

NEUROLOGICAL ALLIANCE AUSTRALIA



Submission to the Royal Commission into Aged Care Quality and Safety

15 April 2019

The Neurological Alliance Australia is an alliance of national not-for-profit peak organisations with a focus on representing adults and children, their families, friends and carers, living with progressive, degenerative, neurological or neuromuscular conditions in Australia. Collectively we aim to promote shared issues and concerns for the improved quality of life for people living with these conditions and funding to support research into the treatment, better management and ultimately a cure for these conditions.

Members of the Alliance include Dementia 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, Spinal Muscular Atrophy Australia, Leukodystrophy Australia and Polio Australia.

SUMMARY OF RECOMMENDATIONS

- 1. Admissions of young people into residential aged care must be significantly reduced or stopped altogether through the implementation of an integrated care model and the provision of accessible accommodation options.**
- 2. People with a progressive neurological condition aged over 65 are adequately supported to stay at home for as long as possible through accurate assessment of any functional impairments, implementation of appropriate plans for their ongoing care and support, and an immediate investment of at least an additional 30,000 home care packages**
- 3. The introduction of a formal ‘fast track’ process for automatic access to Level 4 Home Care Packages for people living with complex and progressive conditions**
- 4. Assessments for any level of support (CHSP or Home Care Plans) for people with progressive neurological and neuromuscular conditions should be undertaken by a health professional (e.g. Nurse; Occupational Therapist) with appropriate training/understanding of these conditions**
- 5. Integration of assessment services and easier transfer between CHSP and Aged Care Packages to reduce long wait periods for support to commence.**
- 6. Investment in disease-specific training packages for the aged care sector workforce that address the needs of older Australians living with progressive neuromuscular conditions.**
- 7. State and Federal Governments must come together to develop a sustainable solution to the equitable provision of assistive technology to all Australians.**
- 8. Funding made available for assistive technology in addition to Home Care Package funding to ensure that older people diagnosed with progressive neurological conditions who are living at home can access the assistive technology they need to maintain their independence, quality of life, communication and community access and to support carer health and well-being.**
- 9. If Aged Care is unable to meet the disability needs of older people, the NDIS should develop a safety net model that provides for top-up funding through the NDIS to address needs not met by Aged Care; ultimately, the NDIS should be broadened to include all people with disability, regardless of age.**
- 10. Effective interfaces with allied sectors, particularly health, aged care and palliative care, must be developed to ensure a coordinated inter and multidisciplinary approach to care, specifically the need for better links between aged care providers and primary health/Aged Care Assessment Teams**
- 11. The development of National Guidelines for the management of people with rapidly progressive neurological conditions.**

Introduction

The Neurological Alliance Australia (NAA) is pleased to provide a submission to the Royal Commission into Aged Care Quality and Safety.

The focus of the comments provided in this submission are on key areas that will impact on people affected by living with progressive neurological or neuromuscular diseases in Australia.

The members of the NAA are able to make estimates of the number of people diagnosed with the conditions represented by the Alliance and also the annual cost to the Australian economy through economic impact studies.

Overall, it is estimated that nearly 1.3 million Australians live with these diseases with an annual cost to the Australian economy of over \$36 billion every year.

We believe that people affected by a progressive neurological conditions should be able to access whichever support system best meets their needs, whether it be the National Disability Insurance Scheme (NDIS) or My Aged Care. Currently there is inequity in Government support of people living with these conditions. People under the age of 65 diagnosed with a progressive neurological condition, eligible for the NDIS, will access supports to meet their individual needs. People aged 65 and over must rely on the aged care system which, unlike the NDIS, is capped, means tested and designed to address ageing, not disability.

This inequity is causing many people to be pushed into financial hardship or residential aged care earlier than they wish.

Inadequate assessment and support for people with a progressive neurological condition has led to problems with the level of aged care programme and/or plan funding and longer wait periods as problems in the original assessment and support emerge. This leads to people having longer wait time, increased financial burden and stress and inappropriate level of care. This increases stress to their current function and reduces the capacity for family, friends and health care providers to support their functional needs.

