UTS Ageing Research Collaborative and Partners

Behaviours in the context of dementia:

insights from safeguarding, health and advocacy services

Carers NSW Australia

DEMENTIA LAW network

Ageing and Disability Commission

Dementia Support Australia

Funded by the Australian Government
A service led by HammondCare

UTS

Executive Summary

People living with dementia may experience behavioural symptoms – including aggression and disinhibition – that pose risks of harm to carers, family members and others. This report presents a collaborative research project that investigated behaviours in the context of dementia, with a focus on family carer experiences, allegations of abuse or neglect, and situations with police involvement.

The project analysed: responses to the Carers NSW 2022 National Carer Survey ('National Carer Survey') by carers of people with dementia; case reports from the NSW Ageing and Disability Commission ('ADC'); and service data from Dementia Support Australia ('DSA'). All data were strictly de-identified in accordance with ethics approval requirements.

National Carer Survey: The analysis showed a range of needs among people with behavioural symptoms of dementia and their spousal and family carers. For example, nearly three-quarters (72%) of carers reported providing behavioural supports and over half (51%) reported social isolation. Higher levels of psychological stress were experienced by almost half (48%) of younger carers and over a third (38%) of older carers.

ADC Cases: Reports of alleged abuse or neglect involving a person with dementia centred on older couples, mostly aged over 80 years. Various formal and informal support strategies sought to reduce risks for older people, especially those who wished to remain living in their own homes. Police involvement included responses to domestic violence concerns.

DSA Data: When specialist behaviour support services were provided for a person with dementia in residential aged care, potential concomitant police involvement was infrequent. Specialist supports focused on identifying and responding to underlying reasons for changed behaviours.

The project findings indicate a need for greater awareness and understanding of behavioural symptoms of dementia, enhanced coordination between services, improved attention to carer needs and stressors, and supportive strategies to reduce risks for people with dementia who experience behaviour changes, as well as their carers and families.

Introduction

People living with dementia may experience changes in their behaviour and personality, such as verbal and physical aggression, social disinhibition and/or inappropriate sexual behaviour. Such behaviours can threaten or harm family and community members, are implicated in carer stress,[1] situations of elder abuse[2] and domestic violence,[3] and may lead to police contact and legal proceedings.[4] Preliminary Australian research indicates that at least 40% of people being assessed for dementia experience behaviour that may be perceived as offences or violations, putting them at risk of contact with police and security personnel.[5] Similar rates are reported in other countries.[6]

Aggressive and out of character behaviours in a person with dementia are often very distressing for family members and carers, even more so than symptoms such as memory loss.[7] The early course of these behaviours is poorly understood and there are missed opportunities to prevent escalation to crisis situations.[8] The limited available research about frontline services and professionals, including police and legal services, indicates gaps in knowledge about the behavioural symptoms of dementia.[9] There is therefore a risk of antitherapeutic responses that undermine the rights and dignity of people with dementia, worsen carer stress, and stigmatise and criminalise behaviours that are symptoms of dementia and unmet needs.[10]

Project background and aims

In June 2023, a workshop was convened at the University of Technology Sydney that brought together stakeholder organisations and professionals to share experiences of 'criminal risk' behaviours in the context of dementia, that is, behaviours that could be perceived or experienced as offending behaviour. A workshop report is publicly available and provides further details about the attendees, discussion topics and recommendations, which emphasised a need for earlier identification of risk behaviours and service interventions that support health and wellbeing.[11] The workshop discussion identified areas for research to address gaps in understanding about what currently happens in the community for people with dementia, their carers, and informal and formal responses to behaviours. A recommendation was to analyse data held by stakeholder organisations to gain insights into the situations that come to their attention and the services and supports provided to address behaviours, risks and harms.

