

# Upholding The Rights And Protecting The Safety Of People With Dementia



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## **COVER PHOTO**

Victoria Police and workshop attendees Dementia and Love Symposium. All photos by Lisa White © [thesocialphotographer.com.au](http://thesocialphotographer.com.au)

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# INTRODUCTION

Alzheimer's Australia (2016a) reports that there are more than 353,800 Australians living with dementia and this number is expected to increase to 400,000 in less than five years and rise to almost 900,000 by 2050. Dementia is the second leading cause of death in Australia, the single greatest cause of disability in older Australians, and the third leading cause of disability burden overall. An estimated 1.2 million people are involved in the care of a person with dementia.

The National Framework for Action on Dementia (Department of Health, 2015) and the Guide to Creating a Dementia-friendly Community (Alzheimer's Australia, 2014a) outline the rights of people with dementia, including the right to dignity, choice and quality of life with meaning and purpose.

These rights have been difficult to uphold. Alzheimer's Australia (2014a) surveyed people with dementia to identify what quality of life, meaning and purpose meant to them and identified that people with dementia want support to do the things they did before diagnosis. Despite this, Alzheimer's Australia (2016b) found that people with dementia are twice as likely not to see friends and are twice as likely to experience loneliness than the general public (Alzheimer's Australia,

2016b). In addition, 42% of people with dementia surveyed have also told Alzheimer's Australia (2014b) that people avoid speaking with them because of their diagnosis, while 41% wished they had more social contact with people in the community. At the very time when people with dementia need support from friends and family – many turn away from them. The stigma around dementia means people with dementia are socially isolated.

There are also more overt forms of rights violations experienced by people with dementia. People with dementia are more vulnerable to elder abuse (Department of Health, Victoria, 2016); sexual assault (Mann et al., 2014); financial abuse, emotional abuse, physical abuse and neglect (Department of Health Victoria, 2016).

There is a need to educate police to build an understanding of dementia, including people's experiences of the disease and their needs. Such education could assist in addressing rights' violations such as elder abuse, fraud and other financial abuse, and various forms of assault and neglect. It could also assist in promoting positive outcomes in police encounters with people with dementia – including incidents where people with dementia are reporting missing, or are found to be at risk.

This brief report outlines strategies to respect the rights and protect the safety of people with dementia – through a policing. The strategies were identified at a dementia and policing workshop held at the National Dementia and Love Symposium.

## **DEMENTIA AND LOVE SYMPOSIUM**

In February 2017 a National Symposium on Dementia and Love was hosted in Ballarat by Celebrate Ageing in partnership with The Australian Association of Gerontology, The City of Ballarat, Ballarat Health Services. The Symposium was supported by Alzheimer's Association Vic.

The Symposium focused on interpersonal relationships and all speakers were people with dementia, their families and friends. In preparation for the symposium an opportunity was identified to host a dementia and policing workshop at the Symposium.

In preparation for the workshop – community members began to share stories about policing and the safety of people with dementia. A decision was made to circulate a short online survey to capture the key issues and suggested strategies that could inform the workshop. The survey was confidential – no demographic data was collected. Participants were asked the following four questions:

- 1. Is there a story about a person with dementia, that involved the police or that involved the person's safety or rights being compromised, that you would like to share?*
- 2. What do you think the police need to know about people with dementia?*
- 3. What do you think people with dementia and their families need to know about how the police can assist people with dementia?*
- 4. Are there any other comments or suggestions that you would like to make?*

The survey was posted online two weeks before the Symposium and was completed by 55 people.

The workshop was facilitated by the Symposium Coordinator, Dr Catherine Barrett and Leading Constable Janine Walker from Victoria Police.

The workshop was attended by nine police officers from Ballarat, Bacchus Marsh and Melbourne.

Feedback on the policing workshop was very positive – as highlighted by the following comment in response to a Symposium evaluation question about the highlights:

**“Great to have the police there and engaged as they were.”**



Pictured: Janine Walker, Sue Pieters-Hawke, David Flood

The National Ambassador for Alzheimer’s Australia, Sue Peiters-Hawke commented that the support of Victoria Police for understanding and addressing the rights and safety of people with dementia needs to be replicated in other states and territories.

