

A resource guide informing practice involving people living with dementia and their care partners

# Mapping the Dementia Journey

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## Introduction

This resource guide has been developed from the results of the *Mapping the Dementia Journey* project as a tool to ensure that programs for people living with dementia and care partners are informed by lived experience. The *Mapping the Dementia Journey* project involved the Alzheimer Society of Ontario in partnership with researchers from the Centre for Education and Research on Aging and Health, Lakehead University, and the University of Waterloo, working with participants - people living with dementia, care partners, and health service providers - to construct a visual representation of their dementia journey, a map (Figure 1).



Figure 1. Dementia Journey Subway Map



An advisory group, consisting of people living with dementia, care partners, academic experts in the field, and program facilitators of the Alzheimer Society of Thunder Bay, reviewed the report and provided feedback to inform this tool. This resource guide is intended to serve as a reference tool for facilitators, providing them with information regarding key milestones identified by people living with dementia and care partners, discussion questions, and suggested resources so that they can provide more informed services and be more accountable to their clients.

This tool has been categorized into 4 main categories, based on the themes inductively gathered from the Mapping the Dementia Journey Final Report:

- The System Journey
- Changing & Adapting
- Relationships & Community
- Focusing on Me

Each category has been broken down into smaller, related subcategories. Just as each main theme will have a description explaining the theme, each of the subcategories will have a summary of the experiences and perspectives of those found in the Mapping the Dementia Journey Final Report, followed by discussion questions, and suggested resources related to the topics presented.

It is important to be aware that there is no defined, chronological order to the dementia journey themes. The themes are arranged in this manner purely for organizational purposes. As reflected in the dementia journey map, the dementia journey is complex and multidimensional, with thematic paths interacting and intersecting at various points. The dementia journey is an ever changing one, and there are individual differences with respect to how people living with dementia will experience the various key milestones.

Remember that “every single person is different” (person living with dementia), people will experience things differently and communication across the journey is integral. Take the time to ask lots of questions, and seek out and use helpful resources.

## The System Journey



The System Journey pathway describes key interactions with the health care and social service systems as people living with dementia and care partners move along the dementia journey. This includes interactions with the medical and long-term care system, government legislation, and other support services. This chapter covers 11 sub themes that will be divided more manageably into two sections, one focusing on testing, assessment, and diagnosis, and another focusing on connecting with services.

### Testing, Assessment and Diagnosis

The first half of the system journey encompasses several sub themes related to the system interactions involved with the diagnosis of dementia. This section covers Testing and Assessment, Diagnosis, Finding Out More, Navigating the System, and Planning Ahead.

**Testing and assessment.** The testing and assessment process varies between individuals. What led to seeking out the initial testing and assessment varied; some people noticed changes in themselves, others were encouraged to be tested by family members. In most cases, both the care partner and the person living with dementia were aware that something was “not quite right”, and testing and assessment was needed. It is important to remember that the testing and assessment period is ongoing, not just leading up to diagnosis. The testing and assessment process continues throughout the dementia journey and the experiences with it are ever changing.

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**Diagnosis.** Experiences receiving the diagnosis also vary between individuals. Many participants thought that a diagnosis meant they would experience immediate decline in cognition and were initially unaware that many people can live well with a diagnosis for years. Some found it to be a relief, that being diagnosed validated the changes they were experiencing. Some were surprised with their diagnosis, while others had some inclination that they were experiencing dementia-related changes. Younger people were more often surprised by their diagnosis than older people. For some, diagnosis was a “critical point” marking the beginning of their dementia journey, but others mentioned experiencing dementia with other relatives or friends. How the diagnosis was presented to them varied between individuals and impacted their feelings about starting their journey with dementia. While some individuals received medications, not all people living with dementia take medications or react well to them.

*Tip from people living with dementia: The testing and assessment period can be difficult and intimidating, especially when there are more health service providers than persons with dementia in any single consultation. Be aware of how this affects the power dynamic in the room, and change it to suit the needs and comfort of the person living with dementia.*

**Finding out more.** Having varying levels of information provided to them at time of diagnosis, individuals often sought out information on their own and found themselves reaching out to local Alzheimer Societies whether by recommendation or self-inspired. Whether it be from the internet, books, or speaking to others about it, there was an undeniable need for information, awareness, and education stressed by all people involved, including the person living with dementia, the care partner(s), family members, friends, community members, and health service providers. When it came to information, education, and support groups, the Alzheimer Societies were described as providing the most helpful services by all who had connected with them.

**Planning ahead.** Many participants recognized the importance of planning ahead because they felt that there was no opportunity to go back after their diagnosis, that this journey was travelling in one direction - forward. Oftentimes, a diagnosis was accompanied by an encouragement to plan ahead and get one’s affairs in order. This related to finances, funeral arrangements, and wills, but also preparing for the changing physical and support needs of the person living with dementia. Care partners and people living with dementia stressed the importance of including the person living with dementia in planning discussions.

