

MND Advocacy in Australia

Carol Birks

A Brief History

- 1981 first MND Associations NSW and Vic
- 1984 MND Research Institute of Australia
- 1992 MND Association of Australia
- 1992 International Alliance of ALS/MND Associations
- 1994 – 2006
 - national information resources, national and international meetings, Rilutek listed on PBS
- 2006 national advocacy a key role for MNDAA

About Advocacy

- **Advocacy** is an activity by an individual or group that aims to influence those who make policy decisions
- There are a number of types of advocacy:
 - Self or individual advocacy
 - Informal advocacy undertaken by individuals, their relatives, and friends
 - **Voluntary or community-based organisations** that advocate for individuals
 - Collaborative advocacy
 - joint advocacy with other groups who have the same or similar needs
 - Systems (systemic) advocacy
 - Changing policies, laws, or rules
 - Local, state, national, international
- People with lived experience of MND are key to engagement and success

Why is Advocacy a focus?

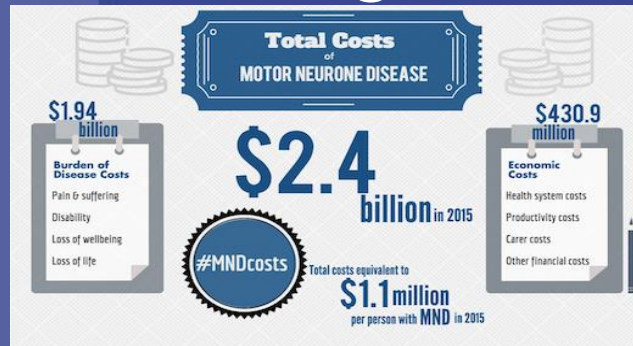
- National Advocacy identified by members as a key role for MND Australia to improve the lives of Australians living with MND
- People with MND in Australia:
 - have complex and rapidly changing needs
 - need a range of supports from health, aged and disability sectors
 - do not have access to equal care and support

Building a case for change

- Gather evidence:
 - members, community, formal reviews, needs assessments, national and international research
- Understand needs of:
 - Members
 - MND Community
- Build networks and strategic relationships
- Be across policies of the government

Presenting a case for change

- 2015 Deloitte Report
- MND Action Framework to identify priority areas:
 - disability (NDIS)
 - aged care
 - assistive technology
 - genetic services
 - health
 - research



MND ACTION

MND AUSTRALIA SEEKS COMMITMENT FROM ALL SIDES OF POLITICS FOR:

1. Improvements to aged and disability care
2. Timely access to a full range of assistive technology
3. Development of National MND Guidelines
4. Access to fully funded genetic services for families with identified genetic mutations
5. A specific commitment to fund specialist MND multidisciplinary clinic nurses
6. Increased investment in research

MND Advocacy Plan

Multi-pronged, consistent, sustained

1. Meet with key decision makers
2. Write submissions to all relevant enquiries etc
3. Develop and update position statements
4. Inform and educate the wider MND community
5. Engage with and mobilise members and the community
6. Build partnerships and collaborations

1. Meetings with decision makers



MND Australia newsletter – March 2016
Photo: MND NSW Board Member, Kirsten Harley with Senator Richard Di Natale



2. Submissions

A statement from MND Australia, the national voice representing all Australians who share the vision of a world without MND



6 steps to improve the lives of people living with MND

MND Australia seeks six commitments from candidates from all sides of politics in the lead up to the 2019 Federal Election to address the urgent need to improve the lives of people living with motor neurone disease.

WHAT DO WE NEED?

1. Improvements to aged and disability care
2. Timely access to assistive technology
3. Development of MND Guidelines
4. No cost access to IVF and pre-implantation genetic diagnosis
5. Funding for specialist multidisciplinary MND clinics
6. Increased & sustained investment in research

What is motor neurone disease (MND)?



