



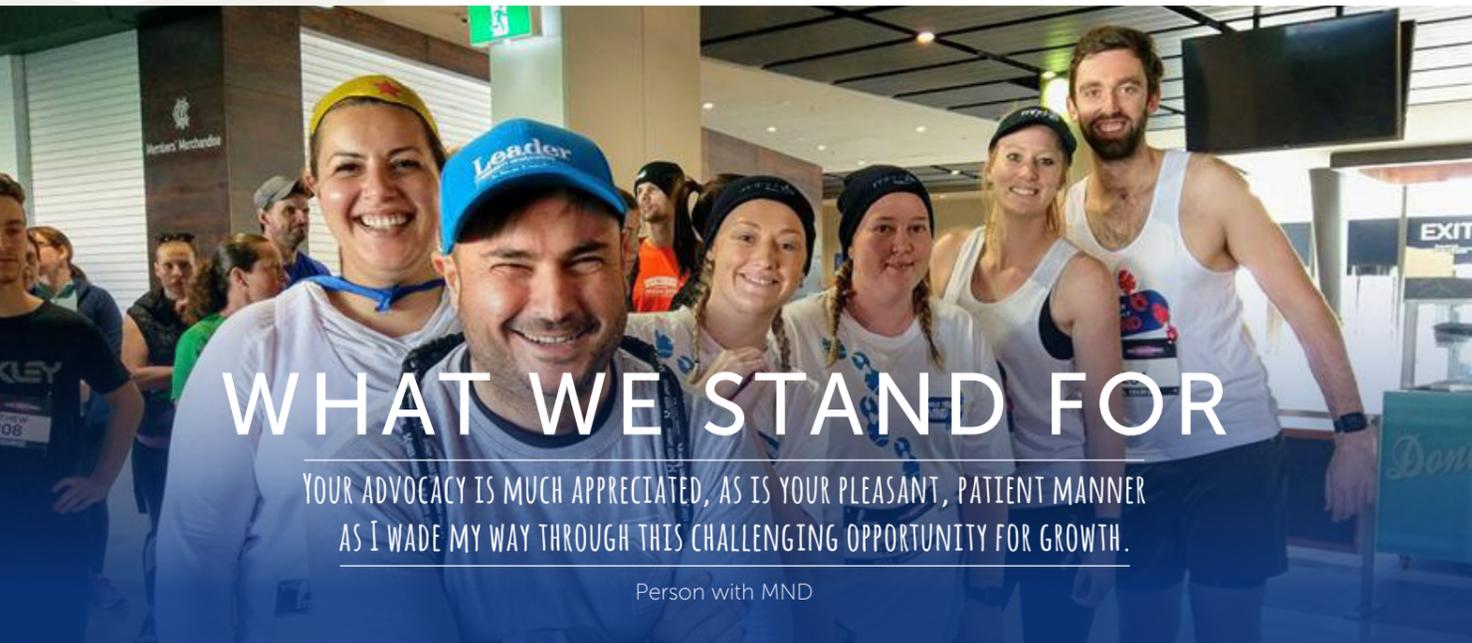
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UNTIL THERE'S A CURE ... THERE'S CARE

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2018 ANNUAL REVIEW



# WHAT WE STAND FOR

YOUR ADVOCACY IS MUCH APPRECIATED, AS IS YOUR PLEASANT, PATIENT MANNER AS I WADE MY WAY THROUGH THIS CHALLENGING OPPORTUNITY FOR GROWTH.

Person with MND

## 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 has 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.

# STATE COUNCIL

MND Victoria continues its focus on providing care and support for people living with MND. By delivering key services, developing better policy, practice and procedure, and linking people to other high quality providers who can meet their needs, we help people live better for longer while fighting MND. Our investment in research is aimed at finding cause, treatment and cure of MND.

