

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



Report for the Alzheimer Society of Niagara

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Introduction

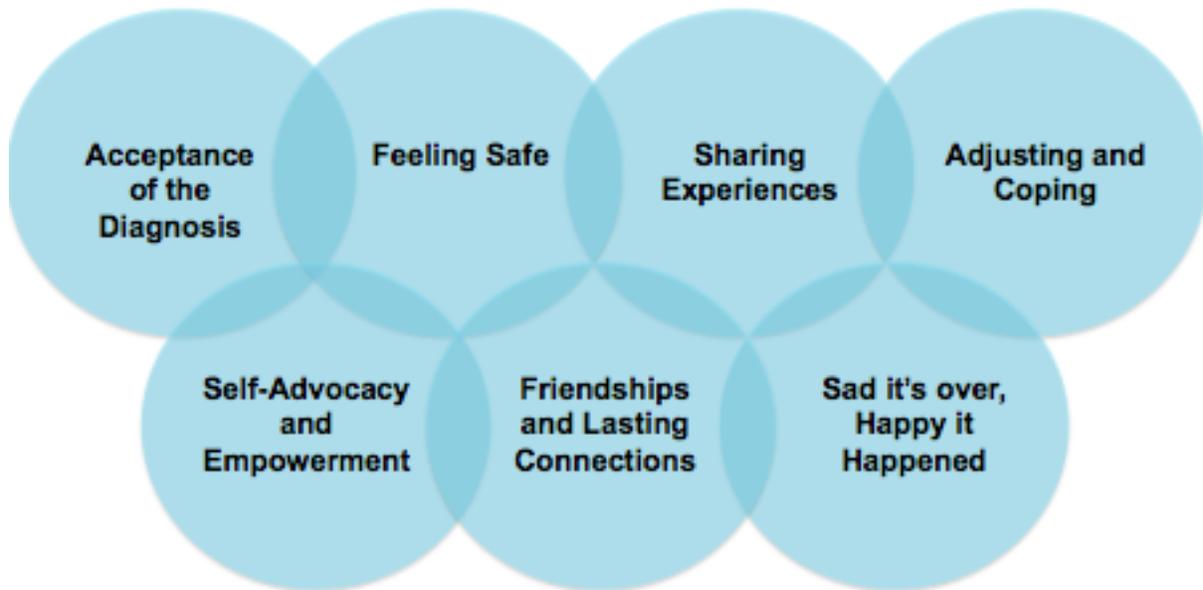
“Taking Control of Our Lives” (TCOL) is an 8-week self-management program for people living with early dementia and their care partners. This program was developed through a Canadian Institutes of Health Research grant led by Dr. Elaine Wiersma, Centre for Education and Research on Aging & Health (CERAH) at Lakehead University, in partnership with the Alzheimer Societies of Ontario and British Columbia, the Alzheimer Societies of Waterloo-Wellington and Thunder Bay, the Murray Alzheimer Research and Education Program (MAREP) at the University of Waterloo and the Centre for Research on Personhood in Dementia (CRPD) at the University of British Columbia, and a team of researchers and people with dementia. After program development and piloting the program, the Alzheimer Society of Ontario began to roll out the program to local Alzheimer Societies in fall 2015.

As one of the early adopter sites, the Alzheimer Society of Niagara supported their staff to be trained in TCOL in fall 2015, and implemented the 8-week program in winter 2016. Using an approach called Dialogue Education™, the goal of the program was 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. To reach this goal, a variety of different topics were covered throughout the curriculum modules, including: Getting Started, Adapting to Change, Emotional Wellness, Building and Keeping Connections, Communication, Finding Meaning and Purpose, Safety, and Staying Well.

