

# Mapping the Dementia Journey

## Final Report

May 2014



Prepared by Elaine Wiersma, CERAH, Lakehead University

## **Research Team**

Dr. Elaine C. Wiersma, PhD  
Centre for Education and Research on Aging & Health  
Lakehead University  
Thunder Bay, Ontario

Dr. Pauline Sameshima, PhD  
Faculty of Education  
Lakehead University  
Thunder Bay, Ontario

Dr. Sherry Dupuis, PhD  
Partnerships in Dementia Care Alliance  
University of Waterloo  
Waterloo, Ontario

## **Alzheimer Society of Ontario**

Dr. Philip Caffery, PhD  
Policy Advisor  
Alzheimer Society of Ontario

Mr. David Harvey, MEd  
Chief Public Policy and Program Initiatives Officer  
Alzheimer Society of Ontario

## **Acknowledgements**

We wish to express our gratitude to Lilly for the financial support of this project. Without this, the project would have never come into being.

Thanks to the Alzheimer Society of Ontario, particularly Phil Caffery, for his leadership on this project.

An immense debt of gratitude goes to the men and women who participated in our focus groups and in our planning day in Toronto in November 2014. The courage to share your stories and experiences is remarkable.

## Table of Contents

Research Team.....	2
Acknowledgements .....	3
Overview of project.....	6
Research Methodology .....	7
Data Analysis .....	9
Findings.....	10
1.0 The System Journey .....	12
Testing and Assessment [also in Changing & Adapting].....	13
Diagnosis .....	15
Finding Out More .....	17
Planning Ahead.....	18
Connecting with Services.....	19
Giving Up Driving .....	20
Navigating the System .....	21
Staying At Home .....	22
Alternative Living Arrangements .....	23
Palliative Care.....	24
Leaving a Legacy.....	25
2.0 Changing & Adapting .....	26
Crystallizing Moments of Awareness .....	27
Catalyst .....	29
Responding to a Diagnosis .....	30
Adjusting to a New Normal.....	32
Reconstructing the Future.....	33
Living for Today.....	35
A Changing Identity and Sense of Self.....	36
3.0 Relationships and Community.....	39
Telling Others About the Diagnosis.....	40
Changing Relationships .....	42
Building Circles of Support.....	44
Challenging Stigma .....	46
4.0 Caring for Myself.....	48
Keeping a Positive Attitude .....	49

Coping with Emotions, Stress, and Anxiety.....	50
Engaging in Meaningful Activity .....	52
Finding Purpose and Meaning .....	54
Reflections .....	56
Future Directions .....	57
Future Research Directions .....	57
Practice Implications.....	57
Policy Implications .....	58
Conclusions.....	59
Contact Information:.....	60

## **Overview of project**

With funding from Lilly, The Alzheimer Society of Ontario along with the Centre for Education and Research on Aging & Health, Lakehead University, and the University of Waterloo, led a process to “map the dementia journey” in plain language from the perspectives and experiences of people living with dementia, care-partners and health service providers in Ontario. The project aims to capture the experiential elements of the journey and align these with key points in the care pathway. The mapping exercise is intended to be a living model that can be built upon and further developed in partnership. As a direct benefit to the Alzheimer Society, this work has the potential to guide program evaluation, contribute to service design, and support awareness campaigns. An experience-based understanding of the dementia journey will also inform public policy and health system planning advocacy efforts with external partners, including primary care, long-term care, community service agencies, regional health agencies, and government.

## Research Methodology

The purpose of this study was to work with people living with dementia and care partners (including family and health and social service providers) to explore the experiential elements of the dementia journey. Using a qualitative approach, the researchers worked with people living with dementia and care partners to create living "maps" of the dementia journey that captured key milestones along the way, factors affecting the key milestones, and how these factors influence the journey for individuals, families, and circles of support who are living with dementia.

Using visual approaches to mapping out the dementia journey, we held twelve focus groups in three separate regions in Ontario--southern Ontario, southwestern Ontario, and northern Ontario. We held four separate focus groups in each of the three regions comprised of specific groups: people living with dementia, care partners early in the dementia journey, care partners later in the journey, and health and social service providers. In total, 14 people living with dementia, 21 early care partners, 3 later care partners, and 14 health and social care providers participated in the focus groups.

The communities in which we gathered the data were quite diverse. The communities ranged from around 100,000 to around 500,000, from northern Ontario to southern Ontario. While we did not incorporate various cultural groups in these beginning stages of the dementia journey, we realize that this is simply the starting point for this work.

Using a mapping concept, we provided an open canvas with a road, and worked with participants to pinpoint various key milestones and experiences along the "journey" or road. Using road signs, we then asked participants to choose a road sign that they felt best represented that aspect of the journey, and had them describe what the road looked like for them at that point. We started our focus groups by asking participants about the start of their journey, and continued asking about what happened next. As participants talked, the researchers worked with the participants to sketch out the road (see Figure 1).

Some of the original participants along with other individuals were invited to a one-day meeting in Toronto. The objectives of this workshop were to:

- bring the voices and experiences of people experiencing the dementia journey to the forefront;
- develop a greater awareness of the differences in the journeys of dementia;
- provide an opportunity to reflect on some of the key findings from the mapping focus groups;
- build on the Dementia Journey maps that were created by research participants by identifying key supports and resources along the journey; and
- discuss how these maps might be used in the future.

Drafts of the maps were presented, and participants were asked to work with the maps to change, add and confirm the findings. They were also asked to reflect on the supports and resources that persons and families would need at each point along the journey.

All data from this workshop, along with the focus groups and original maps, were then analyzed. The research team came up with the concept of subway maps to outline some of the key findings, and at each station, the findings would be presented as the street above the subway, with the corresponding road signs that were identified by participants. In this way, a layered and textual analysis was able to be visually presented. This report and the associated website are the culmination and representation of that work.

Website: [www.thedementiajourney.weebly.com](http://www.thedementiajourney.weebly.com)



Figure 1. An example of a developed map during the focus group.

In addition to the website, the artist researcher on the project, Dr. Pauline Sameshima, has been working on art renderings to illustrate the data and stories that participants told us during the focus group. These pictures are in their final phases of construction at the time of this report.

## **Data Analysis**

Data were analyzed in different ways. First, the maps were explored to gain an understanding of similarities and differences between groups. The maps were summarized, and notes were made as the maps were compared across groups and communities.

Second, the focus groups were transcribed, and entered into a qualitative software program NVivo10. Open coding was conducted by the principal researcher (E. Wiersma) and a research assistant (M. McRae). From there, the open codes were condensed and grouped together into larger themes. These larger themes were then compared against some of the key findings to ensure that the themes from the data analysis were consistent with some of the key themes of the maps. Findings were revised accordingly by bringing the data together.

## Findings

Based on the findings of the data, we discussed many different possibilities of representing the dementia journey. There were a number of factors to consider, including the diversity of the dementia journey for each person, the interconnectedness of aspects of the journey, the complexity of the journey, and the dimensionality of the journey. We finally decided to use the subway and road analogy, essentially the analogy of a transit system. This analogy, we felt, captured the diversity, complexity, interconnectivity, and dimensionality of the dementia journey.

In addition to finding ways to represent the diversity, interconnectivity, complexity, and dimensionality of the dementia journey, we struggled with analyzing the data in ways that would meet the purpose of a resource guide as the project was intended, or to represent the data as is. In essence, participants talked about the many challenges and difficult experiences during their dementia journey. In contrast, participants also talked about the positive aspects of the dementia journey. While we want to present a positive perspective of the dementia journey and not reinforce stereotypes and stigma, the experiences of those individuals who experienced many challenges is still very real. Providing a more authentic and holistic representation of the journey, incorporating the challenges and the possibilities, along with the great diversity in experience is a challenge. One of the most important things along the dementia journey that helped people through some of the difficult times was information and education about the journey.

In addition, there was a challenge in representing the inadequacies of the system and how that contributed to people's experiences of their dementia journey. Given that there are significant inadequacies in the health and social care system for people living with dementia, this also poses challenges in representing the journey. However, presenting both the positive and negative aspects of living with dementia can help in preparing people as they start their journey. In essence, we see this representation of the dementia journey as a living model and document, one that will continue to evolve and change as systems and communities evolve and change, and as we continue to gather input and feedback from other groups of people living with dementia and care partners, including those from other cultural groups.

We chose to focus the interconnected dementia journey on four aspects or themes of the journey: The System Journey, Changing and Adapting, Caring for Myself, and Relationships and Community. The overview of this journey can be found in Figure 2. The multidimensionality of the dementia journey, as we have chosen to represent it, means that the writing of the report may not follow chronologically the different parts of the dementia journey, particularly as some key parts of the dementia journey occur over time, while other parts of the journey may be more time-limited events. In addition, parts of the dementia journey intersect among themes, meaning that presenting the journey in writing becomes challenging to capture this multidimensionality. As such, we present the dementia journey according to the themes, rather than chronologically.



Figure 2. Dementia Journey Subway Map

## 1.0 The System Journey

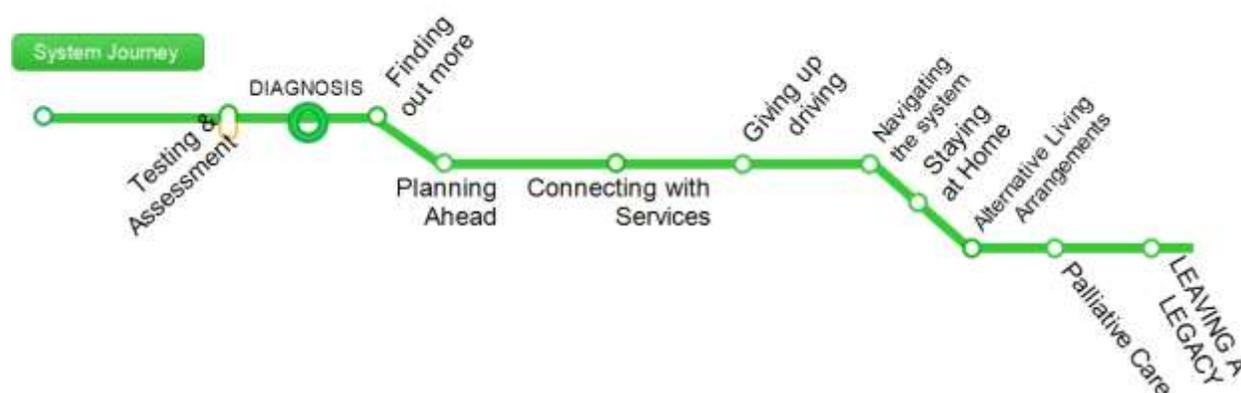


Figure 3 The System Journey

The **System Journey** represents the interactions with the health and social care system, particularly the medical and long-term care systems. The system journey captures the places where people living with dementia and care partners interact with the formal care system, government legislation, and other support services needed throughout the dementia journey. The system journey components include:

- Testing and assessment [also overlaps with **Changing & Adapting**]
- Diagnosis [also overlaps with **Changing & Adapting**]
- Finding out more
- Planning ahead
- Connecting with services
- Giving up driving
- Navigating the system
- Staying at home
- Alternative living arrangements
- Palliative care
- Leaving a legacy

Overwhelmingly, people described challenges with the system journey, as documented in the quotes to follow.

