



ANNUAL REVIEW 2019



Until there is a cure, there is care

WHAT WE STAND FOR...

OUR MISSION

MND Victoria's Mission is to provide and promote the best possible care and support for people living with MND.

"People living with MND" includes people who have been diagnosed, those yet to be diagnosed, carers, former carers, families, friends, workmates and any other person whose life is, or has been, affected by a diagnosis of MND.

CORE VALUES

Our service is to people living with MND, above all else. We do not undertake anything that does not contribute, or have potential to contribute, to improving quality of life for people living with MND.

We respect and value the contribution made by each and every member of the MND community and give full consideration to their contribution.

We support, encourage and value innovation that improves opportunity and quality of outcomes. We share absolute integrity and are ethical in our practices.

OUR OBJECTIVES



To provide the best possible support for people living with MND.



To collect and share quality advice on living with MND.



To create and foster links between people living with MND by providing opportunities for interaction.



To raise awareness of MND and the needs it creates.



To develop and maintain relations with MND Associations within Australia and overseas.



To advocate, foster and maintain links that can help us achieve our mission.



To encourage and support research initiatives and disseminate knowledge of research progress.



To achieve our mission through innovation, sustainability and best practice.



"Having a wheelchair through MND Victoria really allowed me to continue enjoying things that I love, like going to the football and meeting friends and anything that allows you to live a bit more normally is wonderful"

ROBBIE, DIAGNOSED AT 34.

Front Cover Image: Robbie and his Mum

UNTIL THERE IS A CURE, THERE IS CARE

STATE COUNCIL

MND Victoria continues its focus on providing care and support for people living with MND, through the delivery of key services and linking people to other high quality providers who can meet their needs. We help people live better, for longer, throughout the disease progression.

We continue this work in a constantly changing landscape. We have seen significant changes across the last 12 months, and also across the last few years, which have impacted on both our work, and the people with MND, their families and carers whom we support.

This year has seen the finalisation of the roll out of the National Disability Insurance Scheme (NDIS). We have provided support coordination to 223 clients with NDIS plans across the year. Whilst overall support for people with MND through the NDIS is significant and an improvement on past support, the NDIS remains a constantly evolving program. Our team has worked hard to stay up to date with changes and implement the required practice, software and reporting changes, often with little notice.

Our advocacy to "Make Aged Care Fair" has continued across the year highlighting to governments the inequity of support for those diagnosed with MND under 65 and those diagnosed over 65. Long waiting lists for aged care packages mean older people with MND may never get the level of government funded support required to live as well as possible for as long as possible.

This year has also seen a change in leadership of MND Victoria with our CEO of 25 years, Rod Harris, retiring and our new CEO, Kate Johnson, taking up the reins. Rod's advocacy, innovation and commitment to supporting people living with MND and to supporting research to find better care and support, effective treatment, and ultimately a cure for MND, has made a huge impact in the sector across the last 25 years and he will be missed.

We welcome Kate to the role and look forward to the insights and further improvement a new approach will bring to the Association.

Across the 18/19 financial year our key activities have included:

- Provision of support to over 655 people with MND through the provision of MND Advisor and Support Coordination services, Assistive Technology provision, Information and Resourcing, Volunteer services and ongoing advocacy.
- Raising over 76% of the funds invested in support through fundraising and fee for service via NDIS.
- Investing over \$350,600 in research into the causes, treatments and cure for MND, including funding 43 allied health professionals and researchers to attend the 2019 International MND Allied Health Professionals Forum and Research Symposium.
- Continuing our close and collaborative work with MND Australia and the other State Associations to ensure common and best practice and goals in negotiating and influencing government practice and policy through systemic changes.
- Advocating to State and Federal government for equity of access to support, services and Assistive Technology for those over 65 and not eligible for NDIS.
- Continuing our work with NDIS which has become a significant contributor to our services as people with MND select MND Victoria as their provider of choice for coordination of support and provision of Assistive Technology.
- Completing an independent audit of the Association's services against DHHS and ISO 9001 standards and remaining an approved provider for DHHS and NDIS.
- Attendance and representation at the 2018 National MND Conference in Adelaide.
- Saying farewell to two long serving senior members of our team: Rod Harris, CEO for 25 years and Julie McConnell, Manager Support Services for 10 years.

- Welcoming our Manager, Support Services, Jo Whitehouse, and new CEO, Kate Johnson.
- Four staff have resigned and we thank Jacqui, Georgie, Hayley and Carly for their contributions. We welcome Sam, Eric and Rachel to the team.