Acting on this recommendation, a project was developed to analyse data from three sources: a national survey of carers in Australia; a statutory agency that receives and investigates reports of abuse or neglect of older people and people with disabilities; and a national organisation that provides specialist behavioural supports in the context of dementia. This analysis aimed to examine:

1. the types of behaviours that feature in data reported by carers and concerned community members that raise concerns about risk factors for, or alleged instances of, offending;
2. responses to those behaviours, including informal and formal responses to reduce risks; and
3. impacts and implications for people living with dementia, carers and other stakeholders.

Data sources

Carers NSW 2022 National Carer Survey

- Biennial national survey
- Collects data on topics such as caring tasks, carer stress and use of aged, disability and health services
- In the 2022 survey, 1196 respondents reported caring for a person living with dementia

NSW Ageing and Disability Commission

- Statutory agency that responds to reports of abuse or neglect of older people or adults with disability
- Data consisted of 17 de-identified case reports from 2022-23 that met the following criteria:
  1. the person alleged to have engaged in abusive or neglectful behaviour was known to have dementia or there were concerns about their cognitive capacity; and
  2. the alleged abuse or neglect could be regarded as potential criminal offending.

Dementia Support Australia

- A national service that provides support, assessment, advice and strategies to address behaviours that affect people with dementia or their carers
- Data were drawn from DSA's two largest programs:
  1. **Dementia Behaviour Management Advisory Service ('DBMAS')**—offers support for mild to moderate behaviours and psychological symptoms of dementia; provided in home and residential care settings
  2. **Severe Behaviour Response Teams ('SBRTs')**—respond to situations involving severe behaviours and psychological symptoms as a result of dementia; provided in residential care settings

The dataset encompassed referrals to DBMAS and SBRTs from 1 April 2022 to 30 September 2023 and identified situations with potential police involvement. DSA estimated police involvement based on broad, non-specific criteria. As such, DSA cannot confirm any police involvement with DSA cases represented in this document. Similarly, DSA does not imply that any real or perceived police involvement with people supported by DSA was associated with criminal behaviour or criminal risk behaviour.

Nine de-identified vignettes were prepared from a sample of DSA service referrals that had police involvement. Maximum variation provided qualitative data on a range of behavioural, personal and contextual factors.

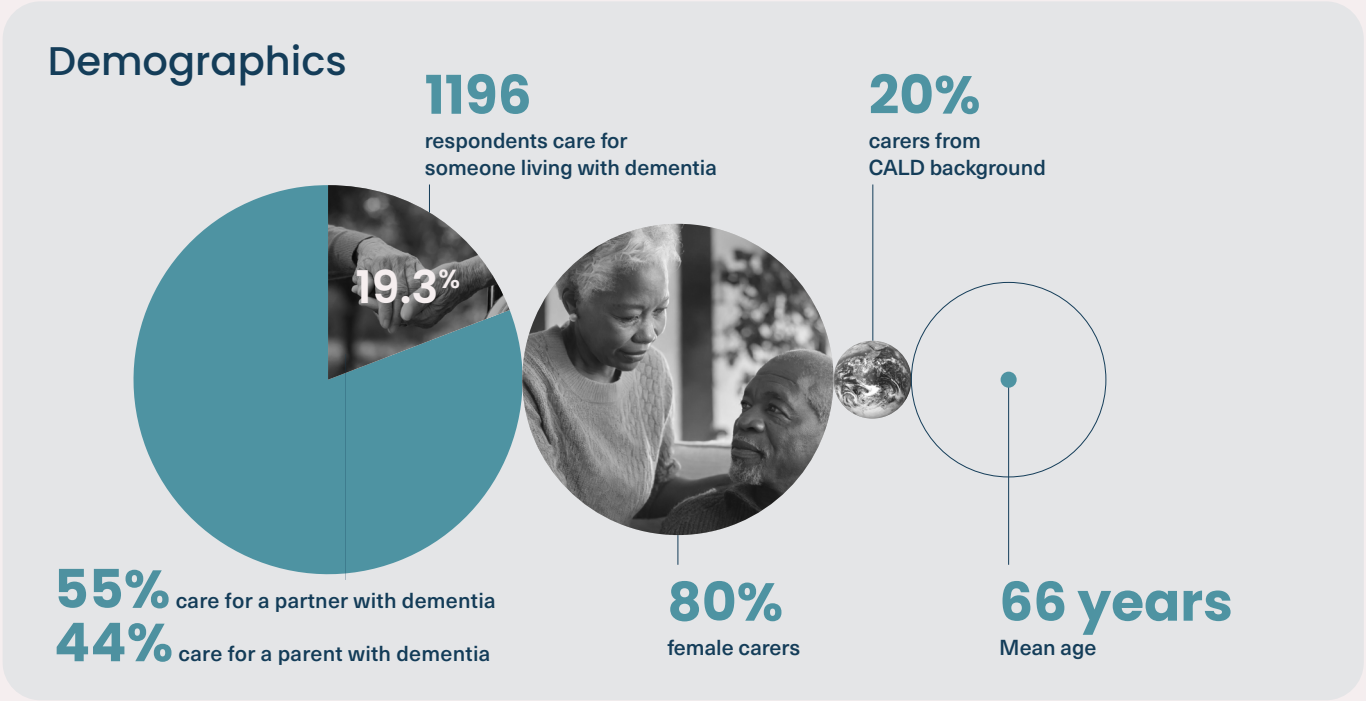
Ethics approval and privacy protection:
The research was ethically approved by the University of Technology Sydney Human Research Ethics Committee (ETH 23-8482). All data were strictly de-identified prior to sharing with the university research team.

