Submission to
the Department of Health and Aged Care's Consultation
on the National Dementia Action Plan 2023-2033

Young People In Nursing Homes National Alliance
February 2023

Submission to the National Dementia Action Plan 2023-2033 Consultation
Department of Health and Aged Care

February 2023

Introduction

The Young People In Nursing Homes National Alliance is pleased to provide this submission to the consultation on the National Dementia Action Plan 2023-2033.

This submission will address the rapid rise in the number of people living with Young Onset Dementia (YOD); the significant and wide ranging lack of services for this group; the very real risk that these young people will be inappropriately placed in residential aged care services because the service options they require simply do not exist; and the need for the National Dementia Action Plan 2023-2033 to make specific provision for this growing group of young Australians.

We make the point that dementia is not a set of diseases that only relate to ageing. These diseases do impact younger Australians in a range of ways that must be recognised and responded to accordingly. We also address the issues faced by people in the stages of disease where support services and clinical oversight is required.

Every individual and family member the Alliance has supported has felt like a pioneer in negotiating the service system and creating support responses that are at best, only makeshift. The lack of any kind of pathway for people across the disease trajectory demonstrates the lack of coherent government policy and industry responses in this area.

Brief, deidentified case studies of people we are working with are included to illustrate the complexity facing people living with Young Onset Dementia in navigating a deficient service system.

About the YPINH National Alliance

Since its inception, the Alliance has provided a range of individual and systemic services to younger people living and at risk of placement in residential aged care (RAC).

Characterised by individuals with complex disability and health issues that can include physical, neurological, cognitive and psychosocial impairments, these individuals commonly require negotiation with programs provided by different government agencies and service sectors to create the integrated service responses they need. A growing number are individuals living with young onset dementia.

As well as working with the disability services system, we work with and across such non disability or mainstream service systems as health, mental health, aged care, housing and justice to achieve the outcomes these younger people and their families' desire.

The Alliance has drawn on its extensive engagement with stakeholders to deliver the systemic advocacy needed to resolve the Younger People In Residential Aged Care (YPIRAC) issue and contribute to other policy development.

We have also worked extensively at the interfaces of the National Disability Insurance Scheme (NDIS) with health, rehabilitation services and aged care and have strong working relationships with State Health programs and services.

As a result of this extended systemic advocacy, the federal government endorsed a Younger People In Residential Aged Care (YPIRAC) Strategy in 2020 that contained dedicated targets to prevent younger people entering residential aged care by 2022; and have no younger person living involuntarily in residential aged care by 2025.

In addition to our policy and service development work, the Alliance routinely responds to requests for assistance from the following people:

- Family members of individuals living with young onset dementia;
- Young people facing nursing home placement;
- Those living in residential settings (both aged care and disability);
- Health networks attempting to discharge young people with dementia and complex health and functional disability support needs to community settings;
- Family members trying to obtain needed supports and services for loved ones;
- Jurisdictional representatives from state and territory disability services programs trying to achieve cross program outcomes for clients;
- National Disability Advocacy Program (NDAP) agencies struggling with the complexity of the issues presented by YPINH;
- Disability service providers trying to manage the complex health and behavioural needs of service users, particularly those living with young onset dementia;
- Nursing home managers seeking additional funding and resources to support the younger people in their care; and
- Support coordinators unable to manage the multi system needs of clients living with young onset dementia.

The individuals and organisations we work with have directly influenced the Alliance's substantial body of work in this area, including our focus on cross sector service methodologies, our multi system work practice and our research and collaborative policy development. This body of work informs this submission.

Working with people with young onset dementia and their families

The Alliance has extensive experience working with individuals living with young onset dementia, their families and other involved stakeholders.

We receive requests for assistance from a range of individuals including family members unable to continue supporting their loved ones at home. Clinicians and allied health workers also approach us for assistance to find the specialist accommodation and support services their patients need. We also receive requests for help from health, disability and aged care providers looking to discharge from acute care or find alternative accommodation for an individual whose needs have escalated beyond their capacity to support.

The last 18 months have seen a significant increase in requests for assistance from families as well as health, aged care and disability providers supporting individuals living with young onset dementia.

In every instance, the Alliance facilitates the collaborative engagement of all actors and supports a partnered approach to outcomes and solutions.

The case studies that are provided as an appendix to this submission detail the intensive and wide ranging work the Alliance undertakes in responding to these requests for help. These case studies also evidence the almost complete lack of accommodation and support services available to respond to individuals living with young onset dementia who are in such desperate need.

Young Onset Dementia Roundtable convened by the Alliance

In response to calls from across the health, aged care and disability sectors for urgent action to address the gaps in awareness and services for people living with young onset dementia, the Alliance convened a *Young Onset Dementia Roundtable* in early December 2022.

The Roundtable provided a valuable opportunity for family members, clinicians, allied health practitioners, service providers and senior government executives to address the key issues facing people living with this progressive neurological condition and those who support them.

A number of key points were made over the course of the meeting. These are outlined in the Roundtable Report that accompanies this submission but include

- The types of dementia affecting younger people are varied.
- Young onset dementia is poorly understood by GPs and misdiagnosis is common.
- Dementia is mistakenly perceived as a disease of old age that requires the same responses.
- An unskilled workforce and worker shortages deliver persistent safety risks to individuals and families.
- Recruiting and retaining workers is a huge problem.
- Uncertainty about the disease trajectory and lack of a pathway or specialist services makes a sense of the future impossible.
- There is a persistent lack of reliable and practical information.
- There are significant financial and emotional costs in caring for a loved one including loss of employment for family members.

