

# Tackling exclusion through a peer-led social program for persons with dementia and their spouses

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## Exclusion from Social Participation

- Since a diagnosis of dementia often comes with a presumption of inability and incompetence, it can reduce opportunities for social participation and contribution (Bartlett & O'Connor, 2007).
- Worrying about judgment by others can contribute to the exclusion of persons with dementia and their partners-in-care. Fear and embarrassment about making mistakes in public has caused persons with dementia and their care partners to withdraw from social situations to avoid stigma and negative reactions (Roland & Chappell, 2015).
- Much of the exclusion persons with dementia experience when it comes to leisure, is often related to their discomfort in social settings with others who do not have a dementia diagnosis (Di Lauro, Pereira, Carr, Chiu, & Wesson, 2015).



## The story of Rick and Amy

We used creative analytical practice (CAP) to represent the findings to “contextualize lived experiences and address the complexity of life and leisure” (Parry & Johnson, 2007, p. 122). In doing so we highlight shared experiences of participants in a composite narrative: the story of Rick and Amy.

## At the point of diagnosis

Rick and Amy learn that Rick has been diagnosed with dementia. Facing the realities of their situation brings frustration. Discussing the diagnosis with friends brings more frustration. Friends try to be sympathetic but they can't relate. Eventually friends stop calling or dropping by because they don't know how to act or what to say. Rick and Amy feel their social life quickly disappearing and loneliness starting to creep in.

## Where to go and what to do?

Rick and Amy attend an educational program and start to find some answers about the disease. Amy begins to attend a support group while Rick goes to a program designed for persons with dementia. Amy finds the support group too structured. It's also education-based and not social. Rick and Amy chat about how no programs are offered for them to participate in together as a couple.

## Research Context and Process

- As part of research by the Partnerships in Dementia Care (PiDC) Alliance, we sought to uncover what makes a peer-led social group (called Memory Boosters) so valued by its members.
- We used a narrative methodology to guide the research process, seeking to “illuminate human experience as it is presented in textual form in order to reveal layered meanings people assign to aspects of their lives” (Josselson, 2011, p. 240).
- We conducted three focus groups, each containing four social group members, for a total of twelve participants. Each focus group consisted of men with dementia and their wives.
- We reviewed the focus group transcripts to identify members' experiences and stories. Through narrative analysis we deconstructed their stories and experiences into overarching themes (Glover, 2003).

## What's next?

Eventually Rick and Amy are told about a newly formed social program for persons with dementia and their care partners and are invited to check it out. While talking with members of the group they're told:

*“You meet new people, and it's a wonderful outing for socializing.”*

*“It's a place where you relax and you can be your silly self.”*

*“What we appreciate most is that it's a safe space.”*

## What would we do without it?

A year later, Rick and Amy continue to attend the social group and as an extension of their social group, they are now part of a bowling league. They also host members from the group for dinner and go out for coffee with other couples after the program. The social group has become such an important part of their world, and they question what they would do without it.

## Discussion

- Persons on the dementia journey have undoubtedly become accustomed to being misunderstood and withdrawing from social situations where they are prone to experience stigma (Innes et al., 2015).
- This composite story highlights ways thoughtfully designed leisure spaces can help bring persons most susceptible to exclusion into the fold of community life.
- Programs, such as Memory Boosters, are more apt to be meaningful for participants when they are driven by persons on the dementia journey. As one participant explained: *“We're the people who know. We want to be listened to about what our needs are.”*



## Future Directions

- The story of Rick and Amy depicts a spousal couple who sought out resources and programs to meet their needs. Since not all couples may be as proactive after a diagnosis of dementia, social programs such as Memory Boosters need to find creative ways to reach people who may be most at risk of exclusion. More must be done to make a difference in the lives of people in need of a safe, social space.
- Participants of this study were men with dementia and their wives. We did not hear from other types of spousal couples or from persons with dementia whose care partner was not their spouse. Future research is needed to explore the diversity inherent in the dementia journey and to understand a variety of social experiences related to leisure and exclusion.



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