The workshop included a presentation on key issues arising from the survey and presentations by Victoria Police. Next, approximately 80 Symposium delegates broke into small groups (with police allocated to each group) and were asked to workshop the following two items:

1. *Issue: describe a factor that is/may compromise the rights and safety of people with dementia*
2. *Strategy: what strategies could be used to promote rights and safety in response?*

Sixteen issues and strategies were identified at the Symposium and a further five were submitted by police officers from the Ballarat West police station following the Symposium.



Pictured: Symposium delegate Edie Mahew gives Police attendees a briefing

This brief report outlines the key themes identified in the survey and the workshop. The aim of the report is to circulate these outcome in the hope of creating further momentum for change. It is important to note that Celebrate Ageing is a self-funded organisation and this workshop and report were unfunded. The report begins by outlining the survey results and then presents key issues and strategies.

# SURVEY RESULTS

The survey results are presented in the following section, by question. Thematic analysis was undertaken to identify broad themes.

## QUESTION 1: TELL US A STORY

Twenty-seven participants shared stories in response to this question. The most common theme related to people with dementia who became lost (9), followed by concerns about the vulnerability of people with dementia (5), abuse by family members (4), concerns about driving safety (2) and sexual assault. For each theme, samples of survey responses are presented.

### **Becoming lost**

- *“Elderly female with dementia went to the letter box one day and wasn't seen for 4 days. Her husband and main carer was frantic when he discovered her gone and alerted the police immediately. A thorough search of the immediate area failed to*

*locate his wife. She was found four days later at the Frankston Railway station and returned home."*

- *"A friend with Younger Onset Dementia accidentally caught the wrong train that took her further away from home. She was diagnosed in her 40s. Her action worried her.....she felt worried, disoriented and confused. When she finally got off the train (about 45 minutes further away from the City), her behaviour appeared to be agitated. She sat in the gutter crying, not knowing the area, and couldn't think and this lead to her inability to speak. Someone called the police. For some reason, it was assumed she was on illegal drugs, so she was handcuffed and taken to a Hospital. She still couldn't speak, and was hitting out out the Police. She was handcuffed to the rail of the bed in A & E. Her blood tests showed no illegal drugs, and eventually a nurse noticed that she appeared to be pointing to her wallet. (Remember she couldn't speak) Inside her wallet was a card stating that she has Dementia and a contact phone number. This event lasted a few hours."*

## **Vulnerability**

- *"Person with moderate stage dementia standing on street corners handing out large sums of money she had withdrawn from her bank account to strangers - police picked her up and helped her find her way home and call her family - good outcome when obvious cognitive decline."*
- *"One client with dementia and still living alone in her own home allowed a tradesman into her house and agreed to his doing some work for her. She was to pay him cash (the end sum being far higher than his original verbal quote) and when she didn't have enough money he offered to take her to an ATM."*

*Fortunately she didn't know how to use one and was due to come to our centre. He was to go back the next day for the balance of the money .... we contacted the local Police who agreed to be at her house when he went the next day after she had been into the bank. Apparently she still paid the amount requested but the Police presence presumably prevented any other problems."*

## **Elder abuse**

- *"We had a client picked up at the shopping centre by the police because her abusive son told them that she was "demented, needed to be in a nursing home and had wandered from her property". This was not at all the case. Her son had been threatening to put her into care and was trying to transfer her assets to himself. Police believed the son until our service became involved. Whilst the client did not have a diagnosis of dementia, the situation illustrated the police response to older people generally."*
- *"John" was placed in an aged care facility against his wishes, with early dementia by his second wife. Using her authority as an Enduring Power of Attorney, his wife sold his two properties (in his name) and purchased one in her own name, distributing the remainder of the profits to her son and grandchildren. "John's" children from his first marriage have been fighting for justice through VCAT for over two years with only a recent order for the stepmother's EPOA to be temporarily suspended. Note that the police were unable to act as matters relating to Powers of Attorney are seen as civil matters. The police were further hindered from taking action by the fact that the affected family member had a cognitive impairment, preventing them from taking statements from him directly."*

