

Taking Control of Our Lives: A Self-Management Program for People with Dementia

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Acknowledgements

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Introduction

This newsletter provides an overview of the research project *Developing a Self-Management Program for People Living with Dementia: Integrating Research, Experiences, and Care Practices*. This newsletter provides background information on the program, including the research team that contributed to the development and delivery of the program, foundations of the program, the six phases involved in the creating and delivering the program, knowledge mobilization activities relating to the program, as well as next steps.

Background

The Centre for Education and Research on Aging & Health (CERAH) received funding for the development of an education program on Self-Management of Dementia. The 8-week program, called *Taking Control of Our Lives* was designed in partnership with a team of researchers, people living with dementia, and Alzheimer Societies across Canada. By including the experiences and inputs of people living with dementia, it allowed for a self-management program that actually works for people living with dementia, their care partners, and others who are personally or professionally affected by dementia. The need for this

program was identified through repeated consultations with persons living with dementia, care partners and health service providers. In these consultations, all identified the desire and ability of people to manage and live well with dementia, but expressed the lack of supports available to do so. Given the widespread use of self-management for other chronic diseases, coupled with the fact that very little has been done to develop a self-management program for people living with dementia, this program successfully filled this gap by integrating research, practice, and lived experiences. The major aims of this project included:

- 1) Accelerating the translation of knowledge into action by developing a self-management program **with** and **for** people living with dementia and;
- 2) Understanding how to effectively and meaningfully engage people living with dementia in research and program development using an integrated knowledge translation approach through Participatory Action Research.

The outcome, an 8-week self-management education program for people living with early dementia, focuses on empowering and supporting people with dementia to develop and/or strengthen and put into practice the necessary knowledge, skills and attitudes to play an active role in living well with dementia. The goal of the program is to help individuals with a diagnosis of dementia to develop skills, increase confidence, and feel empowered to take control of their lives by talking with and learning from others with similar experiences.

“I feel as a group everybody’s voice has been heard and included; and I know – and again, it’s that trusting with a process. I know if there’s ever anything that I did really feel strongly about that I’d know I would be heard.”
– Personal Advocate, Research Team

The Research Team

The research team involved in the making of the self-management program included 19 members, 3 personal advocates living with dementia, 9 researchers and 6 service providers.

The research team worked collaboratively to develop the self-management program. The team met regularly beginning in 2012 to determine the structure and process of the self-management program. This included developing program outcomes, discussing the role of care partners in the program, as well as outlining the philosophy, methodology, and approach to be used in developing the program. Mid-project interviews were conducted with members of the research team to discuss the program development process, their involvement and role within it, and recommendations. Final reflections were also conducted with members of the research team to reflect on the entire program and process.

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Program Foundations

Program foundations included the product and process for the development and implementation of the Self-Management program decided on by the research team. Based on decisions from the research team, the program applied the principles of Social Citizenship as its philosophical foundation, as authentic partnership model and participatory action research (PAR) as the primary methodological approaches, and Dialogue Education™ as a learning framework. The theoretical perspectives underlying the development of *Taking Control of our Lives* are briefly described in Figure 1:

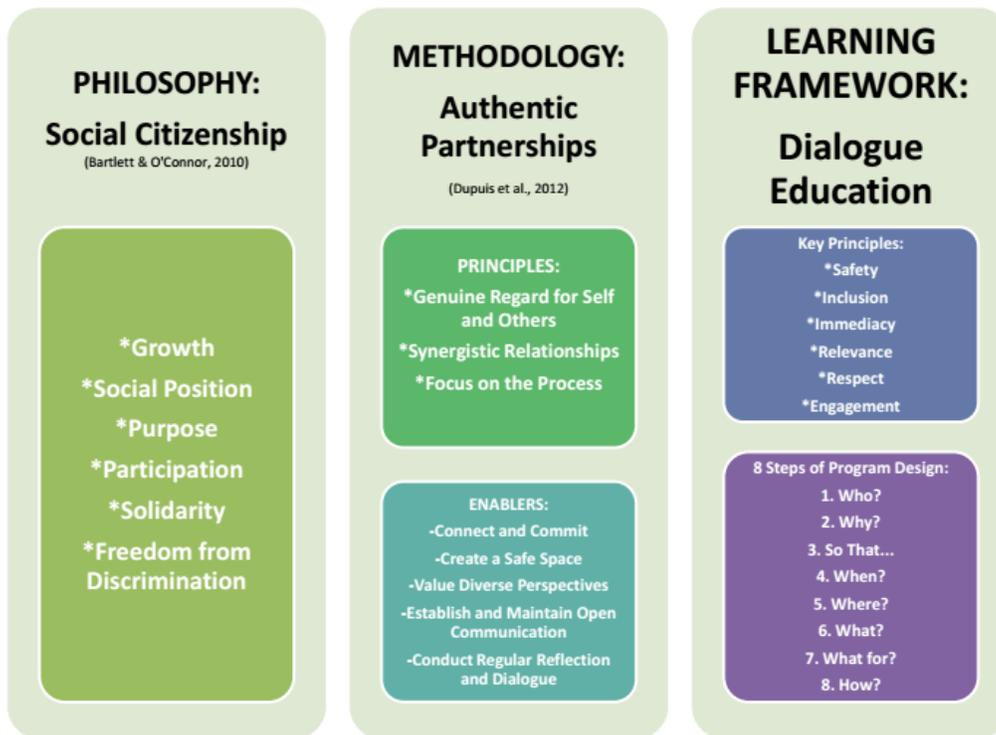


Figure 1 Program Foundations

Authentic and Meaningful Engagement

The self-management program utilized methods and processes for meaningfully engaging people living with dementia throughout the program development phases. The program also allowed for the translation of lessons learned about how to meaningfully engage people with dementia into practical tools to support meaningful engagement of people living with dementia. Supporting self-esteem, confidence, empowerment and improved quality of life for people living with dementia are among the main reasons for why meaningful engagement was so important for this program. Additionally, when we are grounded in a solid understanding of the needs and experiences of the individuals we hope to reach with our efforts, we are more likely to be successful.

What does meaningful engagement look like? It requires attention to four critical areas as outlined in Figure 2: people, relationships, process, and purpose.

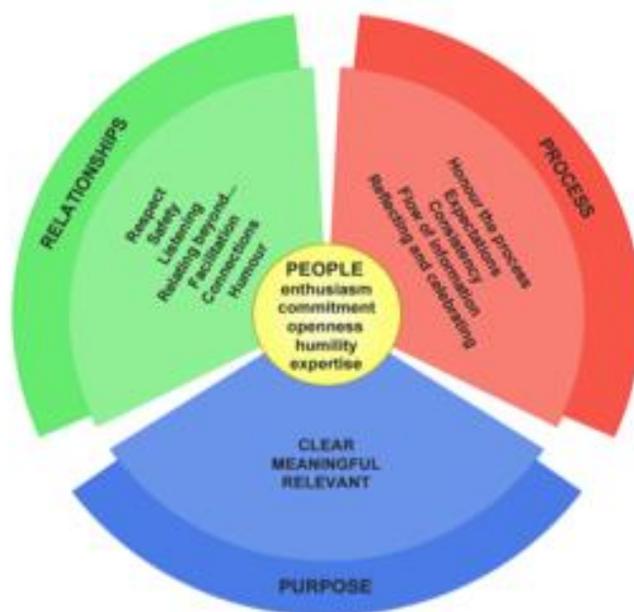


Figure 2 Authentic and Meaningful Engagement

Program Phases

The program was completed in multiple phases, forming the basis of the development and delivery of the self-management program. The process involved key phases outlined in Figure 3: conducting an environmental scan, developing three advisory hubs, developing the curriculum, training the facilitators, piloting the program, and rolling out the program. The different phases of the research process were made possible because of the valuable contributions of those involved.