- Managing the disease trajectory requires a multidisciplinary approach.
- Additional training for NDIS access and planning teams is needed and should include supported decision making for participants.
- Lower staff to resident ratios and aggregated funding make residential age care inappropriate, but often the only available option.
- To support people across the disease course, a case management approach that incorporates capable service coordination is imperative.
- Policy and service development must link health, disability and other service systems.
- Dementia navigators must be introduced to provide ongoing support and advocacy across the disease course.

In considering what services are needed to support people living with young onset dementia, the following service development imperatives were identified by families, clinicians, providers and advocates attending the Roundtable:

- Develop and trial noninstitutional service options. Design, delivery and evaluation is undertaken collaboratively with individuals living with young onset dementia, their families and clinicians.
- “Map the landscape”. Identify existing services and supports as well as service gaps.
- Complete a social and financial impact study. Identify the impact of poor service provision on individuals, families, service systems and the wider community.
- Educate the community, especially GPs; break down ignorance and prejudice.
- Develop a skilled workforce across the health, aged care and disability sectors working with people with young onset dementia. This includes real time mentoring/secondary consultancy for service providers and workers to support the delivery of high quality support and the retention of skilled workers.
- Establish multidisciplinary diagnosis and planning/support to deliver joined up responses.
- Implement a dementia navigator workforce. Navigators educate and support the disease trajectory post diagnosis; accommodate changing circumstances; navigate complex health and disability systems; obtain services and supports.
- Provide more visible and accessible support for families.
- Establish an NDIS young onset dementia pathway for access, planning and service delivery. Include staff capacity building/training and multidisciplinary planning with health services.

One of the Roundtable’s key outcomes has been the formation of a young onset dementia working party. Clinicians, family members and service providers are working to codesign a service response and work with providers to establish the service.

Young Onset Dementia must feature in the Action Plan

With some 27,800 younger Australians currently living with young onset dementia and projections that this number will rise to 39,000 by 2050,[1] the National Dementia Action Plan must give greater prominence to the existence of this condition; and articulate a strategy to engage individuals and families, codesign and deliver targeted services and build a capable and reliable support workforce.

As well as clearly stating that dementia is not just a disease of older age, the Action Plan must acknowledge the diverse presentations that can accompany diagnosis of this condition in young people.

In acknowledging the growing presence of this disease in young Australians, the National Dementia Action Plan's description of dementia[2] should also clearly articulate that young people living with dementia have very different accommodation and support needs and that these must be developed as a matter of urgency.

In this regard, the Australian Institute of Health and Welfare's (AIHW) report on the growing incidence of younger onset dementia in the community, provides sobering reading.[3] It also evidences the continuing trend of placing individuals living with young onset dementia into residential aged care settings.

Reasons for this include, amongst others, that residential aged care is mistakenly believed to provide a "specialist service" for individuals living with dementias; and the lack of appropriate support and accommodation alternatives for young people living with this condition.

Different needs, different services

The needs of young people living with dementia are significantly different to the needs of older people living with this disorder. The AIHW report states that people with young onset dementia often retain good physical health, which can affect the appropriateness of dementia services that are targeted at older people.[4]

However, despite acknowledging the different needs of young people living with dementia, the authors conclude in their Report Summary that in the absence of the "age appropriate"

---

[1] Department of Health and Aged Care, *National Dementia Action Plan. Public Consultation Paper*, November 2022: 6.

[2] Op. Cit.: 7.

[3] Australian Institute of Health and Welfare, Younger onset dementia: new insights using linked data, catalogue number DEM 05, AIHW, Australian Government 2022. Available at https://www.aihw.gov.au/reports/dementia/younger-onset-dementia-new-insights/summary

[4] Op.Cit.: Summary.

accommodation and support services "… people with younger onset dementia may need to enter residential aged care."[5]

The Report then references Recommendation 74 of the Royal Commission into Aged Care Quality and Safety's Interim Report and the federal government's response through the YPIRAC Strategy and Targets.

It declares that achieving the Targets will require "… new policies and pathways to provide short term and long term accommodation and support options for people with younger onset dementia."[6]

Despite this clarion call to action that clearly articulates the need for new policies, pathways and service options for this group, nothing has been done to realise this.

The 2023-2033 National Dementia Action Plan must therefore include a dedicated response that

- references the tailored service options the young onset dementia group requires;
- acknowledges young onset dementia's unique disease trajectory and the lived experience of individuals living with this disease and their families;
- commits to codesign service planning and development with clinicians, individuals and families; and
- uses cross program service coordination to drive development and delivery of these multisystem responses.

The view that people with young onset dementia may need to enter residential aged care because it's the only place that is appropriate, is unfortunately all too common.

Too much effort has gone into placing young people living with dementia in aged care and too little to developing specialised and viable services for this group.

The National Dementia Action Plan 2023-2033 has a unique opportunity to force a change in this pattern.

The Action Plan's proposed objectives

In responding to the 2023-2033 National Dementia Action Plan's proposed objectives, the Alliance offers the following comments.

---

[5] Ibid. Emphasis added

[6] Op.Cit: 2.

Tackling stigma and discrimination

A term that covers a diverse number of conditions, young onset dementia is poorly understood and often equated with the dementias older people experience. As a relatively unknown set of conditions, young onset dementia subsequently has a very low profile amongst GPs and in the broader community.

The many misunderstandings about the disease course and their support needs has meant that the specialised services needed by this group of young people and their families have not been a priority for government or for the service sector.

Poor understanding of the disease and its impact and the lack of appropriate services mean that young Australians living with young onset dementia also experience significant stigma and discrimination.