An evaluation component was built into the program rollout to further ensure that the program is meeting its objectives. Using a similar methodology to the evaluation of the pilot programs, a variety of methods were used. First, participant observation was conducted during the sessions with the groups of people with dementia. Second, focus groups were conducted in the fourth week and the last week of the program with people with dementia and family care partners separately. Finally, debriefing groups were held weekly with the program facilitators (including two facilitators from the Alzheimer Society of Niagara). These focus groups and other data were transcribed and analyzed using a qualitative research data analysis software—QSR NVivo. This report is written using quotes from participants and title pages that the participants created on the last week of the program, capturing visually the most important benefits of the program.

Overview of Key Findings

Overall, participants described positive experiences in Taking Control of Our Lives, and facilitators described the positive experiences as well. The following themes emerged from the data collected from individuals involved in the self-management program:



Acceptance of the Diagnosis

An important theme that emerged from the program was acceptance and openness. Initially, some of the program participants, particularly people with dementia, were hesitant to join the program. However, eventually this hesitancy translated into a willingness to participate. Once this transition occurred, many of the participants expressed that the program was a great experience for them. Ultimately, being a part of program allowed them to accept that this program was something they needed in their lives. The following comments by people with dementia demonstrate this.

“And I looked around and I thought, ‘What am I doing here? What am I doing here? I’m not ready for this.’ And I went to the washroom. Bayley helped me out and I said, “I just need to collect myself”, and I



had quite a few tears that day and this has been the best experience in the world. It has really opened things up for me and made me realize that, yeah, I do belong here and this is where I should be; and I've learned a lot, just in the few short weeks I've been here – just in four weeks.” – Person living with Dementia

“No, no. It's been wonderful. I didn't want to come. Who phoned me and I said – I don't want to go? Was it you? And she said, “Just come, Angelica, and see what – “ and I said, “No. I don't want to come, and I came and it's been marvellous – marvellous” – Person Living with Dementia

Additionally, as suggested by people with dementia, many of the participants in the program were not very accepting and open about their diagnosis. The secrecy and selectiveness surrounding their diagnosis emerged in discussions with people with dementia, expressing that they do not tell many people about it, and if they do, they only tell certain people.

“I think I've done marvellous in four years. I really do. There's no one – I've got good friends, really good friends, and not one of them know; and I'm not making that up because I can fit into the conversations still that they have and if I'm not too sure, I just sit back and listen to them.” – Person Living with Dementia

“My husband and I - unfortunately we don't have any family of our own, but siblings you know. On my side they don't even know because they're all on the east coast. But I have not been open about it with my brother-in-law because he would just fuel the fire. No. I never even let on. I'm sure he doesn't know.” – Person Living with Dementia

However, throughout the program, a transformation occurred in some of the participants. As recognized by care partners and program facilitators, people with dementia became not only more accepting of their diagnosis, but also more open in discussing their diagnosis and the experiences that come along with it to others. This can be attributed to the safe space that the program provided, allowing them to be accepting and open.

“She's come out of the shell that she was in. When we started this program she was in complete denial. She didn't want anyone – and I mean anyone – to know, and that stigma about Alzheimer's that's out there – it's like, “You stink; get away from me” sort of thing. And she has enjoyed this program, as she indicated again this morning, very much; and I've found quite a change in her now. She gets on the phone with one of her friends and she discusses the fact that she goes to this thing and she's much more open about it” – Care Partner

“A lot of the people that are in the group are actually people that I see in their homes as well and I've just noticed a big difference with them in how they're actually communicating with their care partners as well and just being more open

and speaking more openly and sharing their diagnosis with others – like other family members – as well.” Program Facilitator

Being open about a diagnosis was not only seen among people with dementia. The opportunity to be open about the experiences of supporting someone with a diagnosis emerged in discussions with care partners.