## Testing and Assessment [also in *Changing & Adapting*]



Many people living with dementia and care partners described challenges in testing and assessment of cognitive issues prior to a diagnosis of dementia. Testing and assessment come after the “crystallizing moments of awareness” and “catalysts” (found in *Changing and Adapting*.) In some cases, the care partner pressed for assessment, while in other cases, it was the person with the symptoms. In most cases, both the care partner and the person were aware that something was “not quite right”, and testing and assessment was needed. While testing and assessment may be seen to occur over a short period of time, some participants in fact described years of testing and assessment as they were on the border of clinical indicators of dementia.

I was just remembering I did have several times – a couple, I should say a couple of times – tests. I guess the first test was the one where you draw the clock. And I went through that and then the number, where they’re giving you three numbers that he’d come back and ask me to repeat. And at the first there, I did very well on that. She told me that I did very well at remembering all of them. But later on it didn’t work out that way. The last test I forget. It was similar in a way, but it was a lot more difficult and I found it difficult. I don’t think I passed that one. [Person living with dementia]

And he gave him – this is about 3-4 years ago now – the testing that they do now, here at the Society – you know, drawing a little picture, putting the clock, giving him the words to repeat back – that type of testing, cognitive testing. And he sent him to a doctor and I could take you right to his office, but I can’t remember his name. He did pretty much the same testing, only a little bit more in-depth, and said that he really couldn’t give a clear diagnosis of dementia or Alzheimer’s. He gave Levi some things to do to improve his eating habits, to do mental exercises – this type of thing – and to go back in a year, which we did. We went back in a year. Still, he said there was a little bit of a loss there, but nothing that he could define as dementia – if it was dementia, whether it was the older-age vascular type dementia. He couldn’t give a diagnosis of Alzheimer’s, but to come back in six months. [Care Partner]

Testing and assessments can also be quite difficult for people living with dementia. As one person stated, “I find them [the tests] very depressing, personally. I was in the business where memory was all important... Now I can’t remember anything and I can’t remember what I did last week. Probably not very much, but I can’t remember, which I find it’s very depressing.”

Testing and assessments for dementia were described by many participants as a “roundabout”, meaning that the testing and assessments didn’t always clearly lead to a diagnosis, and participants felt that they weren’t always sure where the road was going.

One thing that became very clear as people spoke about their experiences is that there is not a clear pathway for assessments. Some individuals had assessments done by their family doctors, others by Alzheimer Societies, psychologists, specialists, nurse practitioners, and the like. Some participants were immediately referred to a specialist, either a neurologist, geriatric psychiatrist, or geriatrician, while others continued to see their family doctor for testing and assessments.

## Diagnosis

After sometimes years of testing, people finally received a diagnosis of dementia. While we describe “responding to a diagnosis” in Changing and Adapting, here we describe through participants’ words the experiences of receiving a diagnosis. As one care partner described, “The diagnosis is certainly a critical point. You have to face facts.” As a health service provider described, diagnosis is the gateway to the dementia journey. Indeed, the system journey is contingent upon a diagnosis of dementia, and many of the other facets of the journey, including adapting, changing relationships and identities, and system services all hinge upon a diagnosis.

The diagnosis itself was a varied experience for people. Some participants received a diagnosis relatively quickly after testing and assessment, while for others, the process took a long period of time, in some cases, even years. Participants who were younger when signs and symptoms began to appear described having a more difficult time getting a diagnosis, as often time was spent, either by care partners or the person experiencing the symptoms, convincing their doctors that something was wrong. Some participants described being very surprised by a diagnosis, while other participants described having some idea that dementia would be diagnosed. A person with dementia stated, “So I went to the other doctor and he gave me some tests. And he says – yeah, I think you have early Alzheimer’s. There’s nothing we can do for it. There’s no medication for it. Come and see me in a year. I went home and I didn’t say anything to my husband.” Often, the participants who were younger (under the age of 65) were more surprised by a diagnosis. However, for some participants, receiving a diagnosis was also an experience of relief. As one care partner stated, “I was delighted to have it reinforced because I thought – well, I am right.” In contrast, another care partner stated, “Well, in the process of diagnosis I was actually quite shocked because even though I knew what was going on, it was obvious.” As one health service provider stated,

I think with any of us when you’re starting to experience symptoms that you innately feel are out of the ordinary, otherwise why am I suddenly – and then you see multiple doctors and they say nothing’s wrong. So then you start to think – am I crazy? Am I making all these things up? So when you finally get that validation that wow, yes I do have dementia or I do have cancer or I do have heart disease. It’s not good news, but you have an answer – that you’re not going crazy, that it’s real. And I think maybe that sometimes that validation is just like –



A diagnosis was described by many participants as a “steep road down”. Many participants thought that a diagnosis would mean an immediate decline in cognition, and weren’t aware that many people can live well with a diagnosis for years. Participants also felt that the naming of dementia meant starting (or continuing) on a journey knowing that eventually dementia was progressive.

yeah, I still know who I am. I still have my personhood. I know what I am. I know it's real and what's not. So sometimes I think there's comfort in that as well.

Participants also described varying experiences with how the diagnosis was presented to them. Some participants described having a very supportive health care provider who gave them the diagnosis. These health care providers were compassionate, helped participants to work through what to do next, and provided them with information. Health care providers who were not supportive typically didn't provide participants with any information or support, and simply told participants to "get their affairs in order." In some cases, health care providers didn't even mention dementia or specific types of dementia, and didn't talk about what dementia actually was. How health care providers presented the diagnosis to participants made a significant impact on participants' responses to the diagnosis. One care partner described the process of diagnosis for her partner:

I guess we're going to probably look at the diagnosis issue because that's where we all start. Things were very good for us; and along with the diagnosis, we were getting many negative things – like first of all, you can't drive any longer. You cannot drink any longer. You cannot get insurance to travel any longer. Go get your papers all sorted out and maybe the Alzheimer's Society can help you. You can try that. So here you are – everything's cool – and all of a sudden you're down to this narrow pathway and doors are being shut.

Many of our participants described being prescribed medication to try which would maintain functioning. Some participants were not able to tolerate medications. In most cases, participants felt that medications were important, and that everyone should be offered the opportunity to try medications. In some cases, participants attributed their continuing wellness to medications and to starting these medications early on in the dementia journey.

## Finding Out More

In most cases, participants went through a period of responding to a diagnosis and trying to come to terms with what this meant (described in **Changing & Adapting**). After this, however, many participants wanted to find out more, particularly in light of the little information that some of them were given by their diagnosing health care provider. Participants described the various ways that they tried to learn more about dementia. A participant living with dementia stated, “I read on the internet too – of course, after I was diagnosed I looked up all kinds of information about dementia and vascular dementia.” Another participant living with dementia stated, “I ordered a book. I wanted to be alone when I read about it.” While some of this information was seen to be helpful, some participants felt that it didn’t capture the realities of dementia: “Again, to me, often it seems a bit sugar-coated. The information that’s published can be a bit sugar-coated because you may not be ready. And a lot of times you’re not ready for a certain kind of information.” The need for information, awareness, and education was stressed as being important throughout the journey for all people involved, including the person living with dementia, the care partner(s), family members, friends, community members, and health service providers.



Finding out more was described by participants as “entering the school zone”. While often participants searched for information on their own, they also found out more about dementia from the Alzheimer Societies. This also meant that they were not alone on their journey, hence the picture of two people walking together.

## Planning Ahead

Since some participants were informed by their health care providers at diagnosis to prepare for the future, many participants described “putting their affairs in order” immediately after diagnosis. One care partner stated, “So we had to start thinking about getting our affairs in order. We went to the lawyer. We got all that done and make funeral arrangements and everything else.” A person with dementia stated, “We have the will too, and the children know about it. They know exactly who to contact, where the things are – even down to how do we want to have our funerals.” Another care partner described how her husband had made arrangements: “He’d already made sure, but the minute he had vocabulary problems, he made sure all our finances were absolutely in order and all of that stuff taken care of. Well, then he’d done everything that could be done.” A health service provider described the importance of planning ahead for people living with dementia and their families:

I think that would start from the beginning – from diagnosis to community and just reminding them how important it is for them to talk to their families about what they want – what they want to see for themselves, even if they don’t see themselves – you might never make it to long-term care. You might never get to that route. But if you were, what would you want for yourself?

While not everyone planned ahead, many participants described the importance of planning ahead. Planning ahead didn’t just relate to finances, funeral arrangements, and wills. A few participants, particularly care partners, talked about thinking about the possible issues that may arise in the future, such as needing long-term care, home care, or having to provide physical care to their loved ones with dementia. While these were not always things that could be immediately planned for, certainly participants thought about what may happen in the future.



Planning ahead was described by participants as moving straight ahead along the journey in one direction only. Planning ahead means, of course, planning for the future, and participants stated that this meant there was no opportunity to go back in the opposite direction. The road was one way only.

## Connecting with Services

Connecting with services reflects participants reaching out to use various services. Sometimes, connecting with services meant that participants themselves initiated the connection; less often, it meant that participants were referred to services, although this did happen.

Services related to a number of things: 1) education and information; 2) support groups; 3) help around the home; and 4) help with care of the person living with dementia.

Education and information, in a formal sense, was often found through the Alzheimer Society. Although finding out more was described earlier as participants sought out information on the internet and through books, another way of finding out more information was through the Alzheimer Societies. Some participants were encouraged to get connected with their local Alzheimer Society, while others eventually sought out their local chapter on their own.

Without exception, every participant who had some connection with their local Alzheimer Society described it as the most helpful service they had experienced. As one care partner expressed, "I don't know what I would've done without the Alzheimer's Society." A person living with dementia stated, "I really enjoyed it and we enjoyed it because my husband could be on the support side and I was on the patient side; and he felt that he got a lot out of it and I felt that I wasn't the only one. It was so good we could talk about it." Another person with dementia stated, "You know that you don't have to do it alone now. You can share it." One health service provider stated,

I like the share the road piece. I think that's speaking to the community part, that we're trying to walk with the caregiver and the client themselves to help figure out what it is that they're needing at that time; and that's when those services are trying to do the best that they can – given, unfortunately, the limitations that are surrounding them at times. That's hopefully a place that that's when they've accepted that and they're in that place, so that's a positive.