To ensure people who are over 65 and living with a disability are able to maintain their well-being and live a fulfilled life, it will be necessary to ensure that adequate support is provided for them to:

- stay at home for as long as possible;
- engage in the community;
- stay at work for as long as possible with appropriate support and flexibility in the workplace; and
- ensure their financial security is maintained to cater for such things as housing, aids and equipment and a quality social life.

In general, aged care support has a much greater focus on personal care and in-home support rather than community participation – an important, often vital aspect of life for a person affected by a chronic, progressive neurological condition.

Terms of reference

The terms of reference (ToR) for the Royal Commission into Aged Care Quality and Safety are:

- a. the quality of aged care services provided to Australians, the extent to which those services meet the needs of the people accessing them, the extent of substandard care being provided, including mistreatment and all forms of abuse, the causes of any systemic failures, and any actions that should be taken in response;
- b. how best to deliver aged care services to:
 - i. people with disabilities residing in aged care facilities, including younger people; and
 - ii. the increasing number of Australians living with dementia, having regard to the importance of dementia care for the future of aged care services;
- c. the future challenges and opportunities for delivering accessible, affordable and high quality aged care services in Australia, including:
 - i. in the context of changing demographics and preferences, in particular people's desire to remain living at home as they age; and
 - ii. in remote, rural and regional Australia;
- d. what the Australian Government, aged care industry, Australian families and the wider community can do to strengthen the system of aged care services to ensure that the services provided are of high quality and safe;
- e. how to ensure that aged care services are person-centred, including through allowing people to exercise greater choice, control and independence in relation to their care, and improving engagement with families and carers on care-related matters;
- f. how best to deliver aged care services in a sustainable way, including through innovative models of care, increased use of technology, and investment in the aged care workforce and capital infrastructure;
- g. any matter reasonably incidental to a matter referred to in paragraphs (a) to (f) or that [the Commissioners] believe is reasonably relevant to the inquiry.

Young people living in residential aged care (ToR b. i.)

More than 6,000 Australians aged under 65 live in aged care facilities¹². Of those, around 2,000 have joined the NDIS but so far only 2% of these participants receive housing support in their plans³.

The recently announced Royal Commission into the aged care sector will seek to address the issue of young people living in residential aged care. The NAA wholeheartedly supports this approach in the hope that it will prevent more young people from entering the aged care system.

New admissions of young people into residential care are not acceptable in 2019 and beyond.

Immediate adjustments are needed to:

- Remove barriers to provide young people in RAC with NDIS packages, including Specialist Disability Accommodation allowances that enable young people to leave residential care.
- Ensure the NDIS is integrated with the housing and health sectors so that accommodation options are available, equipment and other disability support needs are met as well as meeting health needs such as nursing and clinical supports.
- Invest in an appropriately trained workforce to ensure young people with disabilities receive the support they need
- Invest in specialist accessible housing and accommodation developments to dramatically increase supply

¹ Summer Foundation Young People in Nursing Homes Fact Sheet www.summerfoundation.org.au

² Around 10% of these are people with Huntington's disease who often require more specialised care than most aged care homes can provide

³ Summer Foundation NDIS Report Card, Outcomes for younger people in residential aged care June 2018

- Commit state disability systems to deliver their full suite of services to young people who remain in aged care while they wait for the NDIS to reach them.

Case study: Shelley is a Family Advocate and has previously worked in the health and aged care sectors.

During the time I worked in Aged Care I nursed many residents under 65 years of age who lived with chronic, deteriorating neurological and other similar conditions. One resident remains clear in my mind, he was a 30+ year old male who entered care because the Home Care Service the family had engaged did not provide him with appropriate care. A nurse who was a friend of the family would visit regularly and saw he was dirty and unkempt and was losing weight rapidly.

The family (who lived some distance away) were informed and they made formal complaints to the service. No action was taken against the care staff by the local area manager. The complaints were genuine, and the service never followed up, no one was accountable for their practice. Rather than 'fight' the system due to Exhaustion, the family felt they had no choice but to move their brother into an Aged Care Facility.

This was devastating as they could not access any other appropriate housing for him. I met the resident, then aged 35, when he moved into care. He had been an electrical engineer and travelled the world extensively with his friends and family. He loved music, the theatre, reading and most of all travelling and experiencing different cultures and food. When he initially entered care, he would have lucid periods and we would talk about his travels, and his face would light up.

