

Dementia and Homelessness

Report to the Victoria and Tasmania Dementia Training Study Centre



Table of Contents

Abbreviations	1
Introduction	1
Background.....	2
Aim.....	4
Method.....	4
Focus Group Specifics.....	5
Results.....	5
The meaning of homelessness.....	6
Understanding client behaviours	6
Getting a dementia diagnosis	7
How staff gain knowledge	8
Knowledge gaps.....	10
Service access and quality	12
Conclusions	13
References	15
Appendix A	16
Appendix B	19
Acknowledgements.....	35

Abbreviations

CDAMS: Cognitive, Dementia And Memory Service

DTSC: Dementia Training Study Centre

GP: General Practitioner

HPP: Homeless Person Program

NARI: National Ageing Research Institute

RDNS: Royal District Nursing Service

VCAT: Victorian Civil and Administrative Tribunal

The opinions, comments and/or analysis expressed in this document are those of the author or authors and do not necessarily represent the views of the Department or the Minister for Social Services, and cannot be taken in any way as expressions of government policy.

Introduction

The National Ageing Research Institute (NARI) undertook this research on behalf of the Victoria and Tasmania Dementia Training Study Centre (DTSC) at La Trobe University.

Through collaboration with partner organisations such as NARI, the DTSC provides a range of multidisciplinary dementia education options and activities aimed at increasing best practice among health professionals in dementia care environments.

The VIC/TAS DTSC is funded by the Australian Government Department of Social Services.

The DTSC wished to scope the education and training needs of service providers in relation to dementia in people who are homeless.

Wintringham Specialist Aged Care was identified and recruited to take part in this research as a provider of aged care services to older people who are homeless. Established in 1989 in response to the frustrations of watching older people die in night shelters, unable to access mainstream aged care services, Wintringham is a specialised welfare company that provides housing and care to older, frail, men and women who are homeless or at risk of homelessness (Wintringham, 2014).

The highly specialised nature of Wintringham's work makes the company almost unique in Australia's welfare system. Wintringham believes strongly in the principles of social justice and the rights of people who are homeless and is widely acclaimed for their research and development and implementation of innovative and responsive aged care services (Rota-Bartelink & Lipmann, 2007 & 2010). Wintringham is different from most other aged care providers in that they see themselves as essentially a housing provider into which they provide quality and appropriate aged care services (Wintringham, 2014).

Background

In addition to the research undertaken by NARI, the DTSC has undertaken a literature review into dementia and homelessness as a summary of existing knowledge on dementia and homelessness was warranted.

The literature search conducted by the DTSC produced scant existing research on homelessness and dementia (or cognitive impairment) in Australia. The studies available were on average more than 10 years old. One prevalence study on homelessness and cognitive impairment in an inner Sydney population showed almost a six-fold increase in cognitive impairment in the homeless population to that of the general population (10% compared with 1.7% respectively). Furthermore, within the homeless population, those with cognitive impairment were significantly older than those without (Buhrich, Hodder & Teeson, 2000). More recently, results from a preliminary report on a study into cognitive impairment in older people who are homeless in inner-

city Sydney (Rogoz et al., 2008) found that 67% showed evidence of cognitive impairment. The authors used Australian Institute of Health and Welfare (AIHW) research to estimate a 6% rate of dementia in older people who are homeless in inner-city Sydney.

It is evident from the most recent 'Dementia in Australia' report from the AIHW that rates of dementia are increasing with the ageing population (AIHW 2012). The limited evidence available about people who are homeless shows rates of cognitive impairment higher than in the general population. Given these trends, the healthcare workforce will be increasingly challenged to provide appropriate care and support for people with dementia in the coming years. Organisations that support older people who are homeless not only face the challenges associated with homelessness, but also those related to recognising and understanding the needs of people with dementia who come into contact with their services.

The very nature of homelessness means a lack of access to many of the supports most people take for granted. Older people can often be excluded from support services because of fierce independence and a reluctance to push their 'rights'; they become invisible. People who are homeless do not come to the attention of aged care services and to some extent, remain invisible. Older people have the same human rights whether homeless or not, and should be able to access appropriate support services (Lipmann, 2009). Morris et al. claim that along with increasing homelessness and inadequate housing options for older people there is also a shortage of relevant policy initiatives to address these issues (Morris, Judd & Kavanagh, 2008).

Lipmann (2009) states that whilst there is considerable government funding going into dementia research and support services for people with dementia, little of this is directed towards people with dementia who are homeless and relates this to the stigma associated with homelessness and the fact people who are homeless do not engage with services. Dementia is most often identified by a person's local general practitioner (GP), usually initiated by a family member, carer or friend. The lack of engagement between older

people who are homeless and aged care services is at the core of the problem (Lipmann, 2009). Funds and resources tend to flow to mainstream aged care services and Lipmann (2009) argues for mainstream aged care funding for welfare organisations that provide services to older people who are homeless (p. 285, Lipmann, 2009).

In more recent times the Australian Government has recognised the need to make older people who are homeless more visible with the Aged Care Act (1997) being amended to make people who are homeless a special needs group. Current services available are detailed on the government website and include different types of community care to help older people who are not in sustainable housing or who are homeless. There is also a residential aged care homeless supplement for services that specialise in caring for people with a history of, or at risk of, homelessness:

<http://www.myagedcare.gov.au/aged-care-services/assistance-care-and-housing-aged>. Whilst not specifically for homeless people with dementia, those assisted by these initiatives will include people with dementia.

Further research is needed to understand dementia in the older homeless population and to understand the education, training and resource needs of those support services (mainstream or otherwise) who engage with older people who are homeless.

Aim

To scope the knowledge, experiences, preferences and education and training needs of service providers who are supporting people who have dementia and are homeless.

Method

One organisation providing aged care services for people who are homeless in Victoria, Wintringham Specialist Aged Care, was identified and recruited to take part in this project.

One focus group was undertaken with staff at Wintringham Specialist Aged Care.

The focus group method is a well-known method in qualitative social science research. The focus group method is largely influenced by hermeneutic phenomenological traditions (Liamputtong, 2009). “Focus groups are particularly useful when a researcher wishes to explore people’s knowledge and experience” (p. 67, Liamputtong, 2009). A focus group can be used as a self-contained research method, and evidence points to focus groups being a valuable method for qualitative data collection (Liamputtong, 2009).