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**Navigating the system.** Navigating the health and social care system and locating the information and resources available was difficult. It was particularly challenging for individuals to know what to do, who to contact and how to do so, when they encountered a crisis where a person living with dementia was suddenly unable to stay home. As all communities are different, there is no one defined pathway for accessing health and social care services, and the progression and experiences along the dementia journey differ between individuals. The opportunity for a system navigator exists, but until this role is filled the advisory group encouraged people living with dementia and their care partners to be advocates for themselves, to be assertive, and to ask as many questions as they need.

### **Connecting with Services**

This second half of the system journey focuses on those sub themes that relate to the services that are required as it progresses further along their journey with dementia. This section includes the subthemes: Giving Up Driving, Navigating the System, Staying at Home, Alternative Living Arrangements, and Palliative Care.

**Giving up driving.** Giving up driving was expressed as one of the toughest challenges that people living with dementia, and their care partners, had to face. Being forced to stop driving was a devastating experience for the person living with dementia and it often led to a care partner having to take on primary driving roles that they may not have had before. Losing their license incited fear in those who had not yet reached the milestone, particularly because of the foreseen effect this event would have on their independence. Many mentioned feeling like they had gone their whole lives driving, so alternative transportation and particularly public transportation was an unfamiliar concept to them.

**Staying at home.** Many people living with dementia and care partners describe staying at home and being supported in their own homes as being important to them. Staying in a recognizable home environment limited confusion and provided comfort to the person living with dementia. For some, being able to stay at home with their loved one meant adapting their home and routine to be more accommodating of impending dementia-related changes. Particular difficulty arose when the care partner found it unsafe to leave the person living with dementia at home alone. Although difficult to do,



recognizing and accepting help was described as an important part of staying at home, both for care partners and people living with dementia.

**Alternative living arrangements.** Alternative living arrangements included apartments, assisted living, retirement homes, and long term care homes. The transition to alternative living arrangements was often prompted by physical or cognitive changes that required more intensive support services than the family or care partner felt they could provide. These transitions were sometimes gradual and planned, but other times were sudden and triggered by a crisis. This transition was not always negative, it provided the person living with dementia with an environment that was more supportive of their needs. Not every person living with dementia requires alternative living arrangements, this transition is defined based on the circumstances surrounding individual capacities and experiences. That being said, it was common to feel the need to use as many services and supports that you could so as to avoid long term care as much as possible.

**Palliative care.** Many people recognized the value of good quality palliative care for the end of life. Providing the person living with dementia good quality care through to the end of their journeys was important, so that they were treated with the dignity and respect they deserved through to the end of their lives.

*Tip from people living with dementia and care partners: “Even when they are accompanied by a care partner, ensure to direct questions for the person living with dementia, to the person living with dementia. Make sure the person living with dementia is involved in the decisions that affect their lives”*



## Discussion Questions:

What was the testing and assessment process like for you? Was it always that way? Has it changed?

How do you feel about accompaniment to your testing and assessments? Would you prefer a close friend or family member accompany you? Would you prefer to do these assessments alone?

What brought you to the Alzheimer Society (or other program)? What are you looking to get out of your experience with us?

What can you do to facilitate an environment where people living with dementia can learn from the experience and advice of others? How can advice like 'get tested as early as you can' be conveyed to the population?

What was your first experience with dementia? Did you know anyone with dementia before your own diagnosis? How was that experience different from or similar to yours?

What does your particular diagnosis actually mean? What does it mean to you? Do you feel you understand your diagnosis sufficiently?

How did you begin to find out more information about dementia? What resources were the most helpful to you? Which resources were the least helpful? Was the information easily accessible? What types of information or resources would you like to see more of?

What does having a diagnosis of dementia mean to an individual? What implications does it have on your life? Did it always feel that way? Have your feelings about your diagnosis changed?

What do you know about your diagnosis? What more would you like to know? Who would you most appreciate hearing this from? How can I make this happen?

Do you feel that you have access to the services you need on your journey? Could it be improved? What types of services or supports are you missing?

What is important to you? What are your needs? How have you begun planning now to make sure those needs are known and supported in the future?

Do you know what types of health and social services and supports are available to people living with dementia and care partners? What are your preferences for health and support services?

How would losing your driver's license impact your life? What supports, services, or adaptations can be made to ease the transition to not driving? Do you feel that there are sufficient services and supports in your community to facilitate your transportation needs?

What are your opinions on alternative living arrangements?

What are you doing to ensure that the person living with dementia is being consulted about the adaptations and changes that are affecting them, that their wishes are being met?

