

MODULE SIX

THE ROLE OF COMMUNITY HOUSING
PROVIDERS IN THE



Care of older people presenting with changes in behaviour



Working with Older Tenants

A TOOL KIT FOR THE NSW COMMUNITY HOUSING INDUSTRY ASSOCIATION

The role of community housing providers in the care of older people presenting with changes in behaviour

The impetus for developing module 6 came after a number of community housing providers identified concerns during the initial toolkit development process that they were seeing older tenants presenting with changes to their behaviour which appeared to be dementia like. They reported that these tenants did not appear to be supported by health or aged care services and raised a question about what they might do in these situations.

Community housing providers can identify internal systems to support effective management as issues get identified. For example, where an older tenant presents several times in quick succession to pay his rent even though this was done the week previously, the staff member dealing with the tenant should reassure him that it has been paid and also message the tenancy manager so that they can start to investigate what might be happening.

If after discussion, there are still concerns, contacting the tenant's next of kin would be a sensible approach. Encouraging the tenant to contact his GP or other health services would also be sensible.

There is a clear role for community housing providers to establish formal working relationships with health services to provide expertise and advice as tenants are identified with emerging health issues. Within the bounds of tenant confidentiality, general advice could be sought to assist in developing a plan for such tenants to identify any support needs and possible services that might be able to assist them.

Community housing providers are increasingly going to be providing housing services to older people who present with changes in their behaviour such as confusion, memory loss, delirium, or uncharacteristic levels of agitation or aggression. These changes can be as a result of a range of health issues that impact on a person's cognition and behaviours.

It is important that a community housing provider, when they identify changes in an older tenant's behaviour, support that tenant to gain access to services to assess what might be happening for them. If the tenant is able to engage with the tenancy manager, they might be able to encourage and support a visit to the tenant's general practitioner for assessment. Contacting the tenant's next of kin would also be a sensible management approach.

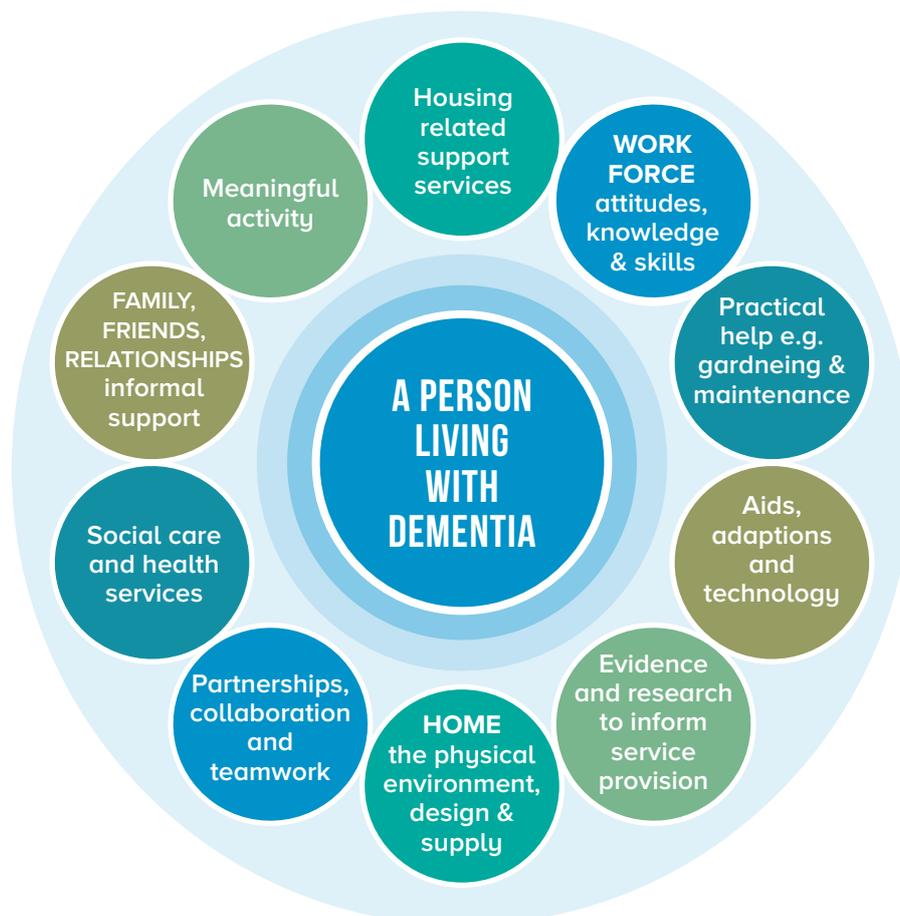
Dementia is the single greatest cause of disability in older Australians (aged 65 years or older) and the third leading cause of disability burden overall.¹