The focus group questions were grouped into three categories:

- questions scoping the knowledge of dementia of the service provider
- questions scoping the prevalence of dementia in the homeless
- questions about the resources available to the service provider and people who have dementia and are homeless.

The interview schedule is included as Appendix A.

The focus group was recorded and transcribed. The transcription was coded for themes using NVivo Qualitative Research Software.

The transcription is included as Appendix B.

This report was prepared by a researcher at NARI with assistance from the DTSC in supplying the Background literature review information and reasoning for undertaking this research.

Focus Group Specifics

The focus group took place at the corporate offices of Wintringham Specialist Aged Care, during a monthly managers meeting.

The focus group took place on 10 June 2014 at 11 AM.

There were eight Managers /Acting-Managers and two Administrative or Operations personnel from the aged care provider in the room during the focus group. Six Managers /Acting Managers made contributions during the focus group.

Results

Six main themes emerged from the focus group data:

- The meaning of homelessness
- Understanding client behaviours
- Getting a dementia diagnosis
- How staff gain knowledge
- Knowledge gaps
- Service access and quality

The meaning of homelessness

The service provider has only a very small percentage of clients sleeping rough.

Being homeless does not necessarily mean a client is sleeping rough.

Some clients are considered homeless even after moving into accommodation because they continue to have special needs. These are clients who have had *“contact with welfare organisations most of their adult life, repeated tenancies and evictions,”* or who continue behaviours acquired during periods of sleeping rough, such as wandering. Clients who are isolated from family and have no other supports are also sometimes considered by the service provider to be homeless.

“It’s understanding that for older homeless people, or people who may now be living in a house but have had a history of homelessness, there are some special needs and it’s understanding that.”

Understanding client behaviours

Understanding client behaviours was considered important by the group. Usually, care staff visit community clients (including homeless clients) once per week. The opportunities for care staff to identify behaviours of concern are therefore limited.

The focus group participants identified the importance of understanding client behaviours related to homelessness.

“A lot of our clients have learnt a lot of ways to mask the fact that they’re struggling.”

“...if you go into the hospital you have to sit and wait for hours, things that can be very challenging for some of our clients, who don’t cope well in those type of environments.”

“I have a client who has a home but he just roams, all day all night, so we can’t even go to his home to find him.”

The importance of understanding client behaviours related to dementia was also identified.

Understanding dementia is especially important in the community setting, because *“a lot of our clients like to take risks.”* The care staff spend a lot of time at VCAT and have very high case management hours because they constantly have to assess whether their clients are able to make informed decisions.

“...for us it’s always that constant balance of do they understand and are they able to make an informed decision? So cognitive impairment is something we spend a lot of time talking about and thinking about for that reason.”

They also spoke of clients who *“present certain behaviours”* which lead care staff to suspect dementia. Over a period of time some behaviours *“makes us question if there’s something underlying there...”*

However, it is often a crisis event that leads to a dementia assessment because, *“there’s no family in there, there’s no one else to notice little things except for us.”*

Getting a dementia diagnosis

It would be very common for their homeless clients to have dementia or suspected dementia, *“probably quite a high percentage.”*

The participants acknowledged the importance of getting a diagnosis when dementia was suspected in their clients, and focused specifically on the difficulties in getting a diagnosis for their clients who are homeless.

It is *“very hard to actually get someone properly assessed, their capacity, when they’re homeless.”*

“I think we spend a lot of time with a lot of our clients pushing and advocating for assessments...”

“Also spending that time building up rapport with a person because it might take five attempts to actually get the assessment done.”

For clients with substance abuse issues there is an additional hurdle to getting a dementia diagnosis:

“...assessments have been refused because someone’s intoxicated. So we would have clients that would be constantly intoxicated, there would be no

point in time when they're sober. We can work really hard to have them at the minimal amount of intoxication. That can be a real barrier when services say no we're not going to assess them because they're intoxicated..."

"For some clients we'd never [see them sober], and putting them into detox just for the purpose of an assessment is actually really bad for their health, so you wouldn't encourage that to happen."

Getting a client into accommodation would take priority over getting a client assessed for dementia.

How staff gain knowledge

There were three main methods of gaining knowledge for their staff members: direct experience working with clients, in-house training and external training.

The importance of client experience and client contact was most often mentioned by the group:

"...there are particular symptoms that we would see in someone..."

"So staff would work with people with Alzheimer's, diagnosed."

"...suspect that there's something not right just because of our experience."

"So staff are pretty good at recognising inconsistencies in what people are telling them, in knowing that something just doesn't seem quite right here."

"...'we don't need to be continually told the same thing over and over again.' We've got a lot of case managers who are very experienced and been working in the industry for a long time."

The service provider has its own in-house training they generally believed was adequate. Managing behaviours and training surrounding behaviour management was seen as important and was undertaken by all care staff at

the service provider. This training was offered online. Some face-to-face training was also being delivered by an internal behavioural management consultant.

“Our online training, we have a couple of different levels of training, so we provide online training for our personal care assistants and care staff.”

“We have a behavioural management consultant who also manages a research project that’s happening...around supporting clients with very complex behaviours who have alcohol related brain injuries.”

“Both are compulsory so we find by the end of the year almost all of our staff have gone through that training.”

“Yeah the majority of our training is part of our training schedule, so we rather do little bits of training throughout the year. We do two days of training where staff do a number of sessions on each of those two days and then they do their online training as well.”

Some staff also participate in external training. External training is generally initiated by individual staff member special requests and done on an ad hoc basis. The case managers were more likely than care staff, to have accessed external training, and up-to-date dementia training.

“..staff will also access external training based on their individual needs. So we have some staff that would do a lot of that and some staff that would do less. That’s really driven at an individual level.”

“Very occasionally we’ll have somebody want to go and do something external.”

“And that staff have also accessed the Alzheimer’s Association, probably haven’t done that for a while, but most of our support staff and case managers have also done that as well.”

In addition, the participants were asked about their preferred formats for training.

The participants indicated they would prefer face-to-face training in short intensive sessions for their staff. It is difficult to release staff for entire days. Half days or a few hours would be easier to accommodate into workloads.

The topics for training must be practical and relevant to their clients. They believed charismatic trainers improve engagement, as do smaller participant groups.

Cost is an issue for the service provider. An \$85 session was considered reasonable, whereas, \$300 or \$400 would take up a year's training allocation per staff member.