Many thanks to our volunteers, formal and informal partners, supporters and staff without whom we would not be able to deliver the support and services that we do. We thank them for their passion, commitment and drive to deliver the best care and support for people living with MND.



David Lamperd *President*



Jeremy Urbach *Treasurer*



Kate Johnson *CEO*

State Council (as at 30th June 2019)

David Lamperd* - President
Katharine Barnett* - Vice President
Jeremy Urbach* - Treasurer
David Ali
Duncan Bayly*
Chris Beeny
Barry Gunning
Jodie-Ann Harrison Fitzgerald*
Angeline Kuek
Wayne Pfeiffer*
Chloe Williams

*Has a personal association with MND



SUPPORT SERVICES

MND Victoria's Support services focus on supporting people living with MND to live better for longer, remain active in their community and to be safe in their environment, through the provision of four key services – Information and Resources, MND Advisor and Support Coordination service, Assistive Technology and our Volunteer service.

- 209 Victorians and 16 Tasmanians newly diagnosed with MND registered with the Association for support during 2018/19.
- 200 Victorians and 20 Tasmanians have active NDIS Plans and a further 50+ are progressing through the pre-participant planning stage. The NDIS rollout has been finalised across Victoria and Tasmania as of 30 June 2019.
- Respondents to our annual client survey rated our Information and Resources, MND Advisor/Support Coordination and Equipment Service as good to excellent at 86%, 89% and 81% respectively, reinforcing the value of the Association and its services.
- We continue our work on refining iCase, our client management system (CMS) and our processes and procedures to ensure that the majority of our time is spent directly supporting our clients and that administration time is minimised. Our CMS continues to assist us in improving the information and data we can access in order to improve services for people living with MND.
- We maintain our strong relationships with service providers and networks across Victoria, Tasmania and nationally, to ensure that people living with MND receive support from well informed, well supported professionals who are aware of the impact of MND and the needs it creates.
- We were advised of 173 deaths in Victoria and 18 deaths in Tasmania in 2018/19.



2018/19: NUMBER OF PEOPLE SUPPORTED

597
VICTORIANS
2017/18: 609

58
TASMANIANS
2017/18: 63

NUMBER OF PEOPLE	VICTORIA		TASMANIA	
	2018/19	2017/18	2018/19	2017/18
With MND registered at 30 June	424	423	40	44
Newly diagnosed with MND during the year	209	212	16	25
With MND whose deaths were reported during the year	173	186	18	19
Living with MND supported during the year	597	609	58	63

“I have spoken often of the amazing and invaluable care and assistance MND Victoria gave us- we could not have managed that ghastly disease on our own ... I am so very grateful that MND Victoria eased the suffering with compassion, skill and practical assistance ”

CARER





MND ADVISOR AND SUPPORT COORDINATION SERVICE

Our team of MND Advisors/Support Coordinators provide individualised support to people with MND, their carers and families. They assist them to navigate the complexities of the various service systems, coordinate the multi-disciplinary support provided and advocate for the best possible care and support for every client.

- 53% of our initial referrals come directly from the person with MND or their family or friends, with the remaining 47% being referred by a medical or allied health professional.
- Our MND Advisors link people with appropriate community services where staff are well informed on the needs of people living with MND.
- We work to ensure a better understanding of MND and the needs it creates by providing one on one and group education and information sessions to health and allied health professionals in residential and community settings.
- Lack of access to aged care packages and appropriate funding for Assistive Technology continues to be an issue of concern and we work hard to advocate for improvements to funding and to support older people with MND and their carers.
- We continue our work in refining our client management system to best support our work and maximise the time our advisors can spend with clients.

“I would like to say how grateful I am that this organisation exists. My MND Advisor has been reliable, has a full understanding of my condition and what I may need to best cope with it”

CLIENT



2018/19: HOURS DELIVERED TO CLIENTS BY MND ADVISORS

9,268

VICTORIA

2017/18: 8,847

386

TASMANIA

2017/18: 487



2018/19: INDIVIDUAL CONTACTS WITH PEOPLE LIVING WITH MND

8,222

VICTORIA

2017/18: 8,134

343

TASMANIA

2017/18: 433



2018/19: NEW MEMBERS WITH MND

209

VICTORIA

2017/18: 212

16

TASMANIA

2017/18: 25



2018/19: REPORTED DEATHS

173

VICTORIA

2017/18: 186

18

TASMANIA

2017/18: 19



ASSISTIVE TECHNOLOGY

Our Equipment Service continues to be responsive in providing and maintaining Assistive Technology (AT) that supports our clients, their carers and families at no personal cost. We work closely with therapists who are directly involved in the support of the person with MND to provide the equipment that best suits the person's needs, for as long as they need it. This year has seen an increase in the number of clients receiving support through the NDIS to access AT through the MND Victoria equipment service. By continuing to grow the pool of equipment, we maintain low waiting times for equipment.