### **Suggested Resources:**

- **Living with Alzheimer's: Taking Action Workbook - Understand AD and memory loss; Partnering with your Doctor; Making Decisions; Legal & Financial Issues**
  - [https://www.alz.org/i-have-alz/downloads/lwa\\_pwd\\_taking\\_action\\_workbook.pdf](https://www.alz.org/i-have-alz/downloads/lwa_pwd_taking_action_workbook.pdf)
- **Living Safely**
  - <https://uwaterloo.ca/murray-alzheimer-research-and-education-program/education-and-knowledge-translation/products-education-tools/by-us-for-us-guides/living-safely>
- **Planning for the Future**
  - [http://www.alzheimer.ca/~ /media/Files/national/shared-experiences/shared\\_experiences\\_section6\\_planning\\_e.pdf](http://www.alzheimer.ca/~ /media/Files/national/shared-experiences/shared_experiences_section6_planning_e.pdf)
- **Dementia and End-of-Life Care (Palliative and advanced care planning)**
  - [http://www.alzheimer.ca/on/~ /media/Files/national/End-of-life-care/EoL\\_Part\\_I\\_e.pdf](http://www.alzheimer.ca/on/~ /media/Files/national/End-of-life-care/EoL_Part_I_e.pdf)
- **Communication Strategies: Ways to Maximize Success When Communication with a Person with Dementia**
  - [http://brainxchange.ca/Public/Files/Events/National/CDRAKE\\_CommunicationStrategies\\_Danylyshen-Laycock\\_.aspx](http://brainxchange.ca/Public/Files/Events/National/CDRAKE_CommunicationStrategies_Danylyshen-Laycock_.aspx)
- **Communication**
  - [http://www.alzheimer.ca/on/~ /media/Files/national/brochures-day-to-day/day\\_to\\_day\\_communications\\_e.pdf](http://www.alzheimer.ca/on/~ /media/Files/national/brochures-day-to-day/day_to_day_communications_e.pdf)
- **Driving (Alzheimer's Australia)**
  - [https://www.fightdementia.org.au/files/helpsheets/Helpsheet-CaringForSomeone07-Driving\\_english.pdf](https://www.fightdementia.org.au/files/helpsheets/Helpsheet-CaringForSomeone07-Driving_english.pdf)
- **Integrated Model of Dementia Care (System Navigation; Coordinated Pathways of Support; System Integration)**
  - [http://www.champlainhealthline.ca/healthlibrary\\_docs/IntegratedModelOfDementiaCare.pdf](http://www.champlainhealthline.ca/healthlibrary_docs/IntegratedModelOfDementiaCare.pdf)

## Changing & Adapting



The Changing & Adapting thematic pathway describes the various changes that people living with dementia and care partners go through as they move along their dementia journey and how they tend to go about adapting to those changes. This chapter encompasses eight sub themes that have been organized into two sections: Changes Along the Journey and Adapting to Change.

### Changes Along the Journey

The first half of the changing and adapting pathway covers several sub themes related to the experiences of change that led to the diagnosis of dementia. This section will cover Crystallizing Moments of Awareness, Catalyst, and Responding to a Diagnosis.

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**Crystallizing moments of awareness.** Individuals often mentioned experiencing crystallizing moments of awareness when they were experiencing signs and symptoms, but were not yet relating them to dementia. These moments were thought to be the result of a variety of factors such as personality, age, stress, medication, or other physical/mental health issues. These moments were sometimes noticed by the person living with dementia themselves, but were more often noticed by care partners. When they began to occur more frequently, these moments of awareness began to ‘crystallize’, implying that what they were experiencing was not normal cognitive function. Some of these crystallizing moments included forgetting words/names, losing things, not recognizing items in front of them, and mood or behaviour changes.

*Tip from people living with dementia and care partners: “You’re not looking correctly if your only focus is on memory loss”*

**Catalyst.** A catalyst was the person, incident, or repetitive incidents that inspired the individual to seek help from a health service provider. Care partners play a significant role in noticing the signs and symptoms, their frequency, and repetitiveness, and so they become the catalysts for their loved one to seek help, even scheduling the appointment for them in some cases. Once these signs and symptoms began affecting their lives more profoundly - affecting interactions with family members, difficulty completing tasks that were once innate - individuals were often encouraged to seek out help.

**Responding to a diagnosis.** Responding to a diagnosis was an ongoing experience that varied between individuals. For some, a diagnosis validated their concerns about the changes they were experiencing. For others, particularly those younger individuals who were diagnosed, were shocked to hear that they had dementia. Many individuals also responded to their diagnosis with fear, sadness, grief, and even anger. It was common for an individual to experience several different emotions when trying to understand and come to terms with their diagnosis. Although it was common for individuals to ‘accept’ their diagnosis, they also mentioned ‘fighting’ it as well.