THE ROLE OF COMMUNITY HOUSING PROVIDERS IN SUPPORTING TENANTS WITH DEMENTIA LIVE AT HOME

In 2018, there is an estimated 436,366 people living with dementia in Australia. Without a medical breakthrough the number of people with dementia is expected to increase to 589,807 by 2028 and 1,076,129 by 2058².

Housing is an essential component of the support and care model in place across Australia to maintain the independence of those living with dementia and assist their carers. Community housing providers, working with partners, are well placed to lead meaningful change in the way people live with dementia while improving community understanding and acceptance. Preventative tenancy sustainment keeps people living at home safely for as long as is possible.

PERSON CENTRED COMMUNITY SUPPORT FOR A PERSON LIVING WITH DEMENTIA



¹ Australian Institute of Health and Welfare (2012) Dementia in Australia

² Dementia Australia (2018). Dementia prevalence data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra

Aboriginal people and dementia

Aboriginal people view health and wellbeing in a holistic manner. The connections with mind, body, spirit, culture and country assist in the provision of health and wellbeing for Aboriginal people including individuals, families and communities experiencing dementia.³

Studies have revealed that Aboriginal people experience dementia at a rate 3 to 5 times higher than the general Australian population. Despite the fact that higher rates of the disease have been reported in Aboriginal people, it still goes largely unrecognised in communities and by health workers and service providers. Geographical constraints in the provision of services, a lack of education and awareness in communities and by health workers and the prevalence of other chronic diseases have all posed considerable barriers to the recognition of dementia as an emerging health issue for Aboriginal people.

Dementia is viewed and experienced differently by Aboriginal people and often goes unrecognised as a medical condition.⁴ The behavioural changes associated with dementia may be viewed as “childlike” or “sickness” or “madness” with many people only seeking assistance when the behaviour breaks cultural norms.⁵

Research in the Kimberley region of Western Australia highlighted the various perspectives of Aboriginal people regarding the causes of dementia including old age, head injury, lack of family visits and brain changes.⁶

Aboriginal people experience worse health outcomes than the non-Aboriginal population resulting in substantial gaps in life expectancy. The burden of chronic diseases in Aboriginal populations is two and a half times greater than the general Australian population with cardiovascular disease, diabetes, kidney disease, cancer and respiratory diseases significantly contributing to the morbidity and mortality of Aboriginal people.⁷ Aboriginal people have higher rates of health risk factors including ones which have been found to be related to dementia.



3 Alzheimer's Australia: Aboriginal and Torres Strait Islander People and Dementia – a review of the research. Paper 41; October 2014

4 Arkles, R. S., Jackson Pulver, L. R., Robertson, H., Draper, B., Chalkley, s. & Broe, G. A. (2010). Ageing, Cognition and Dementia in Australian Aboriginal and Torres Strait Islander Peoples: Neuroscience Research Australia and Muru Marri Indigenous Health Unit, University of New South Wales

5 Ibid p 2

6 Smith, K., Flicker, L., Shadforth, G., Carroll, E., Ralph, N., Atkinson, D., Lindeman, M. Schaper, F., Lautenschlager, N. T. & LoGiudice, D. (2011). 'Gotta be a sit down and worked out together': views of Aboriginal care givers and service providers on ways to improve dementia care for Aboriginal Australians. Rural and Remote Health, 11: 1650, 2011

7 Australian Institute of Health and Welfare. (2011). The health and welfare of Australia's Aboriginal and Torres Strait Islander people, an overview 2011. Cat. no. AIHW 42. Canberra: AIHW.

Assisting and supporting early diagnosis

Early dementia diagnosis makes a difference to individuals, their families and to the services, including housing providers, that are likely to be involved in providing support post-diagnosis of dementia.⁸

Early diagnosis of dementia increases the time that people can spend with the people they love, doing the things that matter the most to them. It allows people to access treatments at a time when they can be most impactful and to mobilise support services both for themselves and for their loved ones. It also enables the person diagnosed with dementia to have meaningful input to making decisions for care and support into the future.

