Dementia Australia™

Serious Incident Response Scheme for Commonwealth funded in-home aged care services

A submission to the Australian Government Department of Health

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About Dementia Australia

No matter how you are impacted by dementia or who you are, Dementia Australia is here for you.

We exist to support and empower the estimated half a million Australians living with dementia and almost 1.6 million people involved in their care. Dementia is the second leading cause of death in Australia yet remains one of the most challenging and misunderstood conditions.

Founded by carers more than 35 years ago, today we are the national peak body for people impacted by dementia in Australia.

We involve people impacted by dementia and their experiences in our activities and decision-making, to make sure we are representative of the diverse range of dementia experiences across Australia. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

Dementia Australia is the source of trusted information, education and support services. We advocate for positive change for people living with dementia, their families and carers, and support vital research.

We are here to support people impacted by dementia, and to enable them to live as well as possible.

Introduction

Dementia Australia welcomes the opportunity to provide a submission to the Australian Government Department of Health's consultation on the details of a Serious Incident Response Scheme (SIRS) for Commonwealth funded in-home aged care services. Our submission has been developed in consultation with people living with dementia, their families and carers, as well as Dementia Australia staff members.

Australians have a right to live free from abuse and neglect. Older Australians also have specific rights and expectations when receiving Commonwealth funded aged care services, which a mechanism like SIRS can more appropriately support.

Dementia Australia supports the introduction of a SIRS that is tailored to in-home aged care services, noting that the definition of 'serious incidents' in this context is defined as physical, sexual or financial abuse committed by a staff member against a consumer.

Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of neurocognitive diseases which cause a progressive decline in a person's functioning. Symptoms can include memory loss as well as changes in speech, reasoning, visuospatial abilities, emotional responses, social skills and physical functioning. There are many types of dementia, including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease.

Dementia is one of the largest health and social challenges facing Australia and the world. There are an estimated 472,000 Australians living with dementia in 2021[1] and around 1.6 million people[2] involved in their care. Without a significant medical breakthrough, there will be almost 1.1 million people living with dementia by 2058.[3]

Dementia is a terminal condition and there is currently no cure. It is the leading cause of death of women in Australia, and the second leading cause of death overall. It is predicted to become the leading cause of death within the next five years.[4]

It is generally not well understood that dementia is a progressive cognitive disability. Dementia is the single greatest cause of disability burden in older Australians (those aged 65 and over) and the third leading cause of disability burden overall.[5] Although dementia is

[1] Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra

[2] Based on Dementia Australia's analysis of the following publications – M.Kostas et al. (2017) *National Aged Care Workforce Census and Survey – The Aged Care Workforce*, 2016, Department of Health; Dementia Australia (2018) *Dementia Prevalence Data 2018–2058*, commissioned research undertaken by NATSEM, University of Canberra; Alzheimer's Disease International and Karolinska Institute (2018), *Global estimates of informal care*, Alzheimer's Disease International; Access Economics (2010) *Caring Places: planning for aged care and dementia 2010–2050*

[3] Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by The National Centre for Social and Economic Modelling [NATSEM], University of Canberra

[4] Australian Bureau of Statistics (2018*) Causes of Death, Australia, 2017* (cat. no. 3303.0)

[5] Australian Institute of Health and Welfare (2012) *Dementia in Australia*

commonly perceived to be an age-related illness, it is not a normal part of ageing. Dementia is more common in older people, but it can affect people in their 40s, 50s and even their 30s.[6]

Proposed responsibility to manage and prevent incidents

The expansion of SIRS to in-home aged care services can provide a much needed safeguarding mechanism for people living with dementia. Dementia Australia agrees that the responsibilities relating to incident management and prevention should broadly be in alignment with residential aged care, including responsibilities to:

- manage incidents, with a focus on the safety, health and wellbeing and quality of life of care recipients
- respond to incidents by taking certain actions
- assess the incident
- collect data relating to incidents to enable the provider to continuously improve its management and prevention of incidents
- include certain procedures in its incident management system and ensure that roles and responsibilities of staff are clear in relation the management, resolution and prevention of incidents and
- keep certain records.

However, we also see one key point of difference in the role SIRS for in-home aged care services. This is the role of informal carers, both as the instigator of harm but also as a recipient of harm. Regardless of whether this is in scope or out of scope for the SIRS expansion, there needs to be some clear guidance and reporting mechanisms around how the role of informal carers is addressed.

Issues of suspected abuse, as observed by home care workers, may involve different reporting processes from those in residential care, and require clear guidelines on scope of practice. Examples of these include:

1) If the worker is self-employed and the client is self-managing (or being assisted to do so by an informal carer), and if the worker observes unexplained bruising/injury to the client or expressions of fear on a consistent basis, to whom should this be reported?

2) If the worker observes injury of the informal carer or fear, what should be the response from the worker?

3) When should an advocate be brought in, and for whom?

4) Who decides if it's a police matter?