## **Adapting to Change**

This second half of the changing and adapting focuses on those sub themes that relate to those adaptations and changes that occurred as the dementia journey progressed

further. This section includes the subthemes: Adjusting to a New Normal, Reconstructing the Future, Living for Today, and A Changing Identity.

**Adjusting to a new normal.** The process of adjusting to a new normal is ever-changing and it extends throughout the dementia journey. Individuals described being cautious about the changes to come, but that they were open to adapting. Some of the ‘new normals’ that individuals experienced included changes to clothing/dressing habits, repetition, lack of interest or motivation for things that were once significant, and forgetting where things were placed or that one had eaten.

**Reconstructing the future.** People living with dementia and care partners described their future as being under construction, that the diagnosis had changed what they had envisioned for their future. Some described the importance of accepting that the future will be different from what they had ever expected. While some felt as though they no longer had control over the direction of their lives since the diagnosis, others felt that they were still in control of their future, but that it would just be different from what they had planned. Being aware, open, and willing to adapt to these changes was important so that one could influence his/her future without dwelling on the unchangeable past.

*Tip from people living with dementia and care partners: “The dementia journey is ever-changing, you have to be prepared to adapt to change at any point, because right when you think you have a handle on it, it’s like a GPS...recalculating”*

**Living for today.** With the future unclear and ever changing, it was important for individuals to live for today, to enjoy and embrace the good in each day. Living in the moment and making the best of each day helped individuals live well and continue enjoying the journey of life.

**A changing identity.** People living with dementia and care partners felt that adapting to the dementia journey also led to changes in their identity. Some people living with dementia felt as though others were defining them by their diagnosis, while others felt their own identities changing as their roles and capacities began to change, and they began to recognize their new found limits. By relinquishing and taking on new roles, both the person living with dementia and care partners felt as though that had significantly changed who they were personally. A changing identity was not necessarily a negative

experience, just merely another change, and people continued to find purpose and meaning in life, just in new ways.

**Discussion Questions:**

Before diagnosis, what did you attribute your experiences with signs and symptoms to?

What changes or experiences led you to seek out a health or social service professional with regards to dementia?

How were you informed about your diagnosis with dementia? What could have made this experience more comfortable for you?

Have your feelings about your diagnosis changed in any way since you were first diagnosed with dementia?

Do you feel that you have sufficient support to deal with the changes you encounter on your journey with dementia?

What types of supports and/or services have been the most helpful in responding to the changes associated with your dementia journey? In what ways could they have better served you?

What elements of your identity have stayed the same since your diagnosis with dementia? What elements have changed? How have you coped with those changes?

What are some ways that you have adapted some of your roles or activities to accommodate your 'new normals'?

Have you experienced any role-change since diagnosis? In what ways has this been challenging? In what ways have these experiences been beneficial?

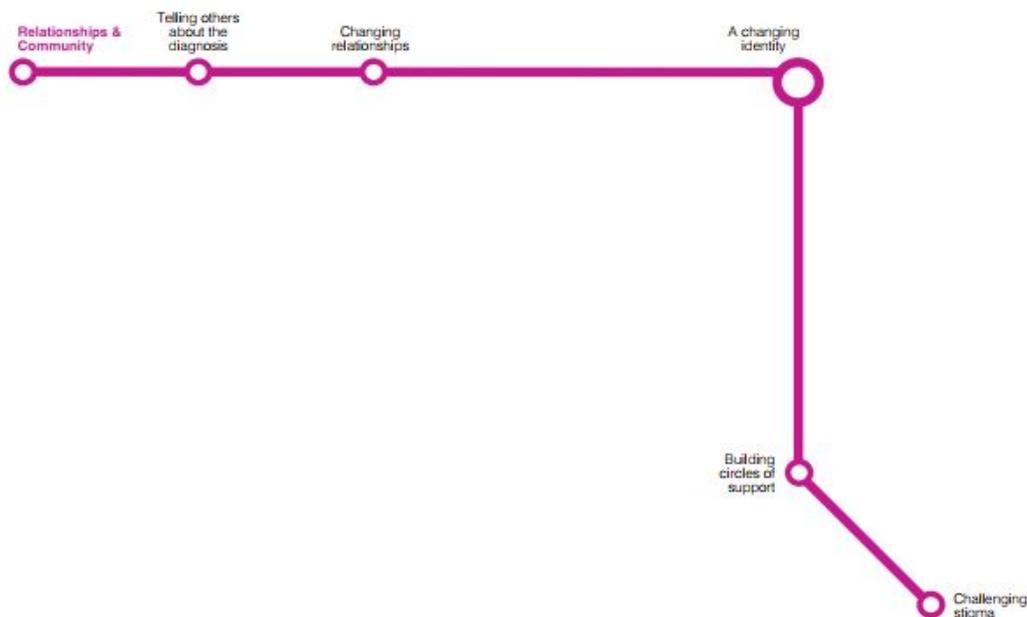
How has your idea about your future changed? Stayed the same? What support would you need to achieve the goals you have for your future?