- We continue to purchase and issue lower cost non-retrievable items ensuring that this equipment can be dispatched quickly.
- We continue our close work with our offsite equipment managers to ensure that equipment is dispatched, retrieved and maintained as efficiently and effectively as possible
- 135 NDIS participants with MND have selected MND Victoria to provide their AT support, mostly through our equipment bundle offer. The bundle allows the changing needs of clients for equipment to be met, without needing to revise their NDIS plan.
- The number of volunteers supporting our equipment service has grown this year, continuing to provide valuable and much needed support to the program.
- We received a number of grants and donations to support our equipment service. These contributions assist us to continue our acquisition of new equipment.

To add to the approximately 3900 items in our equipment pool, significant equipment purchases for the year included:

37	Electric lift / recline armchairs
13	Electric floor hoists
27	Slings for floor hoists
20	Pressure cushions
32	Walking frames
25	eWriters
18	Portable ramps
16	Bed wedges
11	Manual wheelchairs
10	Nebulisers
10	Call bell and switch
8	Tilt in space powerchairs
8	Bedside commodes
5	King single beds
3	Lounge chairs
2	Standing aids

New clients receiving equipment	314
Clients with equipment	392
Equipment items provided	2654
Equipment items recovered	2875
Major equipment repairs	388





INFORMATION AND RESOURCING

We know that early access to good quality, accurate and accessible information is key to responding to the needs of people with MND, their families, carers, friends and others around them. Having the right information at the right time assists people to make informed choices and decisions and to plan for the difficult journey ahead of them.

Our Information and Resourcing team provide online and telephone support for information as well as ensuring that information is readily available through our website, through events, and through the provision of information and education to allied health professionals.

- Our Information nights held every six weeks for people recently diagnosed with MND, their families and friends continue to be well attended and receive positive feedback from participants about the warmth, sensitivity and knowledge of our team members. 160 people attended these sessions across the year.
- Formal events for the year included a Health Professionals forum in Launceston, Service of Hope and Remembrance in Geelong and Melbourne, Ask the Experts Day at the Florey Institute of Neuroscience and Mental Health and our Annual General Meeting.
- We provided 41 information, education and awareness sessions to Health and Allied Health professionals in Victoria and Tasmania.
- We have commenced the issue of an e-newsletter for health professionals providing information and updates on professional development opportunities, research updates and resources, links to newsletters and resources related to MND and information about our services.
- Over 70% of requests to our Information and Resourcing Team come via telephone, with just under 30% coming via email.
- We are seeing a shift to people preferring to access information online with a reduction in the requests for hard copy information and an increase in requests for email/online resources.

2018/19	
Information Kits Distributed	495
MND News-Editions/Copies	(mailed) 6/1,109
	(electronic) 6/754
Information Nights/attendees	8/160
Information by Phone	328
Information by Email	137
Website visits	42,329
Facebook likes	9024

SOCIAL MEDIA ENGAGEMENTS



56K



2.2K



24K

“If you have been diagnosed with MND and haven’t been given any info on MND, for your peace of mind contact MND Victoria and they will put you in touch with an MND coordinator in your area. We live in Bendigo and the MND coordinator for this region was brilliant, the services MND Victoria supply are amazing and give some peace of mind at such a difficult time”

FAMILY MEMBER COMMENT ON OUR FACEBOOK PAGE



VOLUNTEER SERVICES

Volunteer support continues to be essential to the services provided by MND Victoria. Volunteers provide assistance and support across all of our programs – from providing reception and administration support to visiting and supporting our clients, to arranging and delivering fundraising events. Without our volunteer workforce we could not possibly do all that we do for people living with MND.