He said in the aged care home he felt like he was already in his 'coffin'. He would say he had no stimulation and it was difficult to see others he had made friends with dying around him. All he wanted was to have some fun. All the aged care home provided was weekly bingo and pamper days. The aged care home at the time did not provide external outings as they had no bus.

It was devastating for us nurses to watch the resident sit around all day watching TV with little other stimulation. I eventually decided to have long conversations with the family to find out how we could assist their loved one. We made some arrangements to provide him with regular visitors and some stimulating activities.

He was fortunate that the staff were willing to give of their own time and that he had a caring family.

He lived in the Care Home for 4 years until he died peacefully, aged just 39. This young man deserved to have appropriate Home Care services and to be transitioned into young person's housing. I feel it is every one's human right to enjoy their life and be provided with a safe, clean and appropriate housing.

Recommendation:

Admissions of young people into residential aged care must be significantly reduced or stopped altogether through the implementation of an integrated care model and the provision of accessible accommodation options.

The Australian Government's Younger People in Residential Aged Care - Action Plan

Most recently, in March 2019, the Australian Government has announced a "Younger People in Residential Aged Care - Action Plan". This Plan has three goals:

1. Supporting those already living in aged care aged under 45 to find alternative, age appropriate housing and supports by 2022, if this is their goal;

2. Supporting those already living in aged care aged under 65 to find alternative, age appropriate housing and supports by 2025, if this is their goal; and
3. Halving the number of younger people aged under 65 years entering aged care by 2025.

The Alliance welcomes this announcement, supports these goals and the aim in the Plan to, “Continue to work beyond 2025 to minimise to the fullest extent possible the number of younger people aged under 65 years entering and living in aged care.”

Under the heading “Understanding younger people who enter aged care”, the Plan states that the “Australian Government will conduct an analysis of the characteristics of younger people in aged care to understand their needs and what works. This work will also improve data and reporting.”

It will be important for this analysis to include the *reasons* for younger people entering aged care, as we believe this is symptomatic of system failure, and detailed analysis may assist with developing solutions.

Help people to stay at home for as long as possible (ToR c. i.)

Members of the NAA are keen to ensure that people are adequately supported to stay at home for as long as possible and are only recommended for residential care when every other possible avenue of care and support has been exhausted. This will, for example, require an intervention in Aged Care Assessment Team processes to ensure a person’s functional impairment is accurately assessed and appropriate recommendations can be made for their care and support. We do not want people with progressive neurological conditions to run the risk of being admitted to residential aged care facilities earlier than is absolutely necessary.

This also necessitates investment in additional home care packages to alleviate long waiting lists. The wait lists for support, and the limited availability and options for flexible care, are leading to many people falling below a functional level of independence, becoming in need of greater assistance.

The NAA supports the Council On The Ageing (COTA) recommendation for at least 30,000 additional packages to ensure older Australians never have to wait longer than three months⁴.

Case study: John was living with Motor Neurone Disease (MND), cared for by his wife.

In March 2016, John was initially assessed by a Regional Assessment Service (RAS) after a MND Advisor submitted an on-line referral for Occupational Therapy (OT) and Physiotherapy. No other supports were requested by John at this time.

In May 2017, the Community Health OT organised an Aged Care Assessment Team (ACAT) assessment which was completed in June 2017. John was placed on the national queue with a High Priority for a level 4 Home Care Package (HCP).

By late September 2017, (three months after assessment), no package of care had been received. John and his wife were very frustrated. They contacted the former Federal Assistant Minister for Health, David Gillespie requesting assistance. Within two days an ACAT representative contacted John’s wife and explained that they could only advise that an urgent level 4 package still has a 1-3 month waiting period. John’s wife responded, pointing out that it was now 4 months since John’s assessment. Understandably, John’s wife did not feel supported from this conversation. Prior to this conversation, John had chosen to pay for some private personal care support.

⁴ COTA Australia, Position Paper, Keep Fixing Australia’s aged care system, September 2018, p 8

Throughout October 2017, John and his wife reported that they were just managing. They said they are doing OK but wanted reassurance that a HCP was going to be available soon. They continued to pay for private personal care support for John for three mornings per week.