I think they're [people with dementia] getting things to help them along too, as well as myself. And I think we've opened up with each other too. That's the other thing that I've found. We all sort of sat there and stared at each other and wondered – you know, I don't want to say anything. But anyway, yeah, I think it's helped us in that way too.” – Care Partner

“I like to think about ways that I can help other people, but it's also very helpful for me to be able to talk about how I feel.” – Care Partner

Feeling Safe

Another theme that emerged in discussions specifically with people with dementia about the program was feeling safe, and more specifically, being in an environment with no judgement. The feeling of being able to come to the group, express how they were feeling, say what they wanted about their diagnosis or anything in general, and act how they wanted, without the feeling of being judged or stigmatized by others in the program, including the program facilitators was important to them. This theme ultimately reinforces the importance of creating safe spaces for people with dementia.

“I would tell them [other women] to come here – that people are so caring and helpful and there's no stigma attached to it when you're here and that you get great benefit. When this is over, I'm going to contact friends who are getting in that age group too.” – Person Living with Dementia

“Opening yourself up to strangers is, I think, one of the most difficult things to do and sharing your soul as it is. And this has really helped. I've been comfortable. Nobody judges, knowing that this stays here.” – Person Living with Dementia

“I may say something silly, which I do a lot – I know the girls aren't going to say don't listen to her. No, I know, although I never hear you, I know you wouldn't say that and talk about it – she says a lot of silly stuff. I know you wouldn't, so that makes me feel good” – Person Living with Dementia

**NO
judgement
ZONE**

Additionally, the feeling of not being judged by others in the program was a determining factor in the decision of a person with dementia to keep coming back to the program.

“And if you did something silly and you told them, they wouldn’t – no judgment whatsoever. I’m glad you’re here. No, but I mean – really, you wouldn’t have come back.” – Person living with Dementia

“They [facilitators] don’t laugh at anything we say. Sometimes there was a joke we tell and I don’t tell jokes anymore, but it’s been great. It’s been great. Very, very good – and if people come once and don’t come back, that’s their tough luck.” – Person Living with Dementia

The openness among the groups also emerged from reflections with program facilitators. This is demonstrated in the statements below.

“I really felt that it was nice or what worked for me today was that it was clear that the care partners were feeling very comfortable and safe in their environment. They shared some very intense and some really vulnerable moments and were able to support each other in that. So it was nice to see that they were feeling open enough to do that.” – Program Facilitator

“You’re able to just set that stage of those topics and I found the conversations flow much nicer now that we’re much more open and able to be comfortable with each other.” – Program Facilitator

Sharing Experiences

Another major theme that emerged from the program, and specifically from people with dementia, was the importance of having the opportunity to not only share their experiences, but also to listen to the stories and experiences of others. Being a part of the group allowed them to engage in rich conversations and discussions, and to connect with each other because of shared experiences. Participants stated that this made them feel that they were not alone.

“I think everybody’s sharing their experiences and knowing that I wasn’t alone, because I felt alone, and hearing the same – these stories. And I’m thinking – yeah, okay. I’ve been there. I remember that. All those, and then sort of easing into it and feeling more comfortable with the fact that yeah, this is where I should be. This was a great start in learning about it and how to deal with it.” - Person Living with Dementia

“Everybody has the same problems and they can all relate to one another.” – Person Living with Dementia

“I find that there’s nothing more comforting than being with your peers – you know people that are just like you – and dealing with the same things that you’re dealing with.” – Person Living with Dementia

“Even if you never see each other again, you’re not alone. You’ve met people who are all the same.” – Person Living with Dementia

“I think we all contributed, in different ways. That helps everybody, and no, I think that was one of the things that I found, oh my goodness, I’m not alone” – Person Living with Dementia

Additionally, although not stated specifically by care partners themselves, the program facilitators noticed that the opportunity for people in the group to share their experiences, and listen to the experiences of others, was important for validating their own experiences and feelings.