Knowledge gaps

The participants believed their care staff and case managers generally had a good understanding of common dementia symptoms and behaviours. They would be less likely to be able to name specific dementia types and associated diagnostic features.

“They wouldn’t know specifically, they wouldn’t be able to name specifically the type.”

For some staff the observation and investigations of client behaviour could be improved. In their community clients, including homeless clients, there is often a crisis or trigger event that leads to an assessment for dementia, although many subtle clues are often noticed beforehand by their care staff, though these may not be reported.

“...you’ll find there’s been lots of little things that have been happening.”

“I think more on those observation skills, on what they’re observing. Not for all but I just find that the last year we’ve had significant things happen with clients and then actually just doing that investigation.”

It would be useful for the care staff to be more aware of what services such as CDAMS can offer. The staff often have to “sell” services to their homeless clients. “Getting the client to agree to it” is a common barrier for obtaining a proper dementia assessment.

“I think the case managers too would be interested in, is stuff around actually hearing what geriatricians and CDAMS can actually do.”

“When you train case managers to actually understand what a neuropsych is, how to understand a report, people then tend to use them more.”

“I think people use CDAMS to get that diagnosis and you get a report, and often it’s because you need to go to VCAT. But actually utilising those services a bit more.”

The managers often miss training and education advertisements from external providers because there is an in-house training unit, so they won’t know of opportunities unless one of them is on an external provider’s e-mail list.

Service access and quality

The theme most commonly discussed by the group was service access and service quality for their clients who are homeless with participants indicating that, in their experience, it can be very difficult and time consuming to get a client who is homeless assessed for dementia. Waiting time to access a CDAMS clinic was cited as being six months. This appears to be based on participants’ perception rather than a reflection of actual waiting times which vary greatly from clinic to clinic. Participants also stated that mainstream services are “not setup for homeless people.”

Services for people with dementia who are homeless were seen as lacking.

“We have to try and make our clients fit into a service system that’s not really setup for them.”

“...you wouldn’t be able to get anything to them on the streets...”

“For us it’s like a last resort because it’s a nightmare to get the person there.”

Assessing someone who is homeless requires *the “flexibility to be able to engage with the client in a different way.”* The inflexibility of services often contributes to difficulties and delays in getting a diagnosis.

“A clinical setting may not be appropriate” but a client may be open to meeting with someone at a day centre. *“And would someone go and chase him around to assess him? Because in a way that’s what you need, to go to St. Mark’s drop in centre or whatever.”*

Clients who are homeless also commonly will not see through appointments.

“It might take five attempts...”

“...there’s going to be some misses along the way...”

Their clients sometimes face attitudinal barriers from health professionals. Some professionals think their clients are *“hopeless.”* And GPs were reported as often being unaware of what service providers, such as Wintringham, can offer.

There were also a few services which are very useful to people who have dementia and are homeless. The RDNS Homeless Person Program (HPP) was seen as a valuable asset. And one CDAMS clinic was given a special mention:

“If you wanted to know a CDAMS where they’ve been fantastic with our client group it would be Broadmeadows CDAMS, interestingly. Just with our clients, and just the follow up, the involvement with allied health, like extraordinary...”

Conclusions

Older people who are homeless have special needs.

When an older person does not have family or other support networks, as is the case for many older people who are homeless, most, if not all, of their care and support will depend on service providers. Knowledge of dementia and the resources available to service providers are therefore very important to the care of people with dementia who are homeless.

There appears to be a lack of awareness of what homelessness means among some dementia service providers and health professionals, and a lack of appropriate services and resources for assessing and treating a person with dementia who is homeless. The current service system is not flexible enough for people who are homeless.

For a service providing care and support to people who have dementia and are homeless, low-cost, intensive (a few hours or half-day), face-to-face sessions are the preferred features of training and education delivery. For service providers to be interested in external training and education the topics would need to be relevant to their clients and offer more in-depth knowledge and more networking opportunities than what their in-house education and training already provides.

References

- Australian Institute of Health and Welfare, 2012, *Dementia in Australia*. Cat. no. AGE 70. Canberra: AIHW.
- Buhrich, N., Hodder, T., Teesson, M., 2000, Prevalence of Cognitive Impairment Among Homeless People in Inner Sydney. *Psychiatric Services*, Vol. 51, No. 4. pp. 520-1.
- Liamputtong, P., 2009, *Qualitative Research Methods*, 3rd edn, Oxford University Press, Melbourne.
- Lipmann, B., 2009, Elderly Homeless Men and Women: Aged Care's Forgotten People, *Australian Social Work*, Vol. 62 No. 2, pp. 272-86, Availability: <http://dx.doi.org/10.1080/03124070902792454> [Accessed June 2014]
- Morris, A., Judd, B., Kavanagh, K., 2008, The Older Homeless and Marginally Housed: The Forgotten Group? *Parity*, Vol. 21, No. 7, pp. 4-5. Published by the Council to Homeless Persons. Availability: <http://search.informit.com.au/documentSummary;dn=741431226673530;res=IELHSS> [Accessed July 2014]
- Rogoz, A., Burke, D., Price, P., Hickie, I., 2008, Cognitive Impairment in the Elderly Homeless in the Inner-City of Sydney: A Preliminary Report on a Study in Progress. *Parity*, Vol. 21, No. 7, Published by the Council to Homeless Persons. Availability: <http://search.informit.com.au/documentSummary;res=IELHSS;dn=742754167632862>
- Rota-Bartelink, A., Lipmann, B., 2010, Older People With Alcohol-Related Brain Injury and Associated Complex Behaviours: A Psychosocial Model of Residential Care (The Wicking Project). *Care Management Journals*. Vol. 11, No. 2, pp. 112-21.
- Rota-Bartelink, A., Lipmann, B., 2007, Supporting the Long-Term Residential Care Needs of Older Homeless People With Severe Alcohol-Related Brain Injury in Australia: The Wicking Project. *Care Management Journals*. Vol. 8, No. 3, pp. 141-8.
- Wintringham Specialist Aged Care, 2014, "Overview > Profile." *Wintringham Specialist Aged Care*, Web. Available: www.wintringham.org.au/Overview/Profile [Accessed September 2014]

Appendix A

Dementia and Homelessness – Focus Group

Where: Wintringham Specialist Aged Care, Cooperate Offices

When: 10 June 2014, 11 AM

Expected Participants: 5 Managers

Introduction

We are from the National Ageing Research Institute (NARI) and we are undertaking this research on behalf of the Dementia Training Study Centre at La Trobe University.