Key findings

The Carers NSW 2022 National Carer Survey—Carers of people living with dementia

The 2022 National Carer Survey provided insights on the care provided to people with dementia and the needs and risk factors for carers. The survey revealed some notable differences between younger (<65 years, n=562) and older (>65 years, n=634) carers of people who live with dementia.

For more information about the National Carer Survey, see here.



2022 National Carer Survey—Carers of people living with dementia

Needs and risk factors

51%
feel socially isolated

44.8%
experienced financial stress

Respite services
Report unmet needs for respite services, both planned (42.6%) and emergency (39.7%)

Help

The kinds of services and supports that help carers of people with dementia

Those caring for someone with dementia are more likely to access carer services than other carers

Access to a range of health, aged care, disability and mental health services

Carers reported high levels of service inclusion. Their caring role was recognised by family and friends but less so by government.

Caring Tasks

HANDLING FINANCES
86.5%

SUPPORT WITH MAKING DECISIONS
88%

TRANSPORTATION
93.7%

COORDINATING SUPPORT SERVICES OR CARE WORKERS
89.1%

BEHAVIOURAL SUPPORT
72%

ASSISTING WITH HOUSEHOLD TASKS
92%

COGNITIVE SUPPORT
95.9%

PERSONAL CARE
80.5%

2022 National Carer Survey—Carers of people living with dementia

Differences between older and younger carers of people with dementia

	YOUNGER CARERS (<65 years, n=562 / 46.9%)	OLDER CARERS (>65 years, n=634 / 53.1%)
Relationship to person with dementia	Younger carers were less likely to be caring for a partner with dementia **(81.5%)**	Older carers were more likely to be caring for a partner with dementia **(86.1%)**
Caring duties	Younger carers were more likely to be caring for more than one person **(40.7%)**	Older carers were less likely to be caring for more than one person **(9.6%)**
Gender differences	**11.3%** of younger carers were male	**26.8%** of older carers were male
Paid employment	**51.6%** of younger carers were in paid employment; yet **56.1%** of younger carers reported providing care of 40+ hours/week	**6.2%** of older carers were in paid employment
CALD background	**27.9%** of younger carers were from CALD backgrounds	**12.8%** of older carers were from CALD backgrounds

