

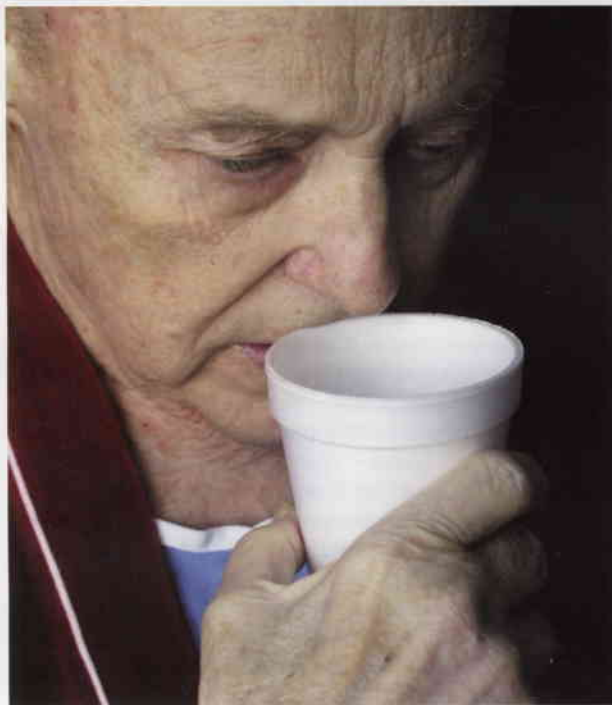
Dementia and Alzheimer's Disease: Listening to people to better understand these disorders

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What is dementia?

The term dementia refers to a chronic, usually progressive, problem of cognition (the mental processes of knowing and understanding thoughts and perceptions about one's environment). This failure of the functions of the brain usually affects memory and almost always affects judgment, decision-making and relationships with others. The rate of failure happens at different speeds and affects different parts of the brain for each person.

Dementia refers to a chronic, usually progressive, problem of cognition



Two things make dementia into a syndrome and not just the memory complaints that most of us have. First, other parts of cognition are affected—usually language, but also attention and concentration, the ability to do simple calculations, or to draw (for example, to draw a clock).

There are many types of dementia, but the most common is Alzheimer's disease. Other types of dementia are diagnosed based on some of their characteristic findings. Because Alzheimer's disease is so common, it is often useful to contrast the other dementias with Alzheimer's disease. Most of the



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other problems seen in these other dementias are also seen in Alzheimer's disease. What happens in the other dementias is that they are seen 'out of order' in comparison to what we see with Alzheimer's disease. For example, many people with Alzheimer's disease eventually have trouble walking, but this is a late sign. When someone with dementia is seen to have a problem with walking early in the course of their illness, that suggests another cause, such as vascular dementia, dementia with Lewy bodies, Parkinson's disease dementia, or some type of frontotemporal dementia.

What is Alzheimer's disease?

Alzheimer's disease is a neurological disorder that affects memory and behaviour and impairs how a person can function. It is characterized by beta-amyloid plaques and neurofibrillary tangles in the brain. There are no known causes, but genetics and lifestyle are thought to play a role. Alzheimer's disease is a problem that primarily affects memory and thinking. Alzheimer's disease used to be called "senility" before it was understood to be a disease. Even today, there are many misconceptions about it, such as the idea that it only affects memory. In fact, Alzheimer's disease affects all aspects of thinking, including a person's ability to function and behave as they usually would have. Although Alzheimer's disease often follows a fairly clear pattern, it is still not known why it starts, or even what does the damage. Because Alzheimer's disease



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has so many effects, it causes a lot of symptoms. The presence of so many symptoms can overwhelm families as they try and cope.

Most people over the age of 65 have annual check ups with their physician; however, unless your family doctor is seeing you on a regular basis, subtle signs of early dementia might not always be evident. It is important that any changes in normal activities, language and personality are discussed with your physician, who can carry out or arrange for further testing.

Although no cure exists for dementia and there is no medication that will stop or reverse its progression, there are treatments that work to improve the quality of life for people living with this disease.

Approved medications, including Ebixa, Reminyl, Aricept and Exelon, can help slow the progression of some symptoms such as those involving memory loss and language difficulties. There are also a number of strategies, such as exercise and vitamin intake, that individuals can use to manage symptoms.

Alzheimer's disease affects a person's ability to learn about what has just happened, what they have just said, or what they have just been told. This results in repetitive questioning about things like appointments, past events or the time of day. The person you care for also may repeat the same story or piece of information in a single conversation. They may become upset or angry when told that they are repeating themselves and their repetition increases with stress and fatigue. The person you care for sometimes may repeat the same single word or phrase over and over.

What is www.dementiaguide.ca?

It has taken over ten years of research to develop an easy to use, informative web enabled method to track symptoms and create a profile that can be used by persons with dementia and their caregivers. This website (www.dementiaguide.ca) makes available to people information on 60 common symptoms of dementia. People affected by dementia can build profiles that I hope will help them to track treatment effects and disease progression. I hope too that the information allows them to speak more knowledgeably to their physicians and to family members, and to show graphs which track the course of the individual symptoms that they select.

The dementiaguide website is based on my experience in asking patients and care partners to set goals for treatment. Often we have done this using a technique called Goal Attainment Scaling¹. With Goal Attainment Scaling patients and care partners first describe their current problems. In Alzheimer's disease, these typically are repetitive questioning, impaired recent memory, less initiative, poor function and impaired social conduct (e.g., withdrawal or being irritable with the grand-kids). For each goal area, they then describe what would count as improvement (both a little improvement and a lot) and what would count as worsening (both a little and a lot). Each person thus has individualized descriptions of each problem, tailored to their 3-6 most relevant issues. Changes on the scale can be summarized to give a score that represents the extent to which that person's goals—whatever they are—have been met.

In the years since, I have helped thousands of people set goals for dementia treatment. A pattern that soon emerged has persisted, including in a controlled clinical trial^{2,3}. Not knowing what "should" happen, patients and their care partners began to describe changes that were not anticipated. They said things like "the fog has cleared" or "my Dad's more like himself". Even today, people commonly describe recovery of initiative, and better insight and better judgment. By understanding these effects and relating them to what we know about how the brain works, we are beginning to have a clearer picture about which parts of the brain are involved, and in which order, in people with Alzheimer's disease. ○

References

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