In late November 2017, five months after assessment, John's condition had deteriorated further and he was admitted to hospital. During this time he was informed that his HCP had been approved, John was never discharged home from hospital and died before they could accept the package.

This is a typical scenario for people living with MND. People are waiting many, many months for Home Care Packages and often dying before they get one.

What to consider when making an assessment

Eligibility for home care packages is assessed by Aged Care Assessment Teams/services.

Often, if it is determined a person is managing, they will have an assessment for Commonwealth Home Support, rather than a home care plan. The Regional Assessment Service (RAS) assessor may not have a health-related qualification. This can lead to inadequate understanding and assessment of someone who has a complex progressive neurological condition. When there are more complex health needs identified, longer wait times have been created as someone waits for an appropriate assessment for their needs, before any funding, or package, becomes available.

A polio survivor states, "I do not feel that the effects of polio are understood by so-called professional interviewers".

There needs to be a better interface between Commonwealth Home Support Program and Aged Care Packages. Someone making the transition, which is the reality for many people with progressive neurological and neuromuscular conditions, are left waiting longer than 18 months for services to commence (after waiting months for an assessment). This leads to further declines in function and often out-dated recommendations for assistance.

There is a need to mandate the appropriate, adequate and expert assessment of a person's disability needs, including the application of an understanding of progressive neurological conditions⁵, and other special needs that a person may have. Here are some examples:

- Aids and equipment
- Flexible respite options (for the person with the condition and their carer(s))
- Appropriate therapy/health service supports with a level of hours of support adequate to ensure a person can remain at home
- Support for the primary carer and family to return to their own personal pursuits and roles is also critical
- Variability in the significance of symptoms (including, but not limited to fatigue, weakness, pain, strength, coordination) that affect someone's need for support, and caregivers' capacity to contribute to this support

There is also a need to ensure an integrated approach to assessing the needs of the individual including the impact and implications for family. Often when ongoing support can be provided, (via a disease specialist

⁵ For example, an understanding that some people have little or no insight into their condition and will insist they are fine and do not need support, when objective clinical evidence shows the opposite to be true.

organisation) the burden of care can be minimised and the family feel more able to sustain the home environment.

Case study: Sue's mother (diagnosed with MS) was in aged care respite earlier last year (2018) due to a mobility scooter accident and an infection.

Sue says, "They got me to put her in respite for 2 weeks (they wanted it to be permanent). She hated it. She was the youngest person there, she was left in bed all day in a room with four other people with the curtains drawn all day and hardly any staff or cognoscente people around.

She loves being in the community, riding her mobility scooter around, going to the shops by herself. Am I crazy for thinking they are recommending the wrong thing?? Also she is a complete pensioner with no assets due to having MS most of her life, so she can't sell any houses to get a nice swanky nursing home to move in to.

Does anyone know much about ageing with MS and what services I should be asking for at home? I'm a bit overwhelmed."

Recommendations:

- (i) People with a progressive neurological condition aged over 65 are adequately supported to stay at home for as long as possible through accurate assessment of any functional impairments, implementation of appropriate plans for their ongoing care and support, and an immediate investment of at least an additional 30,000 home care packages**
- (ii) The introduction of a formal 'fast track' process for automatic access to Level 4 Home Care Packages for people living with complex and progressive conditions**
- (iii) Assessments for any level of support (CHSP or Home Care Plans) for people with progressive neurological and neuromuscular conditions should be undertaken by a health professional (e.g. Nurse; Occupational Therapist) with appropriate training/understanding of these conditions**
- (iv) Integration of assessment services and easier transfer between CHSP and Aged Care Packages to reduce long wait periods for support to commence.**

Lack of aged care sector workforce knowledge (ToR f.)

Case Study: Gillian, Post-Polio Syndrome

Gillian sustained a fall that resulted in a double-fracture of her pelvis. This occurred while being supported by a domestic worker unfamiliar with neurological limb weakness. Gillian is now looking at her options in aged care.

Gillian says, "Because of this fall, I have completely lost my independence, I cannot rely on paid help and am lucky to have kind friends. I did receive help but no longer have any confidence in the provider after the terrible fall. After a lifetime on crutches and a calliper plus a very weakened right leg to boot, I wish to remain at home as long as possible..... if only one could find a reliable and informed person who understands the situation and does not lump one in with "old age". Awareness and training of polio and its implications is really missing."

