>Quoted</td>
<td>• Extreme behaviours of concern - see Section 4.3.2 for further details</td>
</tr>
</tbody>
</table>

Many providers of therapeutic supports will still be eagerly awaiting the outcome of the Pricing Review's investigation into prices for therapy. Assistant Minister for Social Services, Sarah Henderson, has said that the new plan for these prices will be released “in the coming months”.

---

*NDIA Announces "Very Complex Needs" Pricing Tier*
In centres like Griffith and Wagga Wagga, locals fear there may be something in the Water. By Gabrielle Chan

As a child, Tania Magoci spent every weekend at Lake Wyanganna near Griffith, water-skiing, swimming and boating with her family.

She and her siblings would use the serpentine concrete outlet into the lake as a slippery slide. In summer, the slime from algal blooms exacerbated by the run-off from the near by farms made it more fun to slide down the chicanes.

Tania grew up on one of those farms, where her family grew rice and wheat. Now she is questioning whether the conditions of that childhood accelerated her genetic predisposition for motor neurone disease (MND), a progressive disease which attacks the nerve cells controlling muscles allowing movement, speech, swallowing and, ultimately, breathing.

Only 10% of MND cases are associated with genetic factors while the remaining 90% are associated with environmental and lifestyle factors.

The numbers of sporadic (i.e. non-genetic) cases of MND have increased by 250% in the past 25 years in Australia. New South Wales towns including Griffith, Wagga Wagga and Leeton in the Riverina have rates seven times the national average. Coffs Harbour, Tamworth and Port Macquarie are other hotspots for the disease.
Scientists are investigating whether exposure to pesticides, metals and blue-green algae toxins increases the likelihood of contracting the disease. A recent study in the United States found certain pesticides could accelerate MND.

As the drought continues across Australia, heat and dwindling water supplies have accelerated the algal bloom, leaving rural residents concerned that their water supply could be potentially deadly. It is becoming an issue in the upcoming NSW election and potentially in the federal election.

“There are little clusters coming up and down that river stream and it’s scaring me there’s going to be more clusters,” Magoci says.

Her grandfather died of the disease and her 58 year old mother Karen died 10 months after her diagnosis. Magoci says her mother was told she would die and to go home as there was nothing they could do.

The experience, coupled with her own diagnosis, has driven her to become an Australian-style Erin Brokovich - the accidental environmental activist who led the fight against contaminated water in the small US town of Hinkley.

Magoci’s activism led her to Prof Dominic Rowe and Prof Gilles Guillemin at the Macquarie University Centre for Motor Neurone Disease Research. She started a support group for local sufferers of MND after helping her father care for her mother and has now helped 13 sufferers and 20 more who have passed away.

When the 40 year old hairdresser started dropping her scissors, she went straight back to Rowe to be tested. Magoci stopped work when she could longer hold the hairdryer.

Since her diagnosis, Magoci has been on a medical trial which requires a seven-hour trip to Sydney every three weeks to try to find a treatment that may help the people in her support group and potentially her own children, who are teenagers. “One of our members, a beautiful girl, got diagnosed two weeks before me, she is still living but she can’t move any part of her body, she’s got two young kids same as me, she can’t talk, she can’t walk, she can’t move any part of her body,” Magoci says.

“I don’t mind going up every three weeks if I can find a treatment. I don’t even want a cure; if I can find a treatment, something for my kids to hang on too, I will try it.”

The Macquarie team created an MND biobank in 2012 to collect urine samples to screen and identify potential triggers from across the region, particularly from the families of MND sufferers.
But the scheme, which looks at the levels of potential environmental catalysts, has received no government support so Magoci is urging people in her area to donate samples.

Regional airlines cannot fly the samples so Magoci drives them to Sydney because they have to be tested within 24 hours.

She is calling for $2m from the NSW government, less than the $3m in MND funding provided by the Victorian government.

Responsibility for water in rural areas is often split. In Griffith, State Water has control in the river system before it passes to private company Murrumbidgee Irrigation (MI) which delivers the water closer to the town before City Council takes control. Lake Wyangan is half managed by the council and MI.

NSW shooters, Fishers Farmers candidate Helen Dalton, who is in contention for the state seat of Murray on a margin of 3% is urging the government to support the project with $2m in funding.

“People have a basic right to get good quality water,” Dalton says. However Dalton’s husband Nayce has just been appointed chair of MI, though she rejects any concerns over a conflict of interest.