This is evidenced in the chronic lack of age appropriate accommodation and support services for this group. It is also apparent in the continued placement of Australians living with young onset dementia in residential age care.

Despite residential age care's clear shortcomings for this group and the existence of a Younger People In Residential Aged Care (YPIRAC) Strategy[7] that calls for no younger people to be admitted to aged care services by 2022, the widespread lack of services for these individuals sees placement in residential aged care continue to be the default response when crises eventuate.

The consultation paper does acknowledge this, commenting that "...there is a lack of specialist disability accommodation that is suitable for people living with dementia."[8] But it fails to outline a strategy to deliver these specialist services, instead suggesting that individuals explore support services "...outside those provided through My Aged Care and the NDIS."[9]

Residential aged care settings that are designed and resourced to support frail older people in the end stages of life, cannot comprehensively support the multiple and complex needs of younger Australians living with dementias. Their physical agility and strength, their impulsiveness and the development of behaviours of concern that commonly accompany the young onset dementia disease trajectory, pose a significant risk to frail older people in these settings.

As the consultation paper again acknowledges, this is one of the reasons that residential age care providers are increasingly refusing to take individuals living with young onset dementia,

---

[7] See https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability-younger-people-with-disability-in-residential-aged-care-initiative/younger-people-in-residential-aged-care-strategy-2020-25

[8] *National Dementia Action Plan Public Consultation Paper*: 44.

[9] Op.Cit.: 40

stating that "… some residential aged care providers may be reluctant to offer places to [younger] people living with dementia due to their care needs..."[10]

This is something the Alliance has experienced directly in situations where health services are trying to discharge patients with young onset dementia to residential age care services. Most recently, this involved an individual with young onset dementia who had been in hospital for 17 months. Disability service providers had been unable to manage his behaviours and in the absence of any other option, the hospital was keen to discharge to a residential aged care service.

All of the many residential aged care providers approached declined to accept this individual into their care, citing their inability to successfully meet his complex care needs and the risk he posed to their elderly residents. Despite his eligibility, the same reasons were given by a specialist dementia service that also declined to take this individual.

The National Dementia Action Plan's first objective of tackling stigma and discrimination is vitally important. But unless it articulates the different presentations and very different needs of people living with young onset dementia; unless it describes the dedicated responses these young Australians require, the Action Plan risks perpetuating the very stigma and discrimination it seeks to ameliorate.

Improving treatment, coordination and support along the dementia journey

Due to the nature and progression of their disease, people living with young onset dementia variously require services and support from multiple service systems including health, mental health, disability (through the NDIS), housing and sometimes justice. The coordination and integration of services provided by different service systems is challenging and at present, there is no template for multi-program service coordination to deliver these responses.

Tailored responses involving service planning, service development and cross program coordination are imperative to deliver the service options this group needs. At present, Australia's human services system does not undertake the partnership and collaboration needed to deliver these joined up services as a matter of course.

An independent intermediary is needed to bring multiple systems together to collaborate, deliver the integrated responses this group needs and realise the mutual benefit to service users and service systems in doing so.

Impact of the National Disability Insurance Scheme (NDIS)

People with young onset dementia should generally be NDIS participants. All the people under 65 that the Alliance supports are NDIS participants.

---

[10] Ibid.

This group of NDIS participants includes individuals who develop dementia as a secondary disability as a consequence of conditions such as Down Syndrome, as well as those with other types of dementia such as frontotemporal dementia or Alzheimer's disease.

Data obtained from the NDIS indicates that as at 30 June 2022, 4,848 participants had a functional disability related to young onset dementia and Alzheimer's disease. [11]

According to the NDIS data, participants with young onset dementia or Alzheimer's disease live in a variety of places. These include living at home with family, living in disability accommodation and living in residential aged care.

The 2022 living situation of these NDIS participants, is set out in the table below.

Living situation	**Under 45**	**45-64**	**65+**	**Total**
Specialist Disability Accommodation, group home	28	572	175	775
Residential aged care		532	547	1,079
Non institutional setting (home)	48	1,884	906	2,838

A small number of participants who were resident in residential aged care in 2022, had Specialist Disability Accommodation (SDA) approval to move into more appropriate settings. Of these participants, 23 were under 65 and part of the group targetted by the YPIRAC Strategy.

The data also reveals another small group of participants over 65 living with young onset dementia in RAC (<11), who had approval for SDA and Supported independent Living services (SIL). This data indicates that the NDIS can tailor service responses to meet the individual needs of participants with young onset dementia when sufficient advocacy is available and/or the value of community living is evident.

In other cases in which the Alliance has been involved, the NDIS has recommended residential aged care for participants with young onset dementia in the absence of suitable community disability services; and from the mistaken belief that residential aged care can provide a specialised response for individuals living with young onset dementia when it cannot.

As indicated by the AIHW in its 2022 report, linking NDIS data with other data sets is needed to improve data quality for the young onset dementia group overall. Doing so will capture

---

[11] Data provided on request from the NDIS Research Branch, 25 January 2023.

the impact of these progressive conditions over the disease course and enable service gaps to be identified, as well as indicate the services used at different disease stages to inform policy.[12]

As this submission has already indicated, the young onset dementia group is one that needs a tailored multidisciplinary service response delivered through cross program coordination. Yet despite the presence of a significant number of participants living with young onset dementia in the scheme, approaches that recognise this group's unique disease trajectory and the lived experience of individuals and families are not implemented by the NDIS.

