



Issue #11:

WHEN SOMEONE YOU CARE ABOUT HAS ALZHEIMER'S OR DEMENTIA



When living with Alzheimer's or another form of dementia, either as the person experiencing brain changes, or as someone in the role of caregiver, it's important to try to anchor yourself in the present as much as possible. It can be incredibly difficult to do. Dementia affects language, memory and decision making within the affected person's brain. More broadly, it also takes away from the past, fills the present with stress, and fuels fear of an uncertain future.

Alzheimer's and other forms of dementia are also associated with a complexity of stigmas that may be both self-imposed and cultural.

Actions to better manage life with Alzheimer's or other forms of dementia include:

- Learn more about the characteristics of neurodegenerative diseases (disorders that are characterized by the progressive degeneration of the structure and function of the central nervous system) from trusted resources
- Use information to counter myths, stigma and misinformation perpetuated in our culture
- Acknowledge and accept that you will experience a shift in relationships and lifestyle over time

- Gather strength and support from the community, experts and others in similar situations

As if living with dementia wasn't complicated enough, the addition of the global pandemic has meant that there are strict rules and regulations in place that are intended to protect those deemed most vulnerable. This includes people needing memory care in both Assisted Living and Long-Term Care homes. It's placing new stresses on people living with dementia and their caregivers. In some cases, visiting is restricted, and there are new protocols in place to protect against COVID-19 transmission. People may not have access to homecare supports during the pandemic and have no other option but to visit a hospital for emergency medical treatment. Despite living under the influence of COVID-19 for several months, we're still learning how to navigate care in this new environment. It's important to appreciate the toll it has on everyone involved, as people continue to maneuver and find a more comfortable path that protects everyone's best interests.



What is Alzheimer's and how is it related to dementia?

In 1906, Alois Alzheimer, a German psychiatrist and neuropathologist, first shared symptoms he had been studying for over four years in a 55-year-old patient named Auguste Deter. She had experienced symptoms similar to dementia, including disorientation, loss of memory, unpredictable behaviour and trouble with language. Today, Alzheimer's disease is recognized as the most common form of dementia, contributing to approximately 60 to 70% of cases. It is important to note, however, that not everyone with dementia has Alzheimer's disease.

Dementia is an umbrella term for a group of over 400 slowly progressing, neurodegenerative disorders. Most forms of dementia are fatal. They share common symptoms that affect memories, personalities, emotions, executive functioning, language, judgment, and everyday experiences for close to 50 million people worldwide. Some of the more commonly known forms of dementia include:

- Alzheimer's Disease
- Vascular Dementia
- Mild Cognitive Impairment
- Mixed Dementia
- Frontotemporal Dementia
- Lewy-Body Dementia
- Parkinson's Dementia
- Pick's Disease
- Creutzfeldt-Jakob Disease

In North America, there are currently over 6 million people of all ages living with various forms of dementia. Worldwide, the top 10 countries with the most people living with Alzheimer's are Finland, the United States, Canada, Iceland, Sweden, Switzerland, Norway, Denmark, the Netherlands and Belgium. Countries with the lowest rates include India, Cambodia, Georgia and Singapore.¹

Dementia tends to be more prevalent in people over age 65. Still, there have also been cases of early-onset dementia in people of all ages, including in some very rare instances, children. Dementia also seems to affect more women than men. Dementia is not a normal part of ageing.

While there has been dedicated research to identify the causes and possible treatments, no significant progress or breakthroughs have come. Some limited drug therapy seems to slow progression in some people with some forms of dementia for a time, but there is currently no known treatment that is 100% effective. Each situation has nuances that require individualized approaches to care. The number of people living with dementia is projected to reach 82 million by 2030 and 152 million by 2050.²

Myths about dementia

Since so little is understood about these disorders, it has left the door wide open to many myths. Some say that everyone gets dementia as they get older. Others think that if you experience forgetfulness, you'll develop it. Many people believe that those living with dementia don't understand what's going on around them. Perhaps you have heard that it can be prevented by taking vitamins and eating certain foods. Still, others think that having it means you can no longer travel, work or live actively. The Alzheimer's Society of British Columbia has worked hard to address those myths.³

Myth #1: If I'm diagnosed with Alzheimer's disease, it means my life is over.

Reality: If you or someone you know is diagnosed with the disease, you can live a meaningful and active life for many years. Eating a heart-healthy diet, exercising regularly, staying socially connected and doing things that challenge your brain also help to slow disease progression.

Myth #2: My mother had Alzheimer's disease, so I'm going to get it too.

Reality: Familial dementia accounts for less than 5% of all cases.

Myth #3: Dementia is an old person's disease.

Reality: Dementia is a progressive, degenerative disease of the brain. It most often occurs in people over age 65 but can affect people in their forties and fifties.

Myth #4: Memory loss means Alzheimer's disease.

Reality: Not necessarily. You may experience trouble with your memory as you age. However, if memory loss affects your day-to-day ability to function, communicate or is accompanied by a decrease in judgment or reasoning ability, it's best to see your doctor immediately.

Myth #5: Alzheimer's disease can be prevented.

Reality: No single treatment can prevent Alzheimer's disease or dementia. You can reduce your risk by exercising your mind and body, eating a heart-healthy diet, reducing stress and staying socially active.

