



# Living Well with Dementia



ESKATON

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# Introduction

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Dementia is not just a biological condition; it is a human experience.

A diagnosis of dementia does not mean the end of living a full and purposeful life. It does mean navigating changes, some of which may be challenging. However, it is possible to live well, be engaged in a fulfilling life, and remain connected to family, friends and community.

Eskaton advocates for people living with dementia and suggests care partners and family members focus on abilities, rather than disabilities. Although cognitive change can be difficult to navigate, a person can live well despite these challenges with the right coping strategies, a supportive environment and informed care partners.

It is also important to understand that the stigma and negative perceptions associated with the word 'dementia' can also influence perception of the lived experience and is often a primary concern of people and their care partners. The way we talk and think about dementia can either impede or empower those individuals living with cognitive change.

Arming yourself with information and knowledge that supports well-being is the first step to changing the way you think about this diagnosis and a critical key to supporting the health and well-being of both the individual and the entire family.

# How To Live Well With Dementia

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## Lived Experience of Dementia - What is dementia?

Eskaton defines dementia as a shift in the way a person experiences the world.

In the most recent update of the DSM (Diagnostics and Statistics Manual), the term “dementia” was replaced by two new classifications: “minor and major neurocognitive disorders,” with types ranging from Alzheimer’s disease to traumatic brain injuries. The decision for the American Psychiatric Association to remove the word “dementia” was made to reduce the stigma attached to the word. Here is a breakdown of the new term “neurocognitive disorder”:

- Neuro means having to do with the brain
- Cognitive is a way of defining the thinking process
- Disorder means functioning in a new or atypical way

When a diagnosis of neurocognitive disorder (NCD) or dementia is given, it is most likely because the person is experiencing cognitive differences.

Dementia is not a disease; it is a condition that is caused by disease.

Dementia is the name for a group of symptoms that may include memory impairment, difficulties with thinking, problem solving or language, or changes in perception, mood or behavior. However, a diagnosis of dementia is much more complex than just experiencing cognitive differences. It can also come with the need to navigate physical, emotional, spiritual, social and cognitive changes.



*The human experience of dementia will be different for each person. However, there may be some common experiences, which are detailed below.*

<b>Cognitive Change</b>	<b>Human Experience</b>
<i>Language: difficulty with word finding, verbal communication, comprehension</i>	Frustration when communicating. Emotional impact of other people's perceptions.
<i>Processing Information</i>	Feeling outpaced, confused or frustrated when things happen too quickly or when information is delivered too quickly.
<i>Reasoning</i>	Feeling anxious or overwhelmed when unable to make sense of external situations or understand other people's perceptions.
<i>Memory</i>	Feelings of fear, sadness, frustration or grief when unable to remember certain people, places and parts of their life story.
<i>Recognizing</i>	Feelings of isolation, loneliness and a reduced sense of security or belonging when unable to recognize objects, people, places. Feelings of being lost or disconnected.
<i>Changes in executive function (planning and organizing)</i>	Feelings of frustration, reduced sense of autonomy and losing influence when being more reliant on others for support.
<i>Visuospatial awareness</i>	Feelings of being scared, unsteady, unbalanced, destabilized or dizzy when unable to judge distances or view the location of objects. May need reassurance from others to navigate a space for a sense of security. Feelings of independence may feel compromised.
<i>Disorientation to time and place</i>	Feelings of confusion, fear and anxiety in both familiar and unfamiliar surroundings.



## Decoding Distress

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The medical view of dementia often focuses on the disease in the brain and does not consider the lived experience of the person. Feelings of fear, sadness, loneliness, depression, frustration and anxiousness become medicalized as a symptom of disease. When we do not understand how to support the person whose worldview is shifting, and healthcare professionals tell us that the difficulty the person is experiencing is a “behavior problem” or a “symptom of dementia,” well-intentioned care partners and healthcare professional turn to ineffective medications.

The good news is that the majority of distress is actually not the direct result of changes in the brain. These changes may enable the distress, but are not actually the root cause. The typical origin of distress is a loss of various aspects of well-being (such as a sense of autonomy or security). All distress is a form a communicating an unmet need and requires supportive care partners to look for the meaning beyond the surface.