What advice would you give to someone who is experiencing challenges with the changes/adaptations encountered along the dementia journey?

## Suggested Resources:

- **Before/Early Diagnosis (MAREP By Us For Us Guide)**
  - [https://the-ria.ca/wp-content/uploads/2018/11/BUFU-Guide-Before-Early-Diagnosis\\_AODA.pdf](https://the-ria.ca/wp-content/uploads/2018/11/BUFU-Guide-Before-Early-Diagnosis_AODA.pdf)
- **Food & Mealtime (MAREP By Us For Us Guide)**
  - [https://the-ria.ca/wp-content/uploads/2018/11/BUFU-Guide-Food-and-Mealtime\\_AODA.pdf](https://the-ria.ca/wp-content/uploads/2018/11/BUFU-Guide-Food-and-Mealtime_AODA.pdf)
- **Shared Experiences - Telling People**
  - [http://www.alzheimer.ca/~media/Files/national/shared-experiences/shared\\_experiences\\_section2\\_telling\\_people\\_e.pdf](http://www.alzheimer.ca/~media/Files/national/shared-experiences/shared_experiences_section2_telling_people_e.pdf)
- **Shared Experiences - Changes**
  - [http://www.alzheimer.ca/~media/Files/national/shared-experiences/shared\\_experiences\\_section4\\_changes\\_e.pdf](http://www.alzheimer.ca/~media/Files/national/shared-experiences/shared_experiences_section4_changes_e.pdf)
- **Living with Alzheimer's: Taking Action Workbook - Coping with changes; Daily strategies for living with Alzheimer's**
  - [https://www.alz.org/i-have-alz/downloads/lwa\\_pwd\\_taking\\_action\\_workbook.pdf](https://www.alz.org/i-have-alz/downloads/lwa_pwd_taking_action_workbook.pdf)
- **Dementia & Sensory Challenges**
  - <http://www.lifechangestrust.org.uk/sites/default/files/Leaflet.pdf>
- **Don't Make the Journey Alone**
  - <http://www.alzscot.org/assets/0000/0269/dontmake.pdf>
- **Worried About Your Memory?**
  - [https://www.alzheimers.org.uk/download/downloads/id/339/worried\\_about\\_your\\_memory\\_english\\_version.pdf](https://www.alzheimers.org.uk/download/downloads/id/339/worried_about_your_memory_english_version.pdf)
- **The Dementia Guide (Alzheimer's Society UK)**
  - [https://www.alzheimers.org.uk/download/downloads/id/1881/the\\_dementia\\_guide.pdf](https://www.alzheimers.org.uk/download/downloads/id/1881/the_dementia_guide.pdf)
- **Managing Triggers (MAREP By Us For Us Guide)**
  - [https://the-ria.ca/wp-content/uploads/2018/11/BUFU-Guide-Managing-Triggers\\_AODA.pdf](https://the-ria.ca/wp-content/uploads/2018/11/BUFU-Guide-Managing-Triggers_AODA.pdf)

## Relationships & Community



The Relationships & Community thematic pathway examined the milestones along the dementia journey that involve changes and interaction with others. This theme encompasses five subthemes, but only the following four will be discussed in this chapter, Telling Others About the Diagnosis, Changing Relationships, Building Circles of Support, and Challenging Stigma.

### Relationships

The first half of the relationships & community pathway encompassed sub themes related to the experiences and changing interactions between the person living with dementia and other people in their lives. This section will cover Telling Others About the Diagnosis and Changing Relationships.



**Telling others about the diagnosis.** Experiences with telling others about the diagnosis varied between individuals. While some were comfortable telling everyone they knew, others were concerned about the stigma associated with it and were more selective about who they told, or even chose not to disclose it to anyone at all. Some felt comfortable sharing the diagnosis with close family and friends, but not acquaintances. The decision to share the diagnosis was not a straightforward one for many.

**Changing relationships.** Many individuals described changing relationships as they moved along the dementia journey. Changes in relationship roles often occurred with respect to who was responsible for the finances, household chores, and maintenance duties. Primary driving roles sometimes changed as well. Changing moods, behaviours, communication, and intimacy sometimes put strain on relationships. People living with dementia also expressed concern about reaching the point where they no longer recognized their loved ones. While the changes encountered along the dementia journey posed challenges for relationships, positive experiences also came out of it. Caring for a loved one with dementia was sometimes described as a meaningful experience, where the carer grew closer to the person living with dementia and the person living with dementia became more grateful for the love and support of their families.

