



What does the Budget 2020 – 2021 mean for people living with MND?

MND Australia response to the federal Budget handed down by the Treasurer on Tuesday 6 October 2020

MND Australia recognises the global economic impact of COVID-19 and the consequent overwhelming influence on the Budget handed down last week. This big spending Budget, the biggest Australia has seen, rightly focused on providing immediate stimulus to the economy in response to the devastating impact the pandemic has had on so many Australians. We believe, however, that opportunities were missed to hand down a visionary budget that would stimulate the economy as well as provide job opportunities and positive social reform through increased investment in health, aged care, disability and the research sector.

Aged Care

MND Australia welcomes the investment of \$1.9 billion over four years to support an additional 23,000 home care packages. This is a substantial increase on last year when an additional 10,000 home care packages were funded. However, in light of the recommendations of the Aged Care Royal Commission interim report, and the fact that this will still leave 80,000 people waiting for a home care package, this falls well short of what is needed.

It is important to note that just 2,000 of the 23,000 places offered are for level 4 assistance which means that many people living with MND aged 65 and older will continue to be assigned a lower level package. And many will continue to die before receiving a home care package at the level they have been assessed as needing.

With an ever growing national queue and a lack of commitment to reduce waiting times to 30 days and ensure no one is prematurely forced into residential aged care these measures should be seen just a beginning for longer term reform. There will be an urgent need for the government to act quickly in response to the final report from the Royal Commission due in early 2021.

More than \$125.3 million will be provided over three years to replace the Commonwealth Continuity of Support (CCOS) Program with a new [Disability Support for Older Australians program](#) to ensure older Australians with disability who are not eligible for the NDIS continue to receive the supports. This program will only support those currently on the CCOS program and will therefore be of no assistance for newly diagnosed people with MND over 64.

We will continue our campaign to [Make Aged Care Fair](#) and stand ready to work with the government to improve access to support and services for people diagnosed with MND when aged 65 and over.

National Disability Insurance Scheme (NDIS)

The Treasurer Josh Frydenberg announced last week that there would be an additional \$3.9 billion for the NDIS. Many people living with MND under the age of 65 are now accessing services and support through the NDIS and this is having a positive impact on quality of life, safety and community engagement.



We therefore welcome this additional investment and the confirmation that the NDIS will always be fully funded under a Coalition government. However, each year the NDIS gets bigger with more people in the scheme, and as well as inflation and wage growth this means things will cost more. We hope that this extra funding will be sufficient to fund all this without the need to reduce participants funding.

People on carer payment and carer allowance, disability support and aged care pensions will receive two separate \$250 support payments through \$2.6 billion budgeted to provide the payments to eligible people. Payments will be made between November and early next year.

Health

Last week's budget saw a record investment in health over 4 years of \$467 billion up \$32 billion on last year. Of course most of the investment is aimed at funding measures introduced in response to the COVID 19 pandemic.

We welcome the government's commitment to the extension of MBS for telehealth to March 2021. Subsidised telehealth services includes GP, nursing allied health mental health and essential specialist services. We understand that a long-term design is being developed in conjunction with medical groups and the community. We look forward to continued investment and support for telehealth services, where appropriate, as outlined in our [Neurological Alliance Australia \(NAA\) joint position statement](#).

An investment of \$39 billion guaranteed MBS and PBS spending in 20/21 reflects an increase of \$7.9 billion from last year. The PBS new medicines funding guarantees new funding each year for listing of new medicines on PBS and we are hopeful that should one of the clinical trials currently underway prove to be effective that this will help fast track access. We have recently written to Minister Hunt to seek PBS listing for Robinul (Glycopyrrolate), a medication used to manage saliva in people living with MND, and hope this will be considered in light of this investment.

The budget provided investment in rural health to expand training opportunities for doctors, encourage more multidisciplinary care and trial new models in primary health care which may improve access to multidisciplinary care for people with MND living in rural and remote communities. The increased Medicare funding to enable people to access up to 20 psychology sessions as recommended by the productivity commission, in place of the current cap of just 10 sessions also has potential to benefit people living with MND and family carers.

We welcome the \$3.6 million that has been provided to extend the [Greater Choice at Home Palliative Care](#) program nationally through primary health networks. However, with the huge demands for palliative care services in Australia we are concerned that people living with MND will continue to struggle to access palliative and end of life care in a timely manner.

Research

An extra \$1 billion this financial year through the Research Support Program will enable universities to lessen the significant reductions in research support and infrastructure driven by the loss of international student fees. This will help to maintain Australia's international profile in MND research. This support of university research jobs is a welcome interim step towards establishing a more sustainable higher education sector. However, the \$1 billion will not fully repair the damage already inflicted by COVID and will not provide the continuing



support required in the face of the ongoing multi-year impact on international student numbers.

The Government will restore an additional \$2 billion over 4 years through the Research and Development Tax Incentive (R&DTI) to help innovative businesses that invest in research and development. It is doing this by reversing some of the changes to the R&DTI legislation that are currently before the Senate. This funding restoration is welcomed and will provide opportunities for companies to invest in new technologies and treatments sorely needed for MND. Cutting edge technology such as eye-gaze and brain interfaces are critical in enabling people living with MND to communicate and maintain their quality of life. With no effective treatments or cures currently available, industry investment is needed to help bring the many Australian discoveries to the clinic.

The budgets for the NHMRC and MRFF remain virtually unchanged. At the same time, researchers are dealing with extra costs to their funded projects due to the delays and disruptions caused by COVID-19. While the universities benefit from the one-off increase in the Research Support Program, there is no similar support for researchers in Medical Research Institutes. MND Australia remains concerned that NHMRC funding has not increased over the forward estimates to keep pace with inflation, with the net effect that NHMRC funding continues to decline in real terms.

For more information read [Research Australia's Budget Update](#)

Carol Birks – CEO, MND Australia

About MND Australia

MND Australia, its research arm, MND Research Australia, and members, the State MND Associations, form the only national network focused on improving the lives of all Australians living with motor neurone disease (MND) and advancing research to end MND. For over 35 years this national network has helped increase understanding of the disease and advocated for improvements in its treatment and care to ensure people living with MND have the best quality-of-life possible. The six state based MND Associations provide direct support and services to people living with MND in all states and territories.

About MND

MND is the name given to a group of neurological diseases in which motor neurones, the nerve cells that control the movement of voluntary muscles, progressively weaken and die. With no nerves to activate them, the muscles of movement, speech, swallowing and breathing gradually weaken and waste, and paralysis ensues. MND affects each person differently with respect to initial symptoms, rate and pattern of progression, and survival time. Average life expectancy is 2 to 3 years from diagnosis.

There is no known cause for MND (except in a very small number of genetic cases), no effective treatments and no cure. There are no remissions and progression of MND is usually rapid and relentless creating high levels of disability and a consequent need for a wide range of progressively changing supports.

[MND Australia pre- budget submission](#)
[National Action Framework](#)
[\\$25 million, 25 Milestones: Changing the future of MND](#)
[Deloitte report – Economic analysis of MND in Australia](#)