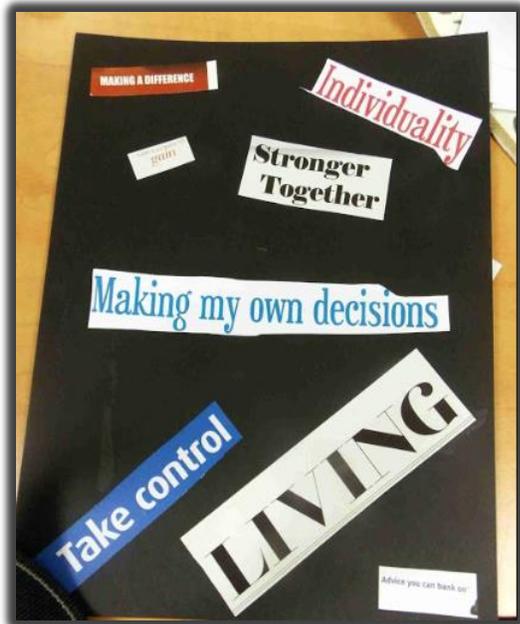
“I think that they tie together that ability to support the person with dementia. I think it’s vital that they can find validation in their own experience in order to draw patience and use them in their day-to-day life if they’re not able – I find that they’re connecting with others and feeling validated in knowing that what they’re going through is normal helps them to be more patient and to support the person that they’re helping in a better way.” – Program Facilitator

The importance of having these rich conversations and discussions was extremely important for care partners and people with dementia. One of the challenges of the discussion was that participants wanted to discuss information, rather than follow the curriculum as it was designed. As suggested by program participants, having the content in front of them, following along on paper and with the conversation, and at times writing in their books, hindered their ability to fully participate in these conversations. The facilitators provided the curriculum materials at the end of each session, writing only key talking points on the board to facilitate the discussion.

“Well I think it was distracting, because everybody was talking and you were sort of looking up and you know getting into all of the conversation, and it just wasn’t working, it just wasn’t working, so it was better to get it at the end. Because I think with everybody being so vocal in the group, and everybody contributed, and everybody talked and it was really hard to follow what was on the paper.” – Person Living with Dementia

“So just the look of relief, I think, we saw on people’s faces and the ability to just be able to really fully participate in it without worrying that they were on the right page or anything.” – Program Facilitator

Listening to the stories of others in the program, as well as the stories embedded in the curriculum content became a source of support for care partners, and especially people



with dementia. Through the sharing of stories and experiences, participants were able to support one another in difficult situations they were facing.

“And you always feel better when somebody else is feeling worse than you as well and see that they’re still having a good time and they’re still focusing; so it’s really nice for us to support the other ones by being here and seeing that we can all help each other.” – Care Partner

Adjusting and Coping

An additional theme that emerged from program participants, which also relates to the sharing of stories, is adjusting and coping. It was through the sharing of stories that allowed people with dementia and care partners to learn about how others were adjusting and coping with dementia, and ultimately how to live well with a diagnosis.

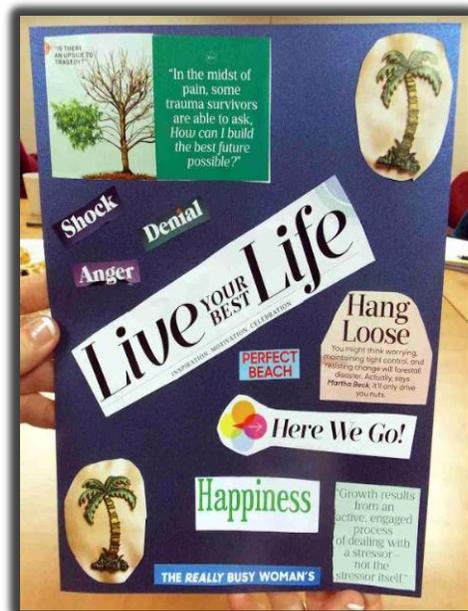
“And that’s another thing about that, that’s what we’ve learned, is you can deal with it. I mean, there’s still going to be bad days, but again if there’s more good days than bad days, than we’re doing ok.” – Person Living with Dementia

“The best thing for me has been the ladies and how they tell their stories and how they’re coping, because I knew that for four years she didn’t need to tell me. It was way back when I didn’t know there was anything wrong.” – Person Living with Dementia

“This has been wonderful. It’s put some ideas into your head too, although I don’t sit and pout about it, I never have done that, never, but it’s nice to know these ladies and what they do and the way they sing, and how they try to keep going.”- Person Living with Dementia

Being involved in the program and learning from others gave program participants the confidence to try new things in their everyday lives, applying what they learned beyond the program.