*Tip from people living with dementia and care partners: Communication is key. Be sure to be open with your partner, and to not only listen, but to learn from the experiences you go through together*

## **Community**

The second half of the relationships & community pathway describes the interactions between the person living with dementia and the larger community. This section will cover Building Circles of Support and Challenging Stigma.

**Building circles of support.** Along the dementia journey, individuals noticed that while some relationships and friendships faded, others blossomed. Sometimes people living with dementia pulled away from their typical social circle because of issues related to the stigma associated with dementia. Some received immediate support from their families from the moment they heard about the diagnosis, while others stated that the



people they met in support groups and while doing advocacy work became their family. Peer support from people who understood firsthand the complexity of the dementia journey was very beneficial for people living with dementia and care partners. Being able to share and engage with people in a dementia-safe space allowed individuals to feel as though they were not alone on their journey.

**Challenging stigma.** Many people living with dementia are aware of the negative stereotypes and stigma associated with its diagnosis. As one person living with dementia stated, “there is no other disease that excludes the person with the disease more than this one,” that it is much more easily accepted to speak about a physical ailment than a cognitive one. Being aware of the stigma affects how people living with dementia interact with others, particularly when it comes to telling others about the diagnosis. Being an advocate for yourself and challenging stigma was described as important by care partners and people living with dementia. Changing the vocabulary and the way people speak about dementia was described as a way to help remove the stigma and allow people living with dementia to be seen and valued as individuals.

*Tip from people living with dementia and care partners: It is important to find the right balance so that people can be properly educated about dementia without scaring them*



## **Discussion Questions:**

How was the experience of telling others about the diagnosis for you? Was this the same feeling your loved ones had?

Did you experience changes to past relationships when telling others about the diagnosis? How did you cope with this?

How have your roles changed or stayed the same since you began the dementia journey? How have you felt about this experience?

Do you feel safe and comfortable in your community?

Do you think that your community is inclusive of people living with dementia? In what ways do you think that the community could be more inclusive?

How has your circle of support changed since you began your journey with dementia? How has it stayed the same? Do you feel that you have enough support, that you are sufficiently socially connected?

What role does the Alzheimer Society play in facilitating social connection? How could this be changed or improved to better suit your needs?

What are some challenges you have encountered with regards to stigma? How have you reacted to these situations? How do you think this stigma can be reduced?

When it comes to challenging stigma, what do you think needs to be done and who needs to be involved to produce the most change?

What does dementia advocacy mean to you? Do you feel comfortable being an advocate for dementia?

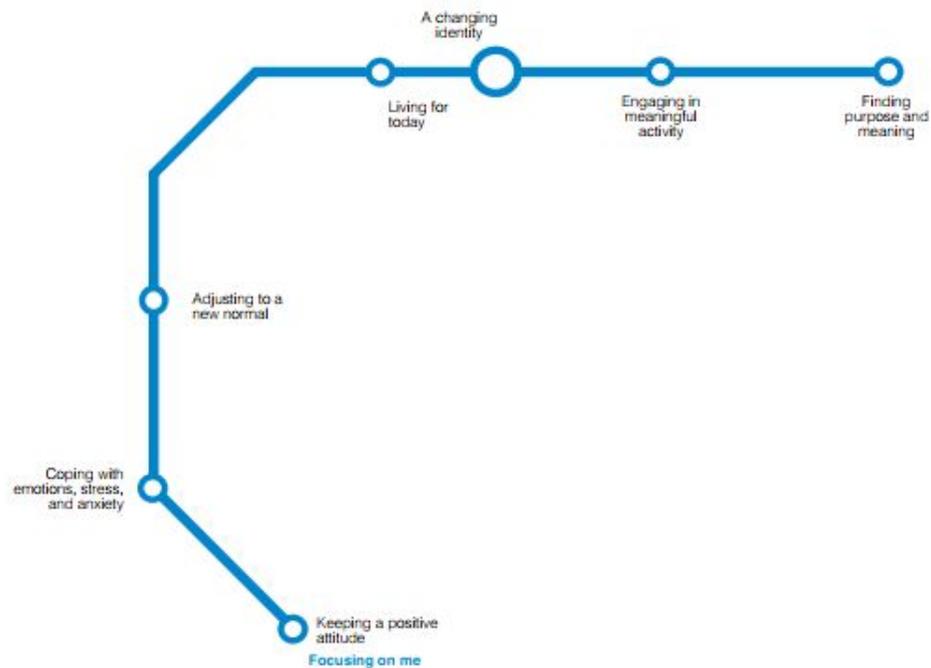
Have you had experience advocating for dementia? Have you been part of any research? Are you aware of the local dementia-related advisory groups and committees? Are you part of any of these groups? What have your experiences been participating in this type of work?