NARI aims to be the centre of excellence in Australia for research into ageing and improving the quality of life and health of older people. NARI is currently co-located with Melbourne Health on the Royal Park campus site in Parkville, Victoria. NARI is recognised as a leading research institute in falls and balance, pain, dementia, physical activity, healthy ageing, public and preventive health, and health systems evaluation. NARI also conducts a broad range of other clinical and psycho-social research including research into cognitive decline and music therapy and older women's health.

The Dementia Training Study Centre (DTSC) at La Trobe University is funded by the Australian Government and aims to develop the dementia care skills of existing and future health professionals. Led by La Trobe University's Australian Centre for Evidence Based Aged Care, the Victoria and Tasmania DTSC has collaborative partnerships with Alzheimer's Australia Tasmania, Alzheimer's Australia Victoria, Bendigo Health, General Practice Victoria, Monash University, National Ageing Research Institute, Austin Health, the University of Tasmania, Professor Dimity Pond and Professor Joseph Ibrahim.

Through collaboration with partner organisations, the DTSC provides a range of multidisciplinary dementia education options and activities aimed at increasing best practice among health professionals in dementia care environments.

Our Purpose

This focus group will explore your knowledge, experiences, preferences, education and training needs regarding dementia in homeless people.

What you say will be analysed for themes and a report will be written and submitted by NARI to the DTSC at La Trobe University.

The Focus Group Process

Thank you for agreeing to be involved in this focus group.

It is understood that you may not feel comfortable or able to answer some of the questions asked in this focus group. You can choose to not answer questions.

We wish to record our conversation today so that we can make an accurate record of what you say.

Some of what you say here today may be used in quotes but your name will not be cited with the quote nor will it appear on any publicly available material. Please feel comfortable in speaking of your experiences in relation to this topic.

Explain that a series of questions will be asked.

Do you have any questions before we start?

- Turn on the audio recorder

Questions

Knowledge of dementia

- 1) What is your understanding of the meaning of 'dementia'?
- 2) What types of dementia are you aware of? Prompt: there are over 100 types
- 3) How would you (or people within your organisation) identify someone with dementia versus someone with other mental health issues? Prompt: many mental health issues have overlapping symptoms and it is not always easy to differentiate.
- 4) What proportion of staff would have received dementia education?
- 5) Have you identified any gaps in the knowledge of your staff when it comes to identifying and/or appropriately helping someone with dementia who is homeless? Prompt: ask for a case study example

Prevalence of dementia in the homeless

- 6) How often do you encounter someone who is homeless and has dementia?
- 7) What types of dementia are common among the homeless people you encounter?

Resources

- 8) What resources are available for someone with dementia who is homeless? Prompt: who do you refer to, are there suitable services?
- 9) What problems or issues need to be considered for someone who is homeless and has dementia? Prompt: what if someone does not have capacity to make decisions for themselves?
- 10) What training resources would help you better identify and/or help people who are homeless and have dementia?
- 11) What training formats do you prefer? Prompt: written materials, hardcopies, e-learning, education days etc.

Appendix B

Dementia and Homelessness – Focus Group Transcript

L: Leslie Dowson, NARI
S: Stephen Gibson, NARI
C: Carol Chenco, DTSC

*The names of the participants have been removed from this transcript as the participants were informed at the start of the focus group that their names would not appear alongside anything they said in publicly available materials.

L: I guess first of all what we really want to know is, what is your understanding of the meaning of the term dementia? When you hear the word dementia what is it that comes to mind?

Memory loss.

L: Memory loss, [name removed], anyone else?

Behaviours.

L: Yeah behaviours.

Cognitive impairment.

L: Yep.

Vulnerable.

L: Vulnerable.

Confusion.

L: Yep.

Agitation in some clients.

L: Agitation, yep, some agitation.

There's a sense you really need diagnosis...

L: Ok.

...It's not just a term you sort of throw around and label...

L: Yep.

...you really have to yeah utilise services to diagnose it properly.

L: Ok, yeah. How many different types of dementia are people aware of? There are over one hundred different types, I know a handful. How many do you think that you would be aware of? Or have experience with?

I'd say a handful. I'd think mainly the Korsakoff's would be our most...

Vascular.

Vascular, Lewy Body's. But then having an understanding of each one...

It's just that umbrella.

...really off the top of my head I wouldn't know. Unless you're working specifically with a client and you're getting more of an understanding of that type of dementia. But overall staff wouldn't know specifically what each one...

L: They would or wouldn't?

Wouldn't.

L: They wouldn't know specifically, they wouldn't be able to name specifically the type.

Or to know what each type presents as.

I think that our staff would be quite good at seeing someone who has an alcohol related brain injury. So they would understand there are particular symptoms that we would see in someone who might have frontal lobe dementia and have a good understanding of that. But maybe not the fine, you know, the group of Alzheimer's or dementia. They might bunch up people who have different types of dementia as one.

Like other types of dementia that present certain behaviours which will impact on how you actually work with that client.

L: Would there be at least recognition that there are different types?

Oh yeah.

We do have vulnerable clients as well, so each dementia, they're level 4's now. So staff would work with people with Alzheimer's, diagnosed.

L: Diagnosed, ok. And what if they didn't have a diagnosis?

You'd spend a lot of time and energy trying to get an assessment.

L: So I guess that leads into the next question which is: How would you or somebody within your organisation identify someone with dementia versus somebody with other mental health issues?

Usually it's feedback from our direct care staff on their behaviour or their level of functioning. Which then over a period of time makes us question if there's something underlying there, whether it is a dementia or it's something else that is medically going wrong with them. In most cases we then refer to the GP to do those investigations which aren't always successful.

L: What about somebody who is homeless?

That could be the tricky thing is actually just getting them medically assessed. So we can often suspect that there's something not right just because of our experience

with similar clients. But very hard to actually get someone properly assessed, their capacity, when they're homeless.

Well how long did CDAMS take for example to do your... .

A 6 month wait list for a CDAMS¹...

That's 6 months.

...But he's not homeless. He's in his own home but we had him assessed. We had our PAS assessment so our clinical team went out and assessed him...

That's a long time though.

...and based on those results they recommended we look further into it. It was a husband and wife team and he was actually eligible for the supplement, not the wife, when we were convinced it would've been the other way around. Yeah 6 months, wait list.