“Well, if you’re in that situation and you have that insight now as to the help and knowing that it’s okay. This is what this person did in that



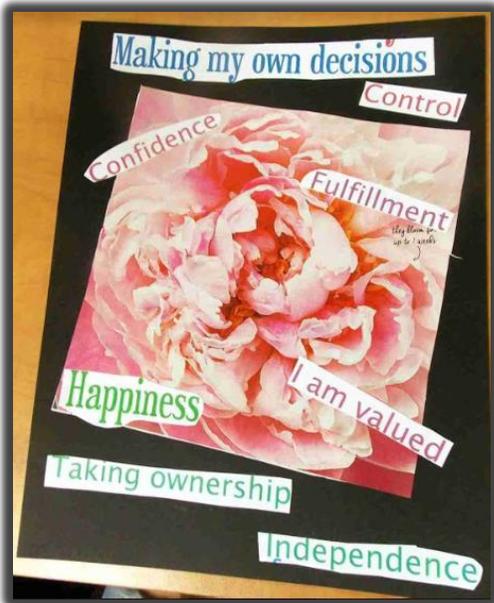
situation and I'm going to try that and see how it works for me.” – Person Living with Dementia

“From ideas that I'm getting from people like Nora that are things that I probably wouldn't have thought of and things we can do” – Care Partner

The program facilitators also noted that program participants gained insight into how to better adjust and cope with a diagnosis, or for care partners, in supporting someone with a diagnosis. One of the facilitators describes a situation in one of the sessions in which they asked the group what stood out for them from the previous week's session, and if anyone tried something different to adapt. One of the care partners talked about the difficulty people have in recognizing dates. To adapt to this situation, the family purchased a day tracker clock. The impact that this had on other participants in the group is demonstrated in a statement from a program facilitator.

“So then the family had purchased a day tracker clock for the week, so it was something that had come up in our group last week. We had suggested that these clocks might be a supportive strategy that can help someone who's having difficulty with the orientation today and you know his energy in talking about how they had this clock and how wonderful it had been for them and how much it had helped today was great; and as a result, the whole room sort of took a look at what that clock looked like and they were talking about buying one for themselves and it was a really great moment.” – Program Facilitator

Additionally, to continue adjusting and coping with their situation, many of the program participants talked about how they referred back to the curriculum and reviewed the content in between sessions. Many of the participants also planned to review the content even after the program ended.



“I look forward to coming every week. I don't know – I go home and I think, “Oh, I'm all alone again”. But I know that's not really what you want to hear from me. No, I really enjoy all the help that everybody has given me and I think this book that we have is very helpful too because you can go and look back and refer back to it, you know?” – Person Living with Dementia

“Trying to follow along in the book - that was a problem. What I did, when I got a little bit of quiet time, I would just sit down and not try to memorize it, but just sort of review it between sessions.” – Care Partner

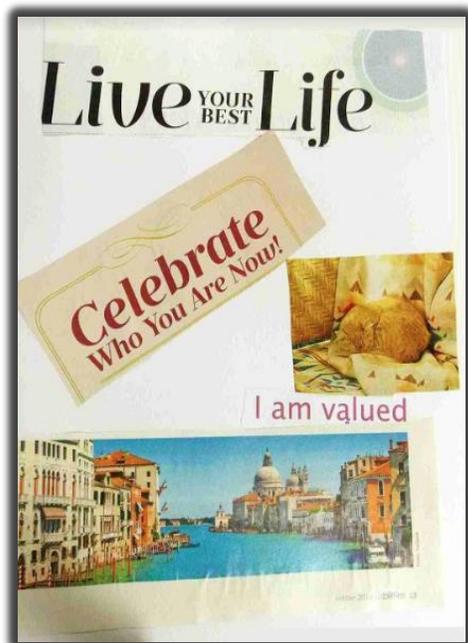
“I like the fact of the binders, so we can read it later, because when we’re discussing, you forget a lot of the stuff you’re discussing when you leave, but then you can go over it. And there was a lot of good things in there for like safety, and stuff like that.” – Person Living with Dementia