Other services that participants connected with were instrumental services in assisting themselves or their loved one to stay at home. This is described further in the theme "Staying at Home".



Connecting with services was described as learning to share the road. Services connected participants with others going through the same journey (i.e., support groups) but also meant that care providers came alongside the care partners and people living with dementia to support them in their journey. Sometimes, however, that meant sharing the caring, learning to accept help, and talking to others about one's experiences.

## Giving Up Driving

Giving up driving was a significant step in the journey, described by both people living with dementia as well as care partners. As one person living with dementia stated, “Independence. Not driving a car is very difficult for me because I’ve had a car since I was very young. And now I can’t. I have to have someone drive me wherever I go.”

In some cases, people living with dementia opted to give up their licenses themselves. There were some individuals who chose to give up their licenses, while other people hadn’t driven themselves and used public transportation. More commonly, however, people living with dementia were told that they could not drive anymore. One care partner described,

Our big moment was when Samuel got the letter saying that he could no longer drive, because he had failed the Drive Safely or whatever that \$500 frigging test is that they made him do on the computer. And he cried for a week. It was like a death. The diagnosis – we dealt with it. We just kept moving forward. But when he got that letter it was like a death in the family. It was horrible. And it was fairly early on.

Being forced to stop driving was very difficult for people living with dementia, as described by the care partner above. People living with dementia who were still driving described the trauma that would be involved in giving up their licenses, and in some cases, felt there was no more reason to live if they would not be allowed to drive. The implications of stopping driving were also profound for care partners. As one care partner described,

I don’t know much about cars myself and unfortunately I’m learning about them because my husband doesn’t drive any longer. And I think that was probably the hardest thing for him to accept and also for me, because it took me at least two years to feel comfortable behind the wheel. I only went where I had to go at first, and now I’m branching out more.

Stopping driving meant a significant change for both the person living with dementia and the care partner, and was described by almost all participants as a significant part of the dementia journey.



Many participants described giving up driving with the “bicycles” road sign, as alternative modes of transportation were needed. Even if people living with dementia were still driving, thinking about the time when they may not be able to drive anymore was described as very difficult.

## Navigating the System

Participants described the difficulties of navigating the health and social care system when they needed care beyond what family could provide. Some participants wondered when they needed to access formal health and social care services, particularly if they were thinking of planning ahead. Some very challenging situations were described, where the care that was needed for the person with dementia was not available. Crises were described such as the person with dementia being unable to stay home due to responsive behaviours, infections, physical health concerns, and the exhaustion of the care partner. Having appropriate care at the time of need was a great concern to the care partners and health and social care providers. As one health care provider stated,

It's interesting because I think some of the other work that I've done, one of the most major issues that family talk about is sort of navigating the whole system and they have no idea. They don't even know what a CCAC is. So sort of having connections like that – if we can make that link here and then identify sort of individuals who can help them navigate throughout – I don't know. It seems we need to do a better job of helping families know what's out there, and then helping them get better access.

While the Alzheimer Society provides a very important social care service throughout the dementia journey, the challenges are described when community resources and other health system services are needed. A health care provider stated,

I think Alzheimer's Society would probably play into it in most people initially; and then the day program, community resources, when the dementia is progressing, that caregivers are starting to feel some burden. They're starting to feel that they need some outside help to cope, to continue on with caring, but they need a little bit of outside resources to continue to cope with the changes.

One of the challenges with navigating the system is that each community is different, with the services available for people with dementia and their care partners varying across regions, and how people journey through the system being also quite different. As such, there is no one pathway for navigating the health and social care system, just key points along the way such as the Alzheimer Society, home care, day programs, hospitals for emergencies, and long-term care homes.



Many participants described the difficulties of navigating the health and social care system, and the particular challenges of knowing what information and resources were available. The health and social care system was described with the “slippery road” road warning sign.

## Staying At Home

Navigating the system also referred to the need for people living with dementia to stay and be supported in their own homes. There were many considerations for staying at home. First, a care partner describes how he has adapted his home and routine to care for his wife at home:

I've adapted to a lot of things. But where we are with it now – where [my wife] is – is that I have to double-lock our home because she wanders. I've lost track of her three times and the first time it happens, it's just terrible, so you kind of survive that. But now I take care of her in the morning – shower, bathe and dress her. But after that, though, ... – it's pretty good. Just need a little more patience and answering the same questions several times in 15 minutes. Beyond that, I'm just taking the enjoyment of who she is right now. I make all her meals. But the home care here in [my community] is – I have no comparison – but it's really terrific. I'm not sure what everybody else thinks, and I keep fairly active too. [Care Partner]



Many participants described staying at home with the sign of falling rocks. In particular, care partners described staying at home with the support of various services as important, but potentially leading to situations where a crisis might occur.

A person living with dementia commented, “I think the future is going to be difficult to manage because you know that you need care. And you are willing to accept help, but you don’t want to be – you would like to have some self taking part in it.” Staying at home and planning for the future was also mentioned by people living with dementia.

One of the key issues of staying at home for care partners was the time when the person with dementia couldn’t be left alone anymore for safety reasons. One care partner stated, “When you get to the point where you can’t leave them alone, that’s a really tough stage. My husband knows, because he took care of his mother. He was wonderful. So you think – you worry about that stage because if you’re isolated yourself, I think it becomes, you don’t want to be.” Care partners expressed concern here for the limitations this would place on their own self-care and opportunities to do the things they like and need to do.

Finally, a key thing with staying at home was recognizing when help was needed and accepting it. Care partners and people living with dementia expressed how it was sometimes very difficult to accept help, even when they knew it was necessary.

## Alternative Living Arrangements

Alternative living arrangements were sometimes chosen by the person living with dementia and care partner, and sometimes were a necessity. One health service provider commented, “I think there are probably situations too where the caregiver and the person with dementia will move to a retirement setting so that they can still be together and still have some quality of life as they build in supports and still have that closeness that they want.” One participant described how he and his wife moved to a retirement home after her diagnosis, while another couple were living in an apartment complex already.

A change in cognitive or physical functioning often led to the necessity for alternative living arrangements. This could happen gradually or suddenly through a crisis. This particularly became a necessity when the person living with dementia was no longer safe at home, was having difficulty living in the home, and could no longer stay alone. One health service provider stated, “...that whole long-term care, home transition when the family realizes that they can’t care anymore.” This sometimes happened when the person living with dementia was admitted to the hospital and was not able to return home, but also occurred when the person experienced some decline at home. Sometimes the move was necessary for the care partner because of exhaustion and burnout. The challenge often was the lack of available alternative living arrangements at the time that they were needed. One health service provider stated, “Ready, but no bed.... They’re ready, but there’s no bed available. The crumpling rock could be, because it’s like you said – you’re in a state of crises. It could be the person has just progressed and then the caregiver just really can’t – compassion fatigue or whatever.”

Despite the significant life change that considering and moving to an alternative living arrangement can be, the change is not always negative. One health service provider commented,

A lot of caregivers, from my experience that I’ve found, is that when people – when their loved ones are provided that opportunity to be in an assisted living or a full-care living environment, it is that feeling of satisfaction that – oh, wow. They’re finally in an environment where they can have the interaction and the stimulation that they need, that I was not able to provide, but I can also partake in it because companionship is also along in there as well. Just because somebody goes to long-term care doesn’t mean that they’ve lost their caregiver. It’s just a different level of caregiving.

Alternative living arrangements, then, can mean apartment living, retirement home, or long-term care homes. Not every person living with dementia requires alternative living arrangements, but the need is dependent on the situation and context of the individual and his or her care partner, and the support available to the family.



Alternative Living Arrangements can include:  
Apartments  
Assisted living  
Retirement homes  
Long-term care homes

## Palliative Care

While palliative care was not brought up by very many people, some care partners and health service providers mentioned the need for hospice and quality palliative care services as people got to the end of their journeys. In particular, people wanted to ensure that their wishes were respected. One person living with dementia stated, “I’m a fighter too. But I know with this disease that my fight’s going to be gone and I’m no longer going to have that voice and I wished I could document something now that said – when it gets to that point that, let me pass peacefully. And I’ve always believed that. It has nothing to do with the disease.” Ensuring persons with dementia could die in comfort with dignity and respect was important.



Good quality palliative care services for the end of life is important.

## Leaving a Legacy

Leaving a legacy was described by a few people living with dementia. In particular, the people with dementia who spent much time in advocacy work felt that their lives were changed for the better because of a diagnosis of dementia, and they worked hard to leave a positive legacy by campaigning for better services for people living with dementia. One person living with dementia tells her story:

Leaving a Legacy:  
Campaigning,  
advocating, and  
championing better  
services for people  
living with dementia.

For me, there's more than I could – I think my life road never – you meet people in life that will change your direction or things that happen to you in life that will change your direction. I don't think I had a really, really important life-changing moment as I did as now. I'm living it right now. I think I found my purpose in life after my diagnosis. I really do. I think that's why I'm on this road. You wouldn't have paid me a million dollars to stand up in front of people - to be anything but a background worker. I liked to be sitting at a table keeping my mouth shut – far from what I am now. To me it was just life-altering. It really was, but in a very positive way. Once I realized and thought about it and decided to be proactive, I realized it was life-altering. There's people I've met along this way that have definitely made me shift and go in this different direction. And I've met more people that made and altered my life's course after my diagnosis than before, and I don't know. You hear it all the time – late in life – but I never thought it would've come with this diagnosis, but it did. So I feel I've been given a lot of gifts and a lot of great things have happened to me that wouldn't have happened to me if I had not had the diagnosis of dementia. I would not be living in the house with my grandchildren. How lucky can I be to have that?... And I just can't explain enough the gifts that have come my way. And that doesn't mean I don't have all the bad feelings too, but they're minimal. They're minimal.

