Support for South Australians living with MND

For the Future

with Aust





Acknowledgment of country.

We acknowledge and respect the Traditional Custodians whose ancestral lands we live and work upon and we pay our respects to their Elders past and present. We acknowledge and respect their deep spiritual connection and the relationship that Aboriginal and Torres Strait Islander people have to Country. We also pay our respects to the cultural authority of Aboriginal and Torres Strait Islander people and their nations in South Australia, as well as those across Australia.

Published 24 February 2022

WHY WE'RE DOING THIS

Motor neurone disease (MND) is the common name for a group of diseases that affect a person's motor nerves – making a person's muscles weaker until eventually they reach a state of paralysis. There is currently no known cure.

There are approximately 150 South Australians living with MND at any one time, with roughly six to eight lost to the disease every month.

MNDSA is the peak body representing MND sufferers for 35 years, providing rapid access to much-needed equipment and services and helping MND sufferers navigate the complex national system to apply for funding packages. They also advance MND research and raise community awareness about MND.

Over 65's represent approximately 65% of MNDSA's clients, or about 100 South Australians at any given time. If an MND sufferer is over 65, when diagnosed they can't access the NDIS, and must instead apply for support via existing Federal systems such as My Aged Care.

These existing systems are overwhelmed, taking months and even years to help patients – time MND sufferers simply do not have. Sadly, up to 80% of



Adelaide grandfather with motor neurone disease urges expansion of support South Australians living with MND over 65 die before receiving the appropriate level of Federal support.

Even where a person living with MND is eligible for the NDIS, there is often a long wait and many hurdles to cross – time and effort these South Australians don't have on their side.

Governments in New South Wales, Victoria, Queensland, and Western Australia all provide their peak MND bodies with financial support. MNDSA receives no ongoing funding from the Marshall Liberal Government.

The Liberals provided MNDSA a mere \$50,500 to assist with equipment purchases back in 2019 – this tiny amount of funding quickly dried up.

What MNDSA needs is ongoing support.

Last year, Labor stood with MNDSA to call on the Marshall Liberal Government to provide support to over 65's living with MND, following repeated requests from the organisation to the Government direct. Those requests have not been met.

"An MND diagnosis is terminal in more ways than the obvious one. It is the immediate and devastating death of the life you have been living and of the trajectory you fancied you were on.

The same is true for those who, out of love and deep integrity, will take up a life centred on the intricacies and toil of caring for you ...

The MND Association is a good shepherd to those that need them. What about the SA Government?"

Craig Delaney, SA grandad living with MND



LABOR'S COMMITMENT

COST: \$2.4 million

Labor will invest \$2.4 million over four years to support South Australians living with motor neurone disease.

This funding will be directly managed by peak body MNDSA, and the four-year funding agreement will commence from July.

\$500,000 each year will fund a multi-disciplinary team of health professionals to assist over 65's with MND unable to get immediate support from government.

This team will consist of allied health professionals likely comprising occupational therapists, a physiotherapist, a speech pathologist and allied health assistant.

Another \$100,000 per year will allow the organisation to offer rapid-access equipment loans to South Australians living with MND.

This funding will enable MNDSA to loan out equipment such as breathing devices, mobility devices, communication devices and everyday living aids, which can prevent people ending up in hospital.

If elected, this measure will be funded in our first budget. MNDSA have indicated that they would commence any necessary recruitment processes immediately after receiving the funding.