- Volunteers regularly complete 74 contacts with clients each month.
- Volunteers provide up to 72 hours of program support at our Canterbury Office each month.
- This year our event in National Volunteer Week to recognise and thank our volunteers was a guided tour of the State Library followed by high tea. Forty five volunteers attended. Service awards were presented to volunteers including – one 25 year Service award, four 10 year service awards and 11 awards recognising 5 years of service volunteering with MND Victoria.
- Special Events continued to be well supported by volunteers including:
 - Walk to D'Feet MND
 - Bunnings sausage sizzle – January 2019
 - 33 Variations performances – March 2019
 - Wandin Park Equestrian Event – March 2019
- MND Victoria was successful in obtaining a Commonwealth Government Volunteer Grant for \$4880 to contribute toward the costs of training, travel reimbursement and completing police checks for our volunteers.

MND Victoria Volunteers make a world of difference

MND VOLUNTEER SURVEY	
94%	of respondents were satisfied or very satisfied with their volunteer role/s
86%	would recommend volunteering with MND Victoria to family and friends
96%	reported they felt acknowledged for their volunteer work
89%	noted they felt supported and well supervised by MND Victoria

	2018/19	2017/18
Number of volunteer hours contributed	6,935	5,313
Number of active volunteers	128	131
Number of volunteers attending training	53	23
Number of new volunteers	20	19
Number of support groups	6	6



“I feel very blessed to have been included in the MND Volunteer family. Very nurturing and supportive”

VOLUNTEER



SUPPORTER DEVELOPMENT

In this financial year we changed our name from Fundraising to Supporter Development to better reflect the focus of our efforts. For some time we have recognised that many of those who support us want a long-term, on-going relationship with us and not just a once-off fundraiser. This became even more obvious when we held our first overseas challenge event in 2017 – Walk to D’Feet MND China.

Those who participated had all been impacted by MND. During the Walk they were able to share with the Association, and each other, why they wanted to raise funds and their desire to become MND advocates.

- We were able to build relationships with each individual challenge participant, many of whom supported the 2018 Kokoda Walk to D’Feet MND event and/or signed up for the 2019 Larapinta Walk to D’Feet MND event. The funds raised through these three events alone has exceeded \$250,000 but, more importantly, these supporters understand the mission of the Association and are strong, on-going advocates for raising funds to deliver care and support to people living with MND.
- We also successfully implemented a pro-active digital marketing and fundraising strategy which resulted in an increase in online funds raised and expansion of awareness of the services provided by MND Victoria.
- Walks to D’Feet MND – Seven events were held including two new Walks in Echuca and Pakenham. The Walks raise significant funds for the Association – over \$340,000 and, just as importantly, they provide a safe and welcoming environment for people impacted by MND to remember loved ones who have died or are going through the disease.
- We continue to raise funds through more traditional avenues such as Christmas and Tax Appeals, Trusts and Foundations, Independently Run Events and Bequests.
- Bequest funds are invested in the MND Care Foundation with the interest being invested in care and support services.
- It is important that we pursue these diverse fundraising options as overall charity giving in Australia has decreased by 6%, competition in fundraising generally continues to increase, and the increased visibility of other MND organisations focussed on raising funds for research has had an impact on the Association’s fundraising.

In summary, in addition to non-government income received in the last financial year, funds were received as a result of:

- Appeals and Donor Updates
- Bequests
- Challenge Events – Kokoda Walk to D’Feet MND, Run Melbourne
- In Memory Donations
- Fundraising – Independently Run Events (F-IRE) raising funds for care and support
- Fundraising – Independently Run Events (F-IRE) raising funds for Research - Benalla Act to D’Feet MND, SuperBall XII, RockOff MND and other donations specifically designating research. These funds are invested by MND Australia to fund the best and brightest Australian researchers.
- Trusts and Foundations
- Walk to D’Feet MND events – Rosebud, Carlton, Bendigo, Echuca, Geelong and Pakenham
- Workplace/Regular giving

	2018/19	2017/18
Bequests and Trusts	491,538	756,898
Unsolicited donations	118,777*	650,777
Donor Development	446,284	556,737
Investments	458,402	349,525
Merchandising	55,030	77,179
Walk to D’Feet and special events	1,057,655	873,366

*This difference is due to re-categorising what is tagged as unsolicited.





FINANCES

In a year that has seen a trend downwards in overall charity giving, competition for donations and the finalisation of the NDIS rollout across the country, the Association has had a good trading outcome, and an audited financial surplus after transfers to the MND Care Foundation.