2022 National Carer Survey—Carers of people living with dementia

	YOUNGER CARERS (<65 years, n=562 / 46.9%)	OLDER CARERS (>65 years, n=634 / 53.1%)
 **Caring tasks**	Younger carers were more likely to report advocacy as a caring task **(80.3%)** Younger carers were more likely to report interpretation/translation as a caring task **(23.4%)**	Older carers were less likely to report performing advocacy (eg, helping dispute a treatment or a decision) as a caring task **(55.5%)** Older carers were less likely to report interpretation/ translation as a caring task **(8.6%)**
 **Financial stress**	Younger carers were more likely to report indicators of financial stress; eg, **37.6%** of younger carers reported spending more in a week than they received **13.5%** of younger carers reported four or more financial stress experiences in past year	Older carers were less likely to report indicators of financial stress; eg, **16.6%** of older carers reported spending more in a week than they received **3.8%** of older carers reported four or more financial stress experiences in past year
 **Wellbeing**	Lower wellbeing among younger carers; nearly half of younger carers **(48.1%)** reported high to very high psychological stress Social isolation was greater among younger carers **(56.8%)**	Higher wellbeing among older carers; **38.2%** reported high to very high psychological stress Social isolation marginally lower among older carers but reported by just under half of responders **(45.5%)**
 **Service inclusion**	Younger carers were less likely to report that aged care, hospital and community services asked about their needs as a carer	Older carers were more likely to report that aged care, hospital and community services asked about their needs as a carer

Ageing and Disability Commission

De-identified case studies (n=17) from the Ageing and Disability Commission were analysed. These cases highlighted the complexity of supporting older long-term couples where both parties have care needs, and where abuse and violence is a factor. This may be part of a long standing pattern of abuse in the relationship or may have developed more recently either as a result of, or exacerbated by, the effects of dementia.

Various types of abuse or neglect were reported, including verbal abuse, physical violence and failure to provide medication.

A range of support services were involved. The responses to these behaviours included a mix of formal measures, such as health and support services and legal interventions, as well as informal strategies, such as financial management and emergency housing. In some instances, provision of help was hindered by denial of need or concerns about the adequacy of the services.

Types of alleged abuse or neglect

NSW Ageing and Disability Commission

De-Identified Case Studies (n=17) 2022–23

Cases involve spousal relationships—older couples, mostly in 80s

Both partners with significant and/or intensifying care needs, including suspected or diagnosed dementia in at least one partner; mutual interdependence for daily caring, emotional and financial supports

Males with suspected or diagnosed dementia more often reported as the spouse engaging in abusive or neglectful behaviour

Alcohol use is a factor in escalating abuse in some cases

Most reports made by service workers or health professionals who have contact with the older people; some reports by close family members

Multiple service providers and formal responders were involved in these case studies

Older people in long-term relationships often had a strong sense of loyalty or duty to a spouse

Some cases involve allegations of neglectful behaviour, such as not providing medications

The case studies revealed challenges in finding affordable and suitable alternative accommodation

Some relationships had a history of domestic violence.

Help Strategies—Formal and Informal

FORMAL HELP/SUPPORTS

- crisis advice through ADC Helpline and Domestic Violence Line
- ADC investigation
- police providing safety responses and managing legal measures like Apprehended Domestic Violence Orders
- healthcare support involved general practitioners, hospital services, and specialists like psychologists and social workers, offering a broad range of medical and social support
- in-home support (eg, aged care and disability care)
- legal services were involved in managing guardianship and power of attorney issues.

INFORMAL STRATEGIES/'SELF-HELP'

- devising plans to maintain safety while staying in the home
- Self help strategies included:
  - locking oneself in the bathroom with a phone
  - having a packed bag to be able to leave quickly
  - arranging to stay with a neighbour

Factors Influencing Help Acceptance

- **A range of support services were involved.** Some individuals declined recommended services or questioned their effectiveness.
- Alleged victims generally demonstrated **reluctance to have police involvement**.
- **ADC investigators** typically appeared to have a **trusted role** in the investigative process.
- A variety of reasons were given for not wanting to leave the home, including a desire to **stay in familiar surroundings or reluctance to leave pets.** A move to residential aged care for either spouse was also not a preferred option as **couples wanted to stay** in their own homes.