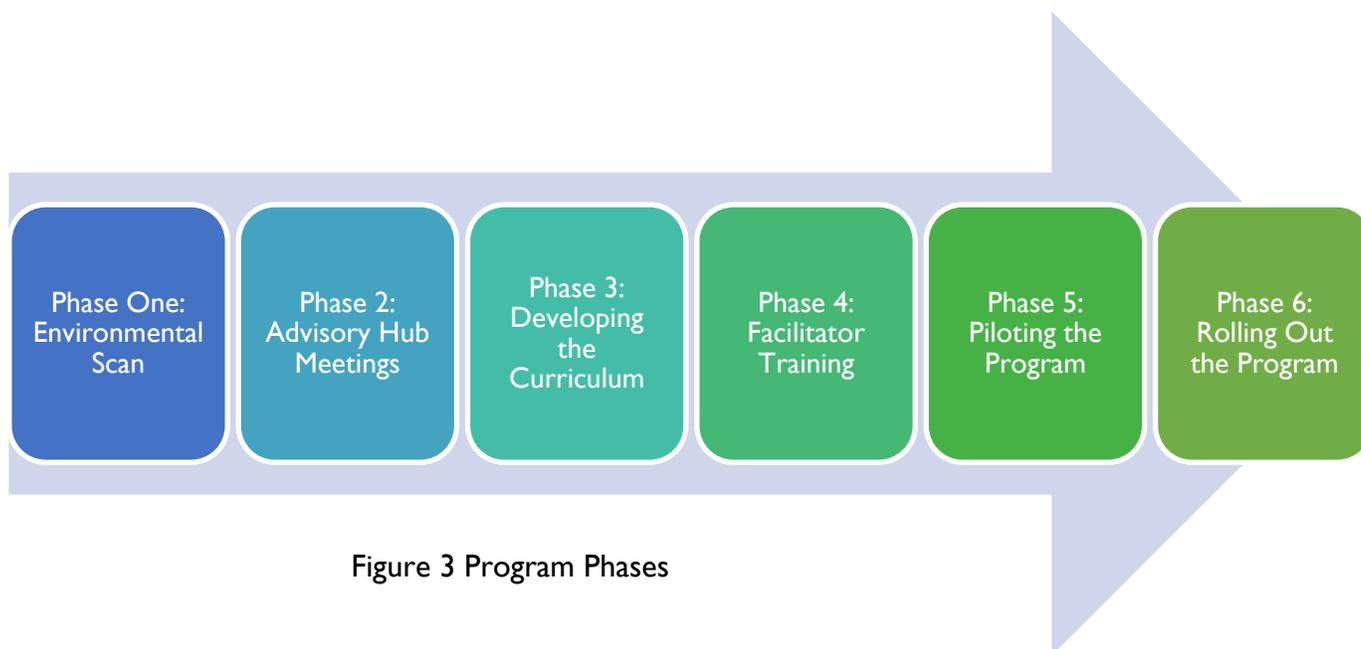


Figure 3 Program Phases

Phase 1: Environmental Scan

Description

The first phase of *Taking Control of Our Lives* involved the completion of an environmental scan, which took place during the summer of 2012. The environmental scan focused on trying to understand factors that might either facilitate or act as a barrier to successful programs for people living with dementia, in order to ensure that the development of the self-management program was appropriate to the needs of people living with dementia.

Data Collection and Contributors

Dementia research, online resources, existing programs, as well as other self-management resources for other chronic conditions were scanned. Key literature reviewed included:



- 🔍 By Us For Us Guides
- 🔍 Living Well with Dementia
- 🔍 Living with Dementia and Mild Cognitive Impairment
- 🔍 Alzheimer Society Literature



Academic literature scanned included:

- 🔍 Chronic disease and self-management
- 🔍 Experiences of living with dementia

In addition to this textual search, information was collected through interviews with health service providers, most of them affiliated with the Alzheimer Societies of Ontario and British Columbia, to learn more about successful programs for people with dementia. Interviews also focused on the sharing of experiences, tips, perspectives and knowledge of working with people living with dementia. These educators, facilitators, and administrators were already working with people who are living with dementia, and provided support groups, developed education, facilitated workshops, delivering public education, and provided numerous other services and supports for people living with dementia as well as their care partners and family members.



26 Interviews with service providers

Focus groups were also conducted with people living with dementia and care partners living in Ontario and British Columbia to gain insight into their experiences of attending different groups offered by Alzheimer Societies and to further inform program development considerations on how to create a successful and effective program.