“This is the state government’s responsibility, they should be pledging $2m but they don’t want to know because they don’t want to be sued. MI do not guarantee water quality, they are in an infrastructure company, a water delivery company.”

Dalton says the algal blooms were happening in the wider region, including Menindee, Balranald and Hay.

“[The state government] are throwing money around like drunken sailors, so $2m should not be a lot in the grand scheme of things.”

Austin Evans, the state nationals MP for Murray, says he would support funding for research but he is not “in charge of the purse strings”. Evans also advocates funding to improve water quality in Lake Wyangan.

“The research element needs to be supported,” Evans says. “MI and the council need to look at ways to improve water quality and lessen the chance of blue-green algae.”

Griffith council did not return Guardian Australia’s calls but in February released a statement reassuring the local residents they were monitoring the water flow from the catchment area into the lake to determine how much sediment and nutrient runoff enters Lake Wyangan north.

The council says it also released 300 megalitres into the lake in January to ensure conditions did not create more algal blooms.
Vps4 Protein Found to Protect Nerve Cells from Degeneration, Study Shows

Enhanced production of a protein called Vps4 was shown to delay the degenerative process in injured nerve cells, which may help researchers to better understand and treat nerve damage in neurodegenerative disorders such as Parkinson's disease and amyotrophic lateral sclerosis (ALS), a study says.

The findings were published in an article, “Rapid depletion of ESCRT protein Vps4 underlies injury-induced autophagic impediment and Wallerian degeneration,” in the journal *Science Advances.*

Nerve cells have tail-like structures called axons that transmit electrical impulses to communicate with muscle cells and other nerve cells. Failure of axonal integrity prevents nerve cells from functioning normally, and may cause axonal death and nerve cell degeneration.

Upon axon injury, these cells can undergo a process of progressive self-destruction called Wallerian degeneration, which is tightly controlled at molecular and cellular levels. For many years, NMNAT-related signals were the only mechanisms known to limit the effect of this process. Despite its relevance for normal and correct functioning of nerve cells, Wallerian degeneration and its underlying mechanisms are still poorly understood.

However, a team led by researchers from the Chinese Academy of Sciences has identified Vps4 to be effective in delaying the degradation of damaged nerves and play an important role in axonal integrity. They found that fruit flies lacking Vps4 protein experienced more severe age-dependent axonal degeneration than flies with normal protein levels.

To further explore this hypothesis, the team conducted the opposite experiment and induced an over-production of Vps4 protein in flies. They found that this strategy was sufficient to suppress injury-induced axonal degeneration.

Vps4 protein is a key component of a cellular machinery involved in autophagy, a cleaning system that ensures the destruction of a cell’s waste and damaged parts. Therefore, the team hypothesized that Vps4 could be contributing to axonal integrity by regulating its autophagic clearance process.

The researchers observed, in the absence of Vps4, an accumulation of autophagic vesicles in axons even before the breakdown of axonal integrity. In contrast, over-production of Vps4 substantially reduced the levels of injury-induced autophagy.
They found that the neuroprotection provided by Vps4 was not restricted to the regulation of the autophagy flux in axons, but also to the prevention of Wallerian degeneration. Experiments in the lab and with mice confirmed that Vps4’s neuroprotective role is also present in mammals.

Collectively, these findings suggest that “the rapid depletion of Vps4 protein may trigger injury-induced autophagy and axonal degeneration,” the researchers wrote. This may help explain many of the features of nerve cell degeneration linked to many human diseases.

Additional studies are still warranted to further explore how Vps4 is depleted upon injury, and how it can be used to develop targeted strategies to prevent axonal degeneration.

“In the future studies, suppressing the rapid degradation of Vps4 may be an important direction and is expected to obtain stronger neuroprotective effects,” Kai Liu, associate professor at the Hong Kong University of Science and Technology (HKUST) and co-senior author of the study, said in a news release.

Moreover, a combination of the Vps4 and NMNAT pathways “may also be a new strategy for the treatment of neural injury and degeneration,” he said.

Although services have improved considerably in SA with the NDIS, our NDIS planner is going on extended leave for several weeks in March/April. We are not sure how this will affect NDIS related services moving forward in the short term, but we will endeavour to keep pushing for quicker and better outcomes. We have met another planner at the NDIS and believe that the transition shouldn’t affect current and new services and hope that outcome times remain the same.