## 2.0 Changing & Adapting



Figure 4 Changing & Adapting

Changing & Adapting refers to the kinds of changes that might occur along the dementia journey, and how people respond and adapt to those changes. This section encompasses the following themes:

- Crystallizing moments of awareness
- Catalyst
- Diagnosis [described under the [System Journey](#)]
- Responding to a diagnosis
- Adjusting to a new normal [also under [Caring for Me](#)]
- Reconstructing the future
- Living for today [also under [Caring for Me](#)]
- A changing identity [also under [Caring for Me](#) and [Relationships and Community](#)]

## Crystallizing Moments of Awareness



Many participants talked about crystallizing moments of awareness, or times when they experienced the signs and symptoms of dementia. Crystallizing means to give a more permanent form. In these cases, certain things were experienced by people living with dementia, often noticed by care partners as well, but were often initially explained away by other factors. However, as these signs and symptoms became more common, increasingly people began to wonder if something was, in fact, wrong. These moments of awareness became more frequent, crystallizing to an awareness that these moments were indeed not normal brain functioning. One person living with dementia described this: “I would put on the stove and I would forget to put things in. Or I would ask for my best friend’s name. I would ask. I didn’t feel comfortable going out to the store. Making decisions was really difficult.” Another person living with dementia also described: “Actually forgetting words – just one word, just one word at a time. I’d be talking to somebody and I would miss a word. Okay. Fifteen minutes later after I’d left talking to that person, the word comes back.” Forgetting things was a key sign as shared by another person living with dementia: “Well, I first noticed something strange – it would be six or seven years ago when I was programming a machine and I had to program a number into a certain register, and I could not remember the number. By the time I got over to the register, it was gone. And so that was the first weird thing.” Key signs and symptoms mentioned by participants included:

- Forgetting words
- Forgetting things on the stove
- Forgetting names
- Having difficulty making and keeping appointments
- Having parts of the day’s activities that were forgotten
- Losing things
- Not recognizing items in front of them

Care partners also noticed some things that weren’t quite right. One care partner described, “It was almost 14 years ago that he was diagnosed. I had wondered for a year or two before. It was just a feeling of – what’s wrong with this picture. And [my husband] had been noticing – he didn’t mention this to me – but he noticed it at work. He just wasn’t focusing. He was forgetting meetings and things.” Another care partner described, “Like he used to carve – he quit carving about 12 years ago. I found he just couldn’t finish anything. He forgot how to do things.”

Often, these signs and symptoms were initially explained away for some of the following reasons:

- Personality
- Lifelong habits such as disorganization

Crystallizing Moments of Awareness is when people know something is not quite right, but they don’t think something is quite wrong yet either. It is the process when key signs or symptoms are experienced, but not recognized initially until they occurred with more regularity.

- Stress
- Alcohol consumption
- Physical sickness
- Age
- Previous mental health issues
- Medication
- Trauma such as loss of a family member

It typically took a catalyst to get individuals to go to see their doctors and ask for help to find out what was wrong.

## Catalyst

Despite experiencing signs and symptoms of dementia, it typically took something more dramatic, or a catalyst, for people to seek help from a health service provider. Sometimes this was a specific event or occurrence; other times it was the ongoing presence of signs and symptoms that could no longer be explained away.



One care partner described the catalyst for her and her husband:

I suppose it was the day he was sent home from work because, although he had mentioned that his short-term memory wasn't right, with him going in and seeing the doctor and nothing happening of it, I sort of took it that – okay, there's nothing wrong, he's just ignoring us. And I just never really thought about it beyond that. So then when they sent him home from work and set up the testing, etc. and we got the diagnosis, it was a pretty big shock to me. Certainly, looking back then over the previous months at least, if not a year or two, I mean you could see what I was putting off to him ignoring me was actually him not remembering. Now I have always been the one to sort of keep track of the kids and who was supposed to be where when. So although it got worse as far as him remembering those things, I never really thought about it because he never was the one to organize those things anyway.

A catalyst was a key event beyond the crystallizing moments of awareness that made people seek help. It was described as going from a paved road to a gravel road suddenly.

Another catalyst that was described was a care partner pushing the person with the signs and symptoms to get help:

[My husband] thought he had done fairly well – I'm fine. I did this good. But he was willing to go to the doctor because I had – he heard me when I called the doctor and said, "Either we get him diagnosed or I'm going to kill him". I was that upset because he was so bad. He would get angry so quick. And he'd be standing there with the drill and right in front of him – he would tell me exactly what it looked like – and he said, "It's gone. You moved it. Where did you put it?" And I said, "Is it that thing right there?" And he said, "Oh, yeah. How did that get there?" So you get so you have a lot of frustration.

Another person living with dementia described how his wife made an appointment with the doctor for him: "I was in construction as an electrician. But, my wife happened to notice that – I find this out afterwards – happened to notice that my moods were changing and I would get happy, and the next time I'd be right down and really giving her a rough time. So she, as it happened, decided that I should go to the doctor, first of all, which I did."

## Responding to a Diagnosis

The response to a diagnosis was particularly varied, and sometimes people experienced a variety of responses once they received a diagnosis. Responding to a diagnosis was not limited to any specific time, except that it occurred after a diagnosis. Some people experienced a long period of adjustment and adaptation, while for others, it occurred rather quickly.

For people living with dementia who were younger and who went through a period of testing and assessment, a diagnosis was in fact a relief for them. As one person living with dementia stated, “Even though the name wasn’t too pleasant in the sound, but yes – it was kind of a relief to know what it was.” Another person living with dementia stated, “Because once I got to the diagnosis and shortly after, for me it was a relief because it was better than this. So the diagnosis for me was a relief.” Finally, another person living with dementia stated that a diagnosis validated her concerns:

Well, when I got the diagnosis it was relief in knowing that I had a valid disease – that I’m not much for labeling things or labeling people, but that’s one time in my life that I was grateful for a label because that gave me an opportunity to be proactive. You can’t fix something when you don’t know what’s wrong, so go back to the half brain I’ve got.

For other people, the diagnosis of dementia was a shock. A person living with dementia described her reaction: “Well, it hits you like nothing on earth, like where am I going from here and what am I going to do? How am I going to handle this? All sorts of things go through your mind, and why me?” One care partner described how she felt when her husband was diagnosed, particularly since she cared for her parents with dementia:

I was angry. I was frustrated. I thought here I go again. I had my two parents with dementia, so I thought – oh shit, here I am. Excuse me – I let it all hang out. And I thought – geez, we’re going to start this all over again. But no, after I got over the initial shock, I knew there was something wrong. I just didn’t know this was going to happen to me again. But after I got over the initial – you know we sort of got used to it.

A person living with dementia described the shock that he experienced with a diagnosis:

To some degree, yeah – disbelief from the standpoint that I thought I was too young for it. I was 59. I thought I was too young for it. To me it just didn’t seem like it was something that hits people at that age. That was my first thought, but there was also a sense of relief because what I had or whatever had been



Responding to a diagnosis was described as “no U-turn” and “no parking”. There is no going back to before a diagnosis, and no opportunity to stop to really reflect because life keeps going.

bothering me had a name and they were putting me on medication to see if it would help. So there was both of that in there. And then there was also that sheer panic – well, how long? That was the big question – how long?

Not only did some people experience shock, but they also experienced fear. One person living with dementia described his response to his diagnosis:

Well, you feel bad because of the diagnosis that it is. I think Alzheimer's has become even more frightening any more than cancer. You know, you're given a cancer diagnosis – you're terrified. But I think Alzheimer's – at least you have a chance to beat cancer in some cases. You don't with Alzheimer's and it's that sense of the inevitable and how do you cope with that and make it easier on the person that has it. And it certainly does.

A diagnosis also meant that people living with dementia wondered about their future, and asked themselves, "how long"? One person living with dementia stated, "Because I know that at first when I got the information, that I had in the early stages of Alzheimer's, all I could think was – oh gee, I'm going to be – a few years down the road and I'm going to be forgetting my kids and forgetting lots of things."

Sadness and grief was also a common reaction to a diagnosis. A care partner stated,

How did we react? Sad. I felt very sad. All of a sudden you realize your life is changing – like a big thing. He cried. I cried. We kind of thought – okay, we'll go home and think about where are we going from here? And then we just kind of thought – okay, you know what? We'll get ourselves together and just go forward. You have to. A step at a time, yeah – don't think too far ahead. And when I do, I guess - I mean, you try to be very practical, realistic.

Some people reacted with anger to their diagnosis, and described fighting for as long as they could. A person living with dementia stated, "Well, if you accept all these things – hell, you might as well roll over and die. That's the way I look at it. You have to keep fighting it as long as you can." Anger also led to acceptance, as described by a person living with dementia: "Before acceptance comes anger. I think it's very difficult until you – I don't know if you ever get used to it. But you have to accept it for what it is. You can't get a pill to correct it. You have to live with it." Acceptance was described as being necessary by a person living with dementia: "And all of a sudden, there is something called Alzheimer's. There is nothing you can do about it. You have to face it."

A variety of emotions and responses were described to a diagnosis of dementia. It is worthwhile to note that many people experienced more than one response, and that responding to a diagnosis was something that was ongoing throughout the dementia journey. The process of accepting a diagnosis and life with a diagnosis was one that was ongoing, and was never finished. Participants described "accepting" a diagnosis, and yet also fighting a diagnosis so they could live as well as possible.

## Adjusting to a New Normal

Adjusting to a new normal goes all the way to the end of the journey. It is not a one-time thing, because the “normal” changes all the time. As one care partner stated, “The adjustment goes all the way to the end.” A care partner eloquently described this process of adjustment:

And we both kind of just kept walking forward. We’re still the same. We’re still the same. We’re still the same. And then six months later you think – well, we’re not quite the same, but now we’re still the same, we’re still the same; and then you keep readjusting and recalibrating every few months... Well, I remember saying to [the doctor], I guess probably in year two, that the only good thing about the nature of the disease was that it was a disease of millimeters, and so the caregiver could adjust by millimeters and change slowly, slowly, slowly. Things, until the very end for us, didn’t go off a cliff, so that kind of made it a little easier to be a growth exercise.

Similarly, as a health service provider described, “Five years. 10 years. It never stops, I don’t think. Well, I mean until a person dies, I don’t think you ever – that’s one of the things that makes it very emotionally challenging is that, because the disease is progressive, the adjustment process is ongoing.”

There are a variety of “new normals” to adjust to as described by care partners. The kinds of things that occurred include:

- The person with dementia losing things all the time and putting them in different places
- Wanting to eat all the time because of forgetting that s/he has eaten
- Going out in a t-shirt or undershirt when he was always immaculately dressed
- Walking around the house in underwear when company is over
- Not dressing for the weather
- Wearing same clothes over again
- Not making choices about things
- Difficulty helping around the house
- Lack of interest in things like family birthdays, etc.
- Lack of motivation
- Repetition



Adjusting to a new normal was described as a “yield” sign, because despite adjusting to a new normal, there is an element of caution in watching out for what might be coming.

## Reconstructing the Future

The future was described as being different from what people living with dementia and care partners had anticipated, and as such, they were reconstructing their future. The first step in reconstructing the future was acceptance that the future would be different from what they planned or thought. As a care partner described,

It makes a detour in your life. You know you had these plans. This is the way you thought your life, your future, was going to be and our old age was going to be. And now it's not and you've have to take this detour that's totally unknown to you and it's just very scary. And I think for the caregiver as well as the person that has it.