Community housing providers' role in assisting and supporting early diagnosis

The day-to-day interactions with tenants associated with tenancy management offer community housing professionals a unique opportunity to recognise where dementia might be an issue.

Community housing staff who are alert may recognise changes in normal patterns of behaviour that could be dementia related amongst their tenants.

It is NOT the role of community housing staff to diagnose dementia, but early identification of such changes would enable staff to provide information and referrals to services that can assess the tenant's health changes.

The role of community housing staff in supporting early diagnosis can be summarised as follows:

- To recognise persistent or notable changes in a person's normal pattern of behaviour
- To ask simple questions which enable the assessment of a person's ability to live safely and independently where signals of cognitive changes or dementia related changes in behaviour are present. This might include asking how a tenant is managing to do their grocery shopping for example.
- To provide regular information and brochures on the benefits of engaging with health and support services. This could be information on how to access My Aged Care or a brochure for a local support group run for older people.
- Where appropriate, to encourage a person to take action to seek diagnosis through active signposting to relevant health and aged care services such as their general practitioner or groups run by a local aged care service provider.
- To consider whether neighbour complaints, disputes and/or reports of anti-social behaviour may signal a behaviour change warranting further investigation.

⁸ Dementia Pathways, Housing's Role, Practice Guide, CIH Scotland, October 2017

Practice Guidance

Triggers, signals or problems that suggest the need for diagnosis

Community housing staff should always encourage tenants to initiate a referral to their General Practitioner if they identify any concerns that might indicate a health condition. Many health conditions can present with similar signs and symptoms to those who are not health professionals. The need for a diagnosis is critical to ensure that appropriate care and support is able to be initiated as quickly as possible for the tenant.

The early symptoms of dementia are very subtle and vague and may not be immediately obvious. Early symptoms of dementia also depend on the type of dementia and vary a great deal from person to person. Although the early signs vary, common early symptoms of dementia include:

- Memory problems, particularly remembering recent events
- Increasing confusion
- Reduced concentration
- Personality or behaviour changes
- Apathy and withdrawal or depression
- Loss of ability to do everyday tasks

Sometimes people fail to recognise that these symptoms indicate that something is wrong. They may mistakenly assume such behaviour is a normal part of the ageing process.

Symptoms may also develop gradually and go unnoticed for a long time. Also, some people may refuse to act even when they know something is wrong.

It is important to remember that many conditions have symptoms similar to dementia so it is important not to assume that someone has dementia just because some of the above symptoms are present.

Strokes, depression, excessive long-term alcohol consumption, infections, hormonal disorders, nutritional deficiencies and brain tumours can all cause dementia-like symptoms. Many of these conditions can be treated.

Ten warning signs of dementia

1. Dementia and memory loss

It is normal to occasionally forget appointments and remember them later. A person with dementia may forget things more often or not remember them at all.

2. Dementia & difficulty with tasks

People can get distracted and they may forget to serve part of a meal for example. A person with dementia may have trouble with all the steps involved in preparing a meal.

3. Dementia and disorientation

A person with dementia may have difficulty finding their way to a familiar place or feel confused about where they are, or think they are back in some past time of their life.

4. Dementia & language problems

Everyone has trouble finding the right words sometimes but a person with dementia may forget simple words or substitute inappropriate words, making sentences difficult to understand. They may also have trouble understanding others. Individuals who speak English as a second language may revert to their mother language and find it difficult to communicate in English. This can be a communication issue for families as it is common for second generation Australian immigrants not to learn their parent's first language.

5. Dementia and changes in abstract thinking

Managing finances can be difficult for everyone but a person with dementia might have trouble knowing what the numbers mean or what to do with them.

6. Dementia and poor judgment

Many activities require good judgment. When this ability is affected by dementia, the person may have difficulty making appropriate decisions, such as what to wear in cold weather.

7. Dementia and poor spatial skills

A person with dementia may have difficulty judging distance or direction when driving a car.

8. Dementia and misplacing things

Anyone can temporarily misplace a wallet or keys. A person with dementia may not know what the keys are for.

9. Dementia and mood, personality or behaviour changes

Everyone becomes moody or sad from time to time. Someone with dementia can have rapid mood swings, for no apparent reason. They can become confused, suspicious or withdrawn. Some can become disinhibited or more outgoing.

10. Dementia and loss of initiative

It is normal to tire of some activities. Dementia may cause a person to lose interest in previously enjoyed activities or require clues prompting them to become involved.