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## Suggested Resources:

- **Enhancing Communication (MAREP By Us For Us Guide)**
  - [https://the-ria.ca/wp-content/uploads/2018/11/BUFU-Guide-Enhancing-Communication\\_AODA.pdf](https://the-ria.ca/wp-content/uploads/2018/11/BUFU-Guide-Enhancing-Communication_AODA.pdf)
- **Role, Health & Wellbeing (MAREP By Us For Us Guide)**
  - [https://the-ria.ca/wp-content/uploads/2018/11/BUFU-Guide-Role-Health-and-Well-Being\\_AODA.pdf](https://the-ria.ca/wp-content/uploads/2018/11/BUFU-Guide-Role-Health-and-Well-Being_AODA.pdf)
- **“I’ll get by with a little help from my friends” (Alzheimer Scotland)**
  - [http://www.alzscot.org/assets/0001/7435/Friends\\_Booklet\\_lo-res.pdf](http://www.alzscot.org/assets/0001/7435/Friends_Booklet_lo-res.pdf)
- **Living with Alzheimer’s: Taking Action Workbook - Caring for our most important relationships: family and friends**
  - [https://www.alz.org/i-have-alz/downloads/lwa\\_pwd\\_taking\\_action\\_workbook.pdf](https://www.alz.org/i-have-alz/downloads/lwa_pwd_taking_action_workbook.pdf)
- **Sex and Intimate Relationships (Alzheimer’s Society UK)**
  - [https://www.alzheimers.org.uk/download/downloads/id/1801/factsheet\\_sex\\_and\\_intimate\\_relationships.pdf](https://www.alzheimers.org.uk/download/downloads/id/1801/factsheet_sex_and_intimate_relationships.pdf)

## Focusing on Me



The Focusing on Me thematic pathway encompasses the actions, interactions, and experiences that people living with dementia engage in for themselves, in order to help themselves live well and enjoy their lives. Focusing on Me encompasses seven subthemes, some of which intersect with other thematic pathways and have been covered in earlier chapters. Only five subthemes will be addressed in this chapter: Keeping a Positive Attitude, Coping with Emotions, Stress, and Anxiety, Engaging in Meaningful Activity, Leaving a Legacy, and Finding Purpose and Meaning.

### Keeping a Positive Attitude

Keeping a positive attitude was described by many people living with dementia and care partners as being important for people to do for themselves as they moved along the



dementia journey. A positive attitude and a sense of humour helped people feel good about their lives and look past the negative. For care partners, looking at the dementia journey positively, as the enriching and fulfilling experience it was, helped with overcoming the obstacles and challenges encountered along the journey. Not getting hung up on the challenges was important and having a positive attitude really helped individuals move forward and continue to enjoy life.

### **Coping with Emotions, Stress, and Anxiety**

The dementia journey is one filled with a variety of emotions, stress, and anxiety, and finding ways to deal and cope with them was very important to people living with dementia and care partners. Feelings of grief, sadness, anger, and frustration were all commonly experienced by individuals moving along the dementia journey. Care partners often expressed feelings of guilt, of wishing they could do more to help their loved one, of wanting to work more for them. Many commented on the value of support groups for coping with emotions, stress, and anxiety as they provided ‘safe’ spaces to vent to people who understood and related to what they were going through. Coping with and managing these emotions often came from building stronger circles of support and keeping active in activities that gave them a sense of purpose and meaning.

### **Engaging in Meaningful Activity**

Participating in activities that were meaningful was important for people living with dementia and care partners. Sometimes individuals felt the need to withdraw from the activities they once loved in an attempt to hide their diagnosis. Others continued to participate in the various leisure activities they had always participated in - like singing, playing cards, travelling, cooking, attending concerts, bowling, and walking. Keeping active and keeping busy whether it was working in the yard, interacting with and caring for pets, or maintaining the home was described as being very important by people living with dementia. For some, the dementia journey turned them on to new activities that they had not engaged in before. Participating in meaningful activities, doing things they enjoyed, and playing an active role in their lives and the lives of their loved ones, gave individuals a sense of purpose and meaning as they moved along the dementia journey.

*Tip from people living with dementia and care partners: Starting the dementia journey does not mean you have to stop doing the activities you enjoyed before. Adapting activities to accommodate the changes one is going through can help them continue doing the things they love. For example, cooking with your loved one instead of always for them.*



## Leaving a Legacy

Leaving a legacy was something that some people living with dementia expressed as being important to them. Some people living with dementia felt inclined to campaign and advocate for the rights and wellbeing of people living with dementia, which was part of how they felt they were leaving a legacy. However, people also mentioned keeping photos, writing in journals, and saving recipes as ways they could leave their legacy behind for their families and close friends.

