

Review into technology and closed-circuit television in aged care

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Contents

- About Dementia Australia.....3
- Introduction.....4
- Changed behaviour of unmet need in people with dementia.....5
- Issues of consent and privacy for people living with advanced dementia.....6
- The use of other technologies as monitoring tools7
- Final recommendations7

About Dementia Australia

Dementia Australia is the source of trusted information, education and services for the estimated half a million Australians living with dementia, and the almost 1.6 million people involved in their care. We advocate for positive change and support vital research.

We are here to support people impacted by dementia, and to enable them to live as well as possible. Founded by carers more than 35 years ago, today we are the national peak body for people living with dementia, their families and carers.

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

No matter how you are impacted by dementia or who you are, we are here for you.

Introduction

Dementia Australia welcomes the opportunity to provide feedback regarding surveillance and monitoring technology in aged care.

Surveillance technology is a significant issue for people living with dementia, their families, informal carers, and service providers. There are an estimated 40,300 people living with dementia in South Australia. Without a medical breakthrough, the number of people living with dementia is expected to increase to an estimated 73,000 people in 2058.

Dementia Australia acknowledges that there is no community consensus on the use of technology such as closed-circuit television (CCTV) in aged care settings. However, we have undertaken some consultation on this issue to inform Dementia Australia's position statement on CCTV.

Common reasons cited for surveillance technology include:

- To document instances of abuse or neglect
- To deter serious reportable incidents, aggression, or abuse
- To reduce accidental injuries, such as falls

Dementia Australia is concerned that there is still insufficient evidence to indicate whether surveillance technology alone can drive improvement in these areas.

A 2019 study of video surveillance in residential psychiatric care found that, although CCTV presence makes residents and staff feel more secure, objective security does not increase¹. South Australia's recent trial suggests that video surveillance may disrupt care delivery therefore having a detrimental impact on overall quality².

¹ Appenzeller YE, Appelbaum PS, Trachsel M. Ethical and Practical Issues in Video Surveillance of Psychiatric Units. *Psychiatr Serv.* 2020 May 1;71(5):480-486. doi: 10.1176/appi.ps.201900397. Epub 2019 Dec 18. PMID: 31847737.

² PWC. (2022, June). SA Health. Evaluation of the CCTV pilot project. Retrieved from <https://www.sahealth.sa.gov.au/wps/wcm/connect/003cf018-d20e-4451-89fe-1f2ed4939052/Evaluation+of+the+CCTV+Pilot+Project.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-003cf018-d20e-4451-89fe-1f2ed4939052-obN9nuq>

The Australian Law Commission warns that surveillance technology may amount to a restrictive practice, with people with intellectual disabilities disproportionately subjected to monitoring in residential care settings³.

At this time, and with the evidence available, Dementia Australia does not endorse a broad surveillance technology program within residential aged care settings but understands that it may be appropriate on a case-by case basis, provided there are appropriate protections, consent and governance in place. It is important that our approach to CCTV is proportionate and targeted, so that people living with dementia are not subjected to 'blanket' surveillance.

Changed behaviour of unmet need in people with dementia

The Royal Australian and New Zealand College of Psychiatrists estimates that changed behaviours affect 29-90 per cent of residents in Australian aged care homes⁴. Changed behaviours can present as aggression, agitation, hallucinations, disinhibition, wandering, or shouting. Changed behaviour or 'behaviours of concern' are often produced by unmet need – pain, infection, distress, confusion, or discomfort – combined with an inability to express these needs to others.

The impact of changed behaviours ranges from mild to severe. However, only a fraction of people with dementia will display actual or threatened violence (seen in Tier 6 and 7 of the Brodaty, Draper, Low Triangle).

The first line of defence against changed behaviours is to remedy (with the goal of eradicating) the clinical, environmental, and psychosocial drivers of unmet need.

We must also ensure that all aged care staff complete appropriate education in dementia care. This will not only lead to better resident outcomes, but increase worker confidence in de-escalation and responsiveness, reduce stress and 'burnout'.

³ Australian Law Reform Commission. (2014, 9 18). The use of restrictive practices in Australia. Retrieved from https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124/8-restrictive-practices-2/the-use-of-restrictive-practices-in-australia/#_ftn11

⁴ Parliament of Australia. (2014). Senate Standing Committee on Community Affairs. Retrieved from Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia: https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Dementia/Report/c02#:~:text=%5B16%5D%20BPSD%20is%20not%20a,in%20Australian%20nursing%20homes%3B%20and

Systemic person-centred care and dementia-accessible environments offer staff and residents the best protection against aggression and violence, whilst improving quality of life and staff satisfaction.