The signals or triggers that can be used to detect changes in normal behaviour patterns can be categorised as personal triggers and / or property triggers.

PERSONAL TRIGGERS

Personal triggers which suggest changes that could be dementia-related include:

- Signs of stress, paranoia or anxiety
- A change in the usual or expected standard of personal care for that person (including clothes, hair and general appearance)
- Repeating stories or retelling events or information (sometimes in an inconsistent way)
- Social isolation and / or a reduction in social interaction
- Low mood or signs of depression
- Less awareness of personal safety than normal, and
- A change in the way someone interacts with their partner

PROPERTY TRIGGERS

Property triggers include:

- More or less interactions with housing services than normal, for example simply being less visible than normal, or calling repeatedly with a similar query or issue despite it being resolved previously
- Changes in rent payments, particularly when there has been a consistent pattern
- Changes to the normal state of someone's garden or home, for example less tidy or more cluttered
- An increase in repairs due to flooding, fires or other hazards that would normally be avoided, and
- Frequent instances of the property being obviously insecure, for example leaving the front and back doors open
- Complaints from neighbours about behaviours such as wandering or agitation

A useful resource in building understanding about dementia that can be accessed by anyone who is seeking more information

NATIONAL DEMENTIA HELPLINE
www.dementia.org.au/helpline

Building a strong housing management approach

Community housing staff can engage in positive conversations to assess if a person can live safely and independently, and understand where and how to direct any concerns, providing the tenant is comfortable with engaging in a discussion about their experience.



Through monitoring the calls and information being received about a tenant, the tenancy manager may be able to identify if there are changes in the normal patterns of a tenant's behaviour. Monitoring in such a way will play an important role in helping the community housing provider be confident in a tenant's ability to live independently in one of their properties.

Simple, informal interactions can help build a picture of whether signs and signals could be dementia related.

Community housing staff should keep conversation light and ask simple questions about the tenant's physical health and wellbeing such as:

- Have you had any recent illnesses?
- Do you have any conditions that affect your day to day life?
- Have you been to see your GP lately? If so, what did the GP say?

All interactions should be carried out sensitively.

People who are living with early signs of dementia can be reluctant to engage in dialogue about their symptoms and may develop coping strategies to deal with their impact or avoid conversations on the topic. Community housing provider staff need to be mindful of this and respect tenant rights to privacy.

PRACTICE POINTS TO GUIDE COMMUNICATION ON DEMENTIA DIAGNOSIS INCLUDE:

- **Discussing options** and solutions positively can build trust and confidence with the tenant while enabling other issues to be shared and identified
- **Recognising problems** that a person may be facing with day to day living should always be in the context of solutions that may be achievable to address those problems
- **Highlighting the benefits** of engagement with health and support services is crucial
- **Using simple, clear and direct language** such as 'I think you would benefit from talking to your GP about this', and
- **Avoiding the use of the word 'dementia'** in these interactions.

Engagement & encouraging diagnosis

Community housing staff should know how and when to encourage people to take action with respect to seeking a diagnosis. This would include knowing how to have sensitive conversations about dementia and how to guide people towards a diagnosis pathway. Proactive tenancy management builds trust and enables engagement.

Tenancy management staff should be aware of the importance of building trust with tenants to enable successful conversations on dementia diagnosis to take place. Where possible, individuals themselves should be encouraged and enabled to seek diagnosis.

It is important that community housing provider staff have basic knowledge of the dementia diagnosis pathway.

When considering how to assist a tenant to explore their potential diagnosis, community housing staff should think about whether support or advocacy may be appropriate. Frontline housing staff should not be expected to provide this support or advocacy but instead make referrals to health, care or support agencies, always with the consent of the tenant.

POTENTIAL PATHWAYS TO DEMENTIA DIAGNOSIS ARE LIKELY TO BE:

- The community housing provider staff member guides the individual (with their consent or consent of their next of kin) to local support services (such as information and advice services, day centres for older people, My Aged Care) that can provide practical assistance with dementia diagnosis or further information on dementia.
- The community housing provider staff member encourages the individual to make a self-referral to their General Practitioner for assessment and diagnosis.
- Community housing provider staff raise concerns with hospital staff (social worker or Aged Care Assessment Team nursing team) about changes they have noticed in the tenant's behaviour if the person is admitted to hospital.
- If consent is withheld, and major concerns are outstanding regarding tenant wellbeing and safety, the community housing provider staff member should establish contact with people identified on the tenancy record as next of kin or the person most responsible to explore options.
- If this fails, consideration should be given to how to engage with the Public Guardian.
- Consider seeking a police welfare check if all other approaches have failed to engage with the tenant and you remain concerned for their safety and wellbeing.