5 focus groups with people living with dementia (31) and care partners (8)

Key Findings

There were many key findings that emerged from this phase. Key findings focused on the following:

"Fit"	Described as trying to determine the appropriateness of the person attending the program, specifically regarding their strengths, challenges, and preferences .
"Feeling Connected & Less Alone"	Recognized as fundamental for people living with dementia who attend programs.
"Boundaries"	Described as challenges in balancing and meeting the needs of both the person living with dementia and their care partners in the group.

“Stigma”	Described as a significant issue in accessing services.
“Flexibility”	Described as central to encouraging group participation and providing a safe space that allows for adjusting to what comes up in the group, who they are that day, where they are at, and how they are functioning or feeling that day.
“Transitioning”	Describing individuals who may no longer be a fit for a program, and the challenges for staff of transitioning them to other services

Additional Key Findings

In addition to the key findings, Phase 1 provided the researchers with several promising practices to consider for content development and delivery of the self-management program. A key takeaway from the environmental scan was the importance of promoting empowerment in people living with dementia. Empowerment in this sense served dual purposes; one being to counter the stigma associated with living with dementia, and the other to support those living with dementia in living with dementia through the development of their self-management skills.



Figure 4 What makes a good facilitator?

Resource Development

A key resource that was created as a result of the key findings that emerged from the environmental scan, titled “Characteristics and Qualities of Facilitators”, outlines criteria identified by people living with dementia and staff who facilitate groups for people living with dementia on characteristics and qualities that make a good program leader or facilitator.

Phase 2: Advisory Hubs

Description

The second phase of *Taking Control of Our Lives* took place between the fall of 2012 and spring 2014. This phase involved establishing three advisory hubs in Thunder Bay and Waterloo-Wellington, Ontario as well as Vancouver,



British Columbia. The advisory hubs were comprised of people living with dementia, care partners, and health service providers who embarked on the process of developing the self-management program content. In addition to the content, advisory hubs were established to provide input into the structure and process for program delivery. Ultimately, the establishment of advisory hubs also contributed to an understanding of how to best involve partners meaningfully and authentically throughout the process.

Data Collection and Contributors

The advisory hubs consisted of 20 people living with dementia and 13 care partners across the three advisory hub locations. The composition of each advisory hub is captured visually.

Each advisory hub met monthly for between 1 to 2 years. These meetings formed the basis of data collection for this phase and included meeting notes containing short summaries of what was discussed during the meeting. This was then later reviewed by the research team and a plan of action was identified on how to address what was raised during the meetings.

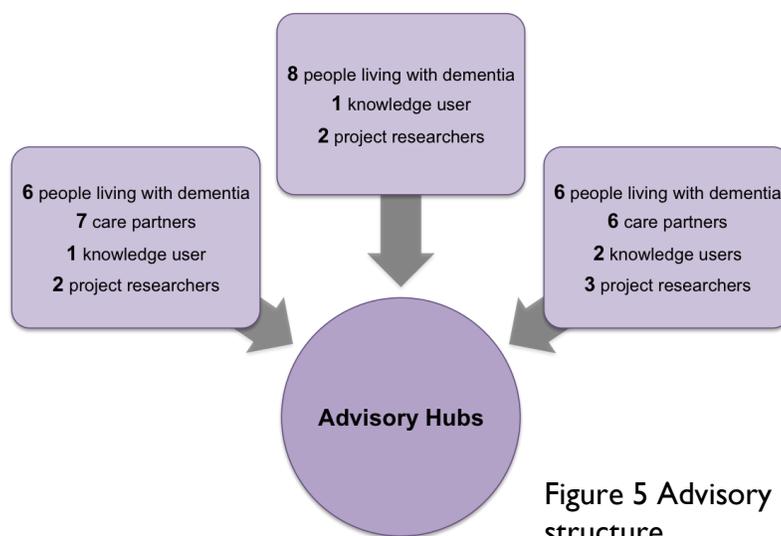


Figure 5 Advisory hub structure

During the advisory hub meetings, members engaged in an iterative process of talking about what self-management meant to them, deciding on key topic areas for the program, and talking more about these areas to get the essence of what was most important about this topic. More specifically, the advisory hubs worked collaboratively to unpack the question, “What is self-management?” by considering what self-management meant from their own perspectives, what they saw as being necessary to self-manage, as well as what made self-management challenging.