For example, if a new care provider does not know the person they are supporting and attempts to help them with an intimate task like bathing or showering, it is possible the person will react negatively and may even physically hit the care partner when he or she tries to touch them. Through the traditional lens of viewing cognitive change, this type of distress might be labeled as a “challenging behavior” or “being combative.” However, if we choose instead to view this type of distress as a form of communication, we begin to see the non-verbal cues as a form of expression of voice and choice. It is very reasonable to assume the person is simply trying to communicate fear and discomfort with the situation.

Traditionally, care partners are taught to manage a person's behavior, which usually means either medicating the person, and/or responding with an array of "interventions" that distract from, but do not resolve, underlying needs, leaving the distress to occur over and over again.

The first step in decoding distress is viewing it as communication that needs to be translated and understood. That means recognizing every emotion, every feeling, and every moment of distress represents something more. It is important to remember that even a brain that has experienced a great amount of change will rewire itself to compensate for these changes. This includes new methods of problem-solving, creating new maps and new narratives, or calling on novel nerve pathways to process and respond to information. What is commonly seen as confused or challenging behavior is actually intentional adaptive behavior by an individual who is finding novel and unique ways to express agency, voice and choice.

***The following list can help you decode personal expressions, which may represent the following:***

- An unmet need (e.g. thirst, hunger, too cold/too hot, etc.)
- Sensory challenges (e.g. confusion with environment, under or overstimulated, etc.)
- New communication pathways (i.e. expressing voice and choice in a new or novel way)
- New methods of interpreting and problem-solving
- Response to physical or relational aspects of environment
- Response to a perfectly normal reactions (e.g. grieving the loss of a spouse, struggling with moving to a new home, etc.)

Remember that not all expression represents distress. For example, it is a common practice to label certain expressions as disruptive, when truly, it is the person simply "being." Think of a person who constantly walks.

Viewed through the traditional lens, this person may be labeled a "wanderer." But when we explore further, we discover the person has been walking five miles a day for the last 25 years and no longer has this opportunity to walk outside since receiving their diagnosis. Imagine if we reframed the way we viewed every expression. Instead of seeing it as distress or a "challenging behavior," what if we acknowledged them as a form of communication?

This new lens can enable us to ensure every person living with cognitive change is able to live well.

