



In this edition

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A Message from the CEO

One of our aims this year is to provide you with more timely access to information and updates. It is pleasing that, in this March edition of our *e-news*, we are able to include information that might previously not have been provided because of the print deadlines and production constraints imposed upon us by our 'old' print newsletter *Forum*.

I would particularly like to draw your attention to the Invitation to members, families and supporters in the ACT or visiting Canberra on 22 March on page 3. This is a great opportunity for you to speak with parliamentarians about living with MND, or for you to mention to your local member that the event is on and that they should consider attending.

Raising awareness about MND is a continuous undertaking and we thank our supporters for their participation in the very successful Illawarra Walk to d'Feet MND last Sunday, 26 February. We have included some photos from this event on page 4.

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We are posting a print edition of some e-news content to members and supporters in March. Please do let us know if you no longer want to receive the print version by emailing admin@mndnsw.asn.au

Graham Opie
CEO

Scientists report progress in the search for MND biomarker

On 22 February MND researchers announced results of a study (45 controls and 54 people with MND) evaluating whether a urine test for the protein 75ECD (p75ECD) could be used for prognostic and disease progression application. The researchers, including Dr Mary-Louise Rogers from Flinders University, South Australia, found that urinary p75ECD did change over time, increasing as disease progresses and motor function declines, even for people with slowly progressive disease. You can read the full paper free online here <http://www.neurology.org/content/early/2017/02/22/WNL.00000000000003741>



Introducing... Marnie Roelink

Coordinator of Support - Central Coast

I am delighted to be joining MND NSW as Coordinator of Support on the Central Coast. My background knowledge and experience has been developed through working in the disability sector in the Hunter Valley for over eight years, where I was involved in the roll-out of National Disability Insurance Scheme (NDIS) in the Hunter Region.



I love networking with service providers and organisations and have a passion for quality of life and equality for people and families with disabilities. I really look forward to working with such a great team here at MND NSW and getting to know participants with MND and the community here on the Central Coast.

Everyone Connects - Wagga Wagga 6 March

Assistive Technology Australia (formerly Independent Living Centre of NSW) Everyone Connects - Consumer Mini-Expos are designed for people with complex communication needs and their families and include interactive stations to trial communication equipment and

computer/tablet access options such as eye-gaze, mounts, switches, apps and software. The cost is free. Register by 4 March. More info here <http://www.mndnsw.asn.au/all-events/events-other-organisations/279-everyone-connects-wagga-wagga.html>



Invitation to members, families and supporters in the ACT or visiting Canberra on 22 March

MND NSW members, families and supporters in the ACT or visiting Canberra are invited to attend a morning tea event at Parliament House

Canberra on Wednesday 22 March. On this day, the Neurological Alliance Australia (NAA) will be

conducting a special briefing for the Parliamentary Friends Group meeting of the Members of the NAA. At past briefing meetings, those with MND have used this opportunity to speak with parliamentarians about living with MND, services available and other MND-related issues of concern. Your local member might also like to know about this event. More info here <http://www.mndnsw.asn.au/blog/200-february-2017/1006-naa-2017.html>



Blair's Games Day

Hi-Reps Fitness in Rouse Hill hosted a special in-house games day to raise awareness and funds for MND NSW. The day was held in support of Hi-Reps fitness member Blair Kurtz and included games, workouts, raffles and a BBQ breakfast. Many thanks to the team at Hi-Reps Fitness and their members for raising \$2,800 to assist MND NSW continue to provide support to people with MND.



Walk to d'Feet MND Illawarra

26 February Bulli Surf Club Bulli

After heavy rain all night, we prepared ourselves for the worst, but Mother Nature was kind to us with the early morning dawning bright and dry. This was the fourth Walk to d'Feet MND held in the Illawarra and the Illawarra showed up in their hundreds, lots of smiling faces and panting puppies.

Our Walk to d'Feet MND events attract some large family groups and the Illawarra Walk was no exception, with groups of 25 and 30 people there to show their support for people living with MND, or to remember a loved one who has died from MND.