Self-Advocacy and Empowerment

Another important theme that emerged from discussions with program participants, and particularly people with dementia, was self-advocacy and empowerment. The program provided opportunities for some of the people with dementia to become self-advocates, feeling empowered to help others understand what living with a diagnosis is like through education.

“My biggest thing was, when you talk about someone with Alzheimer’s all most people think is forgetful, their forgetful, but there’s so much more than that.” – Person Living with Dementia

“I think we talked last week about it being a journey, you know, it’s a whole new journey, and it’s not something we all wanted to have happen, but we have it, and now we have to learn to adjust and try to educate other people if we can – you know, have that opportunity to say ‘wait a minute.’” – Person Living with Dementia



I think at this stage of the game, with all of us just having early onset, you know we still have the capabilities of being able to share that with the people that don’t understand, because we’re the best people to tell them, because we have it, you know that we still have a voice, and that we still have insight, and what we say means something, and we’re not always right, that we just want to be heard and accepted” – Person Living with Dementia

As suggested by people with dementia, as well as in reflections with program facilitators, being seen by others as still capable and being in control of their lives was important for them, as well as having their voices heard by others.

“One woman described herself as how she felt that she had been under this cloud and she has just taken all this in. She’s learned so much from week to week and she said that it’s like a revelation to her now where all of a sudden she is – actually, and she did use the words, ‘like all of

a sudden I've taken control and I'm' – and she was describing a number of examples she's doing whereas before she stopped answering the phone, she stopped answering the door, she just gave all the decisions to her daughter to make and take care of and now she's taking that back now and saying – I know I need help, but there's lots that I'm able to do on my own.” – Program Facilitator

“I know one of them – well, a lot of them would say I'm capable of a lot of things and family needs to learn about what I'm able to do and give me that chance to remember. I'm still here; I still have a voice, and just some of those things that came out through conversation.” – Program Facilitator

Friendships and Lasting Connections

The last theme that emerged from feedback by program participants, including care partners and people with dementia, was the friendships they developed from being involved in the program. This is demonstrated in the following statements from program participants.

“The friendship and comradery was really fantastic.” – Care Partner

“Just the friendships and the openness and nobody making judgments.” – Person Living with Dementia



Friendships were not only formed with other people in the program, but also with the program facilitators. People with dementia especially expressed the positive relationship they had with the program facilitators.

“Well, their approach and how they kind of personally help you go through it and they [the facilitators] seem like friends. They really do.” – Person Living with Dementia

“One thing I enjoyed very much, is the people who were dealing with us, the staff, absolutely fabulous. It couldn't have been better. They never talked at us they talked to us, and they were always open for questions, and very very helpful, and not way off in the clouds. They deserve a lot of credit.” – Person Living with Dementia

As suggested by a program facilitator and care partner, many of the program participants, specifically people with dementia, were interested in staying connected with others even after the program ended.