MND SA have now commenced a 2 hour NDIS Information Session that will be held at the MND SA Office – 302 South Road. This session will run 4 times per year and will provide better understanding and insights to those seeking to access the scheme, but also to those currently accessing the NDIS. It will enable questions and support for those seeking more knowledge and understanding.

Attendance is free, but please book your place.

The first session is Monday the 25th March 2019, starting at 10am for 2 hours.
Australian Communications Consumer Action Network (ACCAN) has today launched Australia’s first independent information resource for telecommunications products suitable for people with disability.

Known as the Accessible Telecoms project, the interactive website and call Centre will be the much needed one-stop shop for information about the accessibility features of both mainstream and assistive telecommunications equipment suitable for people with disability. It is made possible thanks to a National Readiness grant from the National Disability Insurance Agency (NDIA).

As Australia’s peak body representing communications consumers, ACCAN has been advocating for a service that will eliminate the growing information vacuum about equipment and services suitable for people with disability in our increasingly digitally connected society.

“There is an acknowledged lack of up-to-date, appropriate and independent information about telecommunications equipment and services available for Australians with disability,” said Wayne Hawkins, ACCAN Director of Inclusion “We’re pleased that the NDIA understands the significance of this project in assisting Australians with disability to be able to utilise telecommunications to enable greater participation in all aspects of Australian life – economic, social, and cultural and community.”

Telecommunications are now a vital part of our everyday lives, from accessing government services, to keeping in touch with family and friends. This is no less true for the more than 4 Million Australians who identify as having a disability. It is essential that every one of us is able to connect and communicate using telecommunications.

Accessible Telecoms will provide information about the accessibility features of telephone handsets (fixed, mobile and teletypewriters) as well as the accessories which make them usable for people with disability. The service will also provide information about available set-up, training and on-going support that can provide people with disability with the skills and confidence to maximise the benefits of telecommunications access.
Over time the information available will expand to include accessible tablets, mobile apps and software that can enable people with disability to connect with the telecommunications networks.

“I am excited about the new service from ACCAN. The community needs better information about accessible telecommunications suitable for people with disability, and the ACCAN referral service has the potential to provide this,” said Alastair McEwin, Disability Discrimination Commissioner.

“It is so important that we facilitate connectedness and participation across our communities, and creating accessible communications are essential to that.”

ACCAN has enlisted IDEAS (Information on Disability Education and Awareness Service) to deliver the information via their website and call centre.

“It may be a surprise to many people who live without disabilities that accessing truly accessible telecoms hardware and software is very complex. While apps and screen modifications on smart phones can be of some assistance to people with disability, these specifications may not be right for people with particular mobility, sensory, and memory or cognitive conditions,” said IDEAS CEO, Diana Palmer.

“Through Accessible Telecoms, we’re excited to offer people with disability up-to-date and independent telecommunications resources that can be accessed by web, live chat or phone. This is a momentous undertaking, as it marks the first time that people with disabilities will be able to engage with a resource to help them determine exactly what they want from their telecommunications products.”

Accessible Telecoms is available at www.IDEAS.org.au, or by phoning IDEAS on 1800 029 904.

For more information read our

**Accessible Telecoms Information Sheet**

or contact Wayne Hawkins at accessible.telecoms@accan.org.au.
SAY IT FORWARD
advance care planning
information session
2nd April, 2019 4pm - 6pm
Palliative Care SA
Please RSVP.

PLANNING AHEAD SEMINAR
Centennial Park
3rd April, 2019 10am—11.30am
Please RSVP

ATTEND AN EVENT
Can’t find an event in your area?
Why not host your own event! It can be as easy as a conversation over a cup of tea or as big as a workshop or seminar at your workplace.

Advance Care Planning Advisory Service
Call us now 1300 208 582
with your advance care planning questions
9am - 5pm Monday - Friday

FOR SALE

We have been contacted by James who has a modified disability vehicle for sale.
If you are interested, please contact
James
0409 306 969
or
email james@chowilla.com.au

We have been contacted by Lloyd who has a tilt in space reclining wheelchair for sale.
If you are interested, please contact
Lloyd
0432 899 677
or
email lloydellickson@bigpond.com
MND SA “Business Focus” is a new section to our newsletter which will focus on a business who has:

- become a sponsor of a major /minor fundraising event
- provided financial support to purchase equipment &/or service
- become a sponsor of information sessions, training workshops/ conferences

Comfort Air Conditioning Installations is our Major Sponsor for our You, Me & MND sessions throughout 2019, which has allowed us to continue using the preferred venue, WAFC, of our clients. Thank you so much for your support and we look forward to a long and rewarding business partnership with you.