Thank you to everyone who participated and made this another great day. A special thank you also to the supporters who created an Everyday Hero page raising vital funds to support the work of the Association. Big thanks to our local coordinator Shelley-Anne Demirov who worked so hard to bring this day together and last but certainly not least a very special thank you to our sponsors: Bulli Surf Club, Team Flex,

Skydive Australia I.98FM, Snap Printing, Xpresso Mobile Cafe and the wonderful crew from Woonona Lions Club. We can't wait for next year's Walk. You can view more pictures from the day on the MND NSW Facebook page. <http://fb.me/mndnsw>

Thank you to our Walk to d'Feet MND Illawarra event sponsors



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Save the date

Join us at a 2017 Walk to d'Feet MND. The name of this event reflects the hope and inspiration these special days provide for the MND Community. Teams made up of family, friends, colleagues and individuals, regardless of age or fitness levels, walk to raise funds and awareness for research and support for people living with MND.

26
Mar

Walk to d'Feet MND Hunter

Thomas Halton Park
Croudace Bay

Supported by



We Serve

Register now

30
Apr

Walk to d'Feet MND Forbes

Lions Park
Forbes

Supported by



We Serve

Register now

21
May

Walk to d'Feet MND Tweed Heads

Chris Cunningham Park, Tweed Heads

25
June

Walk to d'Feet MND Canberra

Patrick White Lawns, Parkes, ACT

17
Sep

Walk to d'Feet MND Port Macquarie

Westport Park, Port Macquarie *Supported by*



22
Oct

Walk to d'Feet MND Wagga Wagga

Apex Park, Wagga Wagga *Supported by*



Les Gray Plumbing

5
Nov

Walk to d'Feet MND Sydney *Supported by*

Blaxland Riverside Park, Olympic Park Homebush



For more information see <http://www.mndnsw.asn.au/get-involved/walk-to-dfeet-mnd.html>.

Casino High School

Students at Casino High School enjoyed some end of year fun to raise money and awareness for MND, and soak some teachers in the process! An Ice Bucket Challenge was held which raised \$911. Thank you to the staff and students.

Rock to River Row

Last September the inaugural Rock to River Row raised \$2,500 in support of MND NSW. Over five days the team of Jeff Huyben, Stuart Ord, Adam Thompson and Brett Wheeler rowed 500 kms on rowing machines in locations from Uluru to Alice Springs. We thank the team for their stellar effort and support.



Illawarra Combined Seniors Dance Groups

After nine years of holding dances to raise awareness and funds for MND NSW the Illawarra Combined Seniors Dance Group held their last dance in 2016, and donated \$900 from this event. Thank you to Betty Davies who has been organising these fundraising events since 2008.

Carers NSW NDIS e-Newsletter

The Carers NSW NDIS Update is a monthly e-newsletter designed to help carers keep up to date with developments in the National Disability Insurance Scheme (NDIS). Click here to subscribe <http://eepurl.com/bbzL6X>



We appreciate your efforts

Thank you to the following supporters.

- Wendy Whitmore and the Central Coast Fundraising Group who raised \$1,047 from their Christmas Gift Wrapping fundraiser.
- Warners Bay High School, Year 12, 2017 who donated \$500.
- Victoria Haberley who donated \$2,600 from a carnival dunking booth and a comedy night.

Don't miss out! Ticket sales in the ASX Thomson Reuters Charity Foundation Art Union 2017 closing Monday 6 March

All proceeds from the ASX Thomson Reuters Art Union tickets go towards supporting ASX Thomson Reuters benefiting charities, including MND NSW. Don't miss out on these great prizes.

1st Prize: New Lexus RX200T valued at \$80,449 ,

2nd Prize: South Sea Cultured Pearl and Diamond Earrings valued at \$8,437, 3rd Prize: Discovery Murray River Cruise valued at \$2,524

Tickets are \$20 each or three for \$50 at <http://winasx.com/5>. The Art Union will be drawn on 16 March 2017.



Annual Kemsley Cricket Match

The annual Kemsley Cricket Match was played at Chevalier College in November raising \$1,050 for MND NSW. Thank you to Helen Kemsley and the keen cricketers who continue to participate in this event!