“But the same result for the people who had the dementia – they were very friendly and really my sister wanted to keep in touch with some of them; but there was no vehicle for them because they were from different areas of the region and that sort of thing because I think that’s kind of nice – like they shared a lot and it would be really nice if they could see each other occasionally. I don’t know. But both of them are like that.” – Care Partner

“And I think they’re not only going away with some great add-on’s to their own knowledge, but they’re also going away – I saw them exchanging phone numbers – they’re going away with a new support system that they didn’t have before they came in the door. So I was really pleased how that worked out for us in the end.” – Program Facilitator

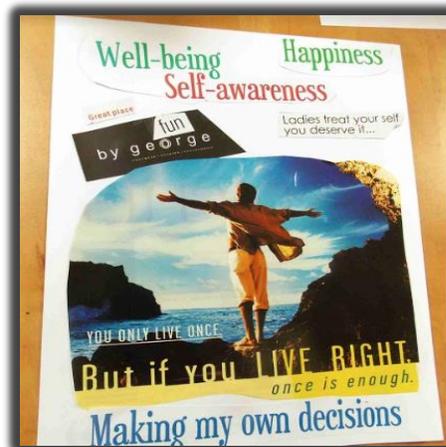
Sad it’s over, Happy it Happened

The final key finding that emerged from the program, particularly among people with dementia, was they were sad that the program was over, but happy that it happened. As suggested by people with dementia, they did not want the program to be over because of how much enjoyment they got from being involved. The program was something that gave people with dementia something to look forward to each week.

“We’re hearing care partners say that we’re late for everything because of the change in her ability to get ready; and all of a sudden we’re here 20 minutes early for this group every time because she wants to be here.” – Program Facilitator

*“The more I came, the more I wanted to” –
Person Living with Dementia*

Based on the positive experiences that people had in the self-management program, many of them suggested that they would recommend the program to others. This is demonstrated in the statements below.



“And usually you get in a group where you don’t know anybody and there’s always one that’s going to irritate you. Everybody’s been so wonderful here. I can’t believe that. I told a friend of mine – I said when you think you’re ready, you get over there. Yeah, it’s been great.” – Person Living with Dementia

“And one thing I learned in the program is that this has been a very wise decision to get involved here. I would recommend it to anybody.” – Person Living with Dementia

Not only did participants express their willingness to recommend the program to others because they enjoyed it so much, but a person with dementia joked with the group about finding a way to be involved with the program again.

“I said we should have a test, and we all fail, and then we can come back.” – Person Living with Dementia

“In our group, one of the things – the moment that stood out to me – was a woman that said afterwards she was speaking with another participant of the group and a few of us were there and she said – you know I hope that there is a test after this so that I can fail it and come and take it again... It really just speaks to the connections that they’ve been able to make with each other and we’ve really watched them build each other up and problem-solve together and really share a lot of their intimate moments with each other.” - Program Facilitator

Next Steps

By honouring and responding to the needs of people living with dementia through the creation of a self-management program, it is evident that this program has had a positive impact on people living with a diagnosis of dementia. This report outlined key themes supporting the benefits of Taking Control of Our Lives. The safe space that the program provided gave participants the opportunity to become accepting of their diagnosis, and open to communicating this with others. The sharing of, and listening to stories emerged as being important for people with dementia and care partners, something that became highly valued. Additionally, the rich discussions and conversations generated in the program became a learning experience for program participants, allowing them to become familiar with new ways of adjusting and coping, giving them the confidence to apply this in their everyday lives. The program also provided the opportunity for some of the participants to become self-advocates, feeling empowered to take on the role of educating others without a diagnosis, helping them to recognize the voices and capabilities of people with dementia. Through the program, participants were also able to develop friendships with not only others in the program, but with the facilitators as well. Many of the participants planned to stay connected even after the program ended. Last, through discussions with people involved, it was evident that Taking Control of Our Lives was something that participants, especially people with dementia, looked forward to. Many of the participants expressed how much they enjoyed the program, and as a result, would recommend it to others.

Given the impact of this program, along with the increasing number of people living with a diagnosis, it is important to make programs like this accessible throughout the province and country. In doing so, others living with, or supporting someone with a diagnosis, can experience the same impact that program participants have described, and ultimately, people with dementia can be better supported in their journey of living with a diagnosis.

**The names used in this report are pseudonyms.*