We offer intelligent Solutions with a Prompt Professional Service.

Comfort Air Conditioning Installations is a well established business servicing Adelaide and all of the surrounding suburbs. Our team of professionals are able to provide you with the knowledge and support on what would be the best air conditioning unit for your home. We are dedicated to delivering the highest standards of workmanship and customer service.

**Our services include:**

- Heating & Installation repairs
- Air conditioning installations
- Ducted air conditioning
- Refrigeration

Monday 9:00am - 5:00pm  
Tuesday 9:00am - 5:00pm  
Wednesday 9:00am - 5:00pm  
Thursday 9:00am - 5:00pm  
Friday 9:00am - 5:00pm  
**Weekend work available on request!**

Get in touch today for more information!

“Sab was great. Punctual, polite, professional and helpful. Look forward to using him on an ongoing basis.”

We are proud to support Comfort Air Conditioning Installations, & be sure to mention this article if you call them for products/services.
5AA afternoon Broadcaster Alan Hickey and his producer Josh Sampson are passionate about supporting MND SA. In January and February we had 3 half hour interviews to promote our SKYDIVE FOR DOLLARS event, thanks to

- Greg & Jean Downton, CEO Karen Percival
- Derrick McManus, Helen Hicks, Mitch Grigg
- Nic Bowman, Eliza Duff-Tytler, Carol Armstrong, Jerry Packer

SKYDIVE FOR DOLLARS

The Sunday Mail called in response to our request for an article on February 24th in support of the skydiving day.

Photographer Dean Martin arrived at the MND SA offices for a photo shoot and the fun began.

Derrick, Nic, Greg and Carol were ready for action.

We thank the Sunday Mail for supporting MND SA.
Our skydiving event to date has raised nearly $40,000 and with another jump scheduled in May, we are confident we will achieve our target of $50,000.

A BIG THANK YOU to the team at SA Skydiving

Unfortunately things didn't go according to plan, and due to weather conditions 4 of our jumpers had to postpone to a future date to be advised.

MND can affect the lower limbs as well as affect the care of the lower limbs and Podiatry Services SA are your one stop shop for all things podiatry.

We can assess, diagnose, prevent, treat and rehabilitate conditions and problems below the knee.

Our services include:

- **Biomechanics**
  - Foot and leg structure examination and how they function during movement
  - People of any age can develop biomechanical problems

- **Podiatry Management**
  - Strapping
  - Stretching
  - Insoles
  - Orthotic Therapy
  - Wedge manufacture
  - Prescription of splints or ankle foot orthoses

- **Routine foot care**
  - Calluses and Corns
  - Heel fissures
  - Tinea (Athlete's Foot)

- **Wound Management**
  - Ulcer care
  - General wound care

- **High Risk**
  - Diabetes
  - Peripheral Vascular Disease
  - Lower Limb Oedema
  - Neuropaths e.g. Diabetic
  - Cognitively Impaired e.g. Post CVA
  - Immuno-compromised e.g. Chemo.
  - Medications e.g. blood thinners

- **Neurovascular Assessment**
  - Macrovascular Disease
  - Microvascular Disease
  - Neuropathy

- **Footwear**
  - Assessment
  - Modification
  - Recommendation
  - Foot protection
  - Footwear fitting

- **One Stop Shop**
  - The only company in Adelaide that is more than just a clinic or service, it is the total Podiatry package - The One Stop Shop for All Things Feet!
  - A diverse range of experience, skills and knowledge to develop this unique concept of offering a broader range of Podiatry services to make it easier for people to access all their podiatry needs from on business
  - The Company Director is a podiatrist which ensures that all services provided are understood, are of high quality, meet podiatry standards, developed, implemented and reviewed with a high level of experience, knowledge and clinical skill
Podiatry Services SA provides:

- **Podiatry in clinics**
  - Podiatry Service SA has two clinics conveniently located throughout Adelaide and provide services in the Plympton and Unley areas.
  - Both our clinics have easy parking and are located near bus stops for easy access by the community.