Regional NSW NDIS Information Sessions

Every Australian Counts team will be hitting the road presenting free NDIS information forums in NSW regional areas where the NDIS will be rolling out from July. Dates: Casino 8 March, Grafton 9 March, Coffs Harbour 14 March, Port

Macquarie 15 March, Wagga Wagga 23 March, Orange 5 April, Dubbo 6 April, Nowra 2 May, Wollongong 3 May, Albury 9 May, Broken Hill 16 May. More info here <http://www.everyaustraliancounts.com.au/information-forums/>



NDIS Information Sessions are also conducted by the Government in various areas of NSW, ACT and the NT. Upcoming sessions are scheduled for Tumbarumba 1 March, Junee 1 March, Tumut 2 March, Kogarah 6 March, Corrimal 17 March, Hillston 22 March, Waverley 13 April, Gundagai 2 March and various dates in Darwin. More info here <http://www.mndnsw.asn.au/about-mnd/gov/156-ndis.html>

Exploring medical decision-making

Researchers from Queensland University of Technology are seeking participation of adults with terminal illness and their family members in a study exploring medical decision-making. Participation involves taking part in a face-to-face, telephone or Skype interview (around an hour). More info here <http://www.mndnsw.asn.au/blog/200-february-2017/998-exploring-medical-decision-making.html>



MND Week
7-13 May 2017

What will you do to raise awareness
this MND Week
Blue Cornflower Day Friday 12 May
is the perfect day for your event

Email fundraising@mndnsw.asn.au
or call 8877 0999 to discuss your plans

The graphic features a central blue starburst shape containing the text. The background is white with a repeating pattern of the MND logo (a blue flower) and the text 'mnd New South Wales'.

Upcoming Support Service events

Click to find out more.

21
Mar

Supporting NDIS participants Living with MND - Northern Sydney for allied health professionals and care workers
Forestville

27
Mar

Past carers lunch
Gladesville

4
Apr

Information Evening for people recently diagnosed with MND
Gladesville

6
May

Day of Hope and Remembrance
Homebush

10
May

Supporting NDIS participants Living with MND - South West Sydney for allied health professionals and care workers
Bossley Park

16
May

Care for Carers
Gladesville

18
May

Living Well with MND
Forbes

8
June

Supporting NDIS participants Living with MND - Western Sydney/Blue Mountains for allied health professionals and care workers
Springwood

13
June

Information Evening for people recently diagnosed with MND
Gladesville

See <http://www.mndnsw.asn.au/all-events.html> for all 2017 events.

Our new keyrings have arrived!

Have a look at our great new keyrings. They have a very bright LED flashlight. Not only do they look great but they come in very handy. Order yours today. <https://www.online.mndnsw.asn.au/products/led-flashlight-key-ring>



Grace's Shave

What an inspiring way to make a difference! Grace is a beautiful young lady who decided to shave her head to help create awareness for MND. Alison, Grace's mother, said, "My beautiful best friend has been hit with this disease so my amazing daughter Grace will shave her head to raise awareness." Thank you Grace and Alison for your support.



ATSA Independent Living Expo at Sydney Olympic Park 10-11 May

The ATSA Independent Living Expo will have over 100 exhibitors displaying products and services in assistive technology, mobility solutions, pressure care, accessible recreation/holiday ideas, modified motor vehicles and more. A key feature of the Expo is the free Conference Program

<http://www.mndnsw.asn.au/blog/200-february-2017/1011-atsa-independent-living-expo-at-sydney-olympic-park.html>



Save the date Saturday 6 May 2017 Day of Hope and Remembrance

This is an afternoon of hope and remembrance for all those whose lives have been touched by motor neurone disease. More information here <http://www.mndnsw.asn.au/all-events/living-with-mnd/181-day-of-hope-and-remembrance-2017.html>.



Upcoming community fundraising events

Click to find out more.