A person living with dementia described how the future was uncertain: "We have no idea what's going to happen to us – not in the near future, like within the next 10 years or so."

A care partner described the future according to her experiences and perceptions:

Sometimes it's either. It's just the daily things. Sometimes it's like – I have no control today, like there's just no control. And then you'll be alright for a little while and then all of a sudden it's like – okay, I have to just get over today. And so it's kind of the same kind of thing. When you go down a detour, you don't know what to expect. And sometimes – we always used to love detours because you get lost on a country road somewhere – we loved doing that when we were traveling around; and going down a detour was fun. But now it's – no, it's totally different. You just don't know what to expect, but it's not anything that's going to be good, is how you feel. You know that this road to Alzheimer's isn't something you're going to enjoy, so it's tough then. You just want to stop and turn around, but you can't.

Not having control over the future could be difficult for care partners: "I just don't because we have no control over the future. I could probably say – okay, this is the route we're going to take, and then something happens. So I just sort of feel that that's out of our – [control]". Other care partners were more positive in their descriptions, as one care partner stated, "Because you're constructing what your future's going to look like – changing from what you've got." Another care partner stated, "We're redefining our life." And another care partner stated, "Everything changes and it's rebuilding."

However, a person living with dementia stated, "Well, you can't change what's already passed, but you can influence your future." For people living with dementia, the



The future was described as something that was under construction.

future was not something that was discussed. The road sign attributed to the future for them was a do-not-enter sign. However, they did describe keeping a positive attitude.

## Living for Today

Part of reconstructing the future was, in fact, living for today. As one person living with dementia stated, “I always thank the Lord when I wake up every morning and I’m feeling okay and it’s another day, and especially if the sun is shining. To me, you have to make the best of every day.” Another person living with dementia stated, “I tend to take each day as it comes. What I can do today that’s going to make everybody happy, go for it. And I’ve got meetings booked six months in advance, so I know I’m good for six months, and then I keep going in advance of that... But I’m not looking 10 years down the line.” Another person living with dementia stated, “But I live life-long. I really embrace the day and deal with all of this stuff and I talk about this on a regular basis.”



Living for today was described with a bicycle sign. This sign represented “getting off the main road”, taking things slow, and enjoying the scenery.

While people living with dementia were aware of the future, they chose to live for today and enjoy the moment. One person living with dementia stated “I’m aware of where I’m eventually headed to. That’s probably one area that I literally don’t think too much about... I just choose not to think too much in the future because I’m too busy with today.” Another person living with dementia stated how dementia taught her to live in the day-to-day, an important life lesson: “I reminisce, so that takes care of the past. But I’m really a day-to-day person, so I don’t look too far in the future... I actually think I should’ve been more that way before I got the diagnosis. Why did I wait so late in life to learn that lesson? I don’t know.” Another person living with dementia stated, “I’m not afraid to die, but I want to live right now.” A care partner reiterated this, and stated, “You live day by day. You can’t live for tomorrow or next week.” Living for today was an important way to stay well and continue to enjoy life.

## A Changing Identity and Sense of Self



Many participants, both people living with dementia and care partners, described a changing identity. A changing identity wasn't something that was solely negative, but was also positive. Participants described seeing themselves differently because of dementia. For people living with dementia, some of their identity ascribed by others became defined by dementia, although people did challenge this. People living with dementia also described having to give up their self-sufficiency, and how to be willing to accept help.

A changing identity was described by the road sign of "pedestrian crossing", indicating the focus on the person, and the changes in identity that were occurring to people through the dementia journey. A changing identity was ascribed to people by others, but was also something that people claimed themselves.

Because he was the one who needed more attention, and I was always the strong one. I could take it. I could do it. And it was very difficult for me to accept that I will need some support. I was always able to give, give, give, give.... But now he's the strong one because he takes care of paying the bills and organizing or going out for shopping. He's there because I can't do it alone. He's now everywhere – the things that I used to do alone, we are doing now together. He's good. He doesn't complain. It's difficult for me to accept that I'm the one now – I'm the weak one. I need the help.

Another person living with dementia described how she protected herself in order to be as self-sufficient as possible, and recognized her own limits: "And I really made a big change. I was always self-sufficient, always strong; and now I've got to the point where I trust others and I depend on others. And I can tell I'm tired or I have a bad day – please, leave me out. I will not go anywhere. I do not want to go to the movies. I just need time for me." Care partners described the changing identities of people living with dementia: "What I once was and what I now am is – it just plays on her mind. What I was and what I am." Another care partner stated, "And starting to take on more roles and watching your loved one relinquish so many roles....Because sometimes they do it gracefully and sometimes not so much."

While the change in identity from being self-sufficient to accepting help was difficult for some people, for some people living with dementia, fighting the disease and becoming an advocate led to a positive change in identity:

I don't know whether it's the accepting of the dementia or it's just accepting the way it is. I think for me it was more, not the accepting that I had dementia, was – okay, I've got to accept the way it is in order to – I'm a fighter. I've had to look for an avenue to come out of this to be fighting, so I guess I couldn't do it any other way. But in thinking about it, I don't think it was acceptance of the disease as it was as – okay, I accept how I am today more than the disease itself. What do I have to do now to do and be the best I can be? So I think it was more along that line than the actual acceptance of the disease.

Care partners described the change in identity as well, particularly as the roles within their marriages, partnerships, and families changed. One care partner described how she was learning new things:

And the roles that you take on as a couple, literally from before you're married – you know, you sort of already have things that he does, things that you do. And all of a sudden he's no longer able to do those things or no longer thinks of those things the way that they would have. And so then you're remaking yourself and learning to do a lot of things that you never thought you were going to have to learn to do.

Another care partner described how his role, and his nature, totally turned around:

Like we all basically – not all, but the caregivers are primarily at home with kids and that's the wife, right? So now, all of a sudden you're thrown into a situation – you've got to be the caregiver. And I think that's where it's a rocky road for me because it's a whole new road for me. And my wife – she was great. She looked after the kids and that and that was – and I guess growing up on a farm and bigger family, it always was the way. The other was the caregiver, right? Now all of a sudden that whole role is totally reversed. And it's your nature too – totally turned around.

Another care partner described how he had changed significantly as a person:

I'm a totally different person now than I was a couple years ago – from my understanding, far more – I have the ability now to sit down and talk to people. And before I was not impatient, but just laid back and didn't get involved with a lot of stuff, I guess you'd say. And very – I would say probably assertive because I refereed hockey and that was part of it; and I was always a supervisor at work too. So now I've learned to go the other way and I'll sit back and kind of analyze and let things flow and just speak when you have to. So it's changed me up – big time.

Finally, one care partner described how her role changed when her husband was admitted to long-term care, and how different and new opportunities have opened up for her:

And I didn't have an identity anymore. I turned my care over to somebody else. And, of course, subsequent to that, he had a crisis and I became the principal caregiver again and kind of slung him back over my shoulder. Before that few weeks, I really kind of kept looking around – okay. Well, now what? What the heck am I going to do? And so when he went into the [hospital], I didn't have that feeling because I'd been there and I found that my life really was changing. People were asking me to make presentations, sit on committees, and things that I'd never imagined happening at this stage of my life. So something quite

amazing had happened, so I don't think I'll ever go through that now again because I know there's always – and I keep myself open.

Identities and roles change throughout our lives, and the role transitions described by people living with dementia and care partners were described in many different ways. What is important to note is that a changing identity wasn't always negative, and people found purpose and meaning in their lives as their sense of self shifted and evolved.

### 3.0 Relationships and Community

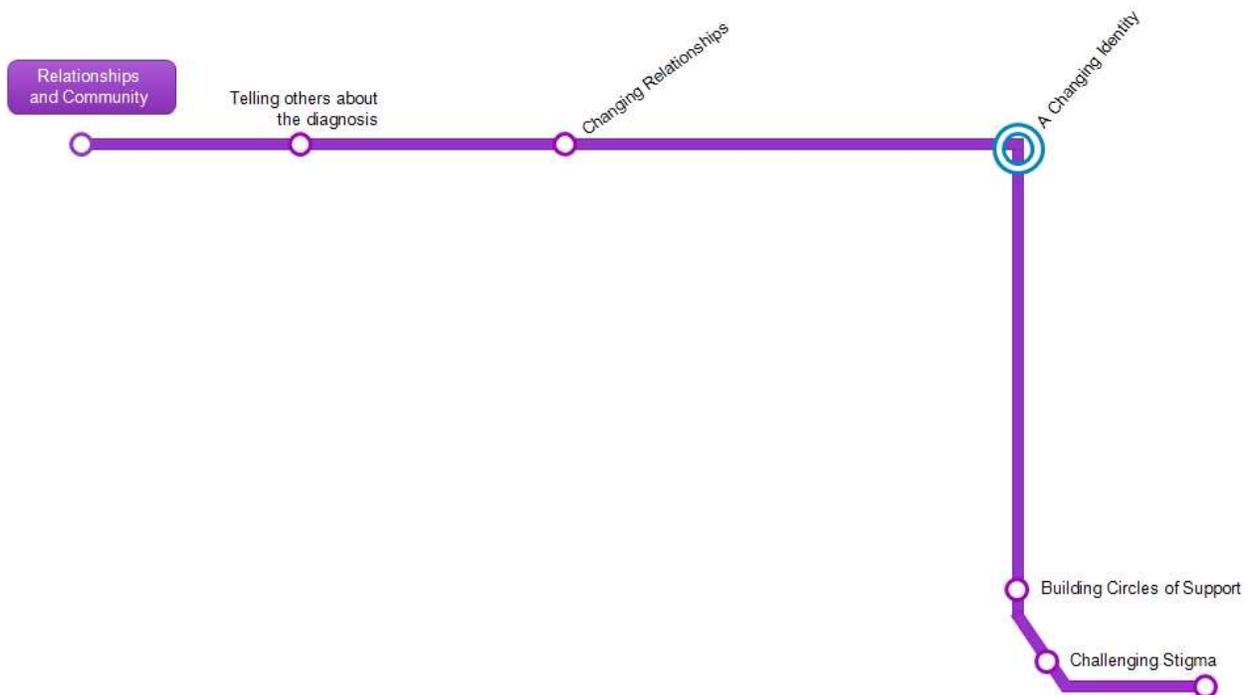


Figure 5 Relationships and Community

Relationships & Community encompassed other people and the interactions with others throughout the dementia journey. This theme focused on the importance of family, friends, and community throughout the dementia journey, and encompassed the following key themes:

- Telling others about the diagnosis
- Changing relationships
- A changing identity [detailed in [Changing & Adapting](#)]
- Building circles of support
- Challenging stigma

## Telling Others About the Diagnosis

Telling others about the diagnosis of dementia was a decision that was quite different for people. Some people chose not to tell people, especially initially, about their or their loved ones' diagnosis of dementia. For one person living with dementia, her independence and past life circumstances led to an initial decision not to share her diagnosis, even with her family. She stated,

I was an orphan at age 10. There were four of us. There was one that was older than me – a year older. The two were younger. So you had to be strong. You always had to behave. You always had to be the best in school. And that somehow stays with you. So it's always – yes, I can do it, I will do it, I will show you I can do it. And that's why – I think that's probably why it makes it more difficult for me to share with others.”