- **Home visits**
  - Designed to meet individual needs to enhance independence, health and wellbeing.
  - People’s homes, retirement villages, independent living units, residential care facilities, hospitals.
  - Ongoing or as a one off due to i.e. a recent surgery or as a result of transport issues.

- **Podiatry in Residential Care Facilities**
  - Efficient and cost effective podiatry services in aged care facilities on a regular basis upon request.

- **Podiatry Locum**
  - We supply Locums across Adelaide during a time of vacancy to ensure the community have ongoing care

- **Other Services**
  - Consultancy
  - Worksite Assessment
  - Educational Presentations
  - Aboriginal Health
  - Training

**Upcoming You, Me and MND Sessions**

The next You, Me and MND session will be held on the 11th of April and we have Mel and Leanne from the Philips Sleep Easy Centre again presenting on respiratory devices available for supporting those with MND.

**Lucky Square winners**

Congratulations to Robert B, February’s winner! Don’t forget to bring a few spare gold coins with you to the You, Me and MND session and buy a square or three. Who will win the next free lunch? You have to be in it to win it. Just $2 a square.
The Extended Care Paramedic Program is a joint initiative of SA Health & SA Ambulance Service (SAAS) that commenced in December 2008. ECPs are highly skilled clinicians who work collaboratively with other health care professionals to manage & treat people in their usual residence. SAAS operates the ECP program for all members of the community. It is proving to be particularly beneficial to both those living independently & also those in residential aged care facilities.

Who are ECPs?
Intensive care paramedics (ICPs) who have completed further specialised intensive training, skills enhancement and placements.

How do patients benefit from the ECPs’ services?
ECPs only attend patients who have made a call to 000. ECP’s in the SA Ambulance Service Emergency Operations Centre assesses the patients’ requirements through phone consultation or emergency crew referral and can dispatch an ECP, which is a single responder in an ambulance response vehicle, as opposed to a traditional stretcher carrying ambulance. ECPs provide alternate care pathways for patients and assist in reducing unnecessary transport to hospital. Attendance by an ECP reduces the disruption to patients and their carers, associated with a trip to hospital.
If, after assessment, the patient still needs to go to hospital, the ECP will arrange this. Patients receive more tailored care and if needed, will be managed in collaboration with other health professionals that are appropriate to their needs.

When do they work?
- On road 24 hours a day seven days a week.

What geographical areas do they cover?
- Adelaide metropolitan and fringe areas as operationally required

What other health care professionals do ECPs liaise with?
- General Practitioners
- Medical Practitioners
- RDNS and Focus Health
- Metropolitan Referral Unit
- Palliative Care services
- Carers Respite Centre
- Adelaide Plastic Surgery
- Sportsmed SA
- Physiotherapists.

How to access an ECP?
- The introduction of ECPs is an enhancement of SA Ambulance Service existing service. The way to access an ECP is by calling triple zero (000).

SA Ambulance Service
GPO Box 3
Adelaide SA 5001
Telephone 1300 13 62 72
www.saambulance.com.au
Congratulations to MNDSA Chairman
Mr Geoffrey Thomas
who was awarded the
Medal of the Order of Australia (OAM)
for Service to Primary Industry
On 26th January 2019.

Hi everyone! My name is Sarah and I’m the new MND Support Administrator at MNDSA. I’ve previously worked in a range of jobs – I used to be a truck driver in the army (a few years ago now!) and my most recent job was at a dermatologist clinic as surgical assistant.

I’m interested in working for MNDSA for a couple of reasons: I have a Bachelor’s degree in Health Science and developed a passion for neuroscience & public health during my degree. After studying a range of neurological diseases, I knew that this was an area of much need and I wanted to get involved.

My Grandfather was diagnosed with MND in 2012 and so, after finishing my degree, I decided to volunteer at MNDSA as a community visitor. I loved volunteering & thoroughly enjoyed chatting & meeting people in the MND community.

As Support Administrator, I’ll be in the office helping Jerry, Ash & Carlye.

I enjoy playing sports and studying French. I also love watching Netflix & documentaries, so if anyone has any recommendations, feel free to pass them on! I look forward to meeting you soon!

Sarah
MND SA OT Carlye Thompson was doing her best “Warney” impersonation in high heels. Now we know why “Warney” sticks to his flats when bowling.

She has fractured her ankle, and now that she is home from FMC is soldiering on and back at work. Thanks so much for the support of our fantastic volunteers who are providing transport so she can visit her clients and continue all her dedicated care.