## Driving

Lady aged 75 with undiagnosed dementia backed her car across the road from her driveway into her [neighbours] car which was parked on their driveway ready to take their children to school. She had no idea how she got there when interviewed by the police who attended the accident. She only stopped driving because her adult daughter told her that her car was too badly damaged to be repaired [which was mostly] true. The daughter probably had no right to stop her mother driving but she acted in the best interest of her mum and other road users. The lady's doctor after being informed had her assessed and diagnosed with dementia and eventually advised revoking of her driving licence some 12 months after the accident.

## Sexual assault

Female resident at aged care facility not interviewed by police re. alleged sexual assault as they were advised she had diagnosis of dementia?? They therefore automatically assume she is an unreliable witness and don't even bother!

## QUESTION 2: WHAT DO POLICE NEED TO KNOW?

All responses related to police education and increased understanding of what dementia is, what the potential issues are related to safety are and how to communicate effectively with a person with dementia. The following quotes highlight the themes:

- Dementia is not a mental illness, it's cognitive impairment, it's terminal it's not contagious, a calm, reassuring approach is needed; they must not be left searching for whatever they are searching for as they may not even know what it is. Need to go to a safe place until their identity is known.
- They need to learn the skills involved in validation, reality orientation and emotional support. The perception of the person is not necessarily reality but their feelings are valid.
- PLWD may appear distressed if they're confused. Police need to know how to calm a person having a panic attack or an outburst in public....suggest they do Mental Health First Aid & role play situations.
- They need to understand that dementia affects the brain in a variety of ways but it is a progressive deterioration in cognitive functioning. A diagnosis does not equal loss of decision making capacity or lack of insight. These two concepts are crucial to protecting and upholding human rights and if you don't understand the distinction or relevance then learn...no excuses.
- People with dementia are not deaf or stupid, plus dementia is an umbrella term for a group of degenerative neurological conditions. Alzheimer's is the most common and affects memory first.
- That a diagnosis of dementia does not mean loss of legal capacity to make statements to the police or to make independent decisions about their own welfare. They should also know that elder abuse is a form of family violence, albeit with significant differences, and should be responded to in the same way.
- People with dementia need to be approached with a gentle attitude including treating the person with respect i.e. finding out their name, introducing yourself, including the person in the

discussion about what is happening. People who are disorientated/confused are very frightened.

- People with dementia respond to calm reassuring approach eg "I would like to help you"

### **QUESTION 3: WHAT DO PEOPLE WITH DEMENTIA NEED TO KNOW?**

The most common response to this question was about letting people with dementia know that the police were there to help. A number of people raised strategies such as safety bracelets and lodging details with the police – these are picked up in the Strategies section of the report. Several survey participants asked whether the police could do anything to assist people with dementia – one participant noted that they thought families were unaware police could offer any assistance. One respondent noted “police are not baby sitters” adding that families need to be “proactive” (the report authors would like to respond to this comment with a note that while police are ‘not baby sitters’ people with dementia are not babies), however, most responses indicated the need for information for people with dementia about how police could assist. The following are sample responses:

- That police are there to protect from possible violence ... even by relatives who may feel that loved ones are being abused or unfairly treated by whomever. That police are always there to facilitate matters.
- People need to understand the process of how police work? It might sound like a stupid question but what do they actually do? What should the public expect from the police? What evidence do they need? How do they get it? Most people think the police operate like they do on TV...reality is very different but most people don't know and don't even ask...what should I expect from you?

