Caring for someone with Alzheimer Disease (AD) can challenge even the strongest individual. The losses involved with this progressive degenerative brain disease affect not only the individual but also those who provide day-to-day care. The Canadian Study of Health and Aging found that people caring for a person with dementia are more likely to experience chronic health problems than those caring for an elderly person who does not have dementia.1

The Alzheimer Society is a national tri-level voluntary agency. The goal to alleviate the personal and social consequences of AD is one of the most important aspects in the mission of the Alzheimer Society of Canada. One way of reaching this goal is to provide help to family caregivers through support and education programs. The Alzheimer Society of Canada produces educational material for distribution to Alzheimer Societies, families and health-care agencies across Canada. In a recent public opinion survey, the Alzheimer Society was viewed as one of the most credible sources of information for families.2

In May 1997, the Society embarked on a project to determine the needs of family caregivers, with the goal of creating a comprehensive, accessible and bilingual resource. The format for each group was similar: introduction of the project by the moderator, introduction of participants, discussion of focus group questions, concluding remarks and completion of a questionnaire. Notes were taken during the sessions, which lasted two hours on average. Participants were told that the results of the focus groups would be reported as a group, and that their identities would not be revealed.

The following questions were discussed:

- What kinds of information, services and support were helpful, or would have been helpful:
  - pre-diagnosis?
  - in the early stage?
  - in the middle stage?
  - in the late stage?
- How do you currently get the information you need?

These areas were chosen based on criteria such as regional representation, involvement of both anglophone and francophone participants, representation of people from urban and rural settings, caregivers whose relatives were at various stages in the disease process and the availability of local Alzheimer Societies to help identify focus group participants and to assist with arrangements for the sessions.

Seventy-six family caregivers participated in the focus groups. Among the participants were wives, husbands, daughters, sons, daughters- and sons-in-law and sisters caring for their relatives with AD. The majority of groups were composed of people specifically invited by the local Alzheimer Societies participate in the focus groups. In two communities, participants were members of an existing caregiver support group.

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In what better ways could that information be delivered?
What other suggestions or concerns do you have?

The Results
The results of the focus groups were analyzed using the notes taken during the group sessions. The kinds of information, services and support needed were grouped into topic areas to be used in developing the new resource. Some topic ideas included: pre-diagnosis concerns, what is AD and what can be expected, dealing with the diagnosis, planning for the future, helping the person with AD, helping yourself, getting help (services, support, education), communication skills, providing care, handling challenging behaviours, creating a safe environment, dealing with transitions, considering placement, and dealing with death and dying.

Suggestions from focus group participants were outlined under a general topic heading. For example, in the area of communication, family caregivers revealed that they need assistance in developing skills to communicate with the person with AD, helping yourself, getting help (services, support, education), communication skills, providing care, handling challenging behaviours, creating a safe environment, dealing with transitions, considering placement, and dealing with death and dying.

Approximately 80 per cent of focus group participants completed a short questionnaire at the conclusion of the sessions. They were asked to indicate on a three-point scale the importance of having information on 21 different topics and to identify other issues that were important to them. It was evident from the responses that caregivers are searching for information on many different topics. Among those that were assessed by most caregivers to be very important were: how to tell your family about AD, how to find information and support for the person with the disease, how to communicate with your doctor and how to find community services.

The Product
The information and insight gained from these family caregivers gave a small working group a wealth of material to work with to create a new resource. In addition to identifying relevant content for the resource, focus group participants provided several suggestions regarding the format of the resource package itself. They stressed that caregivers’ needs for the amount and timing of information vary. Many commented that the information had to be in sections that could be reviewed when an individual was ready. One participant said, “I have The 36-Hour Day and have read half of it. I am not ready to read the end just yet.” These family caregivers also noted that information must be practical and presented in a user-friendly format that includes both a video and written component. It became clear that the information had to be presented by “experts”—family caregivers who are living or have lived the Alzheimer experience.

Taking these and many other comments into account, The Alzheimer Journey was created. The title came from the caregivers themselves who often referred to their experience as a journey. A three-part English and French video and workbook resource was developed to provide families with information on the early, middle and late stages of the disease (Part I: The Road Ahead; Part II: On the Road; Part III: At the Crossroads). Individuals whose lives have been touched by AD host the videos. The video content comprises interviews with caregivers and an individual with the disease as well as role-plays of successful strategies used to cope with AD in the three stages. The workbooks support the videos with information on the stages of the disease and particular strategies for each stage. Checklists and other suggested resources are included in the 24-page workbooks.

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References:

The Alzheimer Journey video series is available from local Alzheimer Societies across the country. The videos are available for loan and the workbook is given to the caregiver. Please check the white pages of your phone book for the Alzheimer Society nearest you or call the Alzheimer Society of Canada at 1-800-616-8816.