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Criminal risk behaviours in people with dementia

Stakeholder Workshop Report
August 2023

DEMENTIA LAW network

UTS

THE UNIVERSITY OF SYDNEY

Executive Summary

In Australia, more than 400,000 people live with dementia and this number is predicted to treble by 2050 in the absence of any disease-modifying treatment or cure. Many people with dementia experience changes in behaviour, which may include verbal and physical aggression, social disinhibition, inappropriate sexual behaviours, and other behaviours, such as dangerous driving and damage to property. Such behaviours can distress, threaten or harm carers, family, other community members and may lead to police contact and legal proceedings—referred to in this report as *criminal risk behaviours*.

Emerging Australian research, led by Dr Fiona Kumfor, indicates that criminal risk behaviours are reported in at least 40% of community-dwelling people being assessed for dementia, particularly younger onset frontotemporal dementia. Of these, nearly a quarter reported contact with police or other authority figures, such as security personnel. A developing body of international research also reports criminal risk behaviours among people with various types of dementia. Yet, despite the apparent prevalence of these behaviours, and Australia's ageing population, there is remarkably little research and public dialogue on this issue.

To start to address this gap, a Dementia Law Network workshop was convened at the University of Technology Sydney on 7 June 2023 to bring together representatives from stakeholder organisations and professions around the complex issue of criminal risk behaviours that may occur among people living with dementia in the community. Workshop participants were from: NSW Police; Legal Aid NSW; Seniors Rights Service; Crime Stoppers; NSW Ageing & Disability Commission; NSW Government (Department of Communities & Justice, Department of Health); Carers NSW; Dementia Support Australia; City of Sydney (Access & Inclusion); and health professions, including neuropsychology, psychiatry, general practice, and community/aged care nursing.

The **aims** of the workshop were to:

- share perspectives and experiences;
- build relationships and networks; and
- identify common themes and priorities to guide future research and collaboration.

FOCUS QUESTION

The **focus question** for the workshop was: How might we better **recognise and respond** to criminal risk behaviours among people with possible or diagnosed dementia in community settings? The workshop activities sought participants' views on:

- the most pressing concern(s) from their professional/organisational perspective;
- identifying relevant stakeholders, both formal and informal;
- the types of risk behaviours and situations that occur in community settings; and
- avenues to address this complex issue through collaborative initiatives.

KEY ISSUES AND THEMES

An overarching concern centred on the need for **non-criminalising responses** to dementia and associated behavioural issues. To this end, several goals were identified as priorities:

- improving awareness and recognition of changes in behaviour that may be a possible sign of dementia;
- better pathways to access appropriate services and supports when behavioural concerns are recognised;
- reducing reliance on police as first responders, including:
    - earlier recognition of and improved responses to risk behaviours in order to prevent situations that lead to police contact; and
    - service models and resources that support police when they are called to respond to problem situations.

OPPORTUNITIES

The workshop discussion identified a number of opportunities for research, training and community engagement initiatives. This report presents these collaboration opportunities in relation to a **continuum of behavioural changes**:

- early signs of changes that are out of character for a person and raise concerns for family, friends and others;
- repeated or escalated behaviours that can lead to contact with police and the criminal justice system;
- and serious and violent behaviours that involve multi-system responses, particularly criminal justice, forensic mental health and aged care systems.

Priorities were identified that focus on earlier identification of risk behaviours in community settings and strengthening responses when contact occurs with police and the criminal justice system. This report presents a research agenda that was developed in collaboration with workshop participants and relevant stakeholders.

Acknowledgements

We thank everyone who participated in the workshop for generously sharing their time, expertise and ideas and for reviewing a draft version of this report. The participation of relevant stakeholder organisations was invaluable, as was the expert input from medical and health professionals who took part in the workshop: Prof Dimity Pond, General Practitioner; Dr Mark Yates, Psychiatrist, member of the RANZCP Faculty of Psychiatry of Old Age; and Ms Jillian McMillan, Clinical Neuropsychologist.

We are grateful to: Lindsay Asquith and Leanne Sobel for their expert assistance in planning and facilitating the workshop; and Caitlin Ong for her skillful work in designing and producing the workshop report.

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Introduction

DEMENTIA

Dementia is an umbrella term that encompasses symptoms, such as changes in memory, thinking and behaviour, that are caused by disorders affecting the brain. Over 100 diseases may cause dementia. The most common dementia diagnoses include: Alzheimer's disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia.

Younger onset dementia refers to any form of dementia where symptoms start under the age of 65. Due to a common misperception that dementia only affects older people, the signs of dementia in people in their 50s and 60s are often downplayed or attributed to other causes, such as midlife stress.