This year,

- The iCase client management system facilitates engagement with the National Disability Insurance Scheme and Aged Care reforms and is almost fully implemented, linking all facets of the organisation.
- We ensured common practice and goals in negotiating and influencing government practice and policy through systemic changes by continuing our close and productive work with MND Australia and its members.
- NDIS has become an increasing contributor to our services when people with MND choose MND Victoria as their preferred provider for Assistive Technology and Coordination of Support.
- We supported 609 people living with MND with Assistive Technology, MND Advisors, information and resourcing and ongoing advocacy. We raised 77% of income through fundraising and fee for service via NDIS.
- We maintained our accreditation with the Department of Health and Human Services and ISO 9001 through our "annual review" and remain an approved service provider for DHHS and NDIS.
- State Council continued to actively monitor and review the Association and its focus on people living with MND, ensuring effective governance and delivering the organisation that its members want and need.
- We invested over \$434,000 in research, including funding 18 people to attend training and conferences to extend and share their knowledge about MND.
- Four staff have resigned, and we thank Alia, Lesley, Babita and David for their service. Restructuring, growth, complexity and demand has seen our team grow, and we welcome Georgina, Deb, Sarah, Sandra, Fran, Melissa, Bec and Isabelle.

Success in our work is only achieved through our staff, volunteers and our partners, both formal and informal. We thank them for their energy, passion and commitment in the fight against MND.

## STATE COUNCIL

(as at 30 June 2018)

- David Lamperd\* – Chairman
- Katherine Barnett\* – Vice Chairman
- 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



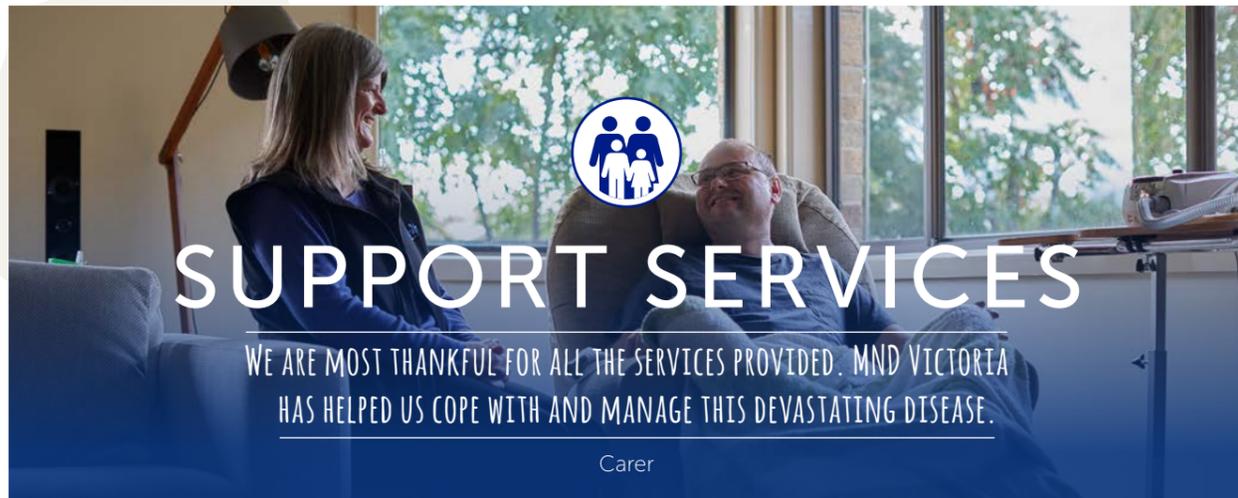
David Lamperd President



Jeremy Urbach Treasurer



Rodney Harris CEO



# SUPPORT SERVICES

WE ARE MOST THANKFUL FOR ALL THE SERVICES PROVIDED. MND VICTORIA HAS HELPED US COPE WITH AND MANAGE THIS DEVASTATING DISEASE.

Carer

MND Support Services deliver key services for people with MND helping them to access services and supports they need, live better for longer, remain active in their community and family, and to be safe in their environment.

- Our MND Advisor Service in Tasmania continues to gain strength and we are examining opportunities to increase this service.
- 212 Victorians and 25 Tasmanians diagnosed with MND registered with the Association for support.
- 86 Victorians have active plans with NDIS and a further 34 are progressing through the pre-participant planning stage. In Tasmania, 3 have plans and 16 in pre-participant planning. Rollout of the remaining Victorian and Tasmanian clients will increase NDIS activity over the next 12 months.
- Client survey results reinforce the value of the Association and its services. Information, MND Advisors and Equipment rating good to excellent by 83%, 88% and 80% of respondents respectively.
- The DHHS Disability recertification and ISO 9001 Surveillance audit were undertaken and passed. Since our first audit in 2009, MND Victoria has never received a non-compliance report.
- We are continuing our advocacy to Make Aged Care Fair for people with MND, working closely with MND Australia and MND NSW. This is a long term campaign.
- iCase, our new client management system, continues its refinement and development, contributing to better information and improving services.
- The health and well-being of our staff remains a high focus, and our external staff supervision program is highly valued by all participants.
- We continue our relationships with service providers and organisations across Victoria and Tasmania to ensure that people with MND receive support from well trained, well supported organisations, aware of the impact of MND and the needs it creates.
- We were advised of 186 deaths in Victoria and 18 deaths in Tasmania.