Date	Event
8 Mar	Carnarvon Ladies Charity Golf Day Carnarvon Golf Club - Lidcombe
2 Apr	Sweat for MND Rofe Park - Hornsby Heights
1 May	Trek Together for MND NSW Peru
6 May	Run MND Sutherland 2 Surf
7 May	MND Week 7-13 May Various across NSW and ACT
7 Oct	MND Awareness Trivia Night Cooma Ex-Services Club
14 Oct	Gundaroo Music Festival Gundaroo Park
12 Nov	Illawarra Chilli Festival Illawarra
25 Nov	Craft Market Greystanes Our Lady Queen of Peace Parish, Greystanes

Do you have a great idea for an event or activity that will raise funds for motor neurone disease care, support and research? Read here about how to get involved <http://www.mndnsw.asn.au/get-involved/fundraise.html>

MND NSW NDIS Workshop for Central Coast service providers a great success

MND NSW is holding a series of workshops this year for allied health staff (occupational therapists, speech pathologists, dietitians and physios) who work with people with MND who are under 65 and have an NDIS (National Disability Insurance Scheme) plan. The first of these was



held on Thursday 9 February on the Central Coast. We had a great turn-out with about 20 allied health professionals attending, with the majority of those attending working as solo private practitioners. They wanted to know more about MND, working in a multidisciplinary way as a solo practitioner and 'MND and the NDIS'.

There was a lot of discussion around the adequacy of NDIS plans people with MND have had approved. Observations were that equipment wasn't factored into the plan, or minimal therapy support hours were offered and the plans did not account for the changing and increasing need for services and support for people with a progressive degenerative condition such as MND. We also covered the role of the MND NSW NDIS Coordinator of Support, a new service that people with MND can access (depending on where they live). Our Coordinator of Support works with the NDIS participant to ensure the plan runs smoothly, identify gaps in service provision, find other services that can assist, address plan issues and negotiate changes that may need to be made with the plan.

We will be holding further workshops in Northern Sydney, South West Sydney and the Blue Mountains for NDIS service providers in March, May and June. The aim is for allied health, care providers and MND NSW to work towards ensuring that people with MND who are eligible for the NDIS have plans that provide the funding for the supports they need to live better for longer. You may like to mention these workshops to your services providers <http://www.mndnsw.asn.au/all-events/health-and-community-care-professional-events.html>

How do I live well with MND?

By Duncan Bayly

Address to the 8th National MND Conference, Melbourne, Victoria. 12 September 2016.

Foreword: Look, I know the punctuation, spelling and other typological niceties aren't right. It's an artefact of using a speech synthesiser that you have to fiddle with these things to get it sounding natural. For instance, I happen to be fully



aware my wife's name is spelled Kat, but unless it's spelled Cat, the program mangles it into something like Kaht. Some of the jokes fall flat too. I blame that on not being able to place the stress or emphasis on the right word or syllable. I refuse to accept that it is because they're not funny.

Many people approached me after the talk to ask why I use a female voice. The machine speaks for me, not as me. I don't want its voice mistaken for mine. As anyone who met me earlier in my life could tell you, I was truly in love with the sound of my own voice. For authentic reproduction, install eTriloquist (www.etriloquist.com) and select the voice Zira. Enjoy! db

It feels very odd to be writing a speech about living well with MND. I am very conscious that the support available to me is not available to everyone. I am also aware that the shock of an MND diagnosis, followed by its generally rapid progression, leaves many people spinning as they lurch from one crisis to another.

I have been let's say, "fortunate" enough to have had MND for nine years, instead of the average two. While I am grateful MND didn't

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claim me seven years ago, I am often in uncharted territory, I didn't expect to make it to 32, and now I'm pushing 40. I have been living year to year, and as I surprise myself with my longevity, I've grown concerned with how long has passed and how I have spent it. I don't want to feel like I've been waiting to die.

Of course, when I was first diagnosed, I immediately tackled a bucket list trip to India, Japan the United States and Canada. I spent six months mooching off friends in London and Amsterdam, until my money started running out, and then I managed to work for another six months. Along with my wife Cat and my friends, I organised two Rides For MND between Amsterdam and London. On the first, I dragged my dad along. On the second, my brother had to drag me along literally! On the back of our tandem bike I would start daydreaming, and had to be shouted at until I started pedalling again! With both rides combined, plus companion events held by friends in New Zealand, Vancouver and here in Melbourne, we raised about 150 thousand dollars for MND Associations around the world. Apart from my wedding day, they are some of the proudest and happiest days of my life.