Over 400,000 people in Australia live with dementia, a majority of whom are community-dwelling.[1] Dementia is now the leading cause of disease burden among people aged 65 years and older. Rates of dementia are 3 to 5 times higher for Aboriginal and Torres Strait Islander people, who are also more likely to develop dementia at younger ages.[2]

DEMENTIA AND CHANGES IN BEHAVIOUR

Many people with dementia experience behavioural signs and symptoms. For some people, these behaviours include social disinhibition, verbal and physical aggression, driving violations, financial recklessness and inappropriate sexual behaviour. These behaviours may threaten or harm others and can lead to contact with police, legal professionals and the criminal justice system.[3] We refer to these behaviours as 'criminal risk behaviours.' The term does not imply an intention to commit an offence, but describes behaviour that may be perceived as criminal offending.

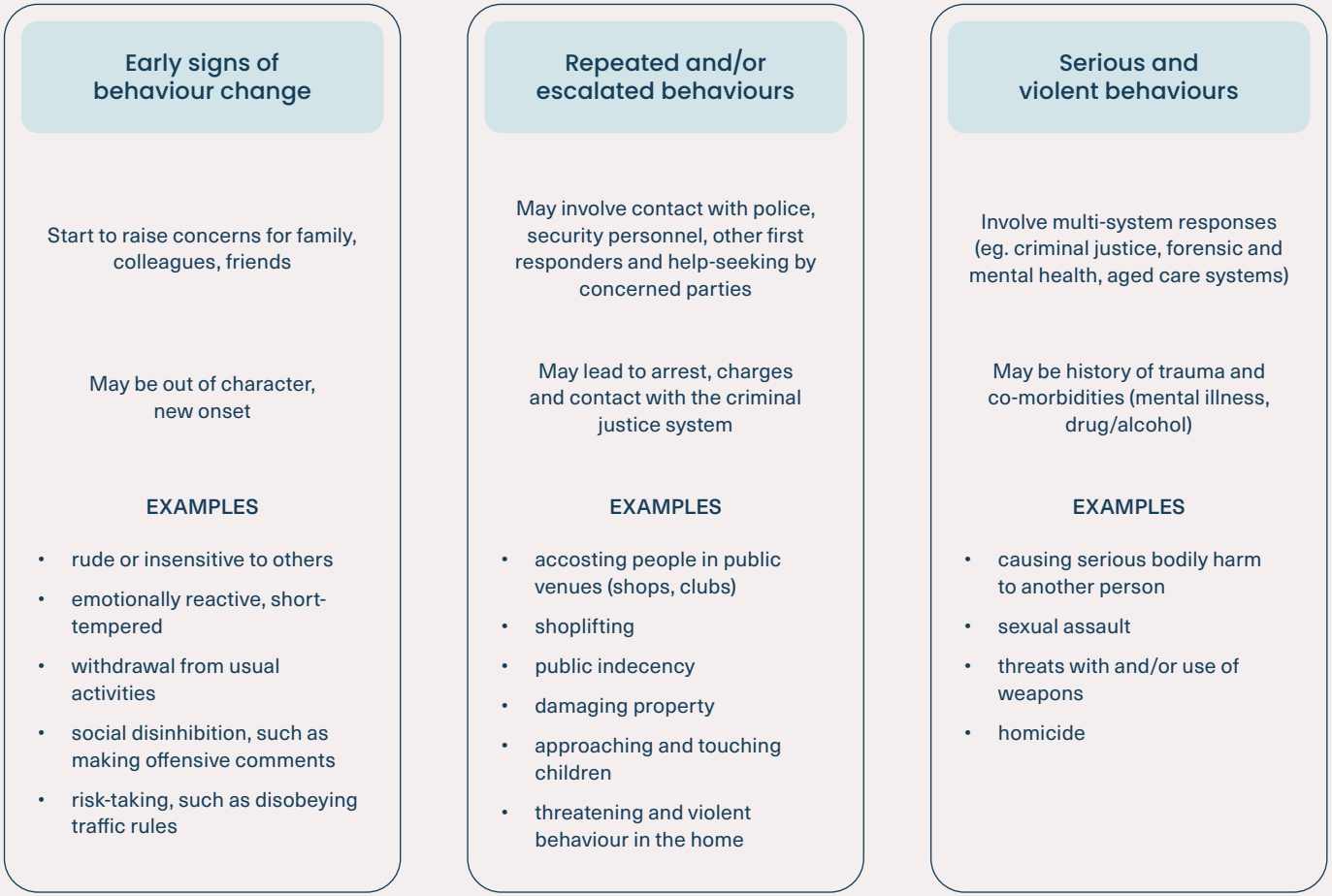
These behavioural symptoms appear to be more common in some dementia subtypes, including individuals with frontotemporal dementia (FTD). Studies in the US, Europe and Japan have found that criminal risk behaviours, such as physical and verbal abuse, theft, traffic violations and inappropriate sexual behaviour occur in at least one-third to over one-half of people with FTD.[4] Preliminary Australian research indicates that criminal risk behaviours are reported in at least 40% of community-dwelling people being assessed for dementia, particularly among those with younger onset dementia, including FTD.[5]

Criminal risk or offending behaviours that occur for the first time in midlife may be warning signs that should trigger referral and assessment for neurocognitive illness, although this is only just starting to be recognised.[6]

What is known about dementia and criminal risk behaviours?