- The 2018/19 year resulted in a trading surplus. The audited financial statements provide a report on the final outcome for 2018/19 and will be available from the Association's office and website after they have been presented at the Annual General Meeting.
- Our income from NDIS increased by 56% with the finalisation of the roll out of the NDIS across the country. NDIS income was 24% of the total income for the year, compared with 16% in the previous financial year.
- Fundraising continues to underpin the Association's finances, and fundraising, paid services and investment contributed 75% of total income.
- We maintain our support for research into care, treatment and ultimately a cure for MND and through the support of events that raise funds for research we contributed \$350,600 to the MND Research Institute of Australia and for our own Nina Buscombe Awards for travel and conference attendance. Funding for research accounted for 7% of our expenditure.
- Our focus remains on service delivery with 82% of all expenditure being applied to services to support people living with MND and to research.
- Our income remains dependent on year to year activities to continue to fund care, support and research, with a strong reliance on the many fundraising events – both large and small – that are delivered by us or on our behalf by our supporters. We monitor our expenditure closely with a focus on efficiency and effective operations, to maximise the funds available for services.
- We maintain low administration costs at 6% of total expenditure, however these costs continue to rise as the monitoring and acquittal processes required by Government and regulators increase. We are constantly working to understand and appropriately allocate the true costs of service provision.
- The Association remains in a strong financial position, with adequate reserves to meet the challenges ahead. Our mission continues – to provide and promote the best possible care and support for people living with MND.



“Thank you for all your hard work, care and compassion. You are very special and we are extremely appreciative”


CLIENT AND CARER

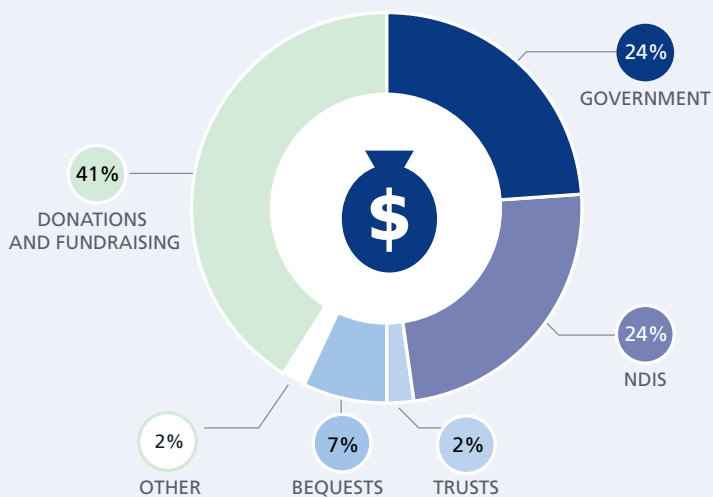
“Our clients always comment about how well they feel supported by our volunteers”

MND VICTORIA STAFF MEMBER




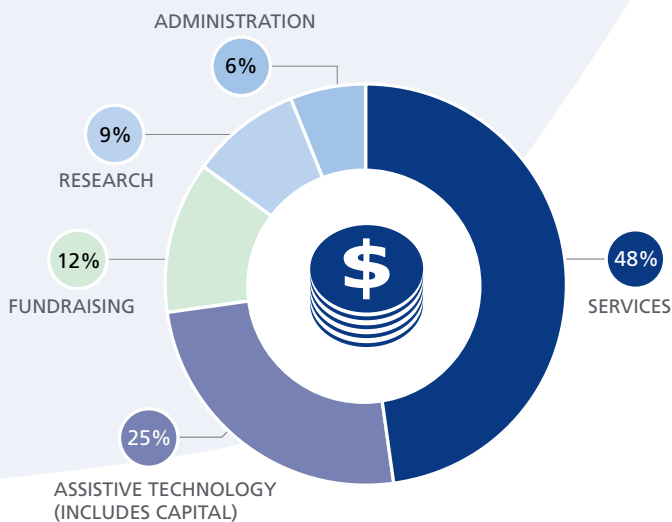
INCOME

	INCOME 2018-19	INCOME 2017-18
Government	\$1,275,991	\$1,185,714
NDIS	\$1,285,461	\$822,800
Donations and Fundraising	\$2,161,313	\$2,373,411
Bequests	\$374,708	\$548,783
Trusts	\$120,205	\$208,115
Other	\$98,230	\$109,162
Total	\$5,315,908	\$5,247,985



EXPENDITURE

	EXPENDITURE 2018-19	EXPENDITURE 2017-18
Services	\$2,282,876	\$2,160,706
Assistive Technology	\$1,191,471	\$1,058,239
Fundraising	\$595,239	\$570,740
Research	\$453,791	\$434,241
Administration	\$277,913	\$244,153
Total	\$4,801,292	\$4,468,079





Motor Neurone Disease Association of Victoria Inc

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