The NAA is concerned that there is a lack of aged care sector workforce knowledge regarding specific progressive neurological and neuromuscular diseases, recognising, treating and addressing symptoms and providing for the disability needs of older Australians more broadly. A solution is for the sector to invest in training packages for the aged care sector workforce. This training could take the form of short on-line modules that lead to professional development accreditation, and could draw on, or be modelled on, the disease “snapshots” currently under development by the National Disability Insurance Agency (NDIA) for internal use by NDIA staff.

Recommendation:

Investment in disease-specific training packages for the aged care sector workforce that address the needs of older Australians living with progressive neurological and neuromuscular conditions.

Case study: Bob was almost 69 when he was diagnosed with motor neurone disease (MND).

From then on everything changed. Bob had to leave his job, and plans to travel with his wife, Julie, during their retirement were cancelled.

Bob said: “Your retirement is completely changed. Where instead of being able to do some travelling etc, that’s been cut out for both of us.

A lot of the money we had earmarked for that we have we spent on house modifications and equipment around the place. We did receive some under MASS (medical aids subsidy scheme) but the rest has been up to us really.”

Bob and Julie applied for Aged Care support not long after Bob was diagnosed and were initially awarded a level 1/2 package in 2013 but despite Bob’s needs increasing, it was just over a year ago that they were finally given the higher level package.

Julie said: “The service providers couldn’t give us the help we wanted and they said ‘oh no, it’s a good idea to bank your money, you’ll need it later on.’ And then we kept on saying ‘we need more help, we need more help’ and they kept saying ‘we don’t have the staff, we don’t have the staff’ so we actually changed ships to another group and some of that banked money we are now using because we need more care than what we can afford through the Level Four package. But I don’t know how long that will last, that’s the problem now.

Moving from the lower to the higher level care package wasn’t without its problems either.

Bob and Julie said: “We’ve only been assessed once and that was not long after diagnosis and I think it was fairly confronting because the whole thing was new and raw. And then about two years ago they wanted to reassess Bob and I said ‘no, there’s need to, don’t you know what his diagnosis is?’ and the two people that rang me from ACAT had no idea what MND was! And then finally a woman rang me and I said ‘Look, this is ridiculous! Reassessing when the needs are just escalating. It’s Motor Neurone Disease, surely you don’t have to spell out the obvious!’ She said ‘I know exactly what it is, and I’ll push everything through.’ And I think that’s when we went onto the Level Four. But they wanted to send someone to the house to reassess you. Silly things like that.

There was a person who came out and we assumed that she knew about MND but by the time you got talking to her a little bit, you found out that she did not know anything about MND. She only tried to push across that she did. Once we found out you felt like saying ‘look, you’d better go because this is just useless!’ We even had to pay for that person to come out.”

Despite being on the high package now, Bob and Julie are still not receiving the level of care and support Bob needs, and have been forced to spend their savings and superannuation on housing adaptations and equipment, which can be extremely costly.

Julie and Bob said: "We bought our own hospital bed and manual chair and shower chair and ramps, a lot of those Tyrex ramps we put in ourselves around the house. And an internal ramp and an external ramp to the carport. We've done all of that.

We do use taxi vouchers a bit. But also we do use the mechanical wheelchair, you know, go out in that, and that means that Julie has got to lift it in and out of the vehicle, which works pretty well but does get a bit tiring for Julie.

Once I can't transfer Bob in and out of the car, we'll be using taxis all the time with the powered chair. But we can't afford to change cars. We're more restricted going out and spend more time at home."

Julie added: "So the Level Four Package... It would be nice to have some psychological support with it, but everything they say 'you've got to pay out of your package', but we need the package for care time rather than anything else.

And from six o'clock in the evening until six o'clock in the morning, or seven o'clock, you don't get anything. That's totally Julie. It would be nice to have some additional care during those hours."

Equal access to assistive technology⁶ (ToR f.)