After I returned to Melbourne, and Cat had joined me, we started to try to establish a life here. Our goal above all else, was a form of normality. We expected MND to be a heavy feature in our lives, but we didn't want to let it stop us from travelling, from entertaining friends and from doing the things we enjoyed, like going to the cinema. Starting out with this mindset; that MND is just a feature, has given us the strength to prioritise how we want to live our lives, rather than have MND dictate it to us. Cat was my only carer for our first two years in Melbourne, but she was keen to continue her career. It is critical to Cat that she keep her skills fresh, and her work has been a form of respite for her, as well as a means of making new friends in a foreign country. However I'm ashamed to admit I didn't

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handle it well at the beginning. In fact, one afternoon, I ran away from home! Ridiculous behaviour for a 33 year old! The last time I'd run away from home, I must have been four, and my parents had found me at the milk bar down the road, trying to buy lollies with leaves!

In order to maintain a normal life, we lean heavily on all the support we can. From the State of Victoria and Merri Health we get funding for Carers who enable Cat to go to work and for me to visit my university for meetings. The Allied Health and Neurology teams at Bethlehem and Merri Health give me critical advice on everything from symptom management to keeping me fed and crucially, able to communicate. MND Victoria provide equipment and advice that are essential for keeping me mobile and of course, my Carers who keep me comfortable and facilitate the work I do.

I have a team of dozens of experts behind me who listen to my problems and translate them to solutions. And I must highlight the immense amounts of support from the family and friends whose loyalty and patience I treasure. So any success I have had since my diagnosis is due to the people and institutions around me.

The Companion Card makes a huge difference to our lives and living them well. Getting half-price tickets to shows movies and events reduces the financial friction of going out and getting involved in Melbourne. It's appreciated because there are so many other frictions to just get me dressed and out the door. A highlight was getting to attend the Australian Open mens and womens finals this year. The same goes for the half-price taxi program which we regularly use and have even used during trips to Sydney and Queensland.

The brief message here, is to take advantage of all the available supports you can. If you can't find a support you think should be there, ask around. Often they are not well advertised.

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Of course, the point of these supports is to provide you with the independence you need to achieve your goals, even a fundamental goal like staying at home around your loved ones and friends. I cannot think of a better or more commendable goal for those with MND, provided you have the support and equipment available to make it safe.

My goal has been to be as independent as possible, but paradoxically, that means accepting an awful lot of help, from being pushed in my wheelchair to having documents and letters scanned into my computer so I can read them at my own pace and leisure. The key is to be ruthlessly outcomes-focussed. What matters most is THAT something gets done, not in how it gets done.

That can take an awful lot of adapting to, especially when you are a particular person like me. But remember that the people around you are doing their best, and trust in them to see things done properly, because the energy expended to get things done in what you know as the right way, might not be worth it. Anyway, those who know me will realise I have a long way to go before I can be seen to be taking my own advice in this regard.

Of course, the most critical goal for many people living with MND, and the key to reaching further goals, is the ability to communicate itself. As our speech slurs until even those closest to us can no longer comprehend us, technology that enables us to fully describe our emotions, thoughts and desires is so very critical to our being involved in the world around us. I remember when my grip on speech loosened, I felt myself gradually but surely disengaging with the social world around me. It's a burden to memorise all the things you want to say and when you have an opportunity to communicate, to triage what you want to say according to the urgency of the request, your energy levels, and the patience and attention of your audience.

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That's why the eyegaze has made such a difference to my life and those close to me. The ability to express myself fully, clearly and easily gives me an indispensable lifeline to those around me. The fact it's mobile lets me engage with people out of the home. This lets me and Cat venture out beyond our house, which is essential to our sanity and expands the group of people I can interact with.

That I have been supported in my goals naturally keeps my eyes open for opportunities to give back. This doesn't need to be grand. In fact, it should start with those nearest to you. It is important that they know how much their efforts mean to you. It's also important that primary carers get a break so they aren't completely exhausted. It can be a stifling isolating job and they need time to recharge and to pursue their own goals.

Sometimes the best way to honour those around you is to be the best person you can be. How you choose to do this is naturally up to you. It may be very simple, but your efforts do not go unnoticed, and provide validation for those who work so hard to keep us comfortable.

If I had to sum up the experience of living with MND in one word, it would be frustration. Frustration at losing the ability to be independent. Frustration as your loved ones struggle to come to grips with your condition and its impact on their lives hopes and dreams.