And even though they had a roof over their head they're homeless in the sense that there's no family, there's only [name removed]'s support.

That's right. So no extra support, we're it. No family, nothing.

So it certainly wasn't treated with high urgency or need or anything like that. Six months is a long time.

I think the staff on the ground are pretty good at picking up whether someone is masking symptoms of cognitive impairment. I think we'd have lots of examples where we'll take a client to the doctor and the doctor will be like "oh no they're fine" and no we really don't think they are. So staff are pretty good at recognising inconsistencies in what people are telling them, in knowing that something just doesn't seem quite right here. So we've certainly had examples of clients who've ended up in hospital, who were homeless or not, and a doctor will sit with them and say "oh no they're fine" and we're like "no, no, you need to do a neuropsych, this person isn't fine". Then when the neuropsych's done the evidence will be there that there is a significant cognitive impairment. I think we spend a lot of time with a lot of our clients pushing and advocating for assessments because it may not be immediately obvious. A lot of our clients have learnt a lot of ways to mask the fact that they're struggling.

I think getting the neuropsych in the first place is really difficult, really difficult. We often push for it once they're in hospital. I think case managers just automatically aim for that, "just go get a neuropsych"! I would say maybe it's a very small percentage of the time they actually do it, and the doctors deem them ok which is really frustrating. They're brilliant actors our clients so it's really difficult.

We will be witnessing things that are going on in the community or in their home or where they're sleeping. And this isn't, you know, there's definitely something more going on here.

L: I was interested in what you just said about homelessness, not homeless from a sense of not having a roof over their head but homeless in the sense of not having other support?

¹ Wait time of 6 months is based on the opinion and perception of the respondent/s

Isolated...

L: Isolated.

...and their particular behaviours as well, they isolate themselves even more. They find services try but it's just very very difficult which is why their case management is important.

I think it's the homeless background, I mean in this particular case it's often too to do with a homeless background. There are a lot of clients we've got who are now in public housing but if you actually talk to them they've had contact with welfare organisations for most of their adult life, repeated tenancies, and evictions in this case. There are numerous issues, so as an organisation we would probably say they're homeless clients. It is definitely not about, you know, "have they got a roof"? There would be very few clients on packages that are actually rough sleepers for us now. Our outreach teams would work with the actual rough sleepers, so the guys in the city or whatever or in the southern region could be benches or whatever. But the packaged care...

But you wouldn't be looking at assessments until you had a roof over their head...

Yeah, nup, no.

...so you wouldn't be able to get anything to them on the streets.

L: So the first case would be to try and get a roof over their head?

Yep.

And [name removed]'s got lots of homeless clients. They live in residential care but we still would say they are homeless clientele, yet they've probably been in care for a long time.

Yeah some are 20 years now...

Yeah.

...We've been looking after them but they've come from night shelters.

Yeah, yep.

L: Interesting. What proportion of your staff would have received some sort of dementia education?

It would be a large percentage I would think. Our online training, we have a couple of different levels of training, so we provide online training for our personal care assistants and care staff. Does that do something in dementia every year or every second?

But we haven't done a face to face dementia with carers for a number of years now.

Because of Alice's training.

We have a behavioural management consultant who also manages a research project that's happening at Wintringham around supporting clients with very complex behaviours who have alcohol related brain injuries.

You would know her, Alice...

Alice Rota-Bartelink.

...who has had the NARI connection.

She will run training, face to face training, for all our staff every year.

So for the last two or three years that's been the focus of our behaviour training is alcohol related brain injury. She's built on it from one year to the next, so she still covers the basic general training at the start but this year, for example, she focused more on developing behaviour management plans to work with our clients.

L: And that's done face to face?

It is, yep.

L: And then there's a separate online component?

Yeah. Both are compulsory so we find by the end of the year almost all of our staff have gone through that training.

And that staff have also accessed the Alzheimer's Association, probably haven't done that for a while, but most of our support staff and case managers have also done that as well.

I think the feedback we've been getting, we've run dementia training to staff a few years in a row, and they were saying "we've heard it", "we don't need to be continually told the same thing over and over again". We've got a lot of case managers who are very experienced and been working in the industry for a long time. What I would say, like we were saying before, they might not be able to tell you off the top of their head what a different type of dementia is but they know where to go to find that. They've linked in with the organisations where they can go and get that information.

Whereas say for our site, we've actually got a need for some of our carers to have some dementia training because they have lacked that over the years. We've got some high care clients, having more of an understanding of that and actually working with a team that's working with those clients, we have a need for that. Our case manager that manages the level 4's is currently doing a cert 4 through Alzheimer's but even he's saying that, you know, he's been regularly to training over the years but his feedback is that it changes every year. There's always a new dementia or a new way of managing the client better for the staff. That's our feedback from our case manager that's doing it externally, is that it changes all the time. Whereas I think when we did it internally it might have got a bit more repetitive.

Also with our client group that do have forms of dementia, it is the behaviours that we find that the staff are dealing with the most. That's why we try and hone in more on the training of the behaviours in that client group.

L: That actually leads into the next question which is: Is there any gaps in the knowledge of the staff that you see in regards to identifying or appropriately helping somebody with dementia? Is there anything that you think is missing or that could be added? You said that you've been focusing on behaviours because that's what the need is.

Probably maybe what [name removed]'s saying. I don't know if our guys would know the most current up to date stuff. I mean I think there'd be a couple of people, and maybe through their nursing background, who might be online or get sort of updates on things. But generally I wouldn't have thought they know the most up to date.

I definitely know from our side there is gaps in relation to the carers about, I think they're pretty good with behaviours in actually reporting behaviours. But if you've got a dementia client that's not necessarily presenting a really noticeable behaviour, we find there's a lot of little things that get missed. Until something significant happens with the client and then we actually find out that there's been a series of events happening that the carers just assumed was normal behaviour.

They're in the community too, the carers might only see them once a week or whatever. It's different to residential where you're constantly monitoring them and seeing them on a daily basis. That's sometimes an issue, that we're not seeing them regularly enough to maybe identify those things a bit sooner.

Yeah so there's definitely a period of time until you actually notice something.

So do you think if there was training, better training for our care and support staff around identifying...

