

# Alzheimer Society

## Southwest Alzheimer Society Alliance Quality Evaluation

In 2015, 6 Alzheimer Society Chapters located in Southwest Ontario (Elgin, Grey Bruce, Huron, London Middlesex, Oxford and Perth) embarked on an evaluation of the Core Support Services. These services included: First Link Learning Series, Individual Support and Support Groups. The evaluation was completed with the support of Ontario Brain Institute and the Centre for Community Based Research.

### Many stakeholders were asked:

What is working well?  
What outcomes are being achieved?

What is not working well?  
What could be improved?



*What did participants say they liked the best:*

### Overall

- Caring, competent, approachable staff with in-depth knowledge of Alzheimer's disease and other dementias.
- Strategic partnerships pursued by the Alzheimer Societies.
- Caregivers and Persons with Dementia who were supported by the Alzheimer Society were more likely to say they learned skills to cope with Alzheimer's disease and other dementias, were more likely to meet new friends and find it easier to express their needs to their physician.
- *"Wouldn't have made it without the staff at the Alzheimer Society, although I had people coming and telling me what to do - I think these people understood the disease better than anyone else and I think that they were able to assist in the care of the person with dementia."* (Caregiver)

**Individual Support** was found to be an essential element of the core support services.

- Immediate availability of staff & flexibility of meeting location throughout the dementia journey.
- Individualized supports for each client's unique context resulted in an increased ability to cope day-to-day.
- Caregivers found the relationships with Alzheimer Society staff were helpful; and as a result knew who to contact when needing support.
- Persons with dementia expressed comfort in talking to Alzheimer Society staff.

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*"I value the particular work – the ability to spend individual one-on-one time with clients and families. That piece is hard to find these days – I think most of us are busy, busy, busy but if the Alzheimer Society will continue to offer that service, I think it is so valuable because I am not sure the rest of us are doing that as well as the Alzheimer Society or with the amount of commitment."* (Key informant)

**First Link Learning Series** is identified as a foundational strength.

- Connected people in similar situations.
- Increased participants knowledge of Alzheimer's disease and other dementias and developed strategies for day-to-day coping; content followed stages of the disease.
- Provided a safe place where participants felt comfortable to express emotions.
- Pre-determined calendar of available sessions is beneficial for recruiting participants.
- *"I think the Learning Series from my point of view was the best experience that I've had for two reasons. One was the educational part of it because you are sitting there and the lights are going off, 'Oh yeah, that happened to me' or 'Oh yeah, that's what I can expect'..... From the educational standpoint the Learning Series has been amazing. And of course the secondary part of that is meeting with people who are sharing the experience with you..... All the time you are learning you are also sharing and I mean some of us have become friends outside of Alzheimer activities."* (Caregiver)

**Support Groups** are a significant resource for people affected by Alzheimer's disease and other dementias.

- Open ended structure and flexible nature of the groups allows clients to access support when needed.
- Simultaneous support groups for Caregivers and those with dementia increased likelihood of participation.
- Caregivers indicated they were more confident in their ability to live well; felt better able to advocate for the needs of the person they were caring for; felt they had more skills to deal with life challenges; were more likely to access community resources as a result of attending a support group.
- Caregivers felt connected with other people in similar situations and made friends at the Alzheimer Society. They developed skills, the ability to cope and learned about Alzheimer's disease and other dementias.
- When persons with dementia attended support groups they were more likely to say they met new friends and found it easier to talk to their physician about what they needed.
- *"Acceptance is key number one. Key number two is the support we get from the Alzheimer Society itself. You can't beat it and that's why I can't miss a group meeting. The Alzheimer Society has been number one as far as I'm concerned in terms of support"* (Person with dementia)

### What else did we learn.....

Caregivers who had connected with the Alzheimer Society more than 20 times in the past 3 years were significantly more likely to agree that:

- ❖ They felt they had more skills to cope with life's challenges
- ❖ The Alzheimer Society connected them with people in similar situations
- ❖ They had accessed other resources within the community
- ❖ They felt better able to advocate for the needs of the person they are supporting
- ❖ They felt more confident in their ability to live well with dementia

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Caregivers who had connected with the Alzheimer Society more than 20 times in the past 3 years were significantly more likely to say that:

- ❖ Making friends at the Alzheimer Society was helpful (very much or much)
- ❖ The Alzheimer Society helped them in times of need
- ❖ The Alzheimer Society helped them increase their knowledge of Alzheimer's disease and other dementias
- ❖ The Alzheimer Society provided a safe place where they felt comfortable to express their emotions

The quantitative data, together with the qualitative data suggests that each of the three different core support services are needed in order to achieve the range of intended outcomes including: (1) greater sense of formal support throughout the journey; (2) increased informal relationships; (3) increased knowledge about Alzheimer's disease and other dementias; (4) greater liberation to talk about the dementia experience; (5) an enhanced ability to cope with the progression of the disease.

### Challenges:

Not enough resources to provide one to one support with delays following up with clients

Increased demand for number of programs offered without increased staff

Increased complexity of client situations resulting in more staff resources

Reduced ability to reach certain caregivers, eg. working or home-bound caregivers

Sometimes support groups are too diverse to provide benefit due to variable types/stages of dementia

Recruitment to Support Groups especially early in their connection with the Alzheimer Society

Awareness in community as to what services Alzheimer Societies offer

Stigma of association with Alzheimer Society

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### Overall Next Steps and Recommendations:

- ❖ To develop an organization-wide theory of change within each Society in order to more proactively rationalize and prioritize: (1) how the core support services and other supplementary programs and corresponding outcomes fit together; (2) how to best allocate limited staff/volunteer resources; and (3) how to more strategically seek additional funds.
- ❖ To develop strategies to increase the frequency of contact for each client to 20 times in 3 years.
- ❖ To continue to seek funding for supplementary programming in which persons with dementia are central clients.
- ❖ To advocate to the Ministry that persons with dementia be considered as central clients of Alzheimer Societies (consistent with its theory of change) and request access to corresponding funding.
- ❖ To develop a strategy that lessens transportation as a barrier to accessing core support services (e.g., OTN support groups).
- ❖ To develop a strategy for program outreach and implementation that will be responsive to the anticipated diversification of the client base (e.g., cultural diversity, religious diversity).
- ❖ To implement an outreach strategy that better engages caregivers who do not tend to access core support services at the Alzheimer Society: employed caregivers, homebound caregivers, and caregivers for middle and end-stage persons with dementia.
- ❖ To continue to pursue systems advocacy on behalf of clients' at local, provincial, and national levels.
- ❖ To increase system-wide planning with community partners that better facilitates collaboration for person-centred supports and referral agreements (e.g., CCAC, primary and acute care, long-term care, mental health)
- ❖ To develop a common Alzheimer Society communication strategy across Societies targeted at partner organizations and the general public that provides a stronger and more consistent message about its mission and available core support services.

### Future Evaluation Recommendations

- ✓ To continue using a community-based collaborative approach and mixed method design in any future evaluations that involves multiple stakeholders through: (1) an evaluation steering committee; (2) multiple methods of gathering information (both qualitative and quantitative); and (3) an evaluation feedback session.
- ✓ To continue using common evaluation tools, and evaluation timelines across all six Societies to maximize the strength of evaluation results and potential impact.
- ✓ To conduct a regular scaled-down evaluation of core support services within each Society on an annual basis and a full evaluation across Societies of core support services every five years.
- ✓ To continue collecting data from persons with dementia, through individual interviews or focus groups as these proved to be the most cost-effective and valuable methods to access their valuable perspectives.