CONTINUUM OF BEHAVIOURS

Behaviours vary in nature and severity, as depicted in the figure on this page. To date, there has been scant Australian research on dementia and criminal risk behaviours, especially among people who live in the community. A recent scoping review of empirical research in the field—led by Nola Ries and Fiona Kumfor—identified only a few Australian studies, which investigated family carer experiences of early-stage behaviour changes[7] and analysed court decisions involving serious criminal offences perpetrated by a person with dementia.[8] Other areas of research in Australia address violence involving residents in aged care facilities and dementia among older people in prisons.



EARLY SIGNS OF BEHAVIOUR CHANGE

In regard to **early signs and symptoms**, family members, friends and colleagues are often the first to notice changes in behaviour and personality. However, these changes can be confusing due to being out of character for the person and are frequently downplayed or dismissed. For people in their 50s and early 60s, behaviours may be misattributed to work and relationship stressors and a 'midlife crisis'. This is due, in part, to a lack of awareness of younger onset dementia, the behavioural signs of dementia and the widespread perception that dementia is a geriatric illness that primarily involves memory loss.

Studies involving spouses and other family members of a person with dementia reveal their experiences of verbal and physically aggressive behaviours and their coping strategies, such as trying to get away from the person or defuse the situation.[9] In a study focused on safety issues, family members described how they perceive and respond to relational and social risks for a person with dementia. They gave examples of trying to prevent or reduce harms, such as by intervening in heated arguments, paying compensation for property damage and stopping a family member with dementia from being overly friendly to children when out for walks.[10]

REPEATED AND/OR ESCALATED BEHAVIOURS

Kumfor et al found that nearly a quarter of people who reported criminal risk behaviours had contact with police or security personnel.[11] A follow-up interview study of carers gained more detail about these situations, including their views on the nature and impact of responses by these authority figures and suggestions for improving responses.[12]

Studies in other countries have shed some light on police interactions with people with dementia. Overall, however, the literature on policing and dementia has largely focused on the risks of older people being victims of crime, rather than people with dementia as alleged 'perpetrators' of crime. This gap in knowledge resonated with workshop participants.

Of the available research, one UK study examined the health characteristics of people aged 50 and older detained by police.[13] Older detainees had a higher level of physical morbidity compared to younger detainees, but similar rates of mental illness and substance misuse. Dementia was suspected in around 10% of older detainees and implicated as a reason for the incident that led to their arrest. Assessment by a healthcare professional was recommended for a majority of older detainees (83%), compared to around half of the younger people. The study concluded that '[p]olice detainees over 50 should be considered to have a health assessment as routine procedure. Further investigation should also be conducted into cognitive impairment in this group.'[14]

American studies have described interactions between police and older people. A study in Ohio investigated police interactions with adults aged 60 and older (n=340).[15] Key findings were that older people were as likely to be suspected perpetrators/disputants (n=74 encounters) as they were to be alleged victims of crime. The majority of the situations involved traffic violations. No arrests occurred and '[p]olice actually comforted/reassured almost one-fourth (24.1%) of these older adult suspects/disputants.'[16] Another study examined characteristics of adults 65 years and older encountered by Crisis Intervention Team (CIT) police officers in one city.[17] Of 352 CIT reports analysed, 51% of older people had a diagnosed 'mental illness' of which Alzheimer's disease or dementia were the most common (19%), followed by depressive disorders (17%). Around one-third of calls related to suicide threats or attempts and another third were to check on a person's welfare or a reported disturbance. Situations involving a person with Alzheimer's or other dementia were more likely to be resolved at the scene, with no further action (23.1%), mobile outreach (15.4%) or referral to a social welfare agency (1.5%).[18]

SERIOUS AND VIOLENT BEHAVIOURS

One Australian study analysed 51 court and tribunal decisions pertaining to 30 homicides where the accused person had a potential diagnosis of dementia.[19] FTD was the most common diagnosis, and was over-represented in these cases, compared to its prevalence in the general population. Almost all the accused persons were male, and in over half the cases, the victim was a current or former intimate partner. The decisions dealt with mental capacity issues, including the accused's mental state at the time of the offence, the impact of memory impairment on a purported confession, fitness to plead and fitness to stand trial.