In her examination of the care received by NDIS participants living with young onset dementia, clinical psychologist Dr Monica Cations points to the scheme's inexperience with progressive illnesses and its inability to adapt to rapidly changing needs. Dr Cations sees these factors as important barriers to accessing the services these participants need.

> …it is not yet known how effectively care provision for people with young onset dementia under the NDIS is meeting its intended aims. Advocacy bodies have raised concerns about the disability sector's lack of experience with dementia especially considering that progressive illnesses are relatively uncommon in the NDIS.
>
> Anecdotal reports note that people with young onset dementia may have difficulty meeting the NDIS eligibility requirements …and that the yearly review practices of the NDIS may be insufficient to adapt to the sometimes rapidly changing needs of a person with YOD.[13]

The need for the NDIS to develop a cohort specific pathway for this group is clear and restated again in the conclusions of the AIHW Report. So too is the imperative for the scheme to partner with health, mental health and other services to deliver the integrated services needed by its participants living with dementias.

In this regard, Dr Cations concludes that the lack of service integration between health and disability services has only served to exacerbate existing service gaps, further limiting access to critically important integrated services that people living with young onset dementia require.[14]

Their experience with the NDIS and the scheme's inability to provide the appropriate accommodation and supports they need, further reinforces the failure of the NDIS one size-fits-all planning model for those scheme participants living with young onset dementia.

---

[12] Australian Institute of Health and Welfare, Younger onset dementia: new insights using linked data, catalogue number DEM 05, AIHW, Australian Government 2022: 2.

[13] Cations, M. "Post-diagnosis young-onset dementia care in the National Disability Insurance Scheme", *Australian and New Zealand Journal of Psychiatry,* Vol 56 (3), 2022: 271.

[14] Op.Cit.: 270.

It is unacceptable for the NDIS to continue relying on residential age care placement for its participants living with this disease and do nothing to forge the partnered relationships with other service systems that are needed for this group.

Instead, the NDIS must collaborate with other services, such as health and mental health and jointly commission the tailored multidisciplinary services the young onset dementia group so urgently requires.

The NDIS is a significant government agency with an interest in dementia service, including the development of specific service pathways and specialist services for people with young onset dementia. As such, the NDIS must be a leading agency in the governance and implementation of the 2023-2033 National Dementia Action Plan.

Not simply a disease of ageing, dementia is a disability experienced by thousands of NDIS participants. The needs of this group must not only be reflected in the ambition of the Action Plan, but also in its machinery.

In addition to the NDIS being part of its machinery, the Alliance recommends that a stream of the National Dementia Action Plan 2023-2033 contain clear objectives for Cross-Agency collaborative service development.

This service development needs funding commitments from the NDIS and other government agencies; co-design and partnership with individuals and families; and implementation of a fit-for-purpose service coordination model that can work across service systems.

Supporting people caring for those with dementia

Family members present at the Alliance's *Young Onset Dementia Roundtable*, made it clear that the dedicated and capable services their loved ones need are so rare as to be virtually non-existent. They also indicated that, despite their desire to keep their loved ones at home for as long as possible, the precarious availability of services to do so can make this impossible.

Worker shortages and poor worker training were identified as persistent safety risks that families have to bear in tandem with the uncertainty of the disease trajectory and the lack of a dedicated pathway or specialist services. Family members spoke about the time and effort it takes to seek out reliable and practical information and the significant financial and emotional cost of caring for a loved one with young onset dementia.

The inability to maintain employment while caring for a loved one with uncertain needs was highlighted, as were the financial pressures families experience as an added but often overlooked stress in supporting a loved one to remain at home.

As well as the lack of services for their loved ones, family members identified the paucity of services available for their own respite and support. Day programs that support individuals with dementia for extended periods of time are needed to provide respite for exhausted family members.

The consultation paper identifies the development of inclusive communities and environments is needed to provide greater support for carers and families.[15] While well intentioned, this does nothing to deliver a greater number of day programs and other options for respite and support that are so greatly needed by families trying to maintain their loved ones at home.

Support for providers

In the section titled *Dementia Support for service providers,* a number of funded services are described that are available to help service providers caring for people with dementias.[16] These include the Dementia Behaviour Management Advisory Service (DBMAS), the Severe Behaviour Response Teams (SBRT) and the Specialist Dementia Care Program (SDCP).

While these are all undoubtedly excellent service responses, the consultation paper locates their operation almost exclusively with residential aged care providers supporting individuals with dementia in their services. There is no comment about provision of these services to disability service providers who may equally need their assistance to manage the dynamic and complex needs of residents living with young onset dementia.

Once again, the Action Plan is hoist on its own petard in its seeming assumption that aged care is the locus of accommodation and support for any individual living with dementia, including young people. In presenting this information as it does, the Action Plan again suggests a view of dementia as a disease of old age that requires the same responses, regardless of age or presentation.

As this submission has already indicated, Individuals living with young onset dementia have very different presentations and needs to older Australians living with this disease. Continuing inappropriate placement of individuals living with young onset dementia in residential age care poses a significant risk, not only to the frail older residents of these services, but to the well being and support of any young people placed there and must cease.

Further, in failing to acknowledge that disability providers support individuals living with young onset dementia in their services, the Action Plan elides both the young onset dementia cohort and the disability providers who may appreciate the advice and assistance of the dementia support services outlined here.

---

[15] *National Dementia Action Plan Public Consultation Paper*: 21.

[16] *National Dementia Action Plan Public Consultation Paper*: 40.

The assistance provided by the DBMAS, the SBRT and the SDCP should be available to disability service providers also and the Alliance recommends the National Dementia Action Plan 2023-2033 reflect this.