# MND ADVISORS

OUR ADVISORS' UNDERSTANDING OF MND IS VITAL IN ASSISTING US TO MAKE THE CORRECT DECISIONS BOTH FOR NOW AND THE FUTURE.

Carer

MND Advisors are the community face of MND Victoria, representing the Association in its contact with people living with MND, and being the navigators of an increasingly complex service system.

- Our Keeping Connected program provides support and increases the effective use of MND Advisor's time focussed on new clients, emerging and high unmet needs.
- Demands and the scope of support provided for NDIS clients through Coordination and Support continues to grow, with 86 active plans in Victoria and 3 in Tasmania.
- Lack of funding for pre-planning activities and support places increased pressure on staff but enhances outcomes for NDIS clients.
- Lack of access to aged care packages and funding for assistive technology has increased our workload and significantly increased pressure on carers and older people with MND.
- Regular meetings with NDIS planners in all rollout areas, as well as consultation meetings at a national level, are improving plan content, timing and initiation.
- Planning undertaken for the year's rollout of new areas improved our capacity to respond effectively to client needs. This was supported by the creation of two new MND Advisor positions.
- Ten MND Advisors (six part time) in Victoria and one (part time) in Tasmania form the front line of the Advisor service, with regular ongoing review of staffing levels and client needs and demand.
- One on one and information sessions for residential facilities and care providers ensures better understanding of MND and the needs it creates.
- Intensive engagement with refinement of iCase is ensuring it meets our needs.
- External supervision continuing supported and led by a consultant.

VICTORIA	2017-18	2016-17	PEOPLE...	2016-17	2017-18	TASMANIA
609 people supported during the year	423	405	with MND registered at 30 June	39	44	63 people supported during the year
	212	196	newly diagnosed with MND during the year	19	25	
	186	170	with MND whose deaths were reported during the year	15	19	
	609	575	living with MND supported during the year	54	63	

Hours delivered to clients by MND Advisors	Individual contacts with people living with MND	New members with MND	Reported deaths
8,847 VICTORIA 2016/17 - 10,288	8,134 VICTORIANS 2016/17 - 4,915	212 VICTORIANS	186 VICTORIANS
487 TASMANIA 2016/17 - 458	433 TASMANIANS 2016/17 - 186	25 TASMANIANS	19 TASMANIANS



# ASSISTIVE TECHNOLOGY

THE EQUIPMENT SERVICE IS EXCELLENT – YOU HAVE ALWAYS PROVIDED US WITH EVERYTHING THAT WE NEED. IT IS SO HELPFUL – THANK YOU VERY MUCH.

Carer

The MND Victoria Equipment Service has been successful and productive providing Assistive Technology (AT) to clients in a year of transition. We continue to provide and maintain aids and equipment to support their family, carer and social engagements with equitable provision of assistive technology at no personal cost.

- Significant purchases of low cost items ensuring that requests can be completed very quickly.
- Continue to work with all our offsite equipment managers to improve dispatch, retrieval and maintenance processes.
- Transitioned to iCase allowing improved work flows, communication and reporting.
- Non-retrievable low cost items program has been expanded to include more types of equipment to significantly reduce recovery and cleaning costs over time.

- We have received several significant grants from Philanthropic Trusts and bequests from supporters which have allowed ongoing acquisition of new equipment.
- An additional staff member has reduced request waiting times, improved responses for asset maintenance, repairs and other ad-hoc issues.
- Volunteers provide invaluable support and backup in a range of important and necessary tasks.
- Equipment consignments to locations outside metropolitan Melbourne are challenging in delivery time frames and costs. We are committed to providing equitable access to equipment across Victoria.
- 104 NDIS participants have chosen MND Victoria to provide their AT requirements, most using our "bundle" offer. The bundle allows the Association to access funds early, reduce costs to NDIS and provide assistive technology during the plan period.