A New South Wales investigation of homicides committed by people aged 55 and older found that a clinical diagnosis of a cognitive disorder was made in 30% of offenders by treating doctors or in medical reports prepared for court.[20] Individuals with a cognitive impairment over the median age of 62 had no prior convictions for a violent offence, which suggests that their cognitive impairment was a contributing factor in the homicides.

Violence in residential aged care facilities has also been the subject of some Australian research. While this topic was outside the scope of the workshop discussion, such facilities can be high-risk settings for physical assaults, as demonstrated by a NSW analysis of 700 police-recorded events in aged care facilities.[21] Dementia was the most common condition among alleged perpetrators (56%) and victims (73%) of violence. Systematic reviews led by Australian researchers on resident-to-resident aggression, abuse and associated injuries revealed high rates of dementia and behavioural symptoms in this population.[22] A national study of deaths resulting from resident-to-resident violence found that nearly 90% of residents involved in such events had a dementia diagnosis and 75% had a history of behavioural disturbances.[23]

The institutional setting of prisons was also outside the workshop scope, however, a developing body of research in Australia focuses on the implications of an ageing prison population.[24] There is a clear need for evidence-based strategies to improve care for people with dementia in prison.[25] An Australian Delphi study produced recommendations from nursing, medical and allied health clinicians who provide prison-based care.[26]

> "30% of older homicide offenders had cognitive disorders."

Workshop—Concerns and Priorities

PRESSING CONCERNS

The workshop was convened in response to clear gaps in knowledge about how to best support people living with dementia who experience behaviour changes that may be perceived as criminal offending. Participants identified a range of pressing concerns and an overarching concern related to the criminalisation of cognitive impairment and associated behavioural issues. Concerns across the continuum of behaviours were:

- Developing appropriate responses to dementia-related behaviour changes, including better identified responsible agencies and access to services and care settings
- Ensuring long-term viability of multi-agency responses that are non-criminalising (e.g. funding, strategic priorities across agencies)
- Recognising risk factors for dementia and influences on behavioural signs and symptoms, including intergenerational trauma, particularly for Indigenous people
- Concern about anti-therapeutic responses taken to reduce risks, including restrictions and potential abuse of people living with dementia, including by family members and informal carers
- The need to support offenders with dementia as they progress through the criminal justice system

Pressing Concerns Identified by Stakeholders

Early signs of behaviour change

- Family and friend carers may experience confusion and lack of support in regard to changed behaviours
- Gaps in community education and awareness of dementia, especially behavioural signs and symptoms, and where to access help
- Inadequate recognition of behavioural symptoms
- Delays in and barriers to timely and accurate diagnosis of dementia

Repeated and/or escalated behaviours

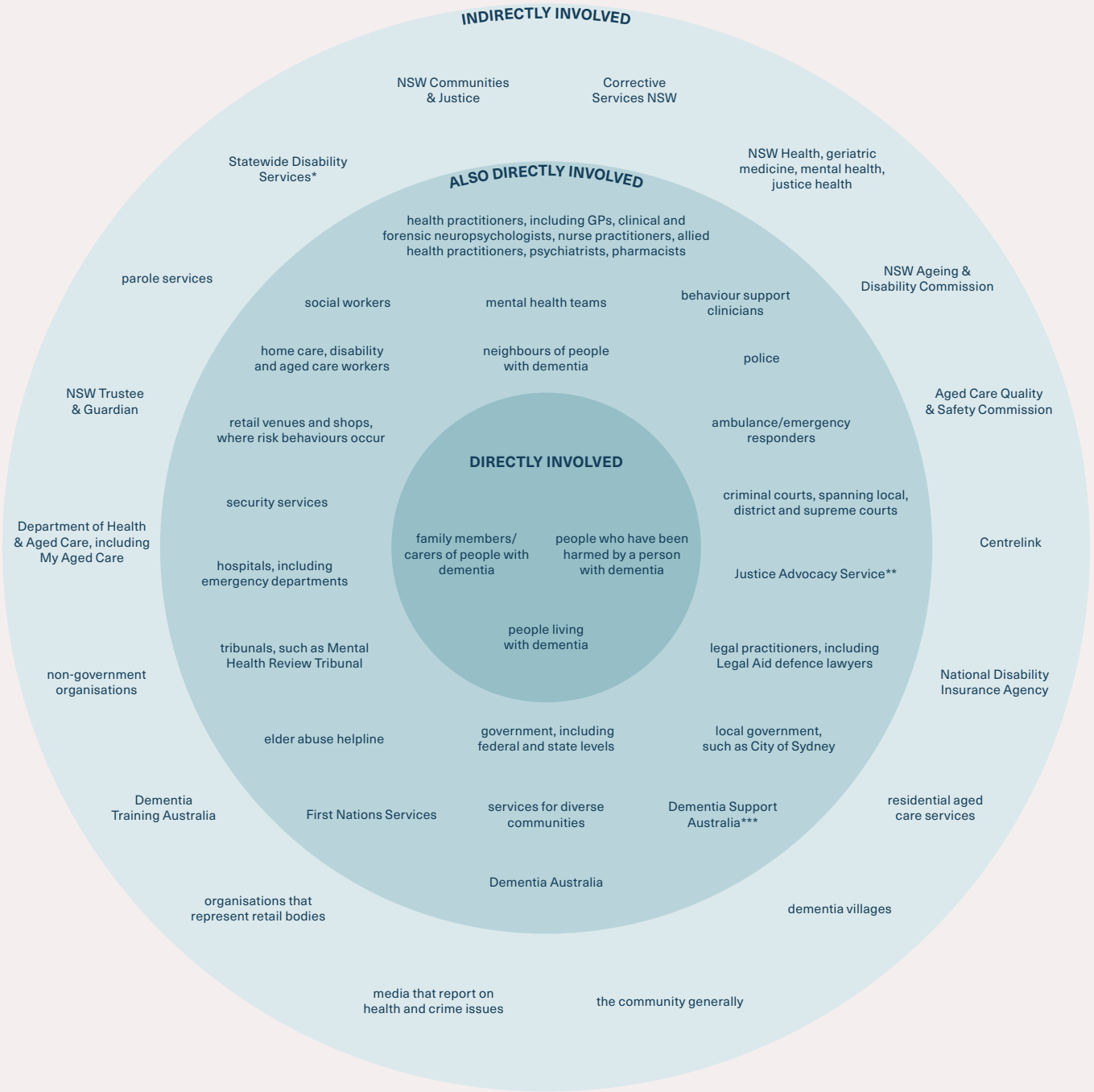
- Use of police as first responders, when this may not be needed or appropriate and may lead to unnecessary escalation
- Emergency responders need to have knowledge and skills regarding dementia, not just mental health
- Dementia can blur the lines between ‘perpetrator’ and ‘victim’ and may lead to misidentification by police
- How the criminal justice system responds to and supports people with dementia
- People with dementia coming into custody without adequate assessment or supports