Similar criticisms can be made of the *Hospital services for people living with dementia* and the *End of life and palliative care*… sections of the paper.[17]

With most individuals living with young onset dementia likely to be NDIS participants, the National Dementia Action Plan 2023-2033 must again include the NDIS as a key stakeholder and active contributor to achieving the Plan's objectives.

Building dementia capability in the workforce

An unskilled workforce and worker shortages deliver persistent safety risks to individuals living with young onset dementia and their families.

While recruiting workers with the necessary skills is a huge problem, so is retaining these skilled workers who deal with complex and challenging situations as part of this critically important work.

At present, disability support workers are trapped in a vicious cycle of insecure, undervalued work and poor pay that pushes workers out of the sector. Those remaining are left to shoulder the burden, while new workers feel immediately overwhelmed, ill-equipped and face the increased risk of occupational violence. Burned out workers leave, and the cycle starts again.[18]

From consultations with family members dealing with the uncertainty and unpredictability of the workforce, who struggle to find and maintain trusted support workers; and comment from clinicians and providers, a range of recommendations have been put forward to address the current workforce gaps for individuals living with young onset dementia and their families.

These stakeholders agree that attracting workers to this niche market can be achieved by

- **Offering no cost training and skill development** (such as that offered by Victoria's free TAFE courses), to new and existing workers to specialise in supporting individuals with young onset and other dementias.
- **Providing on the job support**. Dedicated support for workers and employers managing the dynamic situations that can arise when working with individuals living with young onset and other dementias. Mentoring and secondary consultancy will support worker retention.

---

[17] *National Dementia Action Plan Public Consultation Paper:* 41-42.

[18] Worker comments in an unpublished survey of 1500 disability support workers undertaken by the United Workers Union.

- **Implementing pay scales that acknowledge skills** and the challenging nature of this work.
- **Making regular shifts and full time work the norm**. Casualisation of the workforce and part time work must stop.
- **Developing a career path** that rewards expertise and skills and values the commitment of workers.
- **Recognising the different staffing arrangements** needed to appropriately support people living with young onset dementia. Stops understaffing and prevents workers 'burning out' and leaving the job and the sector.
- **Valuing and respecting workers** as contributing members of the multidisciplinary team that supports the individual. Working conditions, regular shifts, appropriate salaries signal this work is important and the worker's skill and commitment respected.

The aged care and disability workforces not only share individual workers but worker skills that are transferrable between the two sectors. While the consultation paper does explore workforce issues, it does not cover the disability workforce or invite any role for the NDIS or the NDIS Quality and Safeguards Commission.

Because people with young onset dementia are likely to be NDIS participants when they need to access funded support, promoting this group in the Action Plan must necessitate inclusion of the disability workforce alongside the aged care workforce.

With objectives related to workforce in the NDIS Review currently underway, it is critical that the National Dementia Action Plan 2023-2033 has an outward facing set of objectives and strategies that enables it to reach into the disability sector and engage the NDIS and the NDIS Quality and Safeguards Commission in the design and implementation of the Plan.

Given the presence of the growing group of individuals living with young onset dementia, it would be a mistake for the Action Plan to silo its attention to the aged care sector only.

Neither first nor last resort

Comment is made in the *Service provision for younger people living with dementia* section of the consultation paper, that while people living with young onset dementia may be eligible for support through the NDIS, they should also explore support services provided through My Aged Care.[19]

The Alliance absolutely disagrees with the contention that individuals living with young onset dementia should be directed to any aged care service to obtain the support they

---

[19] *National Dementia Action Plan Public Consultation Paper:* 45

require. Aged care cannot continue to be the provider of first or last resort simply because the services these young people require have not been anticipated and/or developed.

Quite apart from the reality that aged care cannot deliver the tailored services these young people need, relying on the aged care system to be a provider of first and last resort simply obviates the need for other service systems to develop – and deliver – the services they are responsible for. It also makes the mutual benefit to be gained from human services programs collaborating on new service design and commissioning of services, even more distant.

A continuing reliance on aged care services and residential aged care particularly to pick up the pieces and fill the gaps created by the negligence and inaction of other human services programs, is precisely why younger Australians have been inappropriately placed in residential aged care for the last 50 plus years.

It is also why in 2020, the federal government developed a YPIRAC Strategy to end the placement of younger people in residential aged care services.

Continuing to use residential aged care as the default response when other services are not available or haven't been developed, simply enables the systems responsible for developing those services to turn away and continue to do nothing.

The aged care system and its residential and other services have been developed and are resourced to support the very different needs of frail older Australians in the later stages of their lives. Their lower staff to resident ratios and aggregated resourcing were never intended to support the complex and dynamic needs of younger people or the significant behaviours of concern that the young onset dementia cohort commonly presents with.

Relying on aged care services to meet the particular needs of the young onset dementia group not only relies on inappropriate and inadequate services to do so. It makes it possible for other service systems to avoid developing the services they are responsible for and condemns aged care services to act as a repository for this consequent lack of action.

Their inability to deliver the supports this cohort requires and the inappropriateness of the services they offer means the 2023-2033 National Dementia Action Plan must not suggest aged care services as an option for individuals living with young onset dementia.

Conclusion

The Alliance commends the work involved in developing the framework and objectives of the proposed National Dementia Action Plan 2023-2033 and would endorse the Plan going forward if it is amended to contain material covering young onset dementia, inclusion of the NDIA in the governance of the Plan and objectives covering the development of targeted pathways and service development.

As we have indicated, people with young onset dementia are a small but important group in the dementia population in Australia. If the growing incidence of dementia is to be adequately addressed in the next decade, individuals with young onset dementia must be represented fully in the articulation of the National Dementia Action Plan 2023-2033.