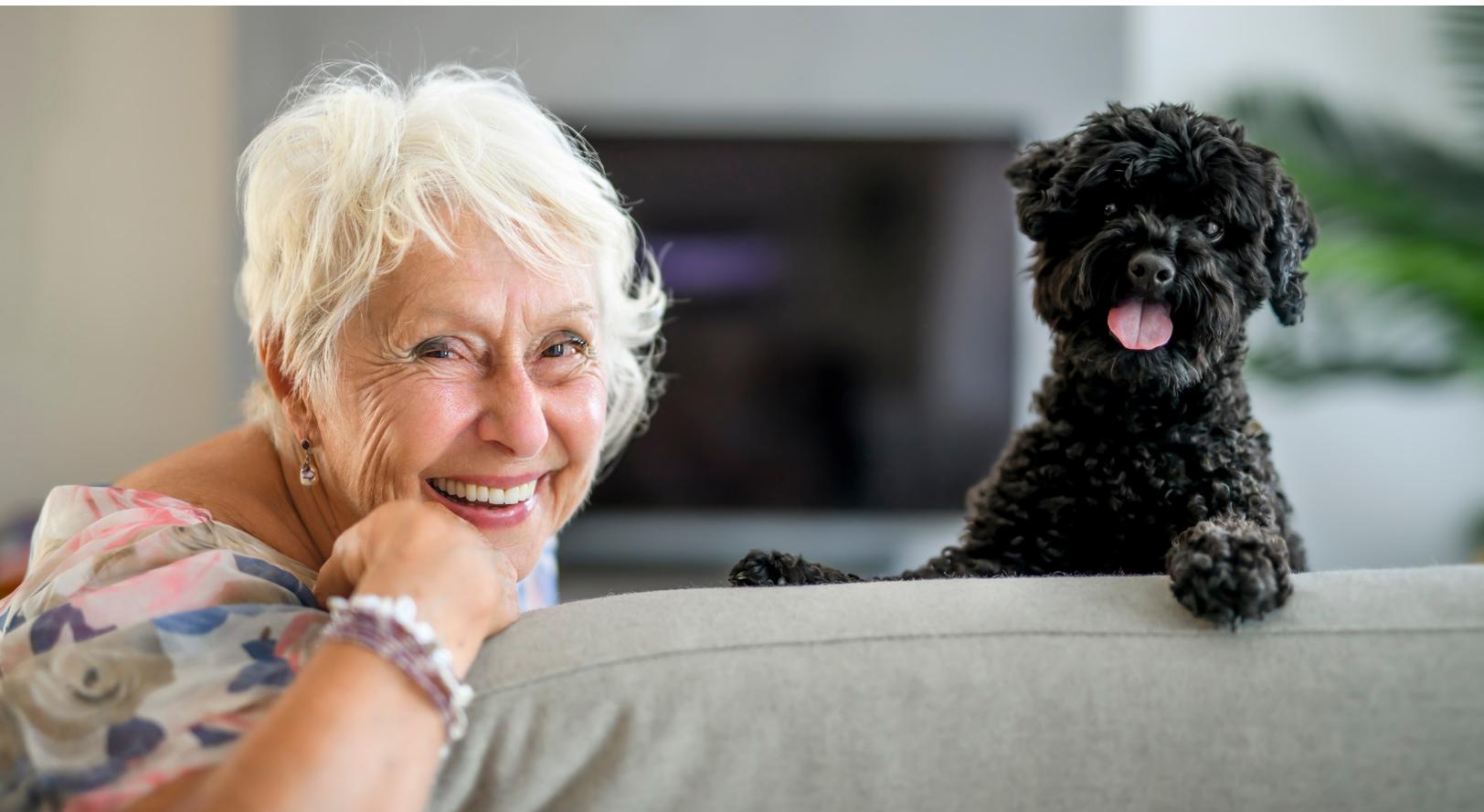
# The Power of Words

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The language we use to talk about dementia has a direct impact on a person's lived experience. It can also have a profound effect on how society views dementia. When asked, "What do people living with dementia feel?", 90% of responses are negative world-wide. This negative paradigm of dementia is the direct result of the negative words, images and feelings that our healthcare system, culture and society attaches to people living with this condition.

The typical biomedical narrative of dementia is that people with dementia lose their brains, memories, minds and, consequently, their identities and personal autonomy. Feelings commonly associated with dementia are fear, shame, sadness, depression and anxiety. These depictions of dementia create a negative stigma for the public, and negatively impact a person's experience with the condition. After all, the words we use affect the way we think, and the way we think affects how we behave. For those living with cognitive differences, using words or phrases that label, belittle or dehumanize people can influence their lived experience. It can change the way they feel about themselves, influence their mood and self-esteem, and impact feelings of happiness or depression. It can also change the way other people think about dementia, increasing the likelihood of a person with dementia experiencing stigma or discrimination.

On the other hand, when we use positive language – words and phrases that empower people living with cognitive change – it can alter how society views and supports the condition. Reframing the way we utilize language can ensure people living with cognitive differences feel valued and included; it can also positively change the landscape by reducing stigma and stereotypes.



## Tips for Language Use:

<b>Instead of:</b>	<b>Consider:</b>
<i>Words describing</i>	Frustration when communicating. Emotional impact of other people's perceptions.
<i>Processing Information</i>	Feeling outpaced, confused or frustrated when things happen too quickly or when information is delivered too quickly.
<i>Reasoning</i>	Feeling anxious or overwhelmed when unable to make sense of external situations or understand other people's perceptions.
<i>Memory</i>	Feelings of fear, sadness, frustration or grief when unable to remember certain people, places and parts of their life story.
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<i>Visuospatial awareness</i>	Feelings of being scared, unsteady, unbalanced, destabilized or dizzy when unable to judge distances or view the location of objects. May need reassurance from others to navigate a space for a sense of security. Feelings of independence may feel compromised.
<i>Disorientation to time and place</i>	Feelings of confusion, fear and anxiety in both familiar and unfamiliar surroundings.

# Navigating a Diagnosis

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A diagnosis of dementia does not mean the end to living a full and purposeful life. It does mean navigating emotional, psychological, physiological, environmental and experiential changes. Despite these new and unfamiliar challenges, it is possible to live well and remain connected and engaged to family, friends and community.