Serious and violent behaviours

- Lack of appropriate places to treat ‘offenders’ with dementia
- Need for transition pathways that support people with dementia moving across institutional and service settings
- People with dementia remaining in custody inappropriately or without adequate supports
- Sexual violence by a person with dementia
- Complexity of services and systems

UNDERSTANDING THE STAKEHOLDER LANDSCAPE

Workshop participants engaged in a mapping exercise to identify the range of stakeholders who are directly and indirectly affected by criminal risk situations involving people with dementia in the community.



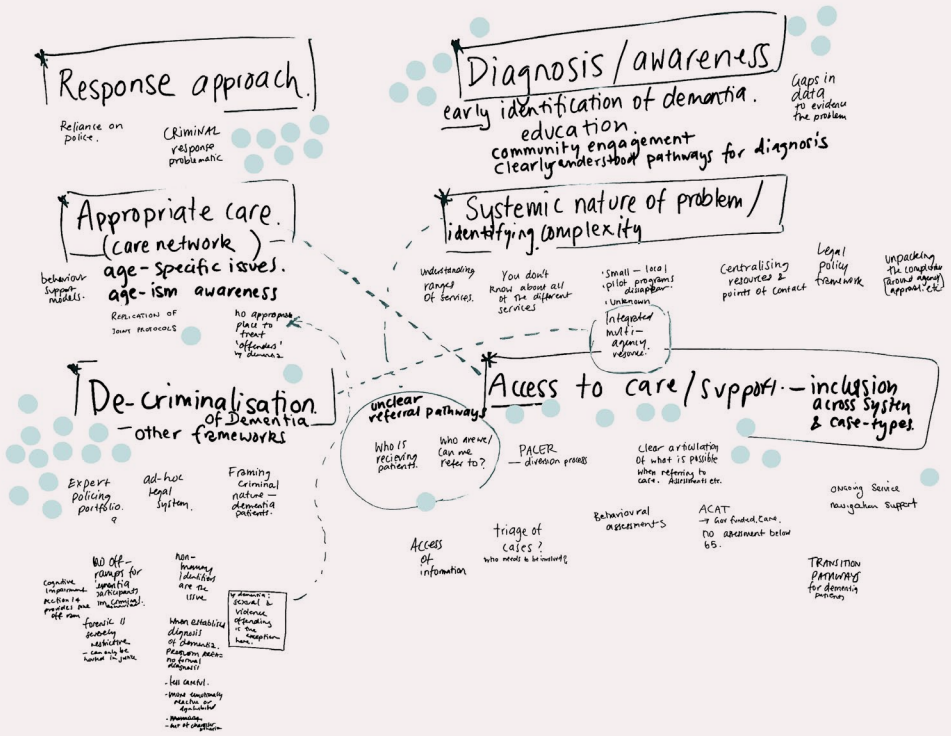
*Statewide Disability Services, which support corrective staff and offenders, including special units to accommodate offenders with cognitive disabilities