MND Australia:

Pre-Budget Submission 2021 - 2022

28 January 2021

Submission to the Royal Commission into Aged Care Quality and Safety

Submitted by:

Inquiry into approval processes for new drugs and novel medical technologies in Australia

Submitted

MND A

On: 13



NATIONAL DISABILITY INSURANCE SCHEME (NDIS) COSTS

Submitted online

MND Australia

On: 24 March 2017



Productivity Commission

DISABILITY CARE AND SUPPORT INQUIRY

Submitted via email to:

MND Australia
PO Box 980
Gladesville, NSW 1575

On: August 2016



Key responses from MND Australia for discussion at the Productivity Commission hearing on Wednesday 13 April 2017

Funding responsibilities of the aged care and disability sectors

The report states that the needs of those who acquire a disability after age 65 would be best met by the aged care system. This is not the case. Most people with progressive neurological diseases over the age of 65 will need services from both systems.

People need to be able to access services based on needs related to their disability and their age - Systems care and support.

The option for the disability sector to fund services for people up to the pension age and for the aged care system to fund services for people over the pension age is a simplistic approach that denies the complexity of support required by people living with a progressive neurological condition. A bridge of continuity of support service funding is imperative. People must be able to access services from both sectors to meet their needs, irrespective of which sector is responsible for funding the package of care.

Access to services based on need must also be irrespective of where a person lives. People with MND living in residential aged care facilities - no matter how old they are - will need top-up funding to purchase extra services to ensure their quality of life.

Early Intervention

MND Australia congratulates the commissioners on their acknowledgement of the importance of early intervention for those newly diagnosed with degenerative diseases. Early intervention is vital for people living with MND. Early access to information and counselling creates a solid base upon which the future of disease diagnosis and management assistance can be addressed through

Information Building Po

consultation

Information, Change and

Support Services Branch

West Gate and Victoria

Street, Melbourne, VIC 3000

Phone: (03) 9601 1111

TTY: (03) 9601 1111

For more information, visit

www.mnd.org.au

or contact us on

1800 000 000

or email info@mnd.org.au

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4. Informing and Educating


- 2002, 2011, 2019 hosted international meetings
 - Melbourne, Sydney, Perth
- 2005 National Conference for health professionals and service providers established
 - Annual then Biennial
- 2008 MND Association support service model
 - Developed and adopted nationally
- 2010 MNDcare website launched
 - redeveloped in 2021 with ILC funding
- 2015 MND Connect meetings established
- 2021 State of Play online research updates

5. Engaging the community



MND Australia
Published by Morag Millington (7) · ★ Favouites · 8 May · 🌐

Australians don't know that you can't access the NDIS if you're aged with a disability aged 65+. Even a non-age related disability like We need to end this age discrimination!
<https://bit.ly/2SA5Xpl>
 #Week2020 #MACF



Graham

Lives with MND
Age 63

Does not receive an NDIS plan to meet his disability needs

On waiting list for NDIS, in access approved care his plan as he needs it



Tony

Lives with MND
Age over 65

- ✗ Cannot receive an NDIS plan as he is over 65 years
- ✗ Stuck on the Aged Care waiting list for over eight months
- ✗ No funding for vital equipment through NDIS

Receives funding for vital equipment through NDIS

mnd
Australia

MND Australia
Published by Morag Millington (7) · ★ Favouites · 21 June · 🌐

Thank you to all the federal MPs and Senators who wore the blue comflower at Parliament House this week in the lead up to Global ALS/MND Awareness Day. Here's a few that we spotted 🌸 #ALS/MNDWithoutBorders



Global ALS/MND Awareness Day
at Parliament House

7,266 People reached
490 Engagements

[Boost post](#)

2 comments 22 shares

Terminally ill mother fears NDIS 'writing off people with neurological conditions'

By published reporter Gae Griffin
Updated 19 Mar 2017, 3:11pm



VIDEO: Kristen Harley says she hopes the NDIS will help people to live well. (ABC 4) News

The National Disability Insurance Scheme (NDIS) has denied a terminally ill mother help to keep communicating with her family.