Additionally, people living with dementia, their families and carers have shared with us that the expansion of SIRS to in-home aged care services also needs to consider the home environment and how it differs to residential care.

[6] There are also some rare forms of childhood dementia, including Sanfilippo Syndrome, Niemann Pick Type C Disease and others.

> “Person living at home often do not adjust their home according to any physical/mental changes due to ageing or illness. Home spaces that should be updated and often are not: toilet, bathroom, kitchen, carpets/rugs, heating, cooling, steps/ramps, security, lighting, communication: phone/mobile/personal alarm - just to name a few. Not adjusting the home accordingly often leads to serious incidents & often the person is alone at home.” Former carer

> “The settings are so different. In home may not have the equipment available, e.g. hoists. There are many more variables in a home setting.” Carer

> “Presumably there is less supervision in the home, so care would need to be taken to ensure a home is clear of trip hazards, so flat surfaces, ramps, railings, clear signage for the person, colour schemes, noises...all need to be pre managed.” Former carer

As reflected in the consultation paper, providers have less control over the care environment within a home setting, which can influence the extent to which a provider can reasonably prevent, identify and respond to incidents.

> “It should be more flexible and less prescriptive. In the home setting there are likely to be many more grey areas in types of incidents which make overly prescriptive rules confusing for providers and likely to lead to either no response or one that creates further problems.” Former carer

There needs to be clear communication with all participants of the service, which is more explicit than in residential care as there is a challenge with multiple providers across multiple service types.

Dementia Australia supports the requirements for managing incidents be consistent with arrangements for residential aged care, whereby a provider must respond to an incident by assessing whether other persons or bodies should be notified of the incident and notifying them if appropriate.

With reference to consumers reporting to the Commission via the usual complaints' channels, a category of carer-on-consumer incident needs to be articulated in the process flowchart. Additionally, where incidents need to be reported to the police, requirements should be the same for in-home aged care services as in residential aged care. This would promote more consistent identification around some of the issues relating to elder abuse and neglect, both by and upon the carer, which is needed.

Regarding consent, providers should have an obligation to report incidents to police, family or other bodies without necessarily needing the consumer’s consent. If it constitutes a serious incident, it needs to be reported to the appropriate authorities regardless of whether consent has been obtained or not. This would be in alignment with social services or domestic violence situations.

Dementia Australia recommends the Department adopt the same consent policies as social services.

Proposed responsibility to notify the Commission of reportable incidents

The in-home context lends itself to adjustments to the requirements for notifying the Commission of reportable incidents. The provider who becomes aware of the issue should be responsible for reporting it. Dementia Australia is of the thought that it should then be the responsibility of the Commission to notify the other provider (if applicable).

In this case, there may need to be a requirement for the Commission to inform the other provider/s and work with the instigator (whichever provider that is) to manage the incident as well as report back on rectification to the original reporter (if they are not responsible for adjusting their own service delivery to address the incident).

There should also be strengthened language around specific provider responsibility for efficient management of incidents and risk mitigation.

> "Prior to providing in-home-care - the provider should assess the premises & the person getting the care. There needs to be a document identifying any risks & assign responsibility for mitigating these." Former carer

> "The risk needs to be measured and deemed to be of a serious nature. People living in their own homes are sometimes more vulnerable than those in a residential aged care facility where there are many checks and balances and pairs of eyes watching. Sometimes it is just a consumer and a support worker in the home and harm can occur and not be reported." Person living with dementia

To support this, the aged care workforce providing in-home aged care services should receive appropriate training and development to feel confident in assessing risk within the home.

There is potentially extra compliance needed in the home because there are multiple service providers and service types being delivered across multiple sites. As such, additional resourcing for the Aged Care Quality and Safety Commission should be considered, in order to be able to support local provider services in auditing and monitoring.

Dementia Australia recommends clearly documented reporting frameworks, including examples, and an easy mechanism for all participants (provider, carer, and consumer) to be able to contact the Commission (with levels of incident and related processes clearly outlined).

Proposed scope of reportable incidents

Dementia Australia largely supports the proposed scope of reportable incidents through SIRS in the in-home services context, with the additional considerations.

> “All incidents noted need action, but unless perpetrated by someone in control of aged care providers, other support needs to be in place before reporting to ensure person is safe.” Carer

In relation to incidents that are not reportable, we agree that it makes sense to exclude the incident from reporting where the consumer refuses a service. The definition of ‘unreasonable use of force’ is appropriate for the in-home aged care services context. Having this definition consistent with the definition in residential aged care makes sense. A potential adjustment that may need to be considered, however is the need to reflect the role of the carer – both as the victim and perpetrator.

This same consideration should be applied in the context of the definition of ‘unlawful sexual conduct’ – the role of the carer needs to be clarified.