It’s great to have you back on deck Carlye and fundraising for your SKYDIVE in May.

Donations can be made to www.mycase.com.au/events/divefordollars

Meet our Walk to D-Feet Poster Pooch ROCKY, much loved pet of Carlye.

We have him modelling our doggie bandanas for the Walk to D-Feet event happening on Sunday May 5th,

Register now:

Earlybird Registrations close on 5th April 2019
February Fundraisers

We have had some wonderful surprises by means of donations during February and we thank everyone for their contributions.

Maddi collected over 1,000 5cent pieces over the Christmas holidays which she donated to MNDSA to help make a difference. This assisted us to purchase a special cup that has allowed someone to come home from hospital drinking thin fluids despite having swallow difficulties.
Thanks Maddi!

Blackwood Uniting Church donated $500 from the sale of Jams, chutneys etc.
THANK YOU to all for your ongoing support

Kotara WYCA Women’s Group Campbelltown donated $300
Thank you so much ladies, your support is appreciated!

Call us on 08 8234 8448 for information on making a donation or fundraising for MND SA
Support Service Events

Are you newly diagnosed with MND? Caring for someone with MND? Would you like opportunity to ask a group of experts your questions on MND?

MND SA conducts regular education and information sessions for people living with MND, family members, carers and friends. MND education and information sessions and support groups are held throughout the year in Metro Adelaide.

There is usually no charge to attend an MND SA education or information session if you are a person living with MND, a family member, carer or friend. However, bookings are essential.

Keep an eye on our events calendar and future Client News throughout 2019 for updates and locations etc.

In 2019, we will be dropping our MND Meditation Class, but starting two new sessions: NDIS Information Sessions and the Falls Prevention Workshop. So look out in our calendar of events of these new sessions.

Complete Program includes:

- Come Walking, Get Talking Carers Support Group – monthly on the first Friday
- Family Information Evening – three times per year on a Wednesday Evening
- Living Well with MND – three times per year on a Wednesday throughout the day
- You, Me and MND Sessions – the second Thursday of each month
- MND Massage Workshop (for client and carer) – twice per year
- *NEW* Falls Prevention Workshop – Twice per year on a Monday throughout the day
- *NEW* NDIS Information Sessions – four times per year on a Monday before lunch
This wonderful carers walking group will continue throughout 2019. MND SA do not coordinate these groups on the day, but provide the information of where to meet. If any carers want meet up with likeminded others for a break and a chat, then please let us know and we will see if we can really start to build this group. Also, if any member of our community want to take this group under their wing and get more interest and participation we will be forever grateful.

If you are keen to come out and do some light exercise with a group of people in similar situations for both physical and psychological health, please come and join us. Bookings are essential, please contact MND SA if you would like to participate.

Next Walk: **Walk #20 – Michael Perry Botanic Reserve**  
(Creek should be flowing by then – hopefully) Friday 5th April 2019 at 11am.

| Parking | Parking on either High Street or Hallett Road, Stonyfell. If using a GPS to find the location, search for “66 Hallett Road, Stonyfell” because you will then be navigated to parking nearby. |
| Meeting Point | At the entrance gates in front of Andrews Walk. (Near 66 Hallett Road). (Pictured above) |
| Distance/Duration | 1.7km circuit / 1 hour return |
| What to Bring/Contact | Sunscreen, hat, drink bottle, appropriate walking clothes, a big smile, and your four-legged pal. To register your interest, or for any questions regarding the walk prior to/on the day, please contact admin@mndsa.org.au. |

Walk #21 – **Kauwi Interpretative Walk**  
Friday 3rd May 2019 at 11am.

| Parking | Vehicles need to be parked along Chrysler Road, Lonsdale |
| Meeting Point | On the left of the building, in front of the bus zone (Pictured above) |
| Distance/Duration | 2.4km return / 1 hour return |
| What to Bring/Contact | Sunscreen, hat, drink bottle, appropriate walking clothes, a big smile, and your four-legged pal. |
| | To register your interest, or for any questions regarding the walk prior to/on the day, please contact admin@mndsa.org.au. |
The MND SA Family Information Evening is a wonderful educational evening specifically designed for family and friends of those affected by MND, to give them the opportunity to learn more about MND and to ask questions that they may have.