I think more on those observation skills, on what they're observing. Not for all but I just find that the last year we've had significant things happen with clients and then actually just doing that investigation. We don't see them all the time so it does take a period of time before you actually notice that there's something not right. And unless they're presenting a behaviour that's aggressive, or something quite significant, they'll report back straight away, but then you'll find there's been lots of little things that have been happening. So that's why I see for our staff there's a little bit of a gap with knowledge...

I think a bit of a challenge for us is probably 90, or 90 might be too high, but don't have anyone else involved. So a very very large percentage of our clients have no other supports. There's no family in there, there's no one else to notice little things except for us. So like you said, if you've only got someone in there once a week it can take a bit of time to really pick up that...

And they're normally not regularly seeing their doctor and other services that might pick that up also.

So early intervention is quite difficult with our community clients and usually when a significant event happens sometimes too much time has passed. Whereas you think if you had of known that in the beginning then you would've been able to put so many interventions in place. Yeah sometimes it'll be a significant event happens...

L: It's often a trigger event?

Yeah, you know, they've gone out wandering and they've been found on the streets in their pyjamas. And then you find out that there have been a lot of different

behaviour that's been occurring. But yeah, difficult when you haven't got someone in the home all the time.

L: And how often would you or somebody on your staff encounter somebody who is homeless and has dementia, so one of your homeless clients? How common is it?

Quite common actually.

Because we have the level 4 packages but then there's a lot of our level 2 packages, quite a lot that have dementia or suspected dementia...

L: Suspected dementia, ok.

...but it's getting those assessments that's tricky.

And because we are obviously focused, we focus on older homeless people, so within that population it's probably quite a high percentage compared to the normal ageing population.

L: It's quite prevalent.

Yeah.

L: And you spoke about alcohol related dementia, any other types of dementia particularly that you find amongst the homeless?

We see vascular quite a lot, got a few with Alzheimer's.

L: A few with Alzheimer's?

Yeah.

I mean one of the, sorry to jump back...

L: It's alright.

...I was just thinking a training gap as well, or something I think the case managers too would be interested in, is stuff around actually hearing what geriatricians and CDAMS can actually do. I think it's really difficult for us to access geriatricians across the board. Some ACAS's you just can't get a geriatrician at all and some you can. But it's almost impossible for us to get a geriatrician out to someone's home, and quite difficult to access a geriatrician in the hospital, unless it's some really serious crisis. Generally it's a fairly quick assessment so it's not picking up on all the stuff that we're saying we notice. But I think it's a bit like the neuropsychs. When you train case managers to actually understand what a neuropsych is, how to understand a report, people then tend to use them more. We use arbias now, we use it quite a lot because I think people now know what you're getting with a neuropsych, whereas a geriatrician and CDAMS. I think people use CDAMS to get that diagnosis and you get a report, and often it's because you need to go to VCAT. But actually utilising those services a bit more. The CDAMS, our experience of what you get from different CDAMS services is so dramatic,...

L: Ok.

...some have been absolutely amazing and others you get three lines on a report after the case manager has spent, because it's never the family, the case manager has spent hours and hours and hours coaxing and cajoling someone to get to CDAMS and you get nothing back, nothing. So I think, I don't know what sort of training it would be but more around stuff from CDAMS I think. Would be really interesting to know a bit more about what services they can actually offer and how do you push for geriatricians and how do we get more help if we actually need it.

And that would also help us in working with our clients and encouraging them because...

Mmm, how do you sell CDAMS.

...the biggest part of the problem is getting the client to agree to it. Like [name removed] said, finding a geriatrician in the community who's willing to go to a client's home is near impossible. Convincing a client, "jump in my car, I'm going to take you somewhere so they can see if you've got capacity", there's just no way. I've got a client and it's taken over a year and it's purely because she had that one incident. Then to get her assessed by a neuropsych I jumped through hoops and drove myself insane, but it finally occurred and they said "oh yeah she is incompetent". It was a nightmare because this client was like "I'm fine, I'm fine".

And that's what causes the stress in our jobs as case managers. You know they're not ok and yet all these other professionals are just saying "oh..". Maybe on the scale, 'there's a case manager', 'there's a package', 'they've got housing'. On the scale of risk we know that our clients move down the, you know [list] because they're not out wandering around all night in their pyjamas standing on a freeway, you know what I mean? They are actually sort of managing but...

You can think of examples can't you, you know the stuff we see in people's homes like clients whose food is filled with maggots...

What's wrong with that [laughs]?

They're making that choice but we don't think they're making that choice because we don't think they have capacity to make that choice. But even things, the really quiet things that you think would trigger other services to be concerned, don't necessarily.

L: So just so I'm clear on what point you're making. Was it that instead of just using CDAMS strictly to get them to VCAT use CDAMS for the purpose of helping the clients? Is that...

For us it's like a last resort because it's a nightmare to get the person there. Generally sometimes the client won't then see through their appointments and so if you've waited 6 months to get in...

And sometimes some clients, you've sometimes only got that small window where you've built up the rapport and you've convinced them to have this assessment. Then if you can't actually get that assessment in that window, sometimes you can lose it or they're not willing to come to the home or anything like that, so you've lost that opportunity.

And I'll tell, I won't say, I would never mention bad experiences with CDAMS, but to be honest for us, and being in Ascot Vale, good experience, Broadmeadows CDAMS. If you wanted to know a CDAMS where they've been fantastic with our

client group it would be Broadmeadows CDAMS, interestingly. Just with our clients, and just the follow up, the involvement with allied health, like extraordinary, and so good in fact we're like "oh my goodness, are you sure, is this really CDAMS?!" You know, it's just interesting, so something they are doing in the way they practice with our particular clientele, that homeless clientele, they've been very impressive. So I don't know what is going on out there but they've been really good.

L: That really leads to the next question which is about the resources available for someone with dementia who is homeless. Who do you refer to and are there suitable services out there?

They're there it's just getting them there, I think that's the problem.

And I think they're generally not setup for homeless people. They're very mainstream services, so that idea of if you go into the hospital you have to sit and wait for hours, things that can be very challenging for some of our clients, who don't cope well in those type of environments.

I think we do all utilise HPP, so the RDNS Homeless Persons Program, we work alongside them. They do a lot of that you know; a taxi driver finding them in the middle of Richmond, "Where are they?", "They've got an appointment in 20 minutes, I've got to race them to!" That's part of what they do and we'd go insane without them. The flipside is when they discharge them we're completely stuck, so we can't do that. Sometimes it's just a matter of introducing a carer to them so they've sighted them, otherwise they don't know who they're looking for on the street.