- I think that it is important that there be no fear attached to the need to request assistance from the police. Also to have readily at hand contact details of local police and where possible to attend some of the excellent training sessions available by a number of members of the police force in personal safety and day to day living.
- People need to know when it is appropriate to call the police, what assistance to ask for and exactly what the police approach will be. I don't think anyone wants to see the police bundle a person suffering from dementia into the back of a police van. The damage that could be done to already fragile relationships is almost unmeasurable.
- They need to know that help is at hand. Reassurance that they'll be listened to.
- We need to understand what services are provided at a time of need such as when someone goes missing. Basically what can and can't police do. ... I asked the local police officer whether they would send out a helicopter to try and locate my mum. She said no and explained that this is a very expensive resource... like my mum wasn't worth it.
- Police are caring people and are primarily interested in community safety. There's good cops and less than good but overwhelmingly good people.
- Families need to know about Vulnerable Persons registers, and that they can contact their local police station to report possible "wanderers".
- Police there to serve and protect everyone. This includes investigating crimes reported by people with dementia. The community liaison officer can support with visits, information and service referrals.

- Police Seniors register staff can keep an eye out particularly re suspect neighbours can communicate concerns about safety to family (as disease progresses)
- Ensure the person with dementia has identity information with them at all times, also contact details of carer or family.
- Families need to be informed that there is a 'vulnerable person's register' & to register their loved one with dementia on this register at all police stations in the areas they frequent.
- Provide past addresses where the person has lived, as the person may be trying to return there. Even possibly a past work place. family should provide good history of where they have been lost in the past, where and what they have been doing/going. Where do they like to go usually. Up to date photos and descriptions.

# WORKSHOPPING STRATEGIES

This section covers the issues and strategies identified in the Symposium workshop, as well as the strategies that were included in the survey responses.

## DEMENTIA FRIENDLY COMMUNITIES

- *Need to normalize dementia as a part of our community to create greater understanding and acceptance*
- *Get people with dementia out of their 'lock down' environments, challenge the isolation and get them involved in community outings*
- *Dealing with families during times of crisis [is an issue]. Services need to work as a team to provide support and allow people with dementia to stay at home longer*
- *Ongoing dementia awareness education for council staff to help address isolation for people with dementia and the lack of understanding about dementia in communities and services*

## **MISSING PERSONS**

- *Investigate the Safely Home program in Qld then get systems and sponsors to implement it or something similar on state wide level – safety bracelets could include ID and emergency contacts etc*
- *Some people with dementia are being locked in their houses for 'safety' or comfort of carers – provide GPS tracker with carers details and history*
- *Family to document information for police proactively eg: places they normally go, photo, how they are likely to react when they come in contact with the police,*
- *Liaise with Ballarat Police regarding their Safe Return Program*

## **VULNERABILITY**

- *People with dementia could have photos of regular visitors so they don't open their doors to strangers*
- *Implement Vulnerable Persons Register like the one in Ballarat which is maintained by Victoria Police – and include process for identifying people with dementia*
- *Ensure all police regions have Senior's Liaison Officer like Ballarat Police to build relationships with community members and service providers and to reduce vulnerability.*

## **ABUSE**

- *Legislative changes like those from DV/child abuse to protect older people from deprivation of liberty, neglect, assault ... also revisit laws on evidence collection*

## **SEXUAL ASSAULT**

The issue of police failing to do an intensive investigation is a report of sexual assault is made by a person with dementia. Need to:

- *Introduce training/education for all police about dementia and how to deal with reports of sexual assault by person with dementia or their family, friend or carer – on their behalf*
- *Take action against the alleged offenders*
- *Treat people with dementia, carers, family and friends well with regard to court appearances*

## **AGGRESSION**

- *Identify strategies to determine what is dementia and what is ICE or mental illness. Consider GP trackers or wrist band.*

## **POLICE PROCESSES**

- *Police get repeated call outs to one address but don't have the records readily available to the before going to the job. Need a system of red flags so police attending have background. Ensure Intel Officers get involved in checking such data for multiple call outs and have such concerns addressed by operational police*
- *Online training for police including videos on how to approach, communicate with and reassure people with dementia. Education about different types of dementia and the traits of those and the various ways to respond ... including the importance of patience*
- *Need to address the lack of public awareness of the scope of police role and services*
- *Need to develop a Victoria Police dementia awareness package*

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