

UNDERSTANDING DEMENTIA



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What is dementia?

Dementia is an umbrella term that refers to a variety of brain diseases or conditions. It is not a single disease, but a collection of symptoms that can come from different diseases or injuries.^{1,2} All forms of dementia involve physical changes in the brain that effect changes in the thinking process (e.g. memory, thinking, concentration, judgment, problem solving, functioning) and can affect a person’s ability to perform normal daily activities.

Dementia typically occurs in people over the age of 65 and is progressive, meaning the symptoms someone is experiencing will gradually worsen as more brain cells become damaged and eventually die.¹ There are over 100 causes of dementia. Causes may include repeated strokes, drug or alcohol abuse, advanced Parkinson’s disease, and traumatic brain injuries.

Types of dementia

There are four types of dementia, but no matter what the diagnosis is, the experience of each person living with dementia will be different. It is important not to generalize or categorize people based on the type or severity of dementia the individual is experiencing.

Alzheimer’s Disease (AD)	Vascular Dementia (AD)
Most common type of dementia (~64%).	Second leading type of dementia (~20% of cases)
Progressive course (gradual decline over time, more parts of brain will be affected).	Can occur either suddenly, following a stroke, or over time (step-wise progression), as a result of small strokes.
Brain chemistry and structure change (develop plaques and tangles) and brain cells begin to degenerate.	Loss of brain cells because of limited supply of oxygen to the brain.
People living with AD tend to experience difficulty with memory, communication (e.g., word finding), decision making and performing everyday activities.	People living with VD tend to experience difficulty organizing thoughts, actions and planning ahead.
Lewy Body Dementia (LBD)	Frontotemporal Dementia (FTD)
Occurs in ~10% of cases.	Occurs in ~2-5% of cases.
Increased deposits of a protein called “alpha synuclein” (Lewy bodies) inside nerve cells in the brain, which interrupt messages to the brain.	Deterioration in the brain is concentrated in frontal lobe and/or temporal areas of the brain.
Symptoms similar to AD and Parkinson’s disease.	Tends to occur at a younger age than AD, but resembles AD in progression.
People living with LBD tend to experience visual hallucinations, muscle stiffness (rigidity), trembling limbs (arms, legs), and fluctuating abilities (daily, hourly).	May have more difficulty regulating emotions (thus perceived changes in personality and mood), changes in communication and judgment.

(2,3,4)

While dementia may be categorized by type and symptom, the reality is people cannot be categorized by their diagnosis, and responses to the disease may vary from person to person. People have unique life experiences, personalities, routines, social networks, and so on – all of which influence the way a person living with dementia experiences the world around them and their own illness.²

People living with dementia may see the world differently because of sensory changes, having better access to memories from the past than the present, environmental factors or other factors. They may also misperceive things (e.g., mistake a shadow for a person) because they cannot see the object clearly. As the illness progresses, older memories are easier to retrieve than more recent memories.⁵ This means people living with dementia may use past memories to help understand their current world. Because of this, care partners may not fully understand or interpret the person's words, actions or gestures immediately.

Remember, the reality of the person living with dementia is authentic to them even if it differs from what you are experiencing. It is important to respect their reality. This might mean going along with a story they are telling you that seems unreal to you.²

Supporting a person to live well with dementia

The perceptions about dementia are often negative. Negative stigma tends to focus on the illness and reduces people with the disease to a series of labels, symptoms or medical terms. In many cases team members, care partners and even other people living in care settings use these negative approaches unintentionally. It is important to continually reflect on our approaches to care and support, as well as any negative social interactions that may arise.

To support people living with dementia, it is crucial to shift these perceptions into a more positive view. This builds awareness, compassion and the skills necessary to support people living with dementia to live life to the fullest.⁵

For people living with dementia to maintain a sense of well-being, they need to live in a supportive social environment, where they are accepted, respected, have meaningful relationships and are supported to grow.

There are many ways to create a supportive environment:

- Get to know the person and show them respect (e.g., greet the person by name, use eye contact, actively communicate with and listen to the person).
- Connect with the person rather than correcting them. Share a moment with the person even if their reality or perception of the moment is different from yours own.
- Acknowledge the person's emotions and respond with respect and empathy.
- Work with the person, rather than for the person. Support the person to use their abilities and to have a say in decisions.
- Enable and support the person to do what he or she otherwise would not be able to do. Create opportunities for meaning and purpose.
- Go with the flow by adjusting to the person's needs and desires.
- Honour the daily rhythms and life patterns of the person.²

Personal expressions (also known as responsive behaviours)

Communication doesn't just happen using words. In fact, most communication takes place through body language and tone of voice. These methods help us express to others what we are thinking, feeling or experiencing. The way a person communicates using words, actions, gestures and reactions to what others are saying are what we call personal expressions. The personal expressions, or behaviours of someone living with dementia may not be easy to understand at times, especially if their verbal communication is limited. We need to think outside the box to understand what they are trying to convey. Try to figure out what the person is trying to communicate and what may have triggered their personal expression.²

"Every communication has a purpose, the challenge is to discover it. No word or action is meaningless, what sounds like nonsense or repetition of the same question or sentence are, to express a feeling, to show a need, to give information or to get a response. What appears to be an inappropriate response or action may be a form of communication."

- Dr. Jennifer Bute, Retired MD, person living with dementia

Personal expressions may be a response to:

- Unmet needs/challenges to well-being
- Stress, frustration, pain, fatigue, hunger, changes in abilities
- Communicating through body language instead of words
- Physical environment, (e.g. room temperature, loud noise, crowds)
- Social environment (e.g. being tested, quizzed, rushed, ignored, not included in plans)
- Dignity distress (e.g. not given a choice, loss of control)²

Medications

There are no medications proven to prevent, stop or reverse dementia. There are a few that help some people in the early stages of dementia think a little bit more clearly but symptoms of dementia do continue to progress even while on medications and there usually comes a point at which they are no longer helping.⁵

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LIVING the Dementia Journey (LDJ) is an award-winning, evidence-informed training program for those who support people living with dementia. Participants gain awareness and understanding that changes not only the way they view dementia, but the way they support people living with it. LDJ was created by the Murray Alzheimer Research and Education Program in collaboration with people living with dementia and their care partners. For more information about LDJ visit the-ria.ca/resources/living-the-dementia-journey/

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