

Social clubs fill gap in dementia support

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Community-based social groups could play a crucial role in empowering people with early-onset dementia, according to new UBC research.

The study, led by UBC nursing professor Alison Phinney, focused on an independently run program known as Paul's Club, which offers social and [recreational activities](#) three days a week out of a hotel in downtown Vancouver. Members range in age from mid-40s to late 60s.

"Of the estimated 1.4 million Canadians living with Alzheimer's and other forms of [dementia](#) by 2031, a few thousand in every major city will be diagnosed before age 65," noted Phinney. "The question is how we can support them so that they can continue to live at home for as long as possible."

The answer, according to Phinney's research, could be day programs like Paul's Club.

The [club](#), founded in 2012 by retired Vancouver nurse Nita Levy and her husband, Michael, provides [members](#) a friendly environment without medical or hospital associations—hence the "club" monicker and the choice of a hotel for a meeting place. The focus is on having fun, so dementia is rarely mentioned or discussed.

The club runs from 10 a.m. to 4 p.m. to give members' families a break from caring from their loved ones. Each day starts with morning coffee, often followed by chair yoga, a dance or other light workout before the group heads out for lunch and a walk in the neighbourhood. Ice cream at

a local gelato shop caps off the day.

While the club doesn't follow a strict schedule, the one constant is the group walk. Linking arms or holding hands with the Levys or club volunteers, members stroll in groups of twos or threes, stopping frequently to admire the scenery or talk to other people.

"By observing and talking to the members, we found that walking in the neighbourhood and interacting with others kept them connected to the community," said Phinney, a researcher with Vancouver Coastal Health Research Institute. "They felt that they still belonged—something that wouldn't have been possible had they stayed at home."

The Levys founded the club following the death of a beloved brother-in-law as a result of early-onset dementia. They saw a need for services for younger people with dementia as most programs are suitable for older people, and very few are targeted to those with dementia.

"Young-onset dementia is incredibly challenging because they're still fairly active and healthy and suddenly they're no longer able to work," said Phinney. "Being part of the club keeps them busy and healthy and gives their family respite, making it more feasible for members to stay at home longer."

Phinney's research is funded by the Alzheimer's Society of Canada. Its next stage will examine a more traditional adult day program for [older people](#), including some living with dementia.

"Walking in the Neighbourhood: Performing Social Citizenship in Dementia," has been accepted for publication in *Dementia: The International Journal of Social Research and Practice*.

More information: [open.library.ubc.ca/cIRcle/col ...](http://open.library.ubc.ca/cIRcle/col...)

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