Sydney woman Kristen Harley has motor neurone disease (MND) and will lose the ability to move and speak.

The former academic applied to the NDIS for technology that allows people to use eye movement to communicate and do other regular activities, such as opening doors.

But Dr Harley's request was refused last Wednesday.

"It's pretty upsetting because it obviously affects me but it also affects my 18-year-old daughter [Dini] and my husband [Dennis] and family and friends around me," she told the ABC.



15,926 People reached
1,740 Engagements

237 reactions

30 comments 85 shares

[Like](#) [Comment](#) [Share](#)



Right care. Right place. Right time.

Sign the petition

To show you care about the rights and quality of life of all Australians living with motor neurone disease (MND) and their carers.

www.mndout.com.au



6. Partnering and Collaborating



PARLIAMENTARY FRIENDS OF MEMBERS OF THE NEUROLOGICAL ALLIANCE AUSTRALIA

invitation

The Co-Chairs of the Parliamentary Friends Groups and the CEOs of the ten Members of the Neurological Alliance Australia members of the Neurological Alliance Australia (NAA), including morning tea, on 22 March 2017, commencing at 11.00 am.



Members' Login Contact

What is ALS/MND Find a Member Association Support for PALS & CALS Events/Programs About Members

Global Day

Every year the International Alliance of ALS/MND Associations celebrates 21 June as the global day of recognition of ALS/MND – a disease that affects people in every country of the globe.

ALS/MND is a global problem. It does not discriminate on the basis of race, ethnicity, socioeconomic status or region. There are people living with ALS/MND all over the world. For every person diagnosed, the impact of the disease will be forever felt by their loved ones.

Alliance members across the world use the hashtag #ALS/MNDWithoutBorders on June 21 to raise awareness and funds on Global Day.

Why June 21?

June 21 is a solstice – a turning point – and each year the ALS/MND community undertake a range of activities to express their hope that this day will be another turning point in the search for cause, treatment and cure of ALS/MND.

Join the fight... Spread the word

Global Day is an event that knows no boundaries, so everybody can be involved. Any event (big or small), any activity, any act, can be a part of raising awareness of ALS/MND.



Key impacts 2006 to 2021

DISABILITY - 2012 - NDIS introduced with bipartisan support

- Recognising people living with progressive neurological conditions, under the age of 65, as an early intervention group within the NDIS
- Allowing existing NDIS participants who turn 65 to continue with the NDIS
- Annual fee for MND Association equipment bundles or rental included in NDIS plans
- First disease specific MND Practice Guide for planners developed
- Disability related health supports (NIV) available to purchase using NDIS funding

AGED CARE - 2018 - Royal Commission into Aged Care Quality and Safety

- Independent MP's come together to support an end to discrimination for people who acquire a disability when aged 65 or older
- Royal Commission into Aged Care Quality and Safety handed down its final report: Care, Dignity and Respect. MND Australia recommendations 1, 2 and 3 encompassed and the need for equity for people with disability receiving aged care recognised

HEALTH AND RESEARCH

- 2006 – Australian MND Registry established
- 2008 - people with terminal conditions able to access superannuation
- 2008 - Riluzole for people with disease duration of less than 5 years
- 2011 - recommendations of the Lockhart Report maintained
- 2018 – NHMRC funding for MiNDAUS
- 2020 – specialist MND multidisciplinary clinics available in all states and ACT
- 2020 – telehealth consultations covered by medicare
- 2021 – MiNDAUS registry launched

The Future

Improve equity of access to:

- Aged care
 - timely needs based in-home aged care funding and support for people with MND
 - assistive technology and calling on the Federal Government to create a single national assistive technology program to support people with MND who are excluded from the NDIS
- Disability - NDIS
 - Continue to ensure the needs of people with MND are met as reviews are undertaken
- Health - Genetic services for Australians with MND
 - genetic services for Australians impacted by MND
 - fast-track access to effective treatments and devices for MND

Thank you!