MND Advocacy in Australia

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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



2. Submissions

A statement from MND Australia, the national



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.

MND clinics

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

What is motor

neurone disease (MND)?



MND Australia:

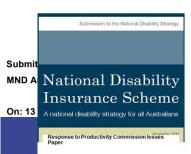
Pre-Budget Submission 2021 - 2022

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





Productivity Commission DISABILITY CARE AND SUPPORTINGUIRY Submitted via email by Gladesville NSW 1675 On: August 2010



Key responses from MND Australia for discussion at the Productivity Commission hearing on Wednesday 13 April 2011

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 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 meets irrespective of which sector is responsible.

Access to services based on need must also be irrespective of where a person lives. People will IMID 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. MND Australia congrahulates the commissioners on their acknowledgement of the importance early intervention for those newly diagnosed with degenerative diseases. Early intervention is for people living with MND. Early access to information and courselling creates, a solid base unon which the nearly of nencle diagnosed with discensizative disease can be addressed through

Insurance S

mn

3. Position statement

Aged Care and People with MND

POSITION STATEMENT

NEUROLOGICAL ALLIANCE AUSTRALIA

















Continuation of expanded Telehealth fo COVID-19 pandemic response

June 2020

Executive Summary

Neurological Alliance Australia (NAA) is a collective of natio representing over 850,000 adults and children living with pr conditions in Australia.

NAA calls on the Australian Government to permanently ex telehealth items introduced in response to the COVID-19 pa scheduled to cease after 30 September 2020. Telehealth of private, the opportunity to provide enhanced options for sa new models of efficient care for the whole population.



INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS

The International Alliance of ALS/MND Associations supports the following fundamental rights for people living with ALS/MND:

These fundamental rights represent the ideal for individuals living with ALS/MND worldwide.

Although the International Alliance and its representatives understand that some of these conditions might not be immediately attainable, this document represents the set of rights all Alliance member organisations should adopt and promote as conditions, systems and resources allow.

People living with ALS/MND have the right to:

- 1) the highest quality care available within their healthcare system
- 2) the highest quality treatment available within their h-141
- 3) information and education that will enable them to pl
- 4) choice with respect to:
 - · health and support workers who are providing tre
 - the location where care takes place, and
 - the type of treatment or support that is provided



- People diagnosed with MND must have access to a range of services to meet their disability needs irrespective of where they live, their age or which sector funds the service
- Access to reasonable and necessary government funded disability supports based on the age of a person when they acquire, or are diagnosed with, a disability is discriminatory and enes article 19 of the United Nations Convention on the Rights of Persons with

ent in Home Care Packages to reduce waiting list for higher level care at home, as ended in the Royal Commission into Aged Care Quality and Safety Interim Report¹. rove the lives of thousands of older people, reduce the need for residential aged care st home care sector employment opportunities during a time of rising unemployment

a will continue to advocate for access to the NDIS for all people with a MND no matter their age when diagnosed. Until this is achieved MND s for:

ents to the ageing-disability interface to ensure access to reasonable and supports to meet the needs of people who acquire a disability when over the

ediate and sustained investment in additional Home Care Packages to reduce the ber of people waiting on the national queue and to boost employment opportunities in

duce a formal 'fast track' process for automatic access to Level 4 Home Care kages for people living with rapidly progressing and complex terminal conditions such notor neurone disease to ensure early intervention and access to supports to meet dly changing needs

ed Care is unable to meet the disability needs of older people, the NDIS should











MND Australia believes:











POSITION STATEMENT

Alternative therapies and people diagnosed with MND

Background:

There is ongoing and growing interest in alternative, off label and unproven treatments within the ALS/MI community globally. For the purposes of this Position Statement these terms refer to treatments or intenthat have not been scientifically proven via clinical trials to be safe and to improve outcomes for people w ALS/MND.

Those with ALS/MND have always been interested in alternative therapies. It is understandable that whe have been informed that you have a terminal illness and conventional medicine cannot provide effective therapies or a cure that you will look to alternatives which may provide you with some hope.

Palliative Care and Neurological Conditions

Position Statement

This is a joint position statement from Palliative Care Australia (PCA) and the Neurological Alliance Australia (NAA)

Palliative Care Australia is the national peak body established by the collective membership of eight state and territory palliative care organisations and the Australia and New Zealand Society of Palliative Medicine. Together the Palliative Care Australia members network to foster, influence and promote local and national endeavours to realise the vision of quality care for all at the end of life.

The Neurological Alliance Australia is an alliance of not-for-profit peak organisations representing adults and children living with progressive neurological or muscular diseases in Australia. The Alliance was established to promote improved quality of life for people living with these conditions and funding to support research. Members of the Alliance include Alzheimer's Australia, Brain Injury Australia, Huntington's Australia, Motor Neurone Disease (MND) Australia, MJD Foundation, MS Australia, Muscular Dystrophy Australia, Muscular Dystrophy Foundation Australia, Parkinson's Australia and Spinal Muscular Atrophy Australia.

PCA and the Neurological Alliance Australia believe:

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 Thank you to all the federal MPs and Senators who wore the blue comflower



IN VISION

orld free from MND

MND Australia

Published by Morag Millington [9] - ★ Favourites - 8 May - ②

ustralians don't know that you can't access the NDIS if you're sed with a disability aged 65+. Even a non-age related disability like We need to end this age discrimination! os://bit.ly/2SA5Xpl

Neek2020 #MACF





7.266

DD 222

nople reached



at Parliament House this week in the lead up to Global ALS/MND Awareness Day. Here's a few that we spotted * #ALSMNDWithoutBorders

























- Lives with MND
- Age over 6s
- ceives an NDIS plan to Cannot receive an NDIS plan as he is over 65 years
 - Stuck on the Aged Care waiting list for over eight months

Receives funding for vital Mark No funding for vital equipment through NDIS equipment





1,740 Engagements

Boost post

30 comments 85 shares







RELATED STORY: NOIS relieut plagued with problems, FOI

Kirsten Harley applied for technology that allows people use eye movement to

Her request was refused last Wednesday NDIS spokeswoman says it is easy to focus on cases that "aren't right"

Terminally ill mother fears NDIS writing off

people with neurological conditions

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

disease (MND) and will lose the ability to move The former academic applied to the NDIS for technology that allows people to use eve-

activities, such as opening doors.

"It's pretty upsetting because it obviously affects me but it also affects my 11-year-old daughter [Kimi] and my husband [Densil] and family and friends around me "she told the ARC

Like

Comment .

A Share

Right care. Right place.

Right time.

Sign the petition





6. Partnering and Collaborating



















I SUPPORT

THE NDIS,

It's time to make every

Australian count

PARI IAMENTARY 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

embers of the Neurological Alliance Australia (NAA), including morning tea.

v 22 March 2017, commencing at 11.00 am.











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

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

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.

awareness and funds on Global Day

Why June 21?

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!