Another person living with dementia had seen how other people with dementia were stigmatized in her community, so she chose not to share her diagnosis with others.

I'm also aware that very few people know that I have Alzheimer's. I live in a community of little row houses with senior citizens and mentally challenged people and talk is cheap around there, so I just don't share it too openly with others. Actually, I've spoken more about it today than I have in a year.

A care partner described how they have avoided telling people about the diagnosis:

Because we're still hiding – like we're still hiding it from the friends, everybody. There's very few friends that know, because I can't even socialize with them, because if we stay too long with them, they might. If he has a bad day, he will. So yeah, we're like here – like the hidden driveway – so we're stuck there because he doesn't want me to say anything. And people stopped calling –well, his brother and his sister – their friends just completely left them except his sister, the one couple only stayed with them. So that's what he's afraid if you tell, then they'll never come around and we're going to miss our breakfast, and that's what he's at. You can't tell him. So we're – the hidden driveway, just hiding everything.

Other people living with dementia shared their diagnosis with some people, but not with others. Many of them chose to share their diagnosis with family and friends, but questioned whether they should share their diagnosis with acquaintances and the general public. Many people chose not to.

The pastor has arranged two other men of the church to go out with me. We go for a drive or go out for dinner. So that way they know and others know, and I



Telling others about a diagnosis was represented by a winding road sign, because this decision was not always seen as straightforward.

don't make no bones about it. Now if it's wrong – well, then it's wrong. But I don't – like say if I would meet you coming in there, I wouldn't say, "Hey, I've got Alzheimer's". It's only if people remark or say something, I don't mind doing it. But I don't feel embarrassed about it or if they do, well – that's their problem.  
[person with dementia]

Others, however, shared their diagnosis with everyone, and didn't feel that there was a need to hide it. In particular, they felt that this was helpful for them in public so that others would know why they were having challenges or forgetting things.

I do one thing. I'm very ready – very quick to say I have Alzheimer's if I'm out and in a position where I know I'm frustrating the other person. Because by declaring that I have Alzheimer's right away – and it's usually in a store, so if I'm out shopping or at the grocery store or paying for something and I'm not moving as quickly and there might be a line-up, I will declare at that point in time I have Alzheimer's disease. Because what I have found by declaring it, it makes the person that's waiting on me more considerate and therefore they don't get angry, then I don't lose my cool and say something that would be inappropriate; and it just makes the whole thing run smoother. So I'll be quick to declare it in those situations.

## Changing Relationships

Changing relationships were discussed by many participants, and captured the changes in spousal and partner relationships, the changes in family relationships, and the changes in relationships with friends. For some people living with dementia, their concern was the potential future changes in family relationships that may occur. One person living with dementia described,

I think one of the big things I was concerned about is how long is it going to be before I fail to recognize my family. And that's one thing that I was really concerned about, because I've known from other people that people forget or are unable to recognize their own family when they come around. And that really bothered me.

Another person living with dementia described the relationship changes that were occurring, and how this was challenging for her and her husband:

I find that I think it's pretty hard on the husband because I always did everything, and now I'm not as fast as I used to be. I think it's difficult for him and it is for me, and the fact that I can't drive and so on. But I do think on the caregiver it's very difficult for them. And he can't throw me away... But the marriage vows said for better, for worse, till death do you part. And I try to be a good wife. I do the best I can.

Care partners described the challenges with changes that were occurring in their relationships as well. One care partner described the changing relationships with her mother, and how that impacted the family:

The other funny thing is my mom can get real bitchy now – like really bitchy and doesn't want to do things. And my mom would've never. So sometimes with Mom when she gets very angry and crabby, she behaves in a way we never would've expected our mom to behave, and that's been hurtful, more for my sister because she's a softer soul than I am, I think.

Another care partner described how her relationship with her husband had changed, and how challenging that was for her:

But it's really hard. And like when he used to yell at me when we were in a store or something and had everybody turning around looking – it used to really, that's what upset me more – more than the fact that he wasn't behaving like he normally does. I can understand. I should understand that. It was – I was angry because he was doing this and making people stare. But that's what I'm finding



Changing relationships were captured with a “fork in the road” sign, indicating that as relationships changed, the dementia journey often took different roads.

is the things you have to get over. I mean you just have to because it's hard, though. It's really hard.

Another change that occurred in relationships among spouses and partners was the change in communication that occurred, and a corresponding lack of intimacy and closeness. The below conversation between care partners illustrates this:

Care Partner 1: There's a bit of a natural transition, though, because in many ways I do live alone now. We don't talk when we have breakfast. So I mean it's different, but it's not the same as it used to be. And in some ways –

Care Partner 2: He can't talk the same.

Care Partner 3: Yeah. You fill in the back stories, so you don't talk.

Care Partner 4: Well, by the time you fill in the back story, then they've forgotten. So it's pointless. And to discuss any of the family issues and things that are going on, it just doesn't –

Care Partner 1: And they never have a telephone conversation anymore because –

Care Partner 4: Because he doesn't know how to use the phone. My son, who is living away, phoned home for his dad's birthday and I had to tell him and hold it for him to be able to talk to him. And my son was a bit surprised that it had gotten to that point. I mean, he had been home over the summer, so he knew how his dad was; but he didn't realize that it was to that degree with the phone.

Care Partner 1: Yeah. It's a much quieter day – very much you're alone.

Despite some of the more difficult changes that have occurred in relationships, positive changes were also described. One care partner described the changes in her mother and how it has impacted positively on family relationships:

But in many ways it's been a joy to us. I know you might think this sounds awful, but my mother was very staid in her personality – grew up a very strict Catholic, so she never swore. She barely drank. They think she drinks like a fish here now because that's all she talks about and it's kind of cute because all of the things that she repressed come out. So we laugh about that.

Changes in relationships posed challenges, but also created a lot of positive changes in relationships. Spouses became more grateful for each other. People living with dementia became more grateful for their families and spouses and partners. Closer relationships developed. Different friendships were developed, particularly with others who were going through the dementia journey as well.

## Building Circles of Support

Circles of support described the ways, both intentional and unintentional, that people supported the care partners and people living with dementia through the dementia journey. One care partner described “And once we told the family, they were all right behind us.” One care partner described this: “I see the merging – sort of like everybody involved is sort of on the same page or going in the same direction. It’s not really two. It’s many – our daughters and his doctors and me and anybody. We all understand that it is what it is and we’re all sort of going in the same direction.” A key part of building circles of support was the necessity of letting people help:

Care Partner 1: And letting people help.

Care Partner 2: Or learning to let people help. Letting go.

Care Partner 1: Yeah, letting people take over some things.

Another care partner describes the support she found when they chose to talk about the diagnosis and their dementia journey.

I was surprised at the number that hadn’t told anybody about their mate having Alzheimer’s and I couldn’t understand why they wouldn’t. And they were afraid that their friends would leave them and they wouldn’t be accepted. For me, it was nothing to be ashamed of. It isn’t something we do to ourselves. And you never know who you talk to, whether they can be of some help. And we’ve never had a problem with anybody turning their backs or – my family is 100% supportive, just wonderful; and our friends also. So for us, it is a journey and we’re traveling it. We just don’t know what tomorrow’s going to bring.

Others talked about the importance of talking to friends about the diagnosis, and finding support in circles of friends. While some people living with dementia and care partners described how some friends didn’t support them, many friends did. One care partner stated, “Friends are important. You find out who your friends are.”

The importance of peer support was emphasized by many people living with dementia, as described in the quotes below:

One of the big things that I find has been a big help to me is when I hear Fred and Scott talk about their experience and how long they have. And I feel a little more – not enthusiastic, that’s not the right word – but anyway... When I hear them relate their experiences and how long they’ve been involved with it, it sure has been a big help to the way I feel about it.

Well, what I found very helpful here is the fact that we have the Alzheimer’s group that you know you can go there and be with everybody – with each other – and I find that’s very helpful.



Building circles of support was described as a school crossing sign, since the picture indicates two people walking arm in arm together, an appropriate sign for the circles of support.

Go where the people are and I'm so glad that I did. I know I'm not alone with this. And you can talk and share, and I think that's most important because when this happens, you feel – ... and that's why I would suggest to anybody that they go and talk to somebody. Get in with the group that you can share and then you feel a little bit better. At least I feel a little bit better about myself. I don't like what's happened to me, but it's happened and I have to accept it and do the best I can.

A care partner also described the importance of participating in support groups and connecting with other care partners who are also on the dementia journey:

I guess sharing with people. This is a really good – and the things that the Society has done to try to connect people and make people not feel like they're alone or you're the only one dealing with someone who's going through this, and realize there's a lot of people. And it kind of changes your outlook on it and think – well, you know on one hand there's no miracle cure. But I guess maybe you can get a glimmer of hope to think that somewhere maybe with more people sharing and doing.

## Challenging Stigma

The stigma of living with dementia was described by many participants. Dementia is a condition that many people have negative stereotypes and perceptions about, often leading to stigma and discrimination. As one person living with dementia stated, “There is no other disease that excludes the person with the disease more than this one.” Another conversation between two people living with dementia illustrated the stigma of dementia:

Person with dementia 1: They’ve got to give us a chance to prove ourselves. They just can’t shut us down because they think they damned well got the right to do that.

Person with dementia 2: Well, they’re more severe on you because you have dementia, you know.

A health service provider described how many actions and behaviours by people living with dementia became viewed through the lens of dementia:

For the person living with dementia, because everything that they do now – every time they don’t remember something or if they do something, maybe they misplace something – it’s going to be blamed on that, right? Whereas people often do things like that and not have dementia. So everything starts to be viewed through that lens, you know, with the diagnosis.

A care partner described a difficult situation she had experienced when she first starting sharing the news that her husband was diagnosed with dementia:

I think that one of the difficult things is when you share with other people about the fact that there is a case of dementia and some of the reactions, although the first one that I encountered was just so unexpected that I just – it just blew me....I walked into our church foyer ahead of our Christmas banquet last year and this woman charges towards me and then she says, “Oh, I’m so sorry to have heard the news”. And then she said to the woman beside her, “Have you heard the horrible news?” And you know, the place was just packed with people. I thought, my God. “Is he hard to live with?” You know, right in a crowd of people and I burst into tears and turned away...