**Justice Advocacy Service, which supports people with a cognitive impairment who are in contact with the NSW criminal justice system

***Dementia Support Australia, for e.g. the Dementia Behaviour Management Advisory Service

Problem Framing

Participants worked in three discussion groups—each with a mix of disciplinary and professional expertise—to articulate a key problem that is important to address in the context of criminal risk behaviours and dementia. The 'How Might We' framework was used to develop questions oriented towards desired goals or outcomes. Participants then explored what has been tried before to fix the problem, by whom, what worked and what didn't.



1. HOW MIGHT WE GET APPROPRIATE HELP WHEN A PROBLEM IS RECOGNISED?

The framing of this question around when a problem is recognised acknowledges that dementia is generally under-recognised. Delays in obtaining an accurate diagnosis are common, especially for people with younger onset dementia, First Nations people and people from culturally and linguistically diverse backgrounds.[27] Many people go undiagnosed.

Participants identified various existing sources of help, which were described as good services when a problem is identified. However, there may be gaps in awareness of the services and misperceptions about eligibility requirements.

Dementia Support Australia
—Australia wide

Dementia Support Australia (DSA) is a service led by HammondCare, supported with funding from the Australian Government's Dementia and Aged Care Services Fund. DSA offers a range of tailored support services to address behavioural changes and meet the needs of people living with dementia and their care networks. Services are available for people living at home as well as people in residential care settings. These include the Dementia Behaviour Management Advisory Service, the Severe Behaviour Response Team, and the Staying at Home wellbeing and respite program. Workshop participants recognised the value of this service, while also revealing some confusion about when individuals can be referred to this service.

HOW MIGHT WE GET APPROPRIATE HELP WHEN A PROBLEM IS RECOGNISED?

Older People's Mental Health Services
—New South Wales

The NSW Health Older People's Mental Health (OPMH) Services provide public specialist mental health clinical care primarily to people aged 65 years and over. People under 65 years old, including Aboriginal people aged 50 years and older, can also use this service as suited to their needs. OPMH covers community-based, inpatient and residential care services, which are delivered by a range of health professionals with skills and expertise in mental health problems affecting older people and people with age-related frailty. This includes specialist old-age psychiatrists, nurses, psychologists, occupational therapists, diversional therapists and social workers. OPMH services include:

- specialist mental health assessment
- care planning
- short and longer term clinical management
- clinical advice to other key services, health professionals and programs
- collaborative activities to support early intervention and recovery for older people with mental health problems.

OPMH can respond urgently, but has resourcing limitations. Participants also noted confusion regarding who is eligible for support and when.

Police, Ambulance and Clinical Early Response —NSW

The Police, Ambulance and Clinical Early Response (PACER) embeds mental health clinical expertise into police teams to assist responses to people experiencing a mental health crisis. The involvement of skilled mental health clinicians enables timely assessment, trauma-informed care and referrals to appropriate community and welfare services. It also reduces Emergency Department presentations via police and ambulance and reduces demands on police time. After a successful trial in the St George Police Area Command, PACER was expanded to other areas.[28] The service has received praise from the NSW Law Society.[29] Workshop participants were broadly very supportive of PACER, yet identified limitations with respect to scale and resourcing across areas.

HOW MIGHT WE GET APPROPRIATE HELP WHEN A PROBLEM IS RECOGNISED?

Other points of access to services and supports

Workshop participants identified several other points of access to supports for people with dementia-related behaviours, but noted that the process of locating and accessing specialised supports was often 'slow and confusing'. Points of access include:

- GPs, who are referral points to access specialist care, such as from a geriatrician or psychiatrist.
- My Aged Care, which is the entry point to accessing Australian Government-funded aged care services for people over the age of 65 years.
- National Disability Insurance Scheme, which provides funding for eligible services and supports for people with disability, such as behaviour supports for people under the age of 65 years.

There was discussion around the impact of the arbitrary cut-off of 65 years when accessing different services. In addition, there is a need for ongoing service navigation support for people living with dementia and their carers.

2. HOW MIGHT WE BETTER DE-CRIMINALISE BEHAVIOUR IN THE CONTEXT OF DEMENTIA?

Avoiding the criminalisation of behaviours in the context of dementia requires frameworks outside of criminal law to provide appropriate responses—and to replace the restrictive and heavy-handed responses that can occur in the criminal justice system. Various strategies to support de-criminalisation were discussed, ranging from specific programs to address behavioural incidents to broader societal and law reform measures.