CATEGORY	ASSET TYPES...	ITEMS
Bathroom	Toilet seat raisers, over toilet frames, toilet surrounds, shower stools and chairs, mobile shower commodes	97
Bedroom	Bedpans, urinals, bedsticks, bed cradles, pillow wedges, tables, electric bed, pressure reduction mattress	72
Communi-cations	iPads, call bells, switches	76
Daily Aids	Handy bar, pickup reachers, flexible and clamp on mounts	21
Furniture	Armchairs (electric lift / recline), lounge chairs	18
Mobility	Crutches	69
Pressure	ROHO and Memory foam pressure cushions	43
Transfer	Slings	2
Total equipment purchases during the past year		<b>398</b>

New clients receiving equipment	Clients with equipment
<b>258</b>	<b>361</b>
Requests for equipment	Major equipment repairs
<b>1,350</b> 2,582 PROVIDED 2,281 RECOVERED	<b>604</b>



# INFORMATION AND RESOURCING

MND VICTORIA HAS A LARGE ACCESSIBLE BANK OF KNOWLEDGE, RESOURCES AND EXPERIENCE.

Carer

Information remains a key and early element in our response to people living with MND, their families and carers, and to health professionals. Quality information and its application to individual circumstances is essential to get clients started on the right path – the path they wish to travel.

- Multiple posts regarding MND Victoria's position on Voluntary Assisted Dying – that we support patient's rights in all things that are lawful – was well received. Our goal is to ensure that whatever rights are created for people in Victoria, those rights are usable by people with MND.

- Formal events included the Bendigo Health Professionals' Day, Annual General Meeting and MND Week, including Day of Hope and Ask the Experts.
- Our second MND 101 Webinar, an online education session, was held in conjunction with the MS Society.
- The Bendigo Health Professionals' Day brought together over 100 people and featured presentations from Calvary Health Care Bethlehem, Austin Health, Bendigo Health and Goulburn Valley Health, with strong and appreciative feedback from attendees.
- A health information session was presented in Echuca, assisted by local allied health providers, and at Banksia Palliative Care for their friendly visiting volunteers - both highly successful.
- Our "Information nights for Family and Friends", held every six weeks, continue to attract excellent audiences and present fabulous opportunities to learn more about MND.
- A presentation with Dr Bradley Turner (Florey) to 30 University High students was a huge success. The teacher said "Massive thank you for today – the kids have not stopped talking about brains, research and how crap it would be to have MND. They got so much from the experience".
- "Get Walking Get Talking" continued as a program for carers combining mild exercise, a part day out and an opportunity to talk about and share the caring experience.
- New mobile friendly website launched February 2018.

INFORMATION...	2016-17	2017-18
Information kits distributed	574	539
Community Awareness sessions	44	35
MND News/Editions	6/1600	6/1500
Information nights/attendees	8/96	9/227
Health Professional information sessions	9	9

Information by phone	Information by email
<b>467</b>	<b>321</b>
Facebook likes	Website visits
<b>7,477</b>	<b>40,683</b> SINCE FEBRUARY 2018



# VOLUNTEER SERVICES

VOLUNTEERING HAS GIVEN MY LIFE ANOTHER SPHERE. IT HAS SHOWN ME THE STRENGTH OF THOSE WHO SUFFER, THE LOVE AND STRENGTH OF FAMILIES WHO SUPPORT THEM.

Volunteer

MND volunteers continued to provide essential and valued services supporting and enhancing the work of the association throughout a busy year which included many changes within the organisation. The ongoing commitment and contributions of our volunteers has been greatly appreciated.

- Approximately 130 volunteers have provided ongoing commitment to a wide variety of roles through 2017-2018.
- Volunteers in their local communities support events such as local fundraising and walks across the state. This recognises the impact of MND on communities and the respect and support MND Victoria gains from services provided for people living with MND.
- Volunteers provide care and support to clients. The Hand and Foot Massage and Life Story Programs continue to be popular. Our Bereavement Call Volunteers provide connection and support for people who have lost loved ones to MND.
- MND Victoria is committed to supporting and recognising the contributions to the work of the association provided by our volunteers.