While welcome, the individualised funding provided to people with young onset dementia by the NDIS, cannot on its own be effective when there are no suitable services and no policy infrastructure across multiple portfolios and levels of government to govern the responses these people need.

The National Dementia Action Plan 2023-2033 will be a critically important document to guide the operation of service systems in the dementia and health areas.

To have the impact that is required and anticipated, the National Dementia Action Plan 2023-2033 must be comprehensive and include objectives that set expectations for collaboration across the service systems that have a role in the lives of all Australians living with dementia.

Further contact

Dr Bronwyn Morkham
National Director
M: 0437 178 078
E: bronwyn@ypinh.org.au

Appendices

Case Studies

The following case studies are brief summaries of the experiences of three people the Alliance has been supporting. They show the detrimental impact that the lack of integrated services and pathways has on the young onset dementia group.

The financial, social and personal toll this deficit takes on individuals and families is immeasurable, as it is for clinicians and allied health professionals trying to find services to provide much needed support for their patients; and providers struggling to manage complex and dynamic support arrangements.

Without the tailored responses individuals with young onset dementia need, the risk of inappropriate institutionalisation, homelessness and chronic family stress is ever present and intensifies along the journey as the lack of services becomes obvious.

As well as a lack of accommodation and integrated, multidisciplinary support services, there is a lack of specialist service coordination and advocacy for this group. The Alliance has the experience and a strong working knowledge of aged care, the NDIS and disability services and hospital discharge that is essential for this work.

However, the work we do is unfunded and is not part of any government program. The models we use centre on collaboration with a focus on integrated multisystem service design. Despite these being effective tools and work practices, they are not part of the current service systems' interactions.

Tori, 52 years

Diagnosis: frontotemporal dementia
Currently living in hospital in a geriatric rehabilitation unit bed.

For approximately six years prior to Tori's diagnosis, she experienced declining cognition and function. After a marked decline in capacity, she was formally diagnosed with frontotemporal dementia in 2022.

Tori has not had stable accommodation for some time. She has experienced multiple displacements, including from the home she shared with her adult children who could no longer safely support her. When this option failed, Tori moved to live with her ex-husband.

However, her extreme restlessness and wandering overnight meant that Tori's ex husband could not maintain her safety in the community or at home. After several months, the informal support became too much for him and Tori was transferred to a disability short term accommodation service. The NDIS is willing to support Tori in a group setting should one be found.

The service struggled to manage Tori’s dementia related behaviours and was unable to provide the support Tori required, her placement there breaking down after a few months. Tori then became acutely unwell and was admitted to hospital from the respite service.

Despite being medically ready for discharge several days after her admission, Tori had nowhere to be discharged to.

Approached by Tori's daughter for assistance in finding a suitable supported accommodation setting for her mother, the Alliance has convened case conferences and worked extensively with the hospital and the NDIS to source a suitable service. Despite intensive efforts to date by all involved, Tori remains in hospital as no suitable options are available.

Disability services approached to take Tori had neither the capacity nor the capability to care for her and maintain the safety and well-being of other residents using their service.

With nowhere to go, Tori has remained in hospital for the last three months. She is currently in a geriatric rehabilitation bed while she waits for the hospital and NDIS support team to find an accommodation service.

The Alliance has worked with the hospital social work team, Tori’s NDIS support coordinator and the NDIS accommodation team to source an appropriate discharge destination. All actors have collectively spent many days searching for appropriate options, talking with providers and completing application forms in search of both a service with the workforce capability to manage Tori's needs and a service willing to accept her.

Despite there being advertised vacancies in group/shared disability homes, many of these are in established homes for people with intellectual disability. Tori’s support needs and her dementia related behaviours cannot be successfully managed by conventional supported accommodation service models so she is unable to move. Negotiations continue about Tori’s future.

Jack, 64 years

Diagnosis: Alzheimer’s Disease with profound behavioural and psychological symptoms of dementia (BPSD) at age 55
Currently living in hospital in an acute geriatric ward bed.

Jack lived at home with this wife, Carrie, who resigned from her nursing position to become her husband’s full time carer. When Carrie became unwell and was hospitalised, Jack was transferred to a respite service where he remained for 5 months.

The respite service found it difficult to care for Jack who physically assaulted and injured several staff and caused substantial damage to the respite property.

Jack became an NDIS participant and was moved to a disability Supported Independent Living (SIL) service. The disruption of the move and staff lacking the skills to manage his behaviours led to an ambulance being called six hours after he'd arrived at the service and Jack being admitted to hospital.

Once he was ready for discharge, the hospital and Jack's wife made extensive efforts to find a discharge destination for him. A physically strong, agile and impulsive man, Jack’s behaviours and the risks he poses to other residents have seen every residential aged care service approached refuse to take him.

Despite confirming his eligibility for its assistance, a dementia service delivering the Specialist Dementia Care Program also refused to take Jack because of the risk his behaviours posed to other residents.

As part of a plan review and despite previously approving him for both options, the NDIS then indicated that Jack “would not be suitable” for its Specialist Disability Accommodation (SDA) program or it's Supported Independent Living program, instead suggesting that Jack’s “…specific dementia requirements would be best met through residential aged care…”[20]

By this time, Jack had been a resident in the acute geriatric ward of the hospital for 17 months.

Because of its expertise with the aged care, health and disability systems, the Alliance was approached for assistance and worked with the hospital social work team, Jack’s NDIS support coordinator and Jack's wife to find a way forward.