"Off ramps" from criminal justice processes

Off ramps are needed to avoid anti-therapeutic consequences for people with dementia-related behaviours in contact with the criminal justice system. One example is diversion in accordance with section 14 of the *Mental Health and Cognitive Impairment Forensic Provisions Act 2020* (NSW). This provision enables the Local Court to divert defendants with cognitive impairment, including dementia, out of the criminal justice system.

Workshop participants suggested greater use of protocols for accessing dementia-specific support and advice, such as through Dementia Support Australia, when a person with dementia (suspected or diagnosed) has contact with police. Such a protocol could be modelled on the NSW protocol devised to reduce the contact of young people in residential care with the criminal justice system. This Joint Protocol was prepared by the NSW Ombudsman in consultation with stakeholders including NSW Police, Legal Aid NSW, Impact Youth Services, St Saviours, Uniting Care Burnside and Marist Youth Care.

Serious Incident Response Scheme —Commonwealth

The Serious Incident Response Scheme (SIRS) is an initiative to help prevent and reduce the risk and occurrence of incidents of abuse and neglect of older Australians receiving Commonwealth-subsidised aged care and services. It commenced in residential aged care on 1 April 2021 and, on 1 December 2022, was extended to home care and flexible care delivered in a home or community setting. The SIRS sets out arrangements for providers of aged care to manage and take reasonable

Serious Incident Response Scheme cont.

action to prevent incidents with a focus on the safety, health, wellbeing and quality of life of consumers. Commentators have argued that reporting schemes alone are not sufficient to reduce serious behavioural incidents—such as resident-to-resident violence—and must be accompanied by improvements in workforce staffing levels and training.[30]

Multi-disciplinary and specialist expertise

Workshop participants endorsed the strategies of embedding multi-disciplinary expertise and dementia- and aged-specific portfolios in relevant agencies. The PACER model (described above) was highlighted as a positive example of this working successfully. Multi-disciplinary expertise can guide the use of behaviour support models and non-pharmacological and non-legally coercive interventions that can prevent or mitigate the severity of dementia-related behaviour into the future.

These approaches were viewed as providing effective responses to the complexities of dementia-related behaviours and situations, but depend on ongoing multi-agency support and cooperation, and continued funding.

Awareness-raising and advocacy

Awareness-raising and advocacy are vital to improving knowledge about dementia and reducing stigma for people living with dementia and their carers. Across the community and professions, greater awareness is needed of the behavioural signs and symptoms of dementia, response options and available supports and services. Advocacy is also needed to tackle ageism in our society, which provokes prejudice, stereotyping, discrimination and mistreatment on the basis of age. Ageism exacerbates harms for older people with dementia:

> ... older adults living with dementia can face intersectional or combined stigma of ageist stereotypes that overlap with dementia myths. For example, misinformation about dementia is often exacerbated by ageist stereotypes and inaccurate beliefs that dementia is a normal part of the aging process. However, these myths and ageist stereotypes are harmful as they can delay a

HOW MIGHT WE BETTER DE-CRIMINALISE DEMENTIA-SPECIFIC BEHAVIOUR?

Awareness-raising and advocacy cont.

> timely dementia diagnosis and … may exacerbate existing health inequities grounded in the social determinants of health, such as access to health care and support services.[31]

In Australia, Every Age Counts is a national advocacy campaign against ageism, and at the international level, the World Health Organisation supports anti-ageism initiatives. While advocacy was viewed as an important strategy, workshop participants observed that tracking and measuring the progress achieved through advocacy initiatives is limited by gaps in data.

Legal reforms

Law reforms are effective in changing the macro-level legal settings. Examples include age discrimination legislation, which prohibits age-based discrimination in areas such as employment and access to services, as well as reforms to the legislative and regulatory frameworks that govern federally-funded aged care services. Law reforms may be prompted by legal challenges and commissions of inquiry, such as the Royal Commission into Aged Care Quality and Safety. However, these reforms can be *ad hoc* and deficiencies in implementation, resourcing and enforcement may undermine the achievement of the intended legislative objectives.

HOW MIGHT WE BETTER DE-CRIMINALISE DEMENTIA-SPECIFIC BEHAVIOUR?

"Providing access to dementia training for first responders including police" is necessary to create dementia-inclusive communities

National Dementia Action Plan

3. HOW MIGHT WE REDUCE RELIANCE ON POLICE AS FIRST RESPONDERS TO RISK BEHAVIOURS IN THE CONTEXT OF DEMENTIA?

The two goals discussed above—avoiding the criminalisation of behaviours in the context of dementia and improving timely access to appropriate care and supports—align with reducing reliance on police as first responders. Strategies such as PACER for people experiencing a mental health crisis and the Joint Protocol for youth in residential care provide models for how police resources can be deployed more appropriately.