I think our biggest challenge is getting people, we have to try and make our clients fit into a service system that's not really setup for them.

So we need more of that mobile system...

Yeah we really would benefit from that.

...they could come to their home.

A day centre.

Meet them at a day centre or a place that they are comfortable in.

L: So specifically somebody who is homeless with dementia what particular problems or issues need to be considered? I think you touched on that a bit about the services not fitting or the homeless person not fitting into the services. Is there anything else that particularly somebody who is homeless with dementia that especially needs to be considered?

I think that would be part of it, it's just the consistency for them, it could be quite difficult. I mean I have a client who has a home but he just roams, all day all night, so we can't even go to his home to find him. Each client is different.

And would someone go and chase him around to assess him? Because in a way that's what you need, to go to St. Mark's drop in centre or whatever. Would a geriatrician or someone go there...

Yes that's right.

...and go four times to try and catch him? And you know what, there would be people who would, I'm sure there would be.

Also spending that time building up rapport with a person because it might take five attempts to actually get the assessment done. With most services you make your appointment, you miss it, well then you've got to wait for the next appointment. To have someone that's willing to work with someone and know that there's going to be some misses along the way, no services have those resources to do that.

The other thing I know we've spoken about in the past, don't know if it's so much, but is that assessments been refused because someone's intoxicated. So we would have clients that would be constantly intoxicated, there would be no point in time when they're sober. We can work really hard to have them at the minimal amount of intoxication. That can be a real barrier when services say no we're not going to assess them because they're intoxicated...

We never work with them sober.

...we never see them sober so can't you assess them in this state? And we've had some success with, I think arbias now are quite, are a little bit more flexible. They will assess someone who's not too intoxicated and that really helps us. For some clients we'd never, and putting them into detox just for the purpose of an assessment is actually really bad for their health, so you wouldn't encourage that to happen. So that would be, a little more flexibility around that would be really helpful.

Yeah that's true.

And there's certainly an attitude sometimes with some professional GPs that we take our clients to, you know in comparison to say another client. If you try to talk the client into seeing another doctor, because we don't really think that we're being given the proper attention or care, the client refuses then to go and seek another GP. You're often in that scenario where you know this GP is not doing anything for our client because they think "they're hopeless", "they're a homeless person who cares" sort of thing. There's certainly that attitude out there with a lot of GPs. But then trying to get them to go to see somebody else is sometimes just impossible.

L: How often do you encounter that attitudinal barrier around services? About, you know, "they're homeless"?

Oh, quite often.

We get it quite often with doctors.

Depends where they're living.

And to actually get the client to go see another doctor, especially when they've seen their doctor for 20/30 years.

I think that part of it is quite resource intensive as well. I think if our clients try and access services independently they get quite a different response than if they turn up with their case manager. So what we find is we have to send someone with people to appointments to services so they actually get seen or get a better response...

There's no daughter or son.

...there's no one else to advocate for them and I do think clients get a different response when there's a professional with them, but that does mean it's a lot of time and energy on our part to assist people.

A case manager has to be there to support them at these appointments otherwise you don't get any feedback at all.

L: So what training resources? I think we touched a little bit about what training is required. Is there any specific training resources that would help better with dementia?

So for our staff?

L: Yeah for your staff.

I was thinking some training for the services we're taking people to [laughs].

L: Well give me some examples of some training for the services if you think that...

It's almost like cultural awareness training. Like you would do cultural awareness training about someone who's from a different, who's a different nationality, who wasn't born in Australia. It's understanding that for older homeless people, or people who may now be living in a house but have had a history of homelessness, there are some special needs and it's understanding that.

And that a clinical setting may not be appropriate or an appointment based sort of thing, you know, having that flexibility to be able to engage with the client in a different way.

We also, when we pick up a client, so homecare packages I'm talking about, we write a letter to the doctors. We say "we're now case managing this client, if you've got any issues..." and we never get a response. Quite often they don't know what the package is or what it's about. It would be very very simple, help us out a lot, if they would just write a letter. I had one doctor once send me a care plan, they wanted to work on it together, and that was like, I was at Moorabbin, like 7 seven years ago. But when you call them and you say "look I've got some concerns about this client", they say "well who are you?", "what are you doing?" And you explain who, "I don't even know what you are" [GP response]. Whereas if we worked together as a team we could've prevented a lot of the issues that have come up over the previous few years for some clients. It's just awareness for them about what providers can do for them.

And it's difficult because the way some clients present to their doctor is completely different to how they present to us. Some doctors aren't even aware that they've had a history of homelessness, or are even aware of what their setting is at home or anything like that.

And institutional care too.

Yeah, wouldn't even know. We get the odd doctor, we've got one in particular who rings us with lots of referrals for his clients who are homeless, or, you know, losing their home or whatever. That's because he doesn't want to deal with them anymore. They're all clients that [identifying features removed] so he'll just refer to us.

At least he's asking those questions.

At least he'll ask.

Yeah, if they're homeless.

A lot of GP's don't even, wouldn't even cross their radar to think about someone's housing and what else is going on in their life.

L: I guess lastly what training formats do you tend to prefer? Do you prefer written materials, presentations, study days, online? What kind of thing would reach your staff?

I think the face to face like presentation and opportunity to maybe...

Practical stuff as well as the face to face.

Workshop ideas...

And even shorter sessions.

...secondary consultation type stuff.

Because when they've been advertised, I was even thinking through NARI. You guys have done that assessment and care, you know it's 2 and 3 days. Often it's quite hard to release staff for that chunk of time. So I think, you know, if people knew they had to go to something for the morning or an afternoon, so they can still balance with their client responsibility. Those sort of things would be quite appealing I think, to case managers too. I think, yeah, shorter more intense type sessions.

L: Shorter, more intense but the face to face is...

Yeah I think people would attend.

L: How often do your staff get study days or study time off? Or is it just a matter of balancing the workload with study...

Depends what's advertised doesn't it really?

We have in house training that's run around once a month, that's like one afternoon a month, face to face. We either have internal staff that provide it, or we get someone external. But then staff will also access external training based on their individual needs. So we have some staff that would do a lot of that and some staff that would do less. That's really driven at an individual level.