Following a discussion on self-management specifically, the advisory hubs engaged in a “dotmocracy” process, essentially a voting process whereby each hub voted on several themes thought to be most important to include in the program. The main ideas and themes voted on were gleaned from resources reviewed by the research team as well as advisory group discussions, and grouped into three areas: physical and instrumental (e.g., staying well), attitudinal and emotional (e.g., maintain hope and a positive outlook), and relational (e.g., building circles of support). Advisory hub members also had in-depth discussions on each of the selected themes, discussing whether it captured their experiences or those of others, adding anything that was missing. A snapshot of the overall process used by the advisory hubs to develop the program content and structure is captured in Figure 6:

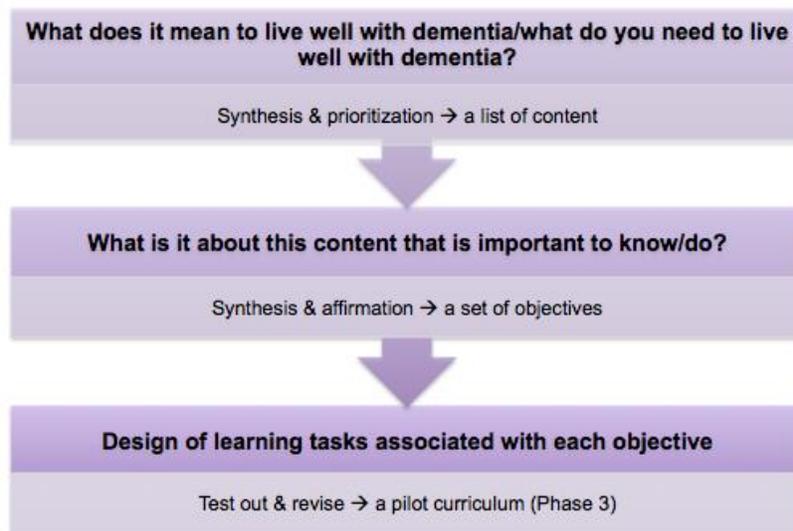


Figure 6 Developing the Curriculum

The advisory hubs also played a key role in determining the program structure. In particular, this included considerable discussion about whether to keep people with dementia and care partners together or separate during the program’s selected themes for inclusion. This discussion focused on the benefits, drawbacks, voices of people with dementia, care partner needs, and specific themes that would be conducive to participating together or separately . Other topics included the length and duration of the program, the order of topics, and other logistical concerns.

Feedback from the advisory hub meetings was also used to develop achievement-based objectives for the program, which advisory hub members also provided further feedback on. The objectives outlined what content would be addressed, what outcomes participants could expect through participation in the program, and how they will achieve this by completing program aspects and engaging in the learning process. Information that emerged from the advisory hub meetings was used to develop a full draft curriculum, as well as inform program delivery which the advisory hubs (for those that wanted to) as well as the research team, reviewed and commented on.

Phase 3: Developing the Curriculum

Some important key themes that emerged from the “dotmocracy” exercise for potential inclusion in the curriculum were as follows:

- 👤 Staying Well Physically
- 👤 Keeping a Positive Outlook
- 👤 Changing and Adapting

- 👥 Communication
- 👥 Memory Loss
- 👥 Acceptance, Grief, and Loss
- 👥 Staying Connected with Family and Friends
- 👥 Reducing Stress and Anxiety
- 👥 Building Circles of Support

These important themes structured the eight weeks of the program.



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Figure 7 Taking Control of Our Lives Program

Resource Development

This phase of the program also allowed for the development of a “Balancing Voices” Guide, particularly from advisory hub discussions on the composition of the program, keeping people with dementia and care partners together or separate during the program’s eight weeks. This guide was developed by the advisory hubs to ensure the voices of care partners and people with dementia were balanced during the program. The guide outlined the benefits of people living with dementia and care partners participating separately and together in the program, and identified possible challenges of participating together as well as some solutions to mitigate these challenges.