The event will includes:

- An overview of MND
- Living well with MND
- How MND SA supports its members and families
- Accessing services to support you
- Opportunities for you to discuss your individual needs and concerns with MND SA Support Services

This session only runs three times per year and is a great evening that encourage many questions by those who attend. If you would like to learn more about MND in a relaxed environment over a meal after work hours, then please consider attending a session in 2019. Please book your place. You can bring with you as many people as you like – we can fit plenty of people if there if need. The next session will be run on Wednesday the 19th of June 2019, starting from 6pm at the West Adelaide Football Club.

There is no charge for you to attend this program, but you will need to reserve you place. Meals are at group participants cost.

RSVP to: admin@mndsa.org.au

phone (08) 8234 8448 or freecall 1800 777 175
Living Well with MND

What is it?

Living Well with MND is an informative day for people living with Motor Neurone Disease, their friends and family. You will be provided with a range of strategies to live well with MND and to maintain independence. You will also have your opportunity to have your questions answered by health professionals with expertise in MND, and to meet others who understand what it is like to live 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 a range of topics as well as meeting others in the MND SA community.

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

This workshop is very beneficial for all people living with MND, whether it is the person with MND, their carer or family etc. This session only runs three times per year. The next workshop will run on Wednesday the 17th of April 2019 at the Thebarton Community Centre. It is imperative that if book your place by contacting MND SA. There is no cost to attend the workshop.

To book your place please contact

MND SA via email on: admin@mndsa.org.au or phone (08) 8234 8448 or freecall 1800 777 175.
MND Massage Workshop

The MND Massage workshop is a wonderful group, that usually have many smiles and sleepy eyes.

So what kind of workshop is it anyway?

A practical workshop to teach participants basic seated and foot massage techniques, along with practical ideas on looking after yourself while performing the role of primary carer.

Who should attend?

The MND and Massage workshop is for anyone wishing to attend, but is most suited for people with MND and their carers. It is preferred that two people book together, so the carer can learn and practise the techniques on their loved one. Attendance is free, but bookings are essential.

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

- The importance of posture
- Stretching at home
- Self-care
- Simple tense and relax exercises
- Diaphragmic breathing and relaxation
- Basis seated massage
- Basic foot massage

If you, the carer wants to learn some basic massage techniques that you can use on Your loved one, then this is for you. Also, it will include some fortification techniques for improving tolerance and endurance for both of you.

This workshop only runs twice per year and the next one will run on Wednesday the 21st of August 2019 at the Brompton Community Centre – 19 on Green Street at 10am. It is imperative that if book your place by contacting MND SA asap. There is no cost to attend the workshop. Remember that this is a two-person workshop, so remember to bring your loved on (or significant other) to massage.
MND SA’s Patron and Ambassadors

Patron
Rosa Matto

Ambassadors
Derrick McManus
Brad Ebert
Mitch Grigg

MND SA’s Regular Supporters

A big THANK YOU to all our regular sponsors
MND SA’s Current Sponsors

A big THANK YOU to all our current sponsors

SA Skydiving

QBE

Vili’s Family Bakery

Storage King

Instinctive Driving

Haycom

Vitality Brands Worldwide

Good for you, good for our planet.
We need volunteers for our Sausage Sizzles!
The dates for this year are:

- Sunday April 7
- Sunday August 11
- Sunday April 14
- Sunday October 13

- Sunday June 2
- Sunday December 8
- Sunday June 9
- Sunday December 15

2 Shifts
9am-12.30 or 12.30 – 3.30pm
(minimum 4 people per shift is our recommendation)

Please contact MND SA 08 8234 8448
to book in a date and shift.

These days are loads of fun & if you want to bring along cupcakes/slices etc to sell you are more than welcome!

MND SA NIGHT OF NIGHTS

Glitz & Glamour Gala Dinner
Limited VIP tickets
Amazing Silent Auction items
Live entertainment

MND SA Gala Evening
Friday 2nd August 2019
Festival Function Centre, Findon

Bookings open from April 1st 2019

SAVE THE DATE
Walk to D-Feet symbolises the hope that one day we will defeat this dreadful disease whilst serving as a memorial to those we have lost.

Meet at the Jimmy Watson Reserve directly in front of the Stamford Grand Glenelg

EARLY BIRD REGISTRATIONS AND T-SHIRT ORDERS CLOSE APRIL 5TH, 2019

DON’T MISS OUT—REGISTER NOW!