## Finding Purpose and Meaning

Individuals moving along the dementia journey found purpose and meaning both despite and because of a diagnosis of dementia. Many found meaning by keeping active and engaging in activities they enjoyed. For some, doing advocacy work where they could speak publicly about their dementia journeys or participating in dementia-related research, advisory groups, or committees brought them a sense of purpose and meaning. Care partners often mentioned the deepened relationships they had developed with their loved one and how fulfilling and enriching caring for them was. Accomplishing tasks, whether it was learning something new, providing some contribution, or helping or advocating for yourself or others, gave them a sense of purpose and meaning.

*Tip from people living with dementia and care partners: “Have patience, stay positive, keep your sense of humour and be an advocate”*



### **Discussion Questions:**

Do you feel that you have a positive attitude towards your dementia journey? What challenges do you face trying to keep a positive attitude? How do you overcome these challenges?

In what ways do you think keeping a positive attitude helps you along your dementia journey? Do the people you interact with also share this positive attitude about the dementia journey?

What emotions have you experienced on your journey with dementia? How do you cope with the negative emotions, stress, and anxiety that can arise as you move along the dementia journey? Do you feel that you have sufficient support to help you through the emotional times?

How have you dealt with the emotions that arise from the 'first times', such as the first time the name of a loved one is forgotten? How have these experiences shaped your journey? How have you overcome these challenges?

How has the dementia journey given you a sense of purpose and meaning? How have you sought out purpose and meaning despite a diagnosis with dementia?

What types of activities do you participate in that provide you a sense of purpose and meaning? Do you feel that you have sufficient access to these kinds of activities?

Do you feel that you are sufficiently informed about and have access to enough programs and activities in your community?

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## Suggested Resources:

- Living and Celebrating Life Through Leisure (MAREP By Us For Us Guide)
  - [https://the-ria.ca/wp-content/uploads/2018/11/BUFU-Guide-Living-and-Celebrating-Life-Through-Leisure\\_AODA.pdf](https://the-ria.ca/wp-content/uploads/2018/11/BUFU-Guide-Living-and-Celebrating-Life-Through-Leisure_AODA.pdf)
- Enhancing Wellness (MAREP By Us For Us Guide)
  - [https://the-ria.ca/wp-content/uploads/2018/11/BUFU-Guide-Enhancing-Wellness\\_AODA.pdf](https://the-ria.ca/wp-content/uploads/2018/11/BUFU-Guide-Enhancing-Wellness_AODA.pdf)
- Living and Transforming with Loss and Grief (MAREP By Us For Us Guide)
  - [https://the-ria.ca/wp-content/uploads/2018/11/BUFU-Guide-Living-and-Transforming-with-Loss-and-Grief\\_AODA.pdf](https://the-ria.ca/wp-content/uploads/2018/11/BUFU-Guide-Living-and-Transforming-with-Loss-and-Grief_AODA.pdf)
- Memory Workout (MAREP By Us For Us Guide)
  - [https://the-ria.ca/wp-content/uploads/2018/11/BUFU-Guide-Memory-Workout\\_AODA.pdf](https://the-ria.ca/wp-content/uploads/2018/11/BUFU-Guide-Memory-Workout_AODA.pdf)
- Shared Experiences - Emotions
  - [http://www.alzheimer.ca/~media/Files/national/shared-experiences/shared\\_experiences\\_section1\\_emotions\\_e.pdf](http://www.alzheimer.ca/~media/Files/national/shared-experiences/shared_experiences_section1_emotions_e.pdf)
- Continuing to Care for Myself
  - [http://www.alzheimer.ca/~media/Files/national/shared-experiences/shared\\_experiences\\_section5\\_care\\_e.pdf](http://www.alzheimer.ca/~media/Files/national/shared-experiences/shared_experiences_section5_care_e.pdf)
- All About Me (Workbook)
  - [http://www.alzheimer.ca/~media/Files/national/Core-lit-brochures/all\\_about\\_me\\_booklet\\_e.pdf](http://www.alzheimer.ca/~media/Files/national/Core-lit-brochures/all_about_me_booklet_e.pdf)
- Apathy, Anxiety & Depression
  - [https://www.alzheimers.org.uk/download/downloads/id/1768/factsheet\\_apathy\\_anxiety\\_and\\_depression.pdf](https://www.alzheimers.org.uk/download/downloads/id/1768/factsheet_apathy_anxiety_and_depression.pdf)
- Living with Dementia Magazine
  - [https://www.alzheimers.org.uk/download/downloads/id/3404/februarymarch\\_2017\\_issue\\_of\\_living\\_with\\_dementia.pdf](https://www.alzheimers.org.uk/download/downloads/id/3404/februarymarch_2017_issue_of_living_with_dementia.pdf)

