



Submission to the Public Consultation Paper for the
National Dementia Action Plan

January 2023

Thank you for the opportunity to respond to the public consultation paper regarding the new National Dementia Action Plan.

Background on mitochondrial disease and dementia

Mito Foundation supports patients with mitochondrial disease (mito) and their families. We estimate that approximately 2500 Australian live with a diagnosis of mito while 1 in 200 carry a gene change that puts them at risk of developing mito in their lifetime.

For many Australians living with mito, including children and adults, dementia is one of their symptoms. Estimates of prevalence vary, but we do know:

- Mito is the second most frequent cause of childhood dementias, with the subgroup accounting for 20% of all identified disorders leading to childhood dementia¹
- Estimates of dementia for some types of mito are as high as 90%²
- Many people with mito are accessing dementia related supports³

In addition to providing support and information to Australians living with mito, Mito Foundation funds essential research into the prevention, diagnosis, treatment and cures of mito, and increases awareness and education about this devastating disease. Mito Foundation was founded in 2009 by several families personally impacted by mito along with professionals with a special interest in mito.

Our work is informed by our Mito Community Advisory Panel, regular engagement with the wider mito community through support services and through research projects.

Endorsement of submission from Childhood Dementia Initiative

Mito Foundation supports all aspects of the submission to this consultation from Childhood Dementia Initiative (CDI). Mito Foundation is a partner of CDI and our CEO, Mr Sean Murray, is a board member of Childhood Dementia Initiative. CDI is shining a light on a group of children and families that have struggled with existing health and disability services.

We consider these aspects of the CDI submission most important to children with mito and their families:

- Improved data collection and reporting
- Reducing risk through implementing genetic screening programs
- Ensuring existing services are suitable for children with dementia
- Investing in care coordination to ensure timely access to specialist services when families need them
- Increasing workforce knowledge and confidence

¹ THEMA Consulting Report. Childhood Dementia in Australia: quantifying the burden on patients, carers, the healthcare system and our society [Internet]. 2020. Available from: www.childhooddementia.org/burdenstudy

² Moore HL, Blain AP, Turnbull DM, Gorman GS. Systematic review of cognitive deficits in adult mitochondrial disease. *Eur J Neurol.* 2020 Jan;27(1):3–17.

³ Informal advice from Dementia Support Australia provided in 2022 to Mito Foundation

The importance of the Action Plan to adults with mito

For many adults diagnosed with mito, cognitive impairment that worsens over time can be one of their most challenging symptoms. These may be accompanied by other symptoms such as muscle fatigue, diabetes, sensory disabilities, epilepsy, cardiomyopathy, gastrointestinal problems, and/or kidney disease.

We have reviewed the consultation paper considering the needs of adults with mito. Mito Foundation supports the Action Plan's proposed objectives and immediate priorities.

Ensuring dementia is recognised at all ages

Building on the submission from CDI to ensure that children with dementia are recognised, we suggest that the Action Plan specifically highlights the importance of the action plan addressing needs at all ages. We suggest that the principles of the Action Plan are modified to state that Dementia care is:

appropriate and accessible to all people, including people of all ages, priority population groups and people from diverse backgrounds

Expanding the scope of priority populations to include those with more diverse disabilities

We support the inclusion of people with a disability as a priority population in the Action Plan. We suggest that the description of this group is expanded beyond the current focus on people with intellectual disabilities. People with complex and/or genetic conditions, including mito, should be included in this description.

The Action Plan can lead to improved recognition of dementia in mito

Our experiences providing information and support to adults with mito suggest that many adults with mito would meet the diagnostic criteria for dementia, but are not being diagnosed and/or not identifying with this term. We have supported adults with mito to access the appropriate services they will require to receive an assessment of their cognitive symptoms and subsequent diagnosis of dementia. We have also assisted our clients, their families and carers to be connected to the correct pathways to manage the ongoing and changing behavioural symptoms. We believe that many factors play a role in delayed diagnosis of dementia in mito:

- Stigma and fear from people with mito and their family members, leading to them not seeking out a diagnosis of dementia.
- A lack of confidence in health professionals leading to them not referring people with mito for assessment.
- A lack of available assessment and diagnostic services, particularly in regional, rural and remote areas.

Efforts to reduce stigma (objective 1), improve diagnostic services (objective 3) and build dementia capability in the health workforce (objective 6) will contribute to improving this for people with mito.

We suggest that objective 3 could be strengthened by including a reference to integration with genomic medicine. As more genomic causes of dementia are discovered through research, strong partnerships with genomic services will assist with early diagnosis of those with a genetic risk factor.

Thank you again for the opportunity to provide this input. Mito Foundation is happy to be contacted for further information on this submission.

Contact person:

Clare Stuart

Policy and Advocacy Manager

clare.stuart@mito.org.au

Phone: 0410 685 181.