Issues of consent and privacy for people living with advanced dementia

There are several ethical challenges that must be addressed if surveillance technology is to be broadly implemented in residential aged care.

Approximately two-thirds of residents are living with moderate to severe cognitive impairment⁵. This has implications for informed consent and the use of CCTV in shared spaces. Signs alerting people to CCTV may not be dementia accessible. Residents with dementia might forget that they gave consent or later withdraw their consent.

Protections must in place for residents who withhold consent. Residential aged care is an essential public health service, and people living with dementia, their families and carers should not feel pressured to choose between receiving the care they need or losing their right to privacy.

CCTV in bedrooms is a significant privacy issue. Residents with advanced dementia and/or limited mobility commonly have bathing and toileting activities performed in their bedroom. Residents may also have private appointments and medical procedures undertaken in their room.

Consideration should be given to how consent and privacy would be managed as a resident's health declines. Deteriorating health will lead to more activities of daily living being performed in the bedroom. An enduring waiver, signed on first admission to a facility, may not reflect a person's changing circumstances or wishes.

For residents with advanced dementia, consent is likely to be decided by the person's family, carer, or substitute decision maker. It is important that proxy decision makers are supported to make a decision that aligns with the resident's values and wishes, even if that decision carries greater risk, and that the decision is free from actual or perceived coercion.

⁵ The South Australian Health and Medical Research Institute. (2020, August 24). Research Paper 8 - International and national quality and safety indicators for aged care. Retrieved from Royal Commission into Aged Care Quality and Safety: <https://agedcare.royalcommission.gov.au/publications/research-paper-8-international-and-national-quality-and-safety-indicators-aged-care>

Dementia Australia recommends a suite of nationally consistent regulatory guidelines on the use of surveillance technology in aged care settings.

The regulatory guidelines would address the forementioned issues, as well as:

- Respecting people living with dementia's right to dignity and privacy
- Stipulations and limits on how and where CCTV can be used
- Provisions for the storage and possession of recordings and data
- Governance and complaints
- Incident responses, including interaction with the Serious Incident Response Scheme and other reporting mechanisms

The use of other technologies as monitoring tools

In principle, Dementia Australia supports enabling technology that enhances the wellbeing and independence of people living with dementia.

The technology must be unobtrusive, evidence-based, and fit-for-purpose.

People with dementia may experience significant changes in perception and ability to filter environmental distractions. Products that appear innocuous to a person without dementia may pose as a hazard or constraint to a person with cognitive impairment. For example, to a person with dementia, a black sensor mat may look like a hole in the floor, unintentionally becoming a barrier to getting safely out of bed.

Products used to monitor residents with dementia should undergo user testing by people living with dementia and meet dementia enabling design principles.

Monitoring technology must always complement, not replace, face-to-face, person-centred care.

Final recommendations

Dementia Australia believes that there is, currently, insufficient evidence to support broad use of CCTV in residential aged care.

By focusing our attention to person-centred care, we can reduce the prevalence of serious incidents whilst increasing quality of life, safety and wellbeing for residents and staff.

To this end, Dementia Australia recommends:

- All aged care and medical treating staff complete dementia education to a level appropriate to their role; including training in non-pharmacologic intervention and de-escalation strategies
- Aged care homes are modified or built to dementia-enabling design principles
- Greater investment in translating person-centred care into routine practice
- Increased use of behavioural support specialists and dementia consultants, such as the National Dementia Helpline

Dementia Australia recognises that monitoring technology continues to be sought and utilised on a case-by-case basis, with potentially greater application in the future.

To ensure that appropriate protections are in place, Dementia Australia recommends:

- Further research into the use of CCTV and monitoring technology in aged care settings
- Nationally consistent regulatory guidelines on the use of surveillance technology in aged care settings
- Products used to monitor residents is evidence-based, safe, undergone user testing by people living with dementia and meet dementia enabling design principles.

Dementia Australia welcomes the opportunity for further consultation on this important issue and extends an offer to facilitate engagement with people living with dementia, their families and carers.