Myth #6: There's a cure for dementia.

Reality: Dementia remains incurable. However, seeking an early diagnosis from a health-care provider and connecting to support and educational resources can positively affect a person's experience of the dementia journey.

Living with dementia

Loneliness, experienced by both the caregiver and person living with dementia, can set in as the disease progresses. Changes in relationships with friends and family inevitably shift, and that can be difficult to process. Try your best to accept change.

A lot of the problems arise from the stigmas associated with dementia. A Canadian study conducted in 2017 showed that close to 60% of people living with dementia felt they were often "ignored or dismissed, had difficulty accessing appropriate services and supports," and were frequently at risk of being taken advantage of. Caregivers are affected by stigmas too:

- 1 in 5 agree that they sometimes feel embarrassed to be seen with the person they care for
- 41% believe their life would be better if they weren't caring for the person in need
- 87% wish that more people understood the realities of caring for someone with dementia
- 2/3 find the experience to be isolating⁴

Generally, stigmas are fear-based and caused by a lack of information. Creating a dialogue can sometimes, but not always, help. There are many community-based supports available. Reaching out to your local hospital or chapter of the Alzheimer's Society can provide you with information such as when discussion and support groups meet. Many of these have moved to online formats during COVID-19.

There have been many exciting art-therapy projects established for people living with dementia. Some groups perform theatre pieces about what it's like to live with dementia. Dance therapy and music therapy have also been shown to be very useful in helping people with dementia live fulfilling lives.

There are also important dementia advocacy, research and training organizations working to keep the public well informed.

- In Canada, Dementia Advocacy Canada provides resources. It hosts a wide variety of events for those who want to "influence the programs and policies" that affect people who live with one of the diseases. They publish a compilation of events occurring all across Canada through their biweekly newsletter. You can sign up at dementiacanada.com
- U.S. based Teepa Snow is renowned for her innovative, yet common sense approach to caring for people who live with dementia. She is a highly sought after speaker. Her company, Positive Approach to Care, shares a range of supports. There are full caregiver certifications, monthly Ask Me Anything sessions, and daily webinars to share strategies and demonstrate or model examples for caregivers to try. During COVID-19, all programming is delivered online at teepasnow.com. Some individuals write, blog or vlog about their experiences living with dementia or caring for someone with dementia.
- Janice Swink lives with mixed dementia and advocates for others living with dementia. She uses social media to share her feelings, symptoms, music, dancing and humour.
- Journalist and author, Greg O'Brien, was diagnosed with Early Onset Alzheimer's several years ago. His book, *On Pluto*, provides an interesting perspective of someone who is living well with dementia.
- Canadian performing artist, Jann Arden, cared for her mother who lived with Alzheimer's dementia. She shared her experiences as a daughter and caregiver over the years in beautifully raw and honest detail. After her mother's death, she published a book, *Feeding My Mother*, which spoke about her life as a family member caring for someone living with memory loss.

Caring for someone living with dementia through COVID-19

Of course, the goal is for the caregiver and person living with dementia to live well. Unfortunately, COVID-19 has complicated that significantly. Public health guidelines for reducing virus transmission are not ideal for people living with dementia, especially those who have progressed to later stages of their disease.

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For people who live in their homes, it has meant changes in homecare, increased isolation, loneliness, increased stress, lack of support and changes in format or cancellations of resources such as support groups.

For people who live in Assisted Living or Long Term Care (LTC), it's meant increased confusion and fear of caregivers and family members wearing masks and full Personal Protective Equipment (PPE). The high transmission rates in congregate care settings have also severely affected movement and activity within these centres. Many residents have been confined to their rooms. They have been unable to have regular visits with their friends and family members. While technology such as video calls enable connections, many people living in later stages of dementia can become confused because they could be experiencing a shift in communication preferences. Visual and verbal communications become less effective as the disease progresses. Tactile and non-verbal gestures become the main modes of communication. In some instances, video/online or window visits have created anxiety and increased emotional stress. Similarly, other supportive care ordinarily available in LTC, such as barbers and entertainment, pet or art therapy, have been unable to run because of strict guidelines for reducing transmission of the virus.

There is also a fear among the workforce supporting homecare and facility-based care. Guests and external support workers could bring the virus to the people living with dementia.

COVID-19 has also given society a glimpse of potential improvements when offering person-centred care to people with dementia. The prolonged effect of the quarantine and social distancing measures, have caused rapid progression of some people's illnesses. We have also observed increased incidence rates of depression in people living with dementia and caregivers. Loneliness has given way to loss of purpose and is creating situations where people fail to thrive.

As community care supports and LTC facilities begin to reopen, it's essential to understand the rules and appeal for the best solutions for individuals because dementia does not follow a predictable path for everyone.

Looking for trusted resources?

There is a lot of misinformation about different remedies that can allegedly cure or alter the course of dementia. Avoid these. They can be distracting and damaging.

Stick with credible and trusted resources to provide information that can be discussed with physicians and other care partners. Keep focus on the present and take each day as it comes. There will be good and bad.

It's perhaps most important to be open to help. Always start with the Alzheimer's Society and Alzheimer's Association and where possible, consider support through your EFAP provider. Professionally trained persons and facilities provide a wealth of information and resources nationally and can direct you to additional local supports.

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