



## A Message from the CEO

As we look back on the past year, the idea of isolation is one that pervades everything in current times. And while it's strange for us all to be living through a time where social distancing is at the forefront of everything we do, it's also a reminder of the isolation people with MND often experience as a fact of everyday life.

While it's been challenging to transform the services we offer into ones that are contact free, MND NSW has aimed to expand the ways we support, communicate and engage with the MND community. These innovations have been adopted not only to cope with the current circumstances, but to strengthen and broaden our organisation for the future. It's only fitting then, that we take this opportunity to revisit the cornerstones of what makes MND NSW the organisation we are—the services, support networks and events that enhance the lives of people with MND and those who love and care for them.

To highlight each aspect of our organisation we're drawing from the words of our community members, particularly those who were involved in our virtual celebrations for MND Week and who sent in photos and quotes about their experiences. You can see these quotes in videos at:

<https://www.youtube.com/user/mndnsw/videos>. I'd like to begin by sharing the following words from Chad Tippapart.

**'Thanks for everything and everyone at MND NSW who are dedicating their hearts and minds to help me and the other MND friends to survive with hope and dignity. Our lives would have been so sad and lost without your help.'**

To everyone who has lost someone to motor neurone disease, everyone at MND NSW and the members of our board offer you our deepest sympathies. We again pledge our commitment to improving the lives of people with MND, their families and carers until we can find a cure for this debilitating disease.

Graham Opie  
MND NSW CEO

# FLEXEQUIP



MND WEEK 2020

My Mum Sandra sadly lost her battle to this cruel disease on the 20th March this year. I miss her everyday and wish she was still here with me and my family! Without MND NSW we wouldn't have gotten through this. We thank you! I hope that one day a cure will be found for this heartbreaking disease!

- Kate Hanna



MND WEEK 2020

Annual events like MND week are temporal markers of our personal and collective journeys with MND, reasons for celebration and grief. My family cherishes the annual chance for our MND community to gather, looking forward with hope and backwards in remembrance. And it provides a focus for awareness- and fund-raising within the wider community

- Kirsten Harley



MND WEEK 2020

Thanks for everything and everyone at MND NSW who are dedicating their hearts & and minds to help me and the other MND friends to survive with hope and dignity. Our lives would have been so sad and lost without your help.

—Chad Tippapart



One of the core pillars of MND NSW, FlexEquip allows people with MND to access life-altering equipment from our library at no cost to them or their families. In our current climate, this access seems more important than ever, allowing people with MND to stay connected to their loved ones and their community. Whether it be an iPad to help with communication or something as simple as a raiser recliner armchair to be able to sit comfortably and be part of household life.

**'Thank you so much for this wonderful service,' Liz said. 'Without this equipment being delivered to me when I need it, there's no way I would be able to stay at home, which is the only place I want to be.'**

In the past year we've provided 1613 pieces of equipment to 342 people. In addition, we've made changes to the service to ensure both the safety of everyone involved as well as ensuring people are getting what they need when they need it so they can retain as much of their independence as they can, for as long as they can.

**'My family would like to thank MND NSW for the support with supplying equipment for mum when needed... Mum was a community minded person who supported and fundraised for many years and loved to be a part of any team sport, Mum was part of many pockets of her local community and is sadly missed by all. Until there is a cure there is care and I was honoured to be your carer, Mum, loved and remembered forever'** —Sharon Rushworth

## EDUCATION & SUPPORT

While 2019 saw us able to deliver face to face education and support sessions, in 2020 our support groups, education and carer programs went online. While we miss seeing people face to face, adapting to this new environment has opened up exciting possibilities—extending the reach of our programs and allowing people to access information packages on demand.

Since July 1 2019 we have held 38 face to face support groups, with a total of 439 attendees. We have also held 4 online support groups with 25 attendees. There have also been 11 online carer support groups. There are two programs available on demand via our online education hub while our biggest event for the year, Ask the Experts was hosted live, streaming on Facebook and YouTube.

One young carer, Naomi, who has been attending our online support group for carers told us:

**'I really appreciate being a part of this group. It has allowed me to feel a sense of empathy and shared experience with other young adult carers. I don't have many peers who have dealt with this situation and especially not this condition; so it has been invaluable to**





MIND WEEK 2020

Wednesday the 6th of May marks 5 years since we lost our beautiful mumma, diagnosed in late 2012, she put up one hell of a fight and kept her bubbly personality right through until the end. We miss her dearly, but are so grateful to have spent many years of laughter and love that will never be forgotten.

—Jordan McKenzie

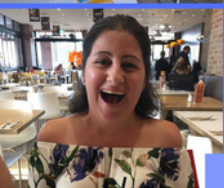
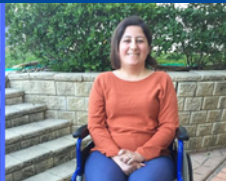


**listen to others experiences. Sometimes someone in the group will articulate what I haven't yet been able to. I appreciate gaining insight as to what may be up ahead and this brings me comfort. Overall it makes the path less scary, lonely and uncertain knowing other people who are also walking along it. It also reminds me that there are joyful moments to be had along the way.'**

## INFOLINE

With everything going on our info line has been busier than ever. This year we've had 11,711 contacts as compared with last year's 9706 contacts. It shows how important InfoLine really is, especially when the experiences of people touched by MND are compounded by the situation we are now living in.