A number of strategies were identified that would help to reduce the reliance on police as first responders, as well as to strengthen their capabilities when called on to respond:

- Education and training to improve awareness and recognition of behavioural signs and symptoms of dementia; this recommendation is echoed in the draft National Dementia Action Plan, which calls for 'providing access to dementia training for first responders including police, paramedics, fire fighters and emergency services workers'[32]
- Improved awareness of and access to health services for people with suspected or diagnosed dementia, such as the NSW Older People's Mental Health Services and Dementia Support Australia services
- Increasing awareness of the role of police in preventing and responding to abuse, neglect and exploitation of vulnerable people including those who are homeless, ageing or those who have a disability
- A PACER model for people with dementia (as discussed above)
- Centralised information services may be helpful (e.g. similar to 1-800 RESPECT or Mental Health Helpline)

- Dementia education and training for GPs such as the training provided by Dementia Training Australia, to strengthen their capabilities in recognising and acting on early signs and symptoms; the draft National Dementia Action Plan calls for a 50% increase in the number of GPs undertaking dementia training over the next 3-10 years[33]

To reduce reliance on police and improve timely access to health services and supports, several persistent problems must be tackled, including: opaque referral pathways; delays in clinical assessment and diagnosis; and under-resourced specialist services. Many people experience waits of over three months and up to 12 months for specialist clinical assessments and strained specialist capacity means that only 35%–40% of new dementia cases are diagnosed.[34] Other problems include: lack of sustained resourcing for promising and innovative pilot programs; and community NGOs and support services with local and cultural knowledge have limited reach and oversight.

HOW MIGHT WE REDUCE RELIANCE ON POLICE AS FIRST RESPONDERS TO DEMENTIA-RELATED RISK BEHAVIOURS?

Collaboration Opportunities in Research, Training and Community Engagement

The workshop discussion identified a number of opportunities to collaborate in research projects, training initiatives and community engagement activities. Gaps were identified in the data and evidence base to understand criminal responses to behaviours in the context of dementia. Suggested sources of data to analyse were:

- Data currently held by health, legal and advocacy services
- Court and tribunal applications and decisions
- NSW Bureau of Crime Statistics and Research (BOCSAR)
- Police—Computerised Operational Policing System (COPS), which is an extensive database that holds information on crimes and other incidents reported to police.De-identified information from COPS records is provided to the NSW Bureau of Crime Statistics & Research, Australian Bureau of Statistics and other agencies for crime statistics compilation.

Examples of questions to build knowledge are summarised here, with a focus on earlier identification in community settings and responses when contact occurs with police and the criminal justice system.

Early signs of behaviour change	• What kinds of behavioural signs and symptoms do family members notice? • How do they and others interpret and respond to those behaviours? • What are the impacts of those behaviours on relationships and activities (e.g. participation in the community, work or other roles)? • What resources and supports would assist families in knowing how to respond to behavioural changes that may be early signs of neurocognitive illness?
Repeated and/or escalated behaviours	• How often does referral for medical assessment happen? For whom? In what circumstances? Is it age alone or age plus other factors that triggers referral? • What is best practice for police and the criminal justice system in the context of new onset of offending behaviour in people aged 50 and older? • Who is the medical/health workforce that will absorb new referrals and conduct assessments in a timely manner? • What are options for alternative first responder models (e.g., informed by the PACER model that embeds mental health workers within police teams)?
Serious and violent behaviours	• What kinds of serious and violent behaviours occur among people with dementia, both in community and residential care or prison settings? • How can we support people with serious behavioural disturbances who cannot be accommodated in residential care settings? • How can we determine when, due to disease progression, the risk of future offending behaviour is no longer a concern?

Conclusion

The workshop discussions underscored the importance of adopting non-criminalising approaches to behaviours in the context of dementia. Key priorities emerged, including: improving awareness and recognition of behavioural changes that may indicate dementia or that emerge in the context of dementia; improving access to appropriate services and support for individuals and their carers; and reducing the overreliance on police as first responders.

Several key opportunities for research now arise in relation to: gaining a clearer understanding of the nature and extent of behavioural changes associated with dementia that increase risk of contact with police and the criminal justice system; the responses to those circumstances; and improving management across various points of contact for people with dementia and their carers. These points of contact include GPs, hospital emergency departments, community services, public venues, and the police. Further work should aim to improve earlier identification of risk behaviours in the community and strengthening the range of available responses should contact occur with police or the criminal justice system.

Looking ahead, it is clear that ongoing collaboration among stakeholders, professionals, and organisations will be essential to effectively address this complex issue. This report represents the start of a new collaborative research agenda and roadmap for future action, emphasising the urgency of recognising and responding to criminal risk behaviours among people with dementia in our communities, in compassionate, safe and appropriate ways.

Endnotes

INTRODUCTION

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