Dementia Support Australia—Behaviour support services

Data from DSA services provided insights on behaviour support needs, especially for people with dementia who live in residential aged care homes. The analysis focused on the referrals that had potential police involvement.

Behaviours—severity and distress

Based on Neuropsychiatric Inventory (NPI)*

Higher

NPI scores for severity and distress

28% had a SIRS reported to DSA**

(in contrast to 14.6% for referrals with no potential police involvement)

* The NPI is a standard screening measure for behaviour in dementia. It assesses the presence of 12 different behaviours (absent or present), the severity of these behaviours (1=mild, 2=moderate, 3= severe) and the distress/disruptiveness this causes caregivers (0=not at all, 1=minimal, 2=mild, 3=moderate, 4= severe, 5= extreme or very severe).

** SIRS – Serious Incident Response Scheme, which requires aged care providers to report serious incidents of abuse or neglect to the Aged Care Quality & Safety Commission

Key Findings

55,000

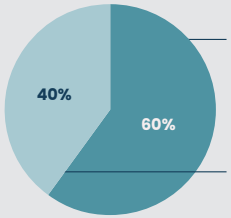
service referrals for behavioural supports

1.2% (n=667) had potential police involvement

♂ 70%

In 70%, the person with dementia was male

(in contrast, under half of referrals with no potential police involvement were for males, **44.8%**)



60% DBMAS referrals (for mild to moderate behaviours)

40% SBRT referrals (for severe behaviours)

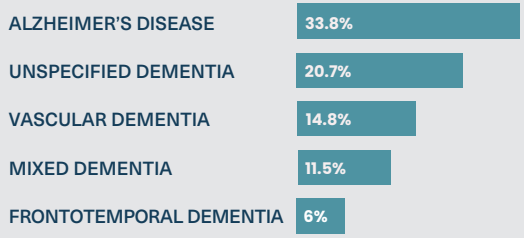
DBMAS & SBRT referrals

80.2 years

Average age

82.4%

Living in residential aged care



Dementia diagnosis (similar to referrals with no police involvement)

Dementia Support Australia—Behaviour support services

Qualitative data

7 vignettes based on DSA service referrals that had potential police involvement

BEHAVIOURS

Physical Threats and Aggression
eg, with knife, scissors

Verbal Aggression
eg, offensive language, combative, verbal threats

Sexual Behaviour
eg, inappropriate comments and touching

Disinhibition
eg, being familiar with strangers

RESPONSES

to identify and address causes of changed behaviours

- Pain assessment and treatment
- Mental health assessment and supports (eg, anxiety, depression)
- De-escalation strategies
- Non-pharmacological strategies
- Social activities
- Emotional reassurance
- Medication review
- Respite services

Discussion

The findings from the three data sources offer important insights on caregiving relationships, stressors, and support needs in the context of dementia and behaviour that raises safety and wellbeing concerns.

Behavioural concerns and caregiving stressors

The data show that many carers of people with dementia provide support in relation to behaviours. Threatening and aggressive behaviour contributes to carer stress and may result in potentially abusive situations and the involvement of adult safeguarding services and/or police. While carer stress may be a contributing factor in such situations, abuse remains entirely unacceptable under any circumstances.

The bidirectional risk factors for and dynamics of abuse accentuate the importance of access to specialised behaviour support services from organisations like Dementia Support Australia.

> Abuse by a carer may be "a response to stressors experienced in a caring role (e.g., high levels of carer burden, care recipient behavioural difficulties)".
>
> T Broady et al, *Literature Review on the Abuse, Neglect, and Exploitation of Adults with Disability and Older People by Carers* (UNSW Social Policy Research Centre, Prepared for NSW Ageing and Disability Commission, April 2024) http://hdl.handle.net/1959.4/102119.