Part of the stigma of dementia is the negative jokes and laughter about dementia, as described by one care partner: “...you’re more apt to hear negative things about it and jokes and stuff like that in the public than you are positive things about Alzheimer’s. How many times do you hear a joke? People are telling jokes about it – like Alzheimer’s and its related to stuff like that.” Another care partner replied, “I think in some ways they mean to be just comical about it to be light, but not realizing it can be hurtful too...” In addition to hurtful jokes, the language that people use can contribute to stigma as described by a person living with dementia:



Challenging stigma was described as a “lane ending” road sign, indicating that everyone was on the same road with the same approach to challenging stigma.

But I think that's really important to have that positive outlook, and George – for sure, that's one of the things that I connected with George on, was that positive. I think one of the things is, is that we fall into the trap and this disease sucks us into the trap of other people using words like “suffering” and so on. When people take those words out of their vocabulary, it helps us realize that it is what it is.

Finally, many people living with dementia and care partners are challenging the stigma of dementia in individual conversations, in relationships, in communities, and in the broader public. One person living with dementia describes her conscious decision to become an advocate:

When I was first diagnosed, I couldn't understand why we couldn't say we had dementia as easily as somebody could say they had a broken leg. In my brain, I could not understand why people would react so differently to the word “dementia” and the stigma that was attached to that. And it was that that really – because I made the conscious decision when I decided I was going to go public and be a spokesperson and advocate. These are the things that went through my mind. Okay, that means everybody's going to know I have dementia. Am I prepared to accept the consequences of my decision in telling people? Because I knew then what those consequences were going to be and they were exactly what you guys were talking about. So I knew when I made that decision to go public that I was going to lose friends, family – they would drift away for whatever reason... And that's what I've told myself, but I knew when I made that decision that that would indeed happen; and what it was going to do – it was going to force me to go through it a little quicker than some of my friends did. So mine veered very quickly because I made a very conscious effort to go public and to do media stuff and to do all of those things that put me in the forefront. So I veered very sharply off to the right.

In conclusion, a person living with dementia described how he challenges stigma in his relationships and interactions: “I know I've had that finger pointed at me several times. I'm getting a little bit sick and tired. I get humour about it, yet when somebody tells me I can't do something – when I know in here I know different. I'm not going to back down and give up.”

## 4.0 Caring for Myself



Figure 6 Caring for Myself/Focus on Me

**Caring for myself** and **focusing on me** captured the things that people living with dementia and care partners did to stay well and to care for themselves. This part of the dementia journey included a number of themes:

- Keeping a positive attitude
- Coping with emotions, stress, and anxiety
- Adjusting to a new normal [described in [Changing & Adapting](#)]
- Living for today [described in [Changing & Adapting](#)]
- A changing identity [described in [Changing & Adapting](#)]
- Engaging in meaningful activity
- Finding purpose and meaning

## Keeping a Positive Attitude

Keeping a positive attitude was described as one of the most important things people could do to care for themselves. Although this could be difficult, many people living with dementia and care partners described how they were able to do this. A person living with dementia stated, "I'm enjoying my life the way I have it now." Another person living with dementia stated, "A good day begins with sunshine, really." One person living with dementia described how he felt that having dementia wasn't the worst thing in the world:

I guess – well, put it this way. As you get older, you have to have something wrong with you. And I think that slowly progressive Alzheimer's is one of the better things. You know, I can still be active and whatnot, so physically I'm fine. But there's probably people that would tell you I'm crazy. They've done that for years.

Another person living with dementia described her positive attitude:

Well, you do the best you can. Some days are maybe not as good as others, but I thank God for every day that I wake up. And for the most part, just carry on and do the best you can. It's always nice when someone phones and I talk to them, and we can get out and have a walk and it's not storming or anything like that. There's lots to be thankful for.

Having a sense of humour was very important to keeping a positive attitude. A person living with dementia stated, "I think a big part of this too is keeping a sense of humour to find your way." Another person living with dementia stated, "I think often times you think of your journey that you're in, but you know you look at the negative parts of it a lot of time. But having humour and sense of humour is important."

Care partners also described how they kept a positive attitude and looked at the positive aspects of going through the dementia journey. One care partner described how caring for someone was a positive experience: "And also, it's just caring for somebody can be a very enriching experience and I'm beginning to recognize what mothers must go through when they're raising children." Another care partner stated, "And the important thing now is acceptance and living as good a life as possible. So that's basically what we're doing now." Another care partner stated, "...you have to make the best of what you've got. You can't change it. You just have to deal with what you're dealing with." Finally, care partners also stated how a sense of humour and laughter was very important: "Sometimes you have to laugh, and I think when you laugh, they laugh. We love to laugh, so I think it is kind of funny when you say that."



Keeping a positive attitude was described as a green light, indicating that it helped move people in positive ways along their journey.

## Coping with Emotions, Stress, and Anxiety



The dementia journey was an emotional journey, both for people living with dementia and care partners. Emotions such as sadness, grief, stress, anxiety, and guilt were all common. A person living with dementia stated how groups were important to “vent”: “I would really like to have something going on so you could come out and share and vent, because sometimes you just swallow and you don’t want to say out loud.”

Another person living with dementia stated how grief was a common feeling, both after diagnosis and throughout the journey: “It’s a grief process – anger, frustration – all of those things are part of grieving. Because certainly the life that you thought you would have together – retirement, etc. – it’s obviously not going to be what you thought it was going to be. So you start grieving early.” A health service provider also commented on the grieving process:

Coping with emotions, stress, and anxiety was described as a “do-not-enter” sign to represent that the negative emotions are not a place where people want to go.

I think also for the client and the individual, they start the grieving process knowing that eventually these stages are going to come and how quickly, and they’re going to be losing – to them I think it’s their individuality, their independence, and just the loss of their dignity.

Anger was another common emotion described by people living with dementia and care partners. This anger was directed at the diagnosis and some of the life changes and losses that came along the journey. A care partner described: “I’m not angry at him. I’m just angry at the whole Alzheimer’s thing and that I have to give this up.” Another care partner also described, “You get very angry sometimes and you just have to step back and recognize that it’s okay to be angry and frustrated.” Another care partner stated how she was angry about giving up some of her meaningful activities:

Well, I’m angry because I have to give up my volunteer work. And my situation is different. I’m not a professional person. I’ve just a regular, average – I didn’t go to college or university. Married young. [my husband] didn’t want me to work. I mean, I did have a job before we got married, but he wanted me to quit that. Had children. Stayed home with the kids. Oh yeah, but it’s not satisfying. Looking after the kids was fine, but housework doesn’t do a thing for me.

One care partner described the challenge between anger and acceptance:

I personally would describe it in my case, and it’s probably commonplace, alternating between rage and acceptance. Intellectually I know I have to accept this and on many days I can accept it. And we have lots and lots of good days. And then all of a sudden I’ll just have an attack. I mean I can only describe it as some kind of – something comes down and grabs me by the throat and turns me into this harridan because obviously the acceptance isn’t perfect. And not only

that, because it's a moving target – I'm messing up my metaphors – but anyway, you accept this and you think, okay – yeah, I can handle that. Yeah, I'm doing a real good job and he's happy – and then some different thing will happen and it's like. Because the person who has dementia changes and declines, the acceptance seems to be never perfect. When you can reach it, it's wonderful. But I also seem to lose it, partly because of change. I don't know, because I'm in a bad mood or didn't get enough sleep. I don't know. If I could figure out what that was it would be great because then I could see it coming and I could inhale some lavender or something.

Guilt was also a common emotion described by care partners. A care partner stated, "...guilt comes up. There's always a new outfit for guilt to wear. It'll show up... If you're working too hard, you feel guilty about that. If you're not working enough, you feel guilty about that. There is just always something."

Coping with these emotions was described through relationships, circles of support (see Building Circles of Support in Relationships & Community), meaningful activity (see next section on Engaging in Meaningful Activity), and finding purpose and meaning (see section on Finding Purpose and Meaning).

## Engaging in Meaningful Activity



Engaging in meaningful activity was described as being important for both people living with dementia and care partners. Continuing to engage in activities that have always been meaningful was very important for people, but also participating in new activities was important. One of the dangers of activity is people living with dementia and care partners disengaging from social circles and activities as they attempt to hide the diagnosis and condition as described by a care partner:

A lot of what I hear too – kind of like in the beginning to middle – is embarrassment. I've heard a lot from patients that say, "I used to go play cards, but I can't remember where we're at in that activity" so they withdraw socially. And I think basically that's a pretty early sign is, early to slowly progressing, and they withdraw socially a lot because of embarrassment.

Engaging in meaningful activity was described as a two-way street. Although the dementia journey had negative aspects, engaging in meaningful activity supports people to continue the dementia journey in positive ways.

A care partner described how he and others started a social club for couples who have partners living with dementia, and how this social support and activity was important:

But I think – and [other care partner] might agree with me on this – one of the best things we have done in the past two years since we've known each other is, we've started a social club and it is for couples that have a partner with dementia. And we might twice a month and we just have a good time and we are under the Alzheimer's umbrella, but we do our own thing. And we sometimes have guest speakers. We have potlucks and everybody who comes loves it. We have a great time. That's what I need to do is, I need to be going forward myself. I'm like a bulldozer in a sense, but I have to do positive things. I cannot sit back and worry about what's coming because we don't know. And so we try to fill our time with positive things and try to find joy in each day. That's what we try to do.

A care partner described how she kept her partner active and participated in activities together:

Well, I keep [my husband] active. You know, I get him to the seniors' centre. Then we go bowling. Then we have a singing group on Thursday nights. Then on Saturday we play cards with another couple. But they're people. They're acquaintances, but they're not friends. But I keep him active.

A person living with dementia also described the things that she continued to participate in: "I continue on with all the things I used to do. I play bridge and cook all the meals and handle all the finances and so on, as I always have done. But I don't remember as well as I used to. And I still have my friends and whatnot." Another person living with

dementia described the activities that he continues to participate in that give his life meaning:

Saddling up, getting on – especially if I'm riding Taffy [horse]. She's the last of our babies. She's 13 now, but she's the last one that I have that was born at our place that I've still retained. The others are the groom mares. But to be able to go and ride and show a horse that you've bred and trained – yeah, that was fantastic to me. And music – I have nothing more fun than going out and playing with the band. But to me, it's riding, or even if I'm not riding, just working with the horses.