Making a referral

Community housing staff should know how to communicate and build trust to encourage a person to engage with their GP with a view to seeking a diagnosis. They should also have a good knowledge of alternate support options to encourage diagnosis, the consent to share information process and how to assess and act on wellbeing risks.

Community housing staff should be clear that their role is to encourage a tenant to take action themselves in seeking support around their health issues and actively guide them to health services. Any engagement by a housing professional with a third-party agency such as health or support agencies on dementia diagnosis must always be supported by the consent of the tenant.

If a tenant resists engaging in dialogue about dementia diagnosis, but outstanding concerns remain regarding the wellbeing or safety of that person, it may be appropriate to engage with carers or family. Without disclosing personal information, and where it is possible to do so, housing staff should ask a family member or carer for their views or perceptions of the person and their ability to cope with day to day living.

If it is not possible to engage with carers or family and there are significant concerns about the welfare or safety of the tenant, housing staff should explore a referral for Guardianship. Where it is not possible to engage with carers or family for Aboriginal tenants, community housing providers should contact the Local Aboriginal Lands Council for guidance and support.

Community housing providers can also contact the Aged Care Assessment Team for their location and request assistance. The Aged Care Assessment Team have a duty of care to respond to such calls for assistance.

Managing risk post diagnosis

Community housing providers should have a good understanding of what they can and should do following a tenant's dementia diagnosis. Typically, this could include promoting the role of housing interventions as part of an integrated approach to dementia care.

Housing has a key role to play in the post-diagnosis process. Community housing providers play a key role in adapting the home environment and should be involved in planning as needs change.



What community housing staff should know and do in assisting and supporting early diagnosis

WHAT SHOULD COMMUNITY HOUSING STAFF DO?

TRIGGERS OR SIGNALS THAT SUGGEST THE NEED FOR DIAGNOSIS

- Provide advice on services that promote wellbeing and independent living
- Manage sensitive conversations

CHECKING AND CONFIRMING A DIAGNOSIS MAY BE OF BENEFIT

- Build a picture of wellbeing through interaction
- Understand a tenant's right to give and / or withhold information
- Know how to assess risk to independent living and where to channel concerns

ENGAGEMENT AND ENCOURAGING DIAGNOSIS: WHAT LANGUAGE TO USE AND WHAT TO ASK

- Encourage dialogue on wellbeing to build trust with the tenant
- Use proactive tenancy management to assess ongoing wellbeing
- Guide referral to GP services for diagnosis
- Engage with family and carers

MAKING A REFERRAL

- With tenant consent, engage with agencies that can support them
- Record and share information that supports tenancy management work
- Engage with family and carers on potential options

MANAGING RISK POST DIAGNOSIS

- Engage with support providers to promote the impact of housing interventions in post diagnostic support
- Encourage early assessment of home environment

Helping a tenant affected by dementia to remain at or return home quickly

Community housing providers have a role to play in delivering interventions that support people affected by dementia to live independently.

Housing workers should understand the key housing interventions that can support people affected by dementia to live independently and should work with health and support services to deliver positive outcomes. Housing workers also play a supporting role in enabling effective admission and discharge processes to hospital.

The role of community housing providers may be summarised as follows:

- **To work with occupational therapists, carers and the family** of people affected by dementia to understand its impact on day to day living, identifying housing interventions to support independent living
- **To encourage the development of multi-agency protocols** and other practice initiatives that support a collaborative approach to dementia care
- **To follow agency policy** regarding absence from a property should an emergency or unplanned admission take place, protecting the housing status of a person affected by dementia
- **To support hospital discharge planning** through involvement in housing appraisals, assessing options for home modifications, housing support or specialist accommodation
- **To encourage engagement** and participation in community activities to prevent social isolation for those living with dementia, as part of a reablement approach to dementia care.

Building partnerships to strengthen the working relationship between aged care health services and community housing

Community housing providers might explore the development of a memorandum of understanding or some other partnership agreement with their local area health service aged care team as a means of building collegiate working relationships between hospital and community housing staff.

Developing respectful working relationships between community housing staff and occupational therapists who are tasked to undertake assessments of any home modifications required is critical to building effective and responsive housing services that are able to support tenants to age in place.