- Regular team meetings and development sessions provide opportunities for volunteers who often work alone in the community, to come together to share experiences and continue to develop their skills and knowledge relevant to their roles.
- Our monthly Volunteer Update newsletter helps keep volunteers up to date and connected with the work of the association.
- During National Volunteer Week in May with a theme of "Give a Little – Change a Lot", our annual volunteer recognition and celebration event at the MCG brought together 45 volunteers and was an opportunity to thank all of our volunteers and recognise the service of long-term volunteers.
- We have recruited volunteers with a breadth of skills and experience which complement and enhance the work of staff. We have developed volunteer roles to support and assist our growing social media and online communication strategies.
- We will continue to look to develop roles for volunteer involvement.



# FUNDRAISING

JUST KNOWING THEY ARE THERE, IS MOST IMPORTANT.

Person with MND

Competition in fundraising continues to increase and is particularly intense in funding for MND. Overall fundraising income was approximately 5% higher than last financial year. This is a good result and continues to support the Association's mission – to provide and promote the best possible care and support for people living with MND.

- Fundraising – Independently Run Events (F-IRE) has seen a significant downturn in events being run. Schools and sporting clubs continue to support their members who have MND.
- Research events are well established with the Benalla Act to D'Feet MND, SuperBall XI and RockOff MND and other research donations raising \$374,000. These funds are invested by MND Australia in the best of the best Australian researchers.
- China Walk to D'Feet MND was an outstanding success raising a total of \$111,000, \$67,000 in this financial year. We seek to capitalise on the trend of people combining major challenge/bucket list items with fundraising for a cause.
- Walk to D'Feet MND – Seven walks - Lakes Entrance, Rosebud, Melbourne, Bendigo, Benalla, Violet Town and Geelong – promoted MND and increased Walk income by almost 10%. The 2018/19 year sees the introduction of the Echuca Walk.

- Income from Appeals and Donor Updates was up 17% but is still well below the income received in 2015/16 financial year.
- Trust and Foundation income rose by almost 90% and contributed \$204,795 to fund programs and equipment purchases.
- In Memory Donations - there is a trend for families to nominate other organisations as donation recipients in lieu of flowers. A large In Memory donation received in June resulted in our In Memory donations contributing \$184,505.
- Bequest gifts contributed 17% to our income and continue to underpin care and support activities long after the donor has died. Bequest funds are invested in the MND Care Foundation with the interest being invested in care and support services.
- The Association extended our investment in the digital fundraising space, improving returns in our recent Appeal from 4% in 2016/17 to 20% in 2017/18. We will continue to develop this fundraising avenue.
- Increased support for our F-IRE events and enhanced digital presence by increasing the Fundraising Officer role to full time and adding a part-time Digital Communications Officer. While increasing our fundraising costs we managed our expenses to return over \$6.00 for every dollar invested.

Number of hours contributed	Number of active volunteers	Number of volunteers attending training	Number of new volunteers	Hours contributed by support groups
5,313	131	23	19	164
2016/17 - 6,865	2016/17 - 133	2016/17 - 25	2016/17 - 24	2016/17 - 473

Bequests and Trusts	Unsolicited donations	Donor development	Walk to D'Feet and special events
\$756,898	\$650,777	\$556,737	\$873,366
2016/17 - \$1,001,106	2016/17 - \$558,031	2016/17 - \$251,781	2016/17 - \$835,192
Investments	Merchandising		
\$349,525	\$77,179		
2016/17 - \$317,000	2016/17 - \$31,175		



# FINANCES

TO DELIVER WHAT IS NEEDED, TO FUND WHAT IS PROVIDED,  
AND TO INVEST IN CARE, RESEARCH AND SUSTAINABILITY.

State Council

In a year of increased competition, NDIS rollout and changes, the Association has had a good trading outcome, and an audited financial surplus after transfers to the MND Care Foundation.