Its work at policy as well as service levels enabled the Alliance to use its policy networks in the NDIS and government to find a solution that was unavailable systemically. After extended negotiations and participation in over 15 meetings, a solution was finally found.

Left to its own devices the system would not have delivered a solution to meet Jack’s needs. The NDIS system relies on support coordinators who do not have the networks, the mandate or the skills in many cases to resolve these multi- system barriers.

Billy, 59 years

Diagnosis: **Frontal Variant Alzheimer’s disease, age 51**
Currently a long stay resident in a specialist dementia service

In the two years prior to his diagnosis, Billy experienced anxiety and depression and stopped working in a job he enjoyed. Billy remained at home supported by his wife.

---

[20] NDIS correspondence indicating the Home and Living Panel decision.

But over the following three years, he experienced severe deterioration in his cognition, communication skills and behaviours. After several admissions to inpatient psychiatry units and failed admissions to different residential facilities, Billy was transferred to a Specialist Dementia Unit.

However, with nowhere to discharge him to, Billy has significantly overstayed the time allowed in the specialist dementia program. As a younger person under 65, Billy was not approved to enter residential aged care and with nowhere to go, Billy's wife called on the Alliance for assistance.

The Alliance brought all involved stakeholders together to work collaboratively, share information, establish Billy’s accommodation and support requirements, negotiate with providers and find a service with capability and capacity.

Following extended negotiation with a disability provider keen to work in this area, Alliance staff secured an accommodation service for Billy. The accommodation provider has agreed to modify the dwelling’s internal and external environment to make it safe for Billy and his support workers. The provider will also work with the Alliance to translate and develop Billy’s care and support routine so that his various health and disability needs and supports are an integrated part of the service response.

With confirmation of these arrangements with the provider and Billy’s wife, the Alliance has continued to resource Billy’s support team and the provider with development of an extensive transition plan. Because of the need to modify the physical environment, the transition process has been lengthy and has been underway for 6 months at this time. Had suitable accommodation and support options been available, though, the transition process would have been much shorter.

To ensure the transition succeeds and Billy settles into his new home successfully, Alliance staff will continue to facilitate the collaboration of all actors and provide secondary consultancy as needed before, during and after Billy moves from the specialist dementia unit. It is anticipated that he will make this move within the next four weeks.

Because he lives with a degenerative condition, Billy continues to experience cognitive and physical decline. His high intensity and complex care needs are proving to be time and resource intensive. However, these resources are essential to ensure that the transition process involving multiple service systems are integrated in his service response and Billy's ongoing care and support is successful.

Roundtable report

ypinh
YOUNG PEOPLE IN NURSING HOMES
NATIONAL ALLIANCE
shaping the future today

Young Onset Dementia Roundtable

Melbourne, 2 December 2022

The Alliance convened the Roundtable in response to calls from across the health, aged care and disability sectors that urgent action was needed to address the gaps in awareness and services for people living with young onset dementia and their families.

The Roundtable provided a valuable opportunity for family members, clinicians, allied health practitioners, service providers and senior government executives to address the key issues facing people living with this progressive neurological condition and those who support them.

Over the course of the meeting, a number of key points were made. A significant starting point was acknowledgement of the variation in the types of dementia affecting younger people and the impact these conditions brought to them and their families. It was agreed that young onset dementia (YOD) is poorly understood both in the broader community and by GPs who are commonly the first point of contact for those seeking assistance. Misdiagnosis is common and as YOD is often assumed to be the same as the different dementias older people experience, it is mistakenly assumed that it requires the same responses (including placement in residential aged care).

Family members present made it clear that the dedicated and capable services their loved ones need are so rare as to be virtually non existent. The family members also indicated that available home care services are precarious due to worker shortages and poor worker training…situations that result in persistent safety risks. Recruiting and retaining workers was also identified as a huge problem.

In speaking of the uncertainty of the disease trajectory and the lack of a pathway or specialist services, family members reiterated that having a sense of the future was impossible. Obtaining useful information about dementia that was relevant to younger people was also identified as challenging as most information assumes that dementia is a disease of old age.

Family members also talked about the time and effort it takes to seek out reliable and practical information. They tend to rely on their trusted clinicians and allied health practitioners for information, who themselves struggle to locate reliable information about available services for their patients and clients.

Clinicians said they depend on their professional networks and feedback from patients to build their knowledge. Allied health colleagues agreed and indicated their frustration at the continuing lack of options for this group, the significant time they spent searching for ever-more-scarce care alternatives and the distress this caused to them and to their clients.

It was the clear preference of family members that their loved ones remain at home as long as possible, particularly when residential aged care was the most available, but mostly inappropriate future option.

The significant financial and emotional cost of caring for a loved one with YOD was also highlighted. As well as losing the income from the individual with YOD, family members have had to either relinquish their employment in order to provide care or worked part time around available support services. The uncertainty and variability of the individual with YOD's support needs and support availability, made maintaining employment very difficult. The financial pressures families thus experience are an added but often overlooked stress in enabling people to remain at home.

When situations escalate and if the supports needed are not there, admission to hospital is often the only option. It was agreed that this is often unsafe and is a bad outcome for the individual, their family and for the health service concerned.

Clinicians at the meeting emphasised that managing the disease trajectory requires a multidisciplinary approach. In the absence of specialised services, clinicians and allied health practitioners indicated that they are often called on to step outside their professional roles and source housing and other services for families in crisis when individuals with YOD can no longer remain at home.

The complexity of the diagnostic process and the time it can take means that access to the NDIS can be difficult. It was suggested that additional training for NDIS access teams and a specific focus on people with YOD in the NDIS access process may be useful. Supported decision making should also be part of NDIS processes for this group.

