
CONFERENCE ABSTRACT**How Canadian caregivers of persons living with dementia are managing in a fragmented system**

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People living with dementia (PLWD) often need many different health and social services throughout their journey, and navigating and accessing these services can be challenging due to a lack of integration in dementia care. PLWD often rely on caregivers, usually family members, to help them navigate the system and access the care and services they need. The importance of better co-ordination and integration of health, community, and residential dementia services has been highlighted in the World Health Organization's (WHO) global action plan on the public health response to dementia and Canada's National Dementia Strategy, however a widespread, robust plan for integrated care for PLWD has yet to be implemented. This leaves caregivers with the task of seeking out and accessing services on their own. The Alzheimer Societies across Canada aim to help caregivers navigate and access services by providing information, education, and support in system navigation to caregivers. In this study, we explored the experiences of caregivers accessing health and social services for their loved ones with dementia, and the role that the Alzheimer Society played in this journey. This work has been informed and guided by members the Alzheimer Society of Canada's People with Lived Experience Advisory Group.

We conducted semi-structured interviews with 34 caregiver clients of the Alzheimer Society across Canada in the Fall of 2022. Interviews were completed by phone or video conference and lasted between 20 and 73 minutes (mean=32 minutes). Participants were all caregivers of a PLWD and ranged in age from 42-89 (mean age= 63 years). There were 10 men, 23 women, and one non-binary person in our sample (caregiver spouse=18, caregiver child=15, caregiver sibling=1). Interviews were recorded and transcribed verbatim. Deductive coding, based on the interview questions, was used to identify themes.

Experiences accessing health and social services varied widely among participants based on geographic location, disease progression or symptoms, existing social support and self-advocacy skills, and finances. Many caregivers had trouble accessing the services that they needed and found the system to be difficult to navigate. In many cases, the Alzheimer Society played an important role in making caregivers aware of the health and community services available and provided guidance on how to access those services in a timely way. Some participants, however, found that despite being provided with information and education, they continued to struggle due to a lack of access to quality care in the community (e.g. adult day programs, respite, and long-

term care). Some participants experienced such extreme distress at being unable to access the care they needed for the PLWD, that they experienced physical and mental health issues themselves.

The Alzheimer Society and similar organizations help to make up for the lack of an integrated care system for PLWD, however, there remain large gaps in the ability of caregivers to access timely, adequate care. Fragmented, disjointed, and difficult to access care can have negative consequences for PLWD and their caregivers, and action is needed to further support the development of integrated dementia care services across Canada.