Formal and informal responses

The data showed the involvement of multiple services, including primary healthcare, aged care, community services and specialist dementia support. This is positive, as it shows the availability of services, including by telephone helplines, to assist people who live with dementia or who are carers. Yet the escalation to harmful situations and police involvement indicates a need for more timely access to preventive supports. This may include education on recognising and responding to behaviour changes, addressing underlying unmet needs of the person with dementia, and respite for carers. Service providers, such as GPs, other health professionals, and aged care workers, have an important role in asking carers about their needs and providing guidance on behavioural support needs. Police responses should focus on diversion to appropriate supports for all parties involved and avoid the inappropriate criminalisation of behaviours that are symptoms of dementia.

> According to people with dementia and carers, "helpful responses [to changed behaviours] included providing clear professional support pathways and supportive environments where people living with dementia can engage in physical, cognitive, social, and spiritual activities".
>
> CV Burley et al, 'Views of People Living with Dementia and their Families/Care Partners: Helpful and Unhelpful Responses to Behavioral Changes' (2023) 35(2) *International Psychogeriatrics* 77, http://doi:10.1017/S1041610222000849.

Impacts and implications

The behaviours and responses had significant impacts for people living with dementia and their carers.

Safety and Quality of Life: Planning and implementation of formal and informal strategies improves safety for both the individual with dementia and those around them, enhancing their quality of life and reducing the risks of harm.

Behavioural Improvement: Appropriate health, care and social supports reduce aggressive and inappropriate behaviours. Modifications to the environment are also beneficial to meet the needs of people with dementia (eg, to reduce unwanted stimulation).

Care Transitions: Increasing care and support needs—for the person with changed behaviours and carers own health conditions—trigger care transitions. These may be planned or reactions to a crisis situation. Examples in the data included: new or additional in-home supports; respite care; moving to residential care.

Implications for service provision and broader community-level responses include:

Support Systems: Address the need for adequate and responsive support for carers, from helplines to emergency services. Effective helplines offer comprehensive information and referral, and are available day and night.

Health, Disability and Aged Care Services: Improve coordination of care and reduce waiting times for access to needed services.

Psychosocial Support: Strengthen screening for psychosocial stress among carers, with appropriate support and referrals (eg, counseling services, support groups, educational resources).

Safety Protocols: Develop clearer procedures and strengthen training for when carers or others face immediate threats or safety concerns due to the behaviours of a person with dementia (eg, for first responders).

Awareness: Raise awareness of: diverse manifestations of dementia (eg, Alzheimer's, FTD); younger onset dementia; and the range of symptoms that people may experience, including changes in behaviour and personality.

Conclusion

This research provides insights on the risk factors for, experiences of, and responses to behaviours that pose risks of harm and abuse in the context of dementia. Responses need to be tailored to individual circumstances and should involve support for carers, training for formal services and responders, and approaches that promote dignity and respect for those living with dementia.

The NSW ADC data on older spousal carers, intensity of caregiving and abuse indicates that further study is warranted in relation to dementia and violence in long-term intimate partner relationships. The complexities in these relationships, often characterised by mutual dependence for care and support, present unique challenges.

The differences identified in the 2022 National Carer Survey data between younger and older carers indicate a need for age-specific support strategies. This includes targeted financial assistance for younger carers balancing work and care responsibilities, and specialised support for older spousal carers managing mutual care needs. In particular, there is a need for appropriate service responses and support mechanisms that account for different cultural perspectives on caregiving and help-seeking within a family environment.

> "... family members, and spouses in particular, are an at-risk group and require support to manage problem behaviors. Caregivers may be reluctant to report DV as they fear it reflects negatively on the person with dementia, but family caregiver training has been shown to reduce caregiver burden and challenging behaviors".
>
> S Reutens et al, 'Characteristics of Domestic Violence Perpetrators with Dementia from Police Records Using Text Mining' (2024) 15 *Frontiers in Psychiatry* 1331915, https://doi.org/10.3389/fpsyt.2024.1331915.

This research has demonstrated the value of analysing existing datasets. In future, relevant services can collect and examine data to shed further light on behavioural symptoms and responses in the context of dementia, including police contact.

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Endnotes

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