And the type of trainer too. Sometimes, you know, I know just recently, and I think there was staff from Delahey, just trying to think, it might have been through the Wodonga TAFE, or whatever. It was the behaviour thing, and we had one case manager go, like on complex behaviours. Came back and said it was excellent, said the trainer was just brilliant. The way that they presented, kept everyone engaged, it was really relevant to their work and everything. So it was...

Good.

...but sometimes you can go to some training where it's not that relevant to your type of clients.

I think it's where you lose people straight away, the terminology and if it's not related to your work.

And if the person presenting isn't that great people just tune out, especially if it's over a long period of time.

Cost is also an issue, significantly for us.

That one's really reasonable too, so our staff go to a fair bit of that.

Because they're all DHS subsidised aren't they?

L: What would be a reasonable cost for something?

What, is it \$85 a day?

Yeah for the day.

That is subsidised by Department of Human Services, but that means staff can attend lots of training so they get opportunities to do different modules throughout a year. Whereas if it's \$300 or \$400 a day that could be, well that's it for the year now, you've used up your individual training budget. And that would turn some staff off doing it. They'd say I'd rather do something a bit cheaper.

L: What would happen to written materials that were handed out to your staff? Would they just be put aside and never read? Would they be likely to read them if they were put up on the wall?

Some would, some wouldn't, it depends on the person.

It depends.

I think there has been forums, hasn't there? Held in the past that have been quite successful...

L: Forums.

...So I was just thinking, one [name removed] spoke at was done by Western Health. It was on, was it on alcohol? Drug and alcohol and homelessness? But it was really good because it was specifically on a topic, really interesting speakers, and they had the auditorium packed. I think depending on what like a forum might come up with, that could be a good way to target similar professionals working with the clients in the area too.

L: And just thinking of resi care, do you have training come into resi care? Or would you release staff to go out to something?

Yeah the majority of our training is part of our training schedule, so we rather do little bits of training throughout the year. We do 2 days of training where staff do a number of sessions on each of those 2 days and then they do their online training as well. Very occasionally we'll have somebody want to go and do something external. We're more likely, if there's a need with a few of our staff or particular training, that we'll include in that day or the 2 day training.

I think the size of the groups too, make a difference. So if you've got a smaller group of participants it's usually a lot better because you've got a lot more engagement with the people there and a lot more involvement where they can share their stories and ask a lot of questions. Whereas I know sometimes when we've had large groups you'd be lucky to engage half the staff.

L: Is there anything else you'd like to ask, Steve or Carol?

C: I'm just thinking that the DTSC could possibly offer some sessions. I don't know if that's something that you might be interested in?

What does that stand for?

C: Dementia Training Study Centre. So a government funded organisation and we do training for health professionals. I mean the idea is translating knowledge into practice. So they like to sort of up-skill health professionals so they can sort of change the culture of the organisation to be more, you know, work more with people who have a greater understanding. Our education sessions, we provide them to various organisations and currently that's fully funded so there's no actual charge for it. We do have some online dementia education modules as well that anyone can access. So anyway that's something we could follow up on with you guys.

That would be good.

S: Has anyone here ever heard of it or seen the online training provider through that site?

No.

S: Oh ok, that's interesting. Part of the role of the Dementia Training Study Centre is to help educate health professionals in the appropriate assessment and management of people with cognitive difficulties. It is an Australia wide program but we're only doing Victoria and New South Wales.

We certainly work I think quite closely with the services out of the Austin Hospital. So there's the AVI consultancy and, what's the other one?

CBDATS.

Yeah, so we work quite closely with them. Yeah, but that sounds like that could be really interesting for us.

C: Yeah well certainly we could have a discussion about, you know, you said you maybe have half a day a month where you do staff training. I mean you could certainly come in for a session and do some training, if you were interested.

Sounds good.

We've had a couple of case managers use the phone service for DBMAS out of St. George's and it's been good. I remember years ago there was a lot more. They would go out and advertise that service and do some training. Honestly I still remember the woman who did it, just really impressive. Now when you ring up it's purely over the phone, obviously, service. We actually asked could they come and do an in-service just about their service and they said we don't even offer that anymore. The only time we'd [DBMAS] come out to your office is if you've got a group of clients

that you want to discuss, but they did offer that as an option. I'm not sure how much Wintringham use DBMAS in residential or community, but very skilled people at the end of those phones about behaviour stuff.

C: They have been running some sessions at St. George's.

See I've not ever seen any training, I've never seen anything advertised. I think we have got a training unit now within the company, Wintringham. I suppose part of what we really have to do to is get those people to disseminate more to the rest of us about what's out there. Because really, unless you're on an e-mail list you just don't see, we don't see things unless one of us happens to get it and then we e-mail each other. We're not on a lot of mail, we're on the NARI one, but I don't know how many others would be around for other training options.

S: I guess just the final thing I'd be interested in, in the context of all the other issues that you're dealing with, you know, where does cognitive impairment/dementia fit? I mean is it right up there as one of the most burdensome and difficult areas? Or is it just part of a minor part of an overall issue that really requires attention to be delivered in a lot of other areas at the same time, and maybe even of greater importance than the dementia care itself?

I personally think it's very important, especially in the community. I think the reason being that a lot of our clients like to take risks and for us it's always that constant balance of do they understand and are they able to make an informed decision? So cognitive impairment is something we spend a lot of time talking about and thinking about for that reason.

We have a lot of guardians, a lot of administrators, like as a high proportion of our clientele. I don't know if that's unusual or not but I think we all feel we're forever in VCAT. As an organisation we are always there.

And high case management hours. So the amount of hours you have to invest in a client in case management time is usually far more than what you're funded for under a general package. And you know, yes we can get this dementia supplement back, it doesn't even, really it's next to nothing and it doesn't even target our clients with significant behaviours. You know, it's fine to try and keep people at home but we haven't got the dollars to support someone that has dementia that needs that behaviour management. If you can't purchase it or get that from another service, that's hopefully funded, you're looking at putting people into care early.

L: Is there anything else? Well thank-you everyone, I think that's really informed me. And I'll turn off the recorder now.

Thank-you guys.

S: Thank-you.

Acknowledgements

We would like to acknowledge the VIC/TAS DTSC who provided funding for this study. Thanks also to Carol Chenco who provided the literature review for this report, Leslie Dowson who undertook the focus group interviews and qualitative data analyses, Leah Zelencich who transcribed the focus group recordings and many thanks to all of the aged care staff at Wintringham Aged Care Services who gave freely of their time and experience during the focus group interviews.