The current system

The National Disability Insurance Scheme (NDIS) provides support for people with disabilities, their families and carers. Rollout of the scheme commenced in 2013. In the aged care sector, My Aged Care is the main entry pathway to the aged care system, providing a central access point to aged care funding. Home care funding for older people living independently in their own home has been consolidated into two main programs: the Commonwealth Home Support Programme (CHSP) and Home Care Packages (HCP) Programme. Under this new funding structure, it is unclear where responsibility lies for addressing the assistive technology needs of older people with a disability, people acquiring a disability because of the ageing process and/or people experiencing frailty.

Access to disability services for people aged over 65 is being restricted as they are required to fit into a "frail aged" service paradigm. This is a major problem for many people with disabilities including neuro-degenerative diseases. It is ageist and potentially discriminatory and tends to deny access to a range of needed services.

Funding and access to assistive technology for people over 65 in Australia is inequitable and confusing. Programs for people over 65 are spread across multiple departments at both the Commonwealth and State level. There is limited coverage under some private health insurance and condition-specific not-for-profits. Despite the spread of funding streams, many people are sacrificing their limited income to self-purchase, waiting longer periods before seeking further assistive technology, which may result in accelerated functional decline, or simply do not have the funds available to support their needs after living with a disability. The lack

⁶ Assistive technology: any item, piece of equipment or product that is used to increase, maintain, or improve the functional capabilities of people living with a disability.

of clarity about what will happen to the Commonwealth Government's Continuity of Support Program after July 1st 2019 makes access to assistive technology all the more precarious.

Short term solutions

Federal and State Disability Ministers to:

1. Confirm funding arrangements after 1 July 2019 and provide clear information to the sector about where older Australians with a disability will go to receive their assistive technology services.
2. Confirm that they will honour their legislative obligations to provide support and services to all Australians living with a disability, by continuing to subsidise the purchase or hiring of assistive technology through state-funded assistive technology programs (such as SWEP in Victoria), until such time as an equitable program is developed for older Australians with a disability.
3. Ensure sufficient funding for assistive technology requirements is available to older Australians.

Case study: 62 year old Lyn has a 70 year old husband Bob who has been living with MS for the past 30 years.

Because of the rules in place with NDIS, Bob can only access My Aged Care, which doesn't give the same amount of assistance as does NDIS. Presently Bob has been waiting 15 months for any action/assistance on his approved aged care level 4 application. In that 15 months they have spent in excess of \$10,000 directly attributable to Bob's needs. With an NDIS package these costs would have been covered.

Disability effects more than the person with the disease, it also has a huge impact on the life of the carer as well as family. In this case if Lyn was the one with MS, she would get an NDIS package and their life and wallet would be a whole lot better off!

Recommendations:

- (i) **State and Federal Governments must come together to develop a sustainable solution to the equitable provision of assistive technology to all Australians.**
- (ii) **Funding made available for assistive technology in addition to Home Care Package funding to ensure that older people diagnosed with progressive neurological conditions who are living at home can access the assistive technology they need to maintain their independence, quality of life, communication and community access and to support carer health and well-being**

Interface with other sectors

Everyone living with a progressive neurological or neuromuscular condition should have access to the right care, in the right place at the right time.

We want to create articulated pathways of care and support, with an emphasis on consumer-directed care, recognising that families and carers can only do so much. The majority of disease-specific organisations have clinical guidelines and training packages available for health professionals working in aged care to have the necessary understanding of how to work with people with progressive neurological and neuromuscular conditions. The introduction of policies to bring about mandated integration between the aged care, health care and disability care systems will ensure people with a disability have their needs met, regardless of which

system they access. This approach will also bring about efficiencies in the NDIS, through the streamlining of services and support.

Recommendations:

- (i) *If Aged Care is unable to meet the disability needs of older people, the NDIS should develop a safety net model that provides for top-up funding through the NDIS to address needs not met by Aged Care; ultimately, the NDIS should be broadened to include all people with disability, regardless of age.***
- (ii) *Effective interfaces with allied sectors, particularly health, aged care and palliative care, must be developed to ensure a coordinated inter and multidisciplinary approach to care, specifically the need for better links between aged care providers and primary health/Aged Care Assessment Teams,***
- (iii) *The development of National Guidelines for the management of people with rapidly progressive neurological conditions.***