With regards to ‘unexpected death,’ the examples provided seem to fit more appropriately with neglect. The definition will need to be adjusted to make it clear that the provider left the client in a life-threatening situation without calling medical assistance (for example, having a heart attack and not calling an ambulance). However, the wording and enforcement of this category needs to be precise or staff may not want to work in case they are deemed liable for someone’s unexpected death in the home. Most staff delivering in-home services are not clinical experts dealing with complex clinical or medical care, so client profiles – or treatment expectations – here may differ slightly from residential aged care. Through this process consideration needs to be given to the inclusion of acknowledgement that staff need to be able to work within – and be held accountable to – their scope of practice.

Additionally, in relation to ‘unexpected death,’ while Dementia Australia supports its inclusion as a reportable incident under the SIRS for in-home aged care services, it should be noted that this is usually managed at the coroners’ court or by autopsy. As such, there is opportunity here for multi-agency involvement and clear communication around roles and responsibilities.

When it comes to ‘stealing from, or financial coercion by a staff member,’ the definition is appropriate, and Dementia Australia acknowledges the exclusion of family members as potential perpetrators as out of scope for this program. However, it is recommended that a link to information and support for providers, that details what they should do to report their concerns in that space.

Within the definition of ‘neglect’, Dementia Australia supports including reference to the impact said neglect has on the consumer and that the same adjustment should be applicable to residential care.

> “All matters that relate to being coerced or forced to do anything, against one's will should be reportable.” Person living with dementia

> “The provider must be responsible for the actions of the [formal] carer.” Former carer

‘Inappropriate use of restrictive practices’ should be a standalone reportable incident, but work will need to be done to define it in the context of the home environment. For example, is stopping someone with dementia leaving their home in case they get lost a restrictive practice? This will need unpacking.

Dementia Australia feels that chemical restraint would be difficult to place under other categories like ‘neglect’ or ‘unreasonable use of force,’ and should therefore remain reportable under ‘inappropriate use of restrictive practices’ through SIRS for in-home aged care services.

The ‘unexplained absence’ incident is slightly more obscure in the context of in-home services due to people’s autonomy and independence that comes from living in their own home. Dementia Australia recommends limiting the reporting of this serious incident to cottage respite, community transport and outing services.

> “All except the last one. This is their home and they can come and go.” Carer

> “I had a bad experience where a man hit me with his walking stick and when I wanted to speak to the respite manager, they didn’t believe me. Providers need to listen to the stories and believe us and record them.” Person living with dementia

> “Our safety is important. It needs to be prioritised. Need to trust that the issue will be dealt with in the right way and that happens through training.” Person living with dementia

Reporting timeframes and priority categories

The reporting timeframes for SIRS for in-home aged care services should reflect those of residential aged care. The tiered reporting categories are appropriate in this context. Specifically, for priority 1 incidents, Dementia Australia believes the 24-hour reporting period should apply as the incidents are serious in nature.

It is equally important, however, that providers have the relevant information and support to report SIRS in that timely manner. Some analysis some analysis of current complaints/incidents in home care (if data is available) could test whether a tiered approach is necessary or whether all incidents should be reported under priority 1.

People living with dementia, their families and carers shared with us overwhelmingly that the reporting timeframes should be in alignment with residential care reporting timeframes for SIRS.

> “Reporting should be same as residential if perpetrator under responsibility of aged care provider. If perpetrator a relative or friend, consideration must be given to person's 24 hour safety. If serious assault, neglect etc, police should be called but person must be removed from situation or arrest made of perpetrator. Also policy of action if care recipient refuses permission to report.” Carer

> “Priority 1 and 2 can only be reported after the discovery or reporting of the incident.” Former carer

> “Priority 2 incident should be reported within 5 days and this should be the case in Residential Care.” Carer

> “All should be reported within 24 hours.” Person living with dementia

Central to the SIRS being effective at keeping people living with dementia, their families and carers safe in the context of in-home aged care, education and training of the aged care workforce is pivotal.

The aged care workforce requires ongoing education specifically on dementia. An understanding of changed behaviours and how to appropriately communicate with people as their dementia progresses (including understanding non-verbal cues), as well as how and when to report serious incidents to the Commission is needed to support the expansion of SIRS for in-home aged care services.

> “Education and training will be key to this initiative working as desired. For example, specific aspects such as hallucinations and delusional thinking must be understood and considered appropriately.” Carer

> “The workforce needs dementia specific training, so they know how to handle incidents. And to know the signs when people are in danger.” Person living with dementia

Conclusion

It is critical that the process of expanding SIRS into the in-home aged care services context is well considered and aligned as much as possible with requirements currently applicable to residential aged care. It is also important that specific nuances outlined in our submission are considered. This will enable support for people living with dementia to live free from abuse and neglect, and have their specific rights and expectations met while receiving Commonwealth funded aged care.

We hope the issues and recommendations identified in our submission assist the Inquiry Committee members to understand the issues people impacted by dementia face.

We would welcome the opportunity for further consultation to ensure that the needs and concerns of people living with dementia, their families and carers are addressed.