There was also unanimous agreement that, in the absence of the accommodation and support responses needed, residential aged care remains the only destination when families are unable to continue providing the support their loved ones require at home. While residential aged care is often erroneously presumed to provide a specialist dementia service, younger people with dementia remain physically agile and can develop presentations that require very different responses to those available in aged care settings.

Their lower staff to resident ratios and the different responses those living with young onset dementia require, make residential age care an inappropriate option for younger people living with this condition. Participants were unanimous in calling for the accommodation and support services this group requires to be developed as a matter of urgency. Continuing to place younger people in residential aged care also puts the Albanese government's commitment to achieve the Younger People In Residential Aged Care (YPIRAC) Targets at risk.

For individuals who live with Down Syndrome and acquire dementia as a comorbidity, diagnostic overshadowing was identified as a particular concern. Ageing in place is difficult for this group as the services in shared supported settings lack the flexibility required to meet people's changing needs.

Service providers present talked about specialised services they operate and noted their particular features. To be successful, the service must recognise the individuality of residents, have an optimistic culture and real time access to clinical advice and support. In addition, providers recognised the importance of working closely with consumers, families and user groups to ensure the service remains relevant.

It was agreed that previous experience with the Young Onset Dementia Key Worker Program demonstrated the importance of the relationship between families, their loved ones and case managers to enable information, advice and advocacy to be provided when needed.

The government representatives from the Department of Health and the National Disability Insurance Agency (NDIA) referred people to both the National Disability Insurance Scheme (NDIS) Review and the consultation on the National Dementia Action Plan as timely opportunities to raise specific YOD issues as well as service development and policy recommendations.

It was further agreed that targeted service development was needed for both residential services as well as home support; and for day activity programs – all of which were identified as essential parts of the response that is needed across the disease course. Capable service coordination and information were also seen as critical components of this needed response. Finally, policy and service development that linked health, disability and aged care services was confirmed as the appropriate framework in which service options for the YOD group should be developed.

In this regard, there was a widely supported call to introduce dementia navigators to provide the assistance and ongoing support and advocacy that people living with YOD and their families require across the disease course. Comment was made that such a role should be similar to that of breast care nurses in Australia who support individuals living with breast cancer; and specialist Multiple Sclerosis (MS) nurses in the UK who offer similar support and assistance to people living with MS. Both roles are central to the care of people living with these conditions from diagnosis through to end of life.

To conclude, participants were asked to each identify three priorities that could be included in submissions to the NDIS Review and the National Dementia Action Plan consultation and shared the following:

- Develop and trial service options that are not institutional. Safety and security are key as is the use of workers skilled in supporting individuals with young onset dementia. Designing, delivering and evaluating these trials must be done collaboratively with people with YOD, their families and clinicians.

- ‘Map the landscape’ to establish service gaps as well as identify any services and supports that might exist. Mapping will identify and support development of appropriate service options.
- Undertake a social and financial impact study to understand the ramifications for individuals and families, health and disability service systems and the wider community if appropriate service responses are not available.
- Deliver targetted education/awareness raising to dispel the notion that dementia is only an older person’s condition; raise awareness of the diverse presentation of YOD; and the inappropriateness of residential aged care as destination. Also targets GPs as first point of contact for assistance.
- Develop a skilled workforce. As well as appropriate training/skill development, Includes real time mentoring/ secondary consultancy for service providers and support workers to support retention of skilled workers.
- Implement a multidisciplinary approach to diagnosis and ongoing planning/support provision. Involves collaboration by health and disability services particularly to deliver integrated or joined up responses, other service systems as needed.
- Develop a dementia navigator workforce. Supports individuals and families to understand the disease trajectory post diagnosis; plan for and accommodate changing circumstances; navigate complex health and disability systems; obtain the service and supports needed in a timely manner.
- Create more visible and accessible support for families.
- Develop a dedicated young onset dementia pathway in the NDIS for access, planning and service delivery. Includes capacity building/training for staff, particularly access and planning teams. Multidisciplinary collaborative planning with health services underpins this pathway.

In agreeing there was a great deal to be done, participants declared their appreciation for the opportunity to hear from the full range of stakeholders including those from government, and looked forward to continuing to work together in 2023.

Young Onset Dementia Roundtable participant list

Family members

Nola Beagley
Sally Munro

Department of Social Services

Debbie Mitchell (apology)	Deputy Secretary, Disability and Carers

Department of Health

Eliza Strapp	First Assistant Secretary, Market and Workforce

National Disability Insurance Agency

Deb Connock	A/General Manager - Government Division

Royal Melbourne Hospital

Assoc Professor Samantha Loi	Neuropsychiatrist, Neuropsychiatry Unit, RMH Principal Research Fellow, University of Melbourne

Specialist Memory Services

Laine Bradley	Occupational therapist

Eastern Cognitive Disorders Clinic

Professor Amy Brodtmann	Cognitive/Behavioural Neurologist Honorary Medical Advisor Dementia Australia
Dr Chris Kyndt	Cognitive and General Neurologist

Down Syndrome Australia

Rachel Spencer	Senior Advocacy Manager

Brightwater Care Group, WA

Janet Wagland	General Manager Disability
Kelly Worlock	Chief Operating Officer

My Care Path

Jayne Maini	Aged care placement consultant

Alzheimer's Australia

Leanne Emerson	Executive Director Services

Yooralla

Terry Symons	CEO
Melissa Cofre	Director, Home and Living

National Disability Services

Heather McMinn	Consultant