

# Shining a Light: Violence in Dementia Caregiving and Receiving Relationships

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Goal of Presentation: to  
increase awareness of, and  
explore helpful responses to,  
violence in dementia caregiving  
and receiving relationships

# Background: Dementia and Caregiving

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- **Dementia is** a set of symptoms caused by various brain injuries and diseases that lead to a progressive deterioration of cognitive functions that increasingly affect daily life (Public Health Agency of Canada, 2017).
- **The number of People living with Dementia (PwD)** in Canada is sharply increasing, with an estimated population of **1 000 000** in 2030 and **250 000** new cases being diagnosed each year after 2040 (Alzheimer's Society of Canada, 2022).
- The vast majority of PwD live in the community, **dependent upon** the care provided by **family and friends**.
- Although most literature focuses on the experience of PwD, there is increased attention to the experience of caregivers, including their **increased risk of negative impacts to physical, mental, financial, and social health**.
- These risks are higher for those already experiencing varying forms of **social and financial marginality** and who are younger.



In November 2020, Lisa Raitt, former MP, shared her experience as a caregiver for a spouse with Alzheimer's Disease. This included being pushed and hit. Police were called, and at one point, had to remove her spouse from the family home. Raitt described her experience:

"You suffer in this, silent and alone. What I wanted to do is bring it out of the shadow."

CBC, 2020

“approximately 40% of patients diagnosed with dementia ultimately exhibit aggressive behavior”

(Morgan et al., 2013, p. 739)

**40%**

Risks may increase depending upon the type of dementia, and its stage.

Caregiver violence towards PwD increases when they are victims of violence themselves

Risks are commonly higher when care recipients have higher needs and when caregivers are socially isolated and under financial stress.

PwD may perpetrate or be the victims of violence; in both cases, this violence is often hidden

**An Untold Story:  
Violence in  
Dementia  
Caregiving and  
Receiving**

Violence may be new following a dementia diagnosis, however there is a higher risk to caregivers if there was a pattern of domestic violence that extended throughout a relationship

Female caregivers are at particular risk of experiencing violence, including of sexual assault

Risks increase if firearms are present in the home

20% of PwD are estimated to perpetrate violence against informal caregivers, who are commonly female aging spouses

More than 1/3 of caregivers report physical abuse, and over 2/3 report any form, including psychological abuse

# Risk factors for Violence in a Care Relationship

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- Higher levels of cognitive and physical impairment
- Caregivers and recipient have symptoms of depression
- Relationship has historically and over time been dysfunctional and conflictual
- Pre diagnosis experiences of violence received by caregiver that may
  - lead caregiver to normalize or not recognize their experience as abuse and therefore not take steps to address it
  - may exist as a past pattern of abuse that becomes worse with dementia.

McMaster University, 2023

## Key legislative/policy contexts

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Long LTC waitlists, limited options for affordable seniors housing which would allow spouses to separate

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Charging practices, including mandatory charging can, in some cases, lead to a caregiver or recipient being charged for self-defensive actions

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Lack of independent Elder Abuse legislation and clear reporting procedures in Ontario contribute



## Best Practices for Justice and Human Services Providers

### **Building knowledge and improving awareness**

*Taking Violence seriously*, rather than considering it a normal or natural part of caregiving/receiving relationships

Implementing *enhanced screening* approaches including:

- Watching out for “innocuous” situations e.g. unexplained fractures, apparent fatigue/confusion/minimizing by caregivers
- Including firearms possession within screening/discussions about safe driving
- When possible and appropriate, including adult children and family in discussions and responses

# Best Practices for Justice and Human Services Providers

## Engaging in Interdisciplinary Practice

- Avoiding siloed practice, including between social services, justice and health workers
- Facilitating the sharing of information between service providers
- Including dementia related cases, particularly where firearms are present, in interdisciplinary forum discussions, including HSJCC, CCs and local risk table discussions
- Working together on cross disciplinary approaches to strength legislative and policy protections and responses

# Best Practices for Justice and Human Services Providers

## Putting Violence in Older Adulthood on the “agenda”

- Conducting more community based, local research to build body of knowledge regarding older adults’ experience in specific regions
- Ensuring that general research and stats collection includes older adults, including those who live in residential care settings (often excluded)
- Prioritizing the education of health care workers on signs of abuse in older adults, including psychological abuse
- Improving accessibility of health services, including translation/multiple language services and community/home-based care such as house calls
- Expanding community education to reach “silent survivors” who may never come to the attention of the justice or health workers, including by drawing in community partners like hairdressers, churches and ministry personnel and veterinarians

# Key Take aways

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Abuse in dementia care relationships is a serious issue that is often in the “shadows”

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Health and justice professionals need to know the signs of abuse, and to adopt enhanced strategies for screening and intervention

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Building Knowledge and Awareness among service providers, the community and policy makers is essential to ensure the protection and well being of people with dementia, and the family and friends who provide them with care.

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