After receiving a diagnosis, it is important that the individual and their loved ones respond the same way they would to a diagnosis of any other chronic progressive condition, such as heart disease, diabetes or stroke. Like these other conditions, dementia is something that must be managed. Cognitive disabilities are a part of dementia, but certain lifestyle modifications, rehabilitation and proactive disability therapy might slow the progression of the disease, enhancing quality of life and well-being for the individual.

Kate Swaffer, leading international advocate in dementia and Chair of Dementia Alliance International, speaks candidly about how the stigma associated with a dementia diagnosis often leads to withdrawal and community detachment. She coined the term 'prescribed disengagement,' which is a phenomenon that typically occurs at the time of diagnosis in which a healthcare provider, either explicitly or implicitly, suggests that the individual should slow down or pull back from everyday activities. This recommendation can result in feelings of isolation and a loss of hope, self-esteem or self-identity.



*Although there is no simple map for navigating life after a diagnosis of cognitive change, taking the following steps can help you or your loved one continue to live well.*

- **Get educated.** If you were diagnosed with “dementia,” this is not a thorough diagnosis. The term “dementia” is an umbrella term used to describe a set of symptoms. Be sure to ask your healthcare provider for a referral to a neurologist or a specialist who is educated about neurocognitive disorders. It is important you know your specific type of disorder in order to best navigate existing or coming changes.
- **Stay connected.** Continue socializing with your family and friends and find a supportive network that understands what it is like to live with a diagnosis of dementia. If you cannot find an in-person network, there are many virtual meet-ups for individuals living with dementia. A study from Harvard Medical School also reports the value of staying engaged, finding that your social connections actually help support your brain health, as every unique social interaction forces the brain to create new connections and pathways.
- **Seek out support.** Schedule an appointment with an occupational therapist to learn how to navigate your cognitive differences. An occupational therapist can help with the following: developing coping strategies, modifying your lived environment, creating routines and helping you retain your strengths and abilities.
- **Create an accessible environment.** By making some simple modifications, you can ensure your home is able to meet your changing needs. Here are some simple modifications you can do today: utilize assistive technologies, swap your lightbulbs for circadian lighting, add motion sensor night-lights, use bright, contrasting colors for furniture and furnishings, simplify the home to eliminate distractions, and create labels for frequently-used items.
- **Embrace a plant-based diet.** Studies from Boston University School of Medicine found that high intake of plant-based foods while limiting consumption of foods high in saturated fat and animal products promotes the maintenance of neurocognitive health.
- **Sleep well.** A study from Harvard Medical School found that sleep cleanses your brain. During the day, beta amyloid protein builds up in the brain. When we sleep, brain cells and their connections actually shrink, allowing for more space between cells. This extra space allows the beta amyloid build-up to be flushed away while you sleep.
- **Get organized.** Think about your future needs and consider updating your long-term care plan. Many individuals choose to explore their options for transportation, housing and care to ensure their decisions and preferences are honored in the future.
- **Stay healthy.** See your primary care doctor regularly and ask for a referral to a specialist (neurologist or neuropsychiatrist). Also, consider going to a memory disorder clinic or joining a clinical trial. It is very possible to navigate dementia while still living a full life. Some of your future goals may have changed, but a diagnosis should not be a reason to pull back from activities you love or stop making plans for the future.



## Processing Grief and Loss

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Grief is a natural human experience we feel in reaction to any type of loss. Grief looks different for each person and is not linear. Rather, it is irregular and ebbs and flows, much like a roller coaster. A person living with cognitive change may also experience grief differently than they did before. They may experience moments of forgetfulness or confuse their feelings of grief and loss with other emotions.

It is important to remember that not all loss is related to death. Indeed, there are three different types of grief that are common amongst people living with cognitive change and their care partners. These include ambiguous loss, anticipatory grief, and disenfranchised grief.