Phase 4: Facilitator Training

Facilitator training for those Alzheimer Society staff who would be leading the program took place to ensure that they were prepared for the program. Two facilitator training events were held—one in Toronto and one in Vancouver. A small evaluation of this training was also conducted. Seventeen trained facilitators participated in interviews about their perspectives and experiences of the training.



Phase 5: Piloting the Programs

Description

Once the program was developed based on input from the advisory hubs, the program was piloted in two locations beginning in the fall of 2014. During the pilots, people with dementia, care partners, and the program facilitators tested out the program and provided feedback based on program experiences. The research team revised and refined the curriculum, integrating key thoughts and outcomes from the pilot sites. A third pilot site was added in the winter of 2015 to pilot the revised curriculum. Eighteen people with dementia, 13 care partners, and 6 facilitators participated.



Ultimately, the purpose of the pilot programs was to conduct a process evaluation, whereby participants at each of the sites were provided with opportunities to comment on the content and structure of the program. The pilot program was eight weeks long lasting two hours in length, with an extra week for a celebration. This timeframe allowed the facilitators and participants to cover each of the program’s eight topics developed by the research team and advisory hubs as well as celebrate their time together and their completion of the program.

Data Collection and Contributors

There were many pieces of qualitative data collected from the pilot programs to inform its evaluation. Participant observations were done during each program sessions to examine how participants were engaging with the content material and to learn more about how participants were experiencing the program and what they were getting out of the program. These observations focused on participant interactions, comments, responses to the curriculum, and other information as appropriate. Reflective focus groups with care partners and people with dementia were conducted after each session to hear their thoughts about the curriculum and content covered during that session, as well as a final focus group with people with dementia and care partners prior to the celebration to reflect on the entire program. Facilitator reflections were also completed after each session to provide facilitators with the opportunity to also reflect on each of the sessions, reflecting on what went well, their facilitation, and any changes required to the program. Finally, photographs of participants' title pages, which were created on the last week of the program summarizing their experiences in the program, provided important insights into participants' experiences.

Key Findings/Outcomes

Data collected during this phase were transcribed and analyzed using a qualitative research data analysis software – QSR NVivo. Key findings and outcomes based on the participants' involvement in the pilot program are captured visually below:

“...a course like this helps us to strengthen the filter that we all have. I think we all have a filter to either reject or accept what happens to us. If you have a weak filter the world comes crashing in on you but if you have a strong filter you can weather the storm so to speak.” Person living with dementia, Pilot program



Phase 6: Rolling the Program Out



As of winter 2017, we have conducted 7 facilitator training sessions training approximately 63 facilitators in Dialogue Education and Taking Control of Our Lives. Twelve local Alzheimer Societies in Ontario have had facilitators trained, with an additional four Societies indicating their intent to train facilitators in the near future. Six Alzheimer Societies are considered early adopter sites, who have already facilitated Taking Control of Our Lives

Next Steps

This newsletter was intended to provide an entire overview of *Taking Control of Our Lives: A Self-Management Program for People with Dementia*, the outcome of a successful partnership between the Centre for Education and Research on Aging & Health, Alzheimer Societies across Ontario and Canada, as well as engagement with people living with dementia, care partners, and researchers. As evidenced throughout this newsletter, the self-management program achieved its aims as outlined in the beginning sections of the newsletter. The meaningful contributions and collaborative efforts from the research team, as well as the participation of those in the program, is what made this program not only possible, but successful. In supporting people with dementia to participate actively throughout the process, a self-management program relevant to people living with dementia and their care partners was designed and implemented. Results from the pilot program suggest that the program fosters the development of skills to self-manage and increases confidence among people with dementia to take control of their lives. The 6 phases of the program could not have been completed without all the hard work and commitment of those involved in each of the phases.



A title page created by a person with dementia during the last session of the program.

The next steps of the Self-Management Program involve building on the success and positive impact of the program to date. Given the positive impacts that this program had throughout all phases of program development and delivery, the research team will continue to engage in future knowledge mobilization activities to bring light to the program's success as well as its impact on people living with dementia both now and in the future as the program continues to be rolled out across the country. The research team will also work to develop new resources and guidelines for engaging people living with dementia authentically and effectively and continue to share these resources and resources developed through this program with other organizations supporting people with dementia.

For more information, please see our website www.rethinkingdementia.ca