I've found the only thing that trumps frustration is patience. And initially, when I was given two years to live, I can't say I had a lot of it. But generally I think I am a patient person. That's what a degree in mathematics taught me, although perhaps it's more properly characterised as perseverance. With patience, I can wait out the frustration as those around me do their best to understand my needs and provide them.

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As for the more existential frustration, there is not much to be done but accept it, and accept the grace that provides whatever help it can. I don't like the sacrifices people make for me, but all I can do is to be the best person I can be.

Of course, it's difficult to cultivate patience and everyone certainly has a limited reserve. The primary thing is to have perspective. A LOT of perspective. A very very LONG distance perspective on your problems. No matter how hard things get, there are still many people out there I would never swap places with. Imagine having MND at any other time in history!

In my nine-year experience with MND, I've seen giant strides in the advancement of the available technology, equipment and advice, all of which have given Cat and I a greater quality of life than we'd imagined.

I wouldn't go so far as to paraphrase the Prime Minister, "There's never been a more exciting time to have MND", but there have certainly been worse times.

So for me living well with MND is a bit like the themes to this conference. Take full advantage of the care and supports available to you. Collaborate and communicate with those supports to build a platform on which you can achieve your goals. Enjoy the conference and I hope you all come away with fresh thinking and renewed energy to assist us all in living well with MND. We aren't so much leaning on the support you all provide. We're standing on the shoulders of giants.

Duncan Bayly

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Report on the Allied Professionals Forum (APF), Dublin 2016

Each year the Allied Professionals Forum (APF) is held the day before the ALS/MND International Symposium. The APF is for allied health professionals from across the globe to come together to share, hear and reflect on how to better support people living with MND at the practical level. In December 2016 there were 16 presentations and over 250 attendees. Gina Svolos, Manager Support Services, and Kristina Dodds, Education and Carer Support Program Coordinator, were very fortunate to be able to attend and represent MND NSW. Kristina was one of the presenters and here is their report.

The first session of the day covered the latest innovations on message and voice banking for people with MND and communication technology. First up was the announcement of the winner of the Prize4Life – the ALS Assistive Technology Challenge. There were two winners who shared the US\$400,000 prize for the further



development of their communication systems. The Challenge attracted 87 groups from 16 countries around the world to submit ALS assistive communication solutions. One of the winners, the EEG-based brain-computer interface Donders Noisetag, allows paralysed patients to communicate with mental activity alone. The other joint winner, the EMG communication and control device Pison Technology is aimed at allowing a person with little or no movement to have full control of a laptop, a phone and home robotics 24/7.

Next up was Lesley Doyle, from Trinity College Dublin, who spoke on message banking and the impact on quality of life for people with MND. She defined message banking as 'the intervention whereby patients with progressive conditions, record phrases that can later be used on electronic communication devices'. Her research



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is in the early stages, but preliminary data shows that message banking is clearly meaningful to patients, as said by one research participant, "... to have your voice instead of using a machine and someone speaking.... it makes it more comforting and it makes you feel like you are still in charge a little bit."

John Costello from Boston's Children's Hospital spoke on message banking vs voice banking. He defined voice banking as the 'process of recording a large inventory of speech that is then used to create a synthetic voice that approximates your natural voice'. Interestingly he also referred to message banking by proxy, where someone such as a sibling, or someone who has a similar voice can do recordings, including legacy recordings, on behalf of the person. He then went through the technology and process involved in recording and storage. The aim is that the person 'message banks' throughout the day using a portable recording device and in his experience it takes an average of four months. 47 people have done this and banked from 122 to 3075 messages each. John spoke of a web portal to upload audio files available free of charge <https://www.tobiidynavox.com/en-GB/support--training/>



Louise Rickenbach, an advisor for the MND

Association UK spoke on the development of a voice banking volunteer on her 'patch', as there is a lack of early access to speech pathology at a time when it is ideal to carry out recordings. Her take-home points included: 1. teams supporting people with MND should discuss opportunities like voice banking early, 2. extra support may be needed for some people to engage with technology and 3. trained volunteers could assist.