A care partner gave this piece of advice:

A good message is exactly that, and letting go of that fear. Because I think the fear of what you hear and knowing – like knowledge is power, but at the same time when you hear about it, it's also – it can be overwhelming and it's like – okay, but then here you are. It sounds horrible. It sounds fearful, but if you can slowly let go of that and think positive and, like you're saying, try to live life – really do the things you love.

## Finding Purpose and Meaning



People living with dementia and care partners described how they found purpose and meaning in life, not only *despite* a diagnosis of dementia, but sometimes *because* of a diagnosis of dementia. One person living with dementia who stopped working upon diagnosis described how he and his wife focused on the farm and raising and showing horses over the time he had been diagnosed. For him, purpose and meaning was found in the daily activity of the farm and care of the horses.

And we have slowed the farm operation down over the period of 15 years. But the horses, to me, have just been a savior in that I have something to do every day. I get up in the morning with a purpose to do it and I think the horses have been a key factor. So that's basically my story up until now.

Finding purpose and meaning in the dementia journey was described by an airplane sign, indicating that purpose and meaning give people a different way to travel through the dementia journey.

Another person living with dementia talked about the need for advocacy and for people living with dementia to talk publicly about their diagnoses. For many people living with dementia, advocacy and challenging stigma has become their purpose and meaning in life.

We've just been talking about that lately – what is it that's going to get the government to start to lighten up their purse strings and it's the squeaky wheel, and the squeaky wheel has to be the face of dementia. And that's how AIDS got it, when all of a sudden they skyrocketed in the funding and it's because all of a sudden it became very high profile and there were lots of faces to it. And that's the same thing that we have to do with Alzheimer's to get the funding we need.

For care partners, many of them described the new meaning they found in relationships with the person living with dementia and others in their families. The following quotes by care partners illustrate this:

It's a wonderful gift to be able to be here with my parents and my sister because I was away for so long from my family too. I just wish the circumstances sometimes were different, right?

So in that respect, it is enriching in that you're caring for somebody else in a way that you thought you never could, from my point of view.

I'm closer to her. She's funny. She's a sweet, loving person.

The other thing too, that I just want to say, is we have these glimmers in our life that are absolutely wonderful. We got quite a nice cheque from the government for our income tax. We each got one. So [my husband] comes to me after a day

or so. He says, “You know, I’m going to let you have that money”, he says to me. “You work so hard. You deserve it. You spend it any way you want”. Well, I mean it was already in the bank and already done with, but just that he came out and said, “You spend that. I don’t want that.”

I’m caring for my wife and we’ve been married 10 years. We were both widowed and she’s a rather remarkable person – very remarkable. Before I got married to her, she got a medal from the Queen for charitable work; and she and her friends would go to boarding houses that were basically at that time warehouses for people who were just warehoused who had emotional and mental problems. And the situation has changed dramatically, mainly through the work of her friends; and she’s built quite a network of people, for which I’m really grateful... But what’s really interesting, first of all, she’s very loving. She does recognize me and she recognizes her friends and family. She can’t talk anymore. Over the past year she’s really had a decline – quite a decline... But now my world is enriched... So in that respect, it is enriching in that you’re caring for somebody else in a way that you thought you never could, from my point of view.

Finally, care partners and people living with dementia described accomplishing things, whether it be developing patience, caring for someone, or speaking publicly and advocating, that they never thought they would have ever been able to accomplish. A care partner described, “It’s amazing what you can do when you have to.”

## Reflections

Mapping out the dementia journey was an interesting exercise, particularly engaging people living with dementia and their care partners. Clearly, from the feedback from people who have viewed the visual depictions of the dementia journey, the journey is diverse, and an attempt to map out the dementia journey in a way that will capture the common experience is an exercise in futility. However, the key elements captured here were common themes among the people living with dementia, care partners, and health and social care providers with whom we spoke. Using artistic and visual methods to describe the dementia journey provides opportunities to present the complexity, interconnectivity, diversity, and multidimensionality of the dementia journey, and to enable the users to choose the aspects of the dementia journey that fit with their experiences, rather than providing a prescriptive journey.

In our attempt to capture the key elements of the dementia journey, there are inevitably aspects that we have missed. Part of this will be resolved as we hopefully continue to gather data and explore more people's experiences of the dementia journey. In particular, as future work will hopefully engage different cultural and diverse groups, we can ensure the representation of the dementia journey captures key elements of these experiences as well.

A final comment is worth noting on the representation of the dementia journey. A number of different possibilities were explored for how to represent the dementia journey. Initially, the dementia journey was represented through a road pictorial, with road signs demonstrating the key elements along the road. After bringing this to a meeting with people living with dementia, care partners, and health and social care providers and obtaining feedback and comments on the maps, it became clear that further work needed to be done and that the road map analogy may not be the best analogy. The research team then decided to represent the journey as a subway map, with the key elements represented on a subway map. The key elements represented subway stations, where people can get on or off, and can exit to the road level, where road signs and a road can then represent the journey. In addition, upon exiting the subway, one can choose how to travel—by taxi, by bus, by car. At each stop, the station and the roads will look different. Providing a journey analogy that captures the multidimensionality of the dementia journey is key. This journey map represents the experiences of people living with dementia and care partners, sometimes often very diverse experiences. While there are likely other ways to map out the dementia journey, we feel that the way we have chosen to map it out captures the complexity, interconnectivity, diversity, and multidimensionality of the journey.

## **Future Directions**

From this initial pilot project, there are a number of different areas to focus on. These will be grouped into the following areas: future research, practice implications, and policy implications.

### **Future Research Directions**

Given that this research involved a very small sample of people living with dementia and care partners from relatively homogeneous groups, future research needs to gain wider perspectives on the dementia journey. Conducting more mapping exercises to ensure that the journey as we have envisioned it reflects people's experiences will be important. This should be done in two ways: 1) conducting more mapping exercises with people living with dementia and care partners; and 2) conducting feedback focus groups on the maps already created.

In addition to conducting more focus groups, an effort should also be made to conduct focus groups with diverse groups. Ontario is a very multicultural province, and efforts should be made to include different cultural groups to ensure that the journey map reflects their experiences as well. In addition, other diverse groups should be considered. Understanding that family structures don't necessarily reflect the traditional nuclear family, gaining insight into the experiences of diverse families will also be important.

One area that we didn't have an opportunity to explore in-depth due to time constraints and difficulties finding participants is the experiences of later care partners—those people who are caring for someone later in the journey at home or in long-term care. These experiences will be important also to capture more in-depth. While we had some later care partners participate in the focus groups, exploring the experiences of this group more in-depth will also be an important contribution to the journey maps.

In addition, exploring the perspectives of more people living with dementia will be important to ensuring that we create a robust journey map that captures different experiences. As such, making more of an effort to include people living with dementia in the focus groups is important.

Exploring more of the system journey is also something that may be helpful to further explore. Many of the Local Health Integration Networks [LHINs] have done this work already through their own exercises. Finding some way to integrate some of this work into the website and the dementia journey may be helpful.

From a more artistic perspective, the subway map is clearly laid out. However, each station (or theme), and what the roads look like "above ground" should be added to. This would be captured by continued feedback and insight if additional focus groups were held.

### **Practice Implications**

There are a number of practice implications from this journey map. These practice implications will be presented from specific to general recommendations. First, a website needs to be created that represents the journey map. While there is a

template website currently created ([www.thedementiajourney.weebly.com](http://www.thedementiajourney.weebly.com)) , it is a basic website. A website that is more interactive and user-friendly is necessary for the information to be presented to the general public. Part of the design of the website should include feedback on specific elements, such as the colours, how the content is presented, the usability of the website, and a number of other design elements. Again, this can be achieved through focus groups and feedback once a draft is created.

An additional feature of the website should include videos of people living with dementia and care partners at each of the key themes along the subway map. Videos ensures that people using the website can connect to the personal stories of individuals. Videos including both the stories of people living with dementia and care partners will ensure that both people living with dementia and care partners connect with the information. It also provides an additional mode of delivery of information. Using videos, pictures, colours, graphics, as well as text will be important features of a usable website for people living with dementia.

In addition, supports and resources for each of the themes along the dementia journey will be needed. This information should be included on the website. As such, having someone to find these resources and group them according to the themes will be important. This enables users of the website to explore further information if they so wish. In addition, it will ensure that materials that have already been created are being used, rather than “reinventing the wheel”, so to speak.

Further need to identify local resources and local system journeys has been identified in the face-to-face meeting in November 2014 as well as in other conversations with care partners, people living with dementia, and service providers. This overall map can be used by local groups (i.e., Alzheimer Societies, Dementia Networks, LHINs) to map out their resources in their own communities.

### **Policy Implications**

The dementia journey map can provide an important direction for policies. Identifying where services and supports are available, and where they are missing, can help to identify future policy decision, both from local Alzheimer Societies, provincial Alzheimer Societies, health care service providers, and government. This dementia journey map can also be used as a community mapping exercise which can then be used for advocacy.

How this dementia journey map is used will also be important considerations as websites may be developed, findings are presented and disseminated, and future work is contemplated. Having a clear vision of the use of these maps and the intended audience(s) will be the key to building future work.

## **Conclusions**

This project, “Mapping the Dementia Journey”, has provided a wealth of rich and detailed data, stories, and information about people’s experiences along the dementia journey. Clearly, this is the start of a much larger project which has great potential for further research and practice. Using innovative visual and arts-based methods can provide greater understanding of the dementia journey from the experiences of those travelling this journey. It is our hope that this beginning can form a firm foundation to create important resources and tools to support and assist people during their journeys through dementia.

**Contact Information:**

Dr. Elaine C. Wiersma  
Centre for Education and Research on Aging & Health  
Lakehead University  
955 Oliver Road  
Thunder Bay, Ontario  
CANADA  
P7B 5E1  
(807) 766-7250  
[ewiersma@lakeheadu.ca](mailto:ewiersma@lakeheadu.ca)

Dr. Pauline Sameshima  
Centre for Education and Research on Aging & Health  
Lakehead University  
955 Oliver Road  
Thunder Bay, Ontario  
CANADA  
P7B 5E1  
[psameshi@lakeheadu.ca](mailto:psameshi@lakeheadu.ca)

Dr. Sherry Dupuis  
Partnerships in Dementia Care Alliance  
University of Waterloo  
200 University Ave. W.  
Waterloo, Ontario  
CANADA  
N2L 3G1  
[sldupuis@uwaterloo.ca](mailto:sldupuis@uwaterloo.ca)

Alzheimer Society of Ontario  
20 Eglinton Ave. W., 16<sup>th</sup> floor  
Toronto, ON M4R 1K8  
Tel: 416-967-5900  
Toll-free: 1-800-879-4226 (in Ontario only)