- The 2017/18 year resulted in a trading surplus of over \$850,828, with significant income from NDIS and bequests. The audited financial statements will report the final outcome for the 2017/18 year.
- NDIS income continues to grow, with over \$822,800 (16% of income) generated as more people become participants. Most importantly, more people are receiving services that address their needs than from previous funding strategies.
- Fundraising continues to underpin the Association's finances, and fundraising, paid services and investment contributed 77% of total income.
- Bequests contributed \$548,783. We invest these funds via the MND Care Foundation to deliver income for service delivery. We ask that you consider leaving a bequest to the Association that will fund the fight against MND in the future and until a cure is found.
- We continue to support events that raise funds for research, and have contributed over \$434,000 to MND Australia for research projects and for our own Nina Buscombe Awards for travel and conference attendance. Research funding accounted for 10% of expenditure.
- Our focus remains on delivery of services with 82% of all expenditure being applied to services to support people living with MND and to research.

- Income remains dependent on year to year activities to continue funding care, support and research, with strong reliance on the myriad of fundraising events both small and large. We closely monitor expenditure, maintaining our focus on effective and efficient operations. There is a fine balance to ensure we have appropriate levels of funds available for services.
- Administration costs remain low at 5%, but have and will increase in dollar terms due to higher monitoring and acquittal processes. The new Client Management System has facilitated better allocation of "back of house" costs to the appropriate cost centre, and assisted in understanding the true cost of service provision.
- Audited accounts will be available from the Association's office and website after they are presented at the Annual General Meeting.
- The Association remains in a strong financial position, with adequate reserves to meet the challenges of the NDIS and Aged Care reforms. Our mission continues to provide and promote the best possible care and support for people living with MND.

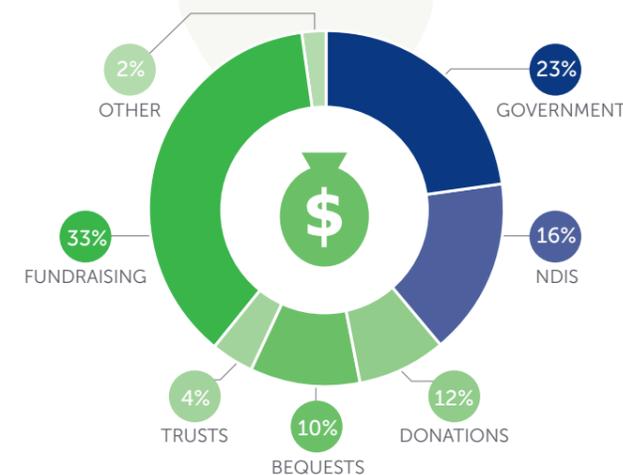
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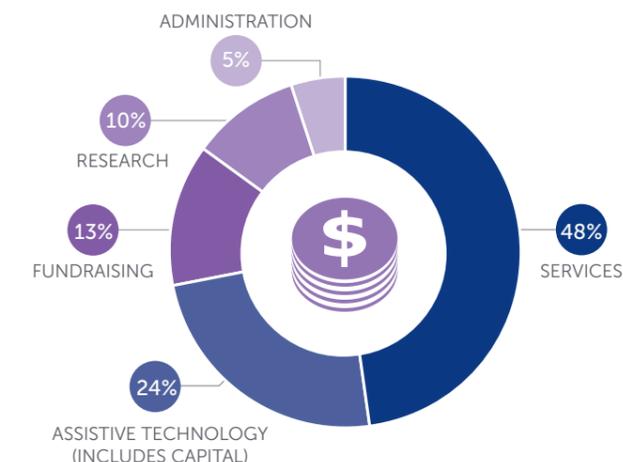
JUST KEEP DOING WHAT YOU DO - KNOWING YOU  
ARE THERE WHEN WE NEED SUPPORT IS VERY COMFORTING.

Carer

	Income 2016-17	Income 2017-18
Government	\$1,204,758	\$1,185,714
NDIS	\$170,933	\$822,800
Donations	\$410,574	\$647,521
Bequests	\$855,248	\$548,783
Trusts	\$145,858	\$208,115
Fundraising	\$1,673,454	\$1,725,890
Other	\$104,944	\$109,162
<b>Total</b>	<b>\$4,565,769</b>	<b>\$5,247,985</b>



	Expenditure 2016-17	Expenditure 2017-18
Services	\$2,064,312	\$2,160,706
Assistive Technology (includes capital)	\$948,451	\$1,058,239
Fundraising	\$464,738	\$570,740
Research	\$462,400	\$434,241
Administration	\$273,641	\$244,153
<b>Total</b>	<b>\$4,213,542</b>	<b>\$4,468,079</b>





Motor Neurone Disease Association of Victoria Inc  
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