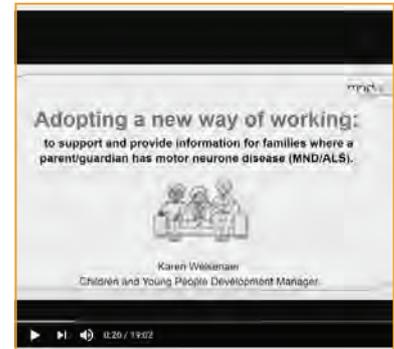
The presentations in the second session were themed around supporting the primary carer. Ronald Hoffman from Compassionate

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Care ALS gave a very powerful presentation using only photographs of people living with ALS and their carers. Using these images he highlighted how carers often need their own specific kind of support, particularly around end of life situations.

Karen Welsenaer from MND UK, spoke about children and young people who have a parent with MND and the 'whole family' approach of the Association. If given early support, children and young people were less likely to develop future emotional trauma.



Mary O'Brien, also from MND UK talked of supporting carers by monitoring changes in the caring role through the Carers' Alert Thermometer (CAT). The CAT asks ten questions in conjunction with a 'traffic light' system that indicates the level of need for each alert and current support available. This can assist during further discussion and problem solving with non-specialist health staff. And finally, Birgit Hovamnd from Denmark, presented her work in supporting carers of people with fronto-temporal dementia and MND.



The first two presentations after lunch discussed research into swallowing issues in MND and people's perceptions of this. Dominika Lisiecka a PHD candidate from University College Cork reported on her research finding that people with MND who have dysphasia (swallowing problems) approach it differently to how their carer approaches dysphasia. She commented that for many people with MND, dysphasia changed the meaning of food for them and that the overarching theme that came out of the research was that people with MND live in the 'here and now'. For carers however, the focus was on safety – excluding food that might cause coughing, changing

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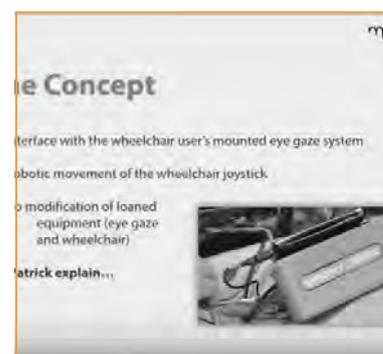
how food is prepared, the need for constant supervision and that feeding tubes were seen as a life prolonging option.

There was an interesting paper by Colin Pearson who works for MND UK. He developed a program called First Contact Group in partnership with the local palliative care service to help introduce people to the valuable support that can be offered by the local hospice. The aim was to encourage people to engage with palliative care



as early as possible to improve ongoing care management, symptom control and quality of life. They offered a drop-in session for people with MND to receive complementary therapies while utilising the hospice service for support from nursing service and other beneficial advice. It was a very successful program and one that is now being replicated in other hospices as it helped to break down the misconception and stigma attached to hospices - that they are just 'places to die'.

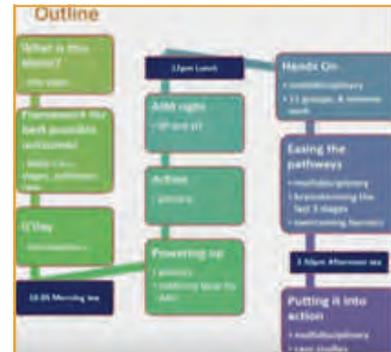
The final session of the day focused on the development of technologies and creative approaches to using technologies. The Eyedrivo was featured and this is a device that allows users to control an electric wheelchair, using only their eyes. Developed by Patrick Joyce and Steve Evans, who both have MND, Eyedrivo is an open (free) project and you can make your own system. Anyone may download, modify, distribute, use or sell – any part of the project. It will be interesting to see how this develops. It doesn't stop the need for a carer to be present but it was described as liberating by the users. More info at <https://www.eyedrivo.org/>.



