

**Advisory Group of people living with dementia
TERMS OF REFERENCE**

PURPOSE

The primary purpose of the Alzheimer Society of Canada's (ASC) Advisory Group of people living with dementia is to guide the ASC Board and staff, via its Chief Executive Officer, in fulfilling its mission to support Canadians with dementia and their caregivers throughout the course of their dementia journey.

People living with dementia can and should have an active role in shaping the work of the Alzheimer Society - work that directly and indirectly affects them. Tapping into the expertise of people with dementia and their families will not only improve the quality of ASC's services and related activities but will make the Alzheimer Society even more relevant, accountable and credible to its many stakeholders. For individuals involved in the Advisory Group, participation offers the opportunity to provide meaningful input, increases the potential for a deeper understanding of multi-faceted issues and makes it possible to learn new skills, thus having the potential to contribute to a greater sense of individual self esteem and mastery.

PROCESS

The Advisory Group will recognize, share and utilize the expertise and skills both from within the group and from other key stakeholders, as required. The Advisory Group members will strive to ensure that their work is carried out with transparency and integrity, utilizing a partnership model that emphasizes genuine regard for all people and contributions.

MEMBERSHIP

The Advisory Group shall be led by two co-chairs, one of whom will be a person with dementia and the other a senior ASC staff person. Members will be predominantly people with dementia who have a keen interest and commitment to improving the lives of people living with dementia and are able and interested in helping to achieve ASC's mission. Members will be sought from every province/territory of the country to reflect the diversity of Canada as well as the diversity of experiences of living with dementia; however, they will not be acting as representatives of people living with dementia in that province but rather will be asked to contribute their own lived experience to the group and its work. Caregivers of people with dementia shall be invited to join; however, they will not equal or exceed the number of people living with dementia.

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Potential members will be interviewed by both co-chairs, where possible, but minimally by the ASC co-chair prior to engagement in order to ensure the best possible experience for the individual and suitability of skill to further the organization's mandate. It is expected that honest communication regarding the individual's current and changing abilities, needs and interests over time will result in a respectful transition into the Advisory Group and eventual retirement from it.

Advisory Group members from the Alzheimer Society federation may include representatives from education, research and advocacy. Others with varied expertise will be asked to consult, as needed. The term of membership will be one year with the possibility of renewal, starting April 1st and ending March 31st to coincide with the ASC's fiscal year.

Key Responsibilities: Advisory Group members will be required to:

- Attend Committee meetings by teleconference call (note: the cost of the teleconference calls is paid by the Alzheimer Society). Experience participating in teleconference calls is an asset.
- Participate in discussions, sharing views and experiences relevant to the agenda. All meetings will take place in English; fluency in English is therefore required.
- Review draft materials in English.

ACCOUNTABILITY

The Advisory Group takes direction from and is accountable to ASC's Chief Executive Officer or his/her delegate and will have regular interface with the Chief Executive Officer.

MEETING SCHEDULE

Teleconferences, funded by ASC, will be scheduled to accomplish the work of the Advisory Group.

MEETING LEADERSHIP

The co-chairs will provide leadership in calling each meeting and developing each meeting agenda with input from group members. Actions will be assumed by all members of the Advisory Group, as appropriate.

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DECISION MAKING

All decisions will be guided by a process that is inclusive and informed. Agreement will be reached by a simple majority vote of members (50% plus one).

- Each member of the Advisory Group will be expected to provide feedback on an issue by a mutually agreed upon date. Any member who is not able to attend a meeting will be expected to provide feedback on an issue by a mutually agreed upon date. If no feedback from a member is received by that date, it will be assumed that the member is in agreement with the proposed action or direction.
- If there are any strong disagreements in opinions by an Advisory Group member to the majority vote, which can not be addressed in the meeting, the following will occur:
 - o After the meeting, the two co-chairs will confer, calling on any other resources they believe would be helpful, to address the dissenting opinion(s).
 - o They will reach decisions on the dissenting opinion(s) and ensuing direction and will provide all members with their decisions and the rationale for them.

ASC staff and volunteer leadership will use a transparent and respectful process to weigh all input from the Advisory Group and will communicate clearly back to the group on the outcomes of this process (ie. advice that will be put into practice and, when that is not possible, the rationale for this decision).

SUPPORT

Alzheimer Society of Canada office will provide logistical and administrative support.

Advisory Group approval _____

Alzheimer Society of Canada
CEO approval _____

Next review date _____