Establishing a relationship that sees the importance of housing as critical to the care and support of an older person is crucial if we are to effectively support older people to stay at home for as long as possible, rather than move into residential aged care facilities.

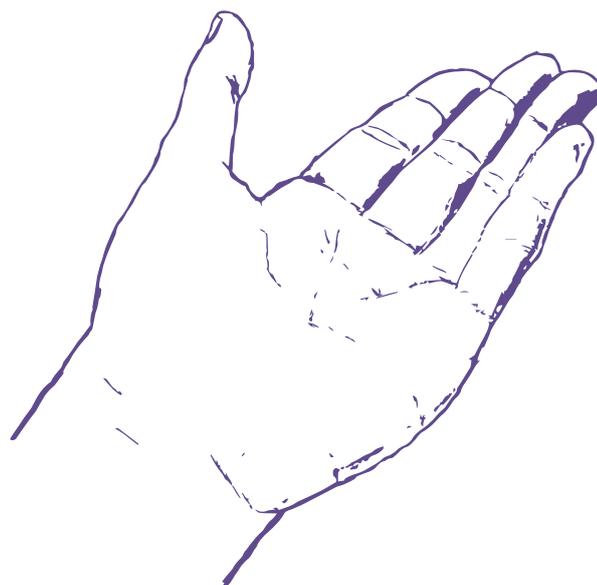
Assessing whether the home environment is suitable

Community housing staff play a supporting role in assessing whether a housing environment is suitable for someone with a dementia diagnosis.

Occupational therapists, as part of the health care team, will take primary responsibility for undertaking housing suitability assessments, with community housing providers overseeing the process to assess suitability and costs for home modifications. Community housing staff should understand the importance of ensuring people affected by dementia can remain in their home for as long as possible.

To support Community housing providers manage the housing needs of their tenants effectively, they might consider establishing a protocol with their local hospital aged care team that would establish an agreed approach to housing suitability assessments so that they are actively engaged in the assessment and review process and are able to actively inform modification planning and decision making.

Detailed information on housing adaptations for people with dementia can be found in the toolkit MODULE THREE : Housing adaptations to meet the needs of an ageing tenant base.



The role of the Public Guardian

All older people should be supported to make their own decisions particularly about their personal, domestic and financial affairs. However for many people with dementia there will come a time when they are unable to make decisions independently

The Public Guardian, supported by the NSW Trustee and Guardian, oversees substitute and supported decision making arrangements for people with a court order or cognitive impairment, including advanced dementia.

This happens through three key mechanisms:

- **Power of Attorney** – gives legal authority to make financial decisions on a person's behalf
- **Enduring Guardianship** – gives legal authority to make health, lifestyle and medical decisions on a person's behalf
- **Advance Care Directives** – sets out a person's wishes and values that should be considered when making medical decisions

It is important that all older people consider how they would like decisions to be made if they no longer have the capacity to make decisions themselves. It is particularly important that people with a diagnosis of dementia set out their wishes formally by appointing a Power of Attorney and Enduring Guardian, as well as completing an Advance Care Directive.

An Advance Care Directive is sometimes referred to as a "living will". An Advance Care Directive is a way to say what healthcare treatments an individual would like to have or refuse, should they be in a position where they are seriously ill or injured and unable to make or communicate decisions about their care and treatment.

An Advance Care Directive may include one or more of the following:

- the person an individual would like to make medical decisions for them if they are unable to make decisions
- details of what is important to them, such as their values, life goals and preferred outcomes
- the treatments and care they would like or would refuse if they have a life-threatening illness or injury

Alternative decision making and end of life care can be very confronting topics for older people, so it is important that they are approached with sensitivity. Seniors Rights Service offers education sessions covering alternative decision making, wills, and other legal issues affecting older people. They also offer free legal advice about alternative decision making arrangements, including Powers of Attorney and Enduring Guardianship matters.

If a community housing provider is aware that a tenant has recently been diagnosed with dementia, they should check with the tenant to see if they are aware of Seniors Rights Service and how to get in touch for support.

If a community housing provider is concerned that a tenant with no family or next of kin is showing severe signs and symptoms of dementia and there are serious concerns for the tenants health and safety, an application can be made via the NSW Civil and Administrative Tribunal (NCAT) Guardianship Division to appoint the Public Guardian as Power of Attorney and Enduring Guardian. This is a very serious course of action and should only ever be considered a last resort where the tenant or their neighbours are at serious risk of harm.