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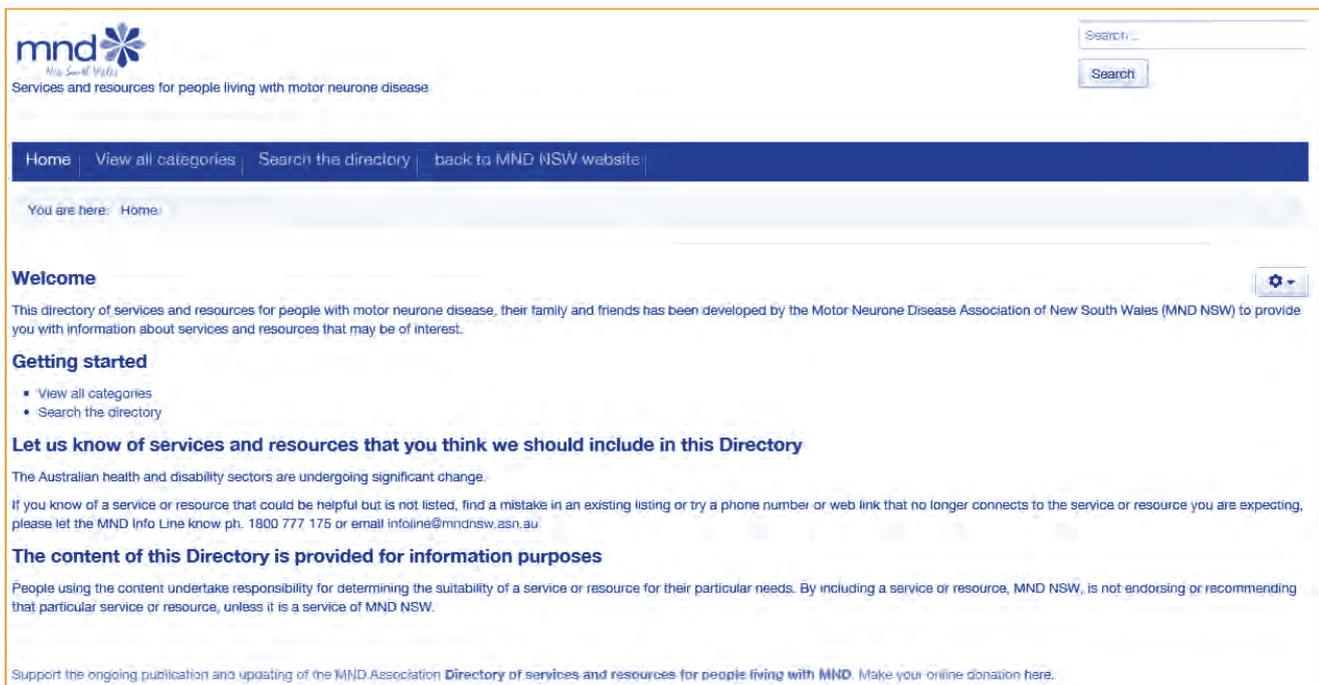
The final presentation was by MND NSW and presented by Kristina Dodds. It reported on a one-day CommSPOT training program conducted for occupational therapists and speech pathologists to develop their confidence with prescribing and assessing people with MND for assistive technology for communication. It was a highly rated workshop and was successful in it's aim of improving confidence of these therapists.



To view these and other presentations given on the day see the MND NSW playlist on YouTube at <https://www.youtube.com/playlist?list=PLKmXsG38R4V-UFW1ocUXL0kODVUxJxsBn>

Are you looking for a service or resource?

Visit the online MND NSW Services and Resources Directory and have a look around. <http://mnd.mndnsw.asn.au>



mnd
New South Wales
Services and resources for people living with motor neurone disease

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You are here: Home

Welcome

This directory of services and resources for people with motor neurone disease, their family and friends has been developed by the Motor Neurone Disease Association of New South Wales (MND NSW) to provide you with information about services and resources that may be of interest.

Getting started

- View all categories
- Search the directory

Let us know of services and resources that you think we should include in this Directory

The Australian health and disability sectors are undergoing significant change. If you know of a service or resource that could be helpful but is not listed, find a mistake in an existing listing or try a phone number or web link that no longer connects to the service or resource you are expecting, please let the MND Info Line know ph. 1800 777 175 or email infoline@mndnsw.asn.au

The content of this Directory is provided for information purposes

People using the content undertake responsibility for determining the suitability of a service or resource for their particular needs. By including a service or resource, MND NSW, is not endorsing or recommending that particular service or resource, unless it is a service of MND NSW.

Support the ongoing publication and updating of the MND Association Directory of services and resources for people living with MND. Make your online donation here.



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volunteers**