**'It's so traumatic to lose a loved one to MND. The help we had from MND NSW for our mum, assisting with aids in her final days and helping us to understand what was happening as it all happened so quickly that we couldn't keep up, was so appreciated. MND affects patients in different ways and at varying speeds and our mum didn't have much time before it took her from us. I will never forget the help and support that you provided.'** —Kim Leckey



MIND WEEK 2020

My gorgeous sister Nahrain Toma gained her angel wings this year on the 22nd of February, aged 37. She touched so many people and despite her illness, we had so much fun and met so many lovely people. She is sorely missed by everyone. I can not wait for the day when there is a cure and nobody has to face this horrid disease. Thank you MND NSW for all the support along the way.'

—Nineveh Youkhanna



## VIRTUAL FUNDRAISING

Our Walk to d'Feet MND event that took place in Sydney in November 2019 was the last face to face fundraising event we held where we were all able to get together in person. Since then, we know the MND community are missing our events (so are we) and so we've launched a range of virtual fundraisers.

While people may have been feeling isolated, by joining in, our community has come together to support each other. This included our MND Week online celebrations where people sent in their stories and photos to show their experiences with MND. We were overwhelmed by the amazing response and it took us months to post all these incredible stories. During this time we also launched our online fundraising platform **mndblue.org.au** which includes a personal challenge platform, an in memory platform, our cornflower blue platform (where you can plant a virtual cornflower for someone you love) and our Walk to d'Feet platform—now including a Virtual Walk to d'Feet to take place on Sunday 18th October. If we can't be together physically, we can still share an amazing community experience.



MIND WEEK 2020

My father and best friend David Robinson passed away on 24 April 2016 from this monster disease at just 59 years of age. The pain and impact of his loss on myself and my family is incalculable. Thank you so much MND NSW for the incredible work that you do everyday in raising awareness and funds for a cure, not all heroes wear capes.

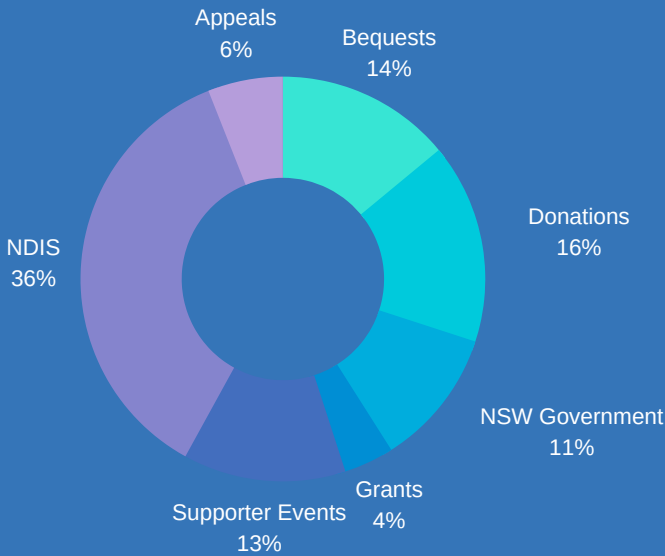
—Belinda Robinson



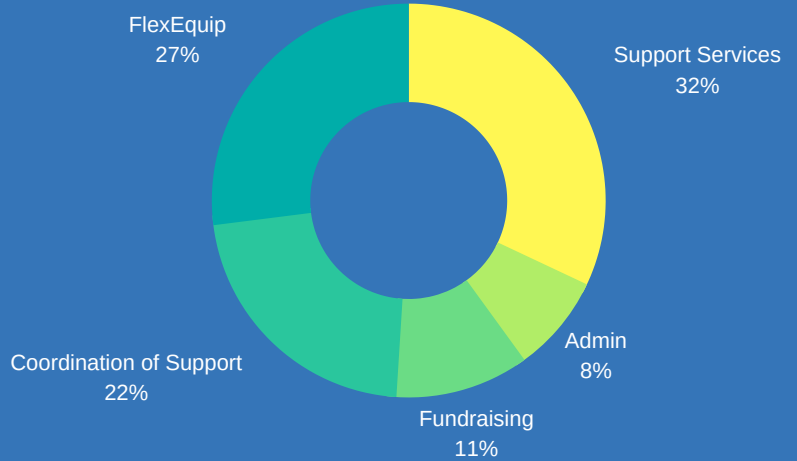
**'To me and my family Walk to d'Feet is a way of honouring a husband and father. People living with MND are such brave, amazing people, and we need to do all we can to help find a cure and support the wonderful people who provide vital resources to help those living with MND'** —Pat O'Hara

# THE IMPORTANCE OF YOUR SUPPORT

## Income



## Expenditure



## WE NEED YOUR SUPPORT!

We're not exaggerating when we say that we couldn't do what we do without the support of our donors and fundraisers. This is especially true as we face the current situation with COVID-19 placing more stress on families affected by MND and in turn, increasing the pressure on our services due to greater demand. If you would like to support people with MND and their families please consider becoming a (virtual) community fundraiser, a volunteer, a public awareness ambassador or make a life enhancing donation.



Title: Mr / Mrs / Miss / Ms /Dr

Name: .....

Address: .....

Suburb: ..... State: ..... Post Code: .....

Phone: ..... Mobile: .....

Email: .....

**Amount:**

**\$10   \$20   \$50   \$100   Other (please specify) \$.....**

Name on Card: .....

Card No: \_\_\_\_\_

Expiry: \_\_\_\_ / \_\_\_\_

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