- **Ambiguous loss** is a type of loss that occurs without closure or understanding. A person might experience this type of grief if he or she no longer feels they are the same person. Care partners or family members may also experience this type of loss as a loved one's needs change during the disease process.
- **Anticipatory grief** occurs when you are expecting a loss. This is also common among people who are living with a terminal illness or a progressive disease, as well as their care partners or loved ones. This type of grief occurs when anticipating a loss, such as the loss of a companion, changing roles in the family, financial changes, or the perceived loss of "what could have been."
- **Disenfranchised grief** occurs when a loss is not acknowledged or accepted by others. Grief associated with the experience of living with dementia can be disenfranchised because of the lack of awareness or stigma related to the diagnosis. Many individuals will even avoid sharing their diagnosis with others out of fear of how they will be perceived, causing them to navigate these changes alone and for their grief to remain hidden.
- **The process of dealing with grief** may also have emotional, physical, psychological, and social impacts on the person experiencing the loss. If you are living with cognitive change or caring for a loved one who is, be patient with yourself if you are struggling to navigate the roller coaster of grief. Seek out help to talk through your experience and find new ways to connect, find joy, grow and relish every moment.

# Creating an Accessible Home

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Your home environment can have a big impact on your daily life and well-being. Here are some things you can do to make your home more accessible for your changing needs.

## Hallways and stairs

- To reduce the risk of trips or slips, remove any rugs or mats that are at the top or bottom of the stairs or in hallways.
- Mark the edge of each step to help you judge their depth and feel more confident when getting around.
- Enhance lighting in hallways or utilize motion sensor lights for nighttime navigation.

## Living room

- Make this space feel cozy and comfortable, which will serve as a gentle reminder that this is a place to relax.
- Use a clock that displays the days of the week, date and time clearly.
- Swap out any glass furniture for high-contrast color furnishings so they're easier to distinguish from their surroundings.
- Display photos of loved ones.
- Utilize labels on cabinets of frequently-used items.
- Avoid using highly-patterned flooring materials as they can be visually confusing and overstimulating.
- Keep floor tones similar between rooms so it is easier to move around more freely.
- Open the curtains during the day to let in as much natural light as possible to help set the body's natural circadian rhythm.



## Kitchen

- Label cupboards and drawers so it is easier to locate items.
- Add an automatic shut-off mechanism to the oven to avoid accidentally leaving it on after using it. (Newer ovens typically have this mechanism built in.)
- Store items away safely to minimize clutter.
- Install smoke alarms and carbon monoxide detectors in and near the kitchen.

## Bedroom

- Install a motion-activated night light near the bed to increase nighttime wayfinding.
- Reduce the number of choices in the closet (e.g. clothes, shoes and cosmetics) to make getting dressed easier.
- Laying out clothes in the order they will be put on can help make the process easier.
- Select PJs and bed linens that contrast in color to the rest of the room so the bed is easier to see.
- Install smoke alarms and carbon monoxide detectors in and near the bedroom.

## Bathroom

- Install a flood prevention plug that will let water out of the bath automatically when it becomes too full.
- Opt for one that also changes color to indicate whether the water is too hot.
- Use contrasting tones for the walls, towels, grab rails, soap and toilet seat to make them easier to see and recognize.
- Consider bigger modifications to increase the bathroom's accessibility. For example, install a walk-in shower or a bath seat along with no-slip mats and hand rails.

## Assisted Technology

Technology can be used to empower people living with cognitive change to live more independently. These devices may help a person cope with some of the complex cognitive and physical changes that may occur when living with a neurocognitive disorder.

- Smart home technology (e.g. automated lights, thermostats, blinds, locks, garage doors, shut-off devices, TVs, tablets, etc.)
- Virtual assistants (e.g. automated prompts, medication reminders, appointment reminders, night/day clocks, etc.)
- Wearable devices (e.g. fall detectors, GPS location sharing, etc.)
- Household management (i.e. smart home devices that talk to each other and notify a loved one of changes in routine)



# Staying Connected

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Human beings are social creatures and our nervous systems expect to have others around. In fact, countless studies show that being isolated from others is linked to negative physical and emotional health outcomes. The desire to seek out social companionship is hardwired in our DNA and this does not change with a diagnosis of dementia.

The dynamics of your relationships may change after you receive a diagnosis, but there are many ways for you to stay connected and engaged with your community. It is important to share your diagnosis with your friends and family when you are ready. This may occur immediately or it may occur after some time has passed. It is important that you decide your future goals and how you want to live, and that you communicate these wishes to your family and friends.

When sharing this news, be sure you let people close to you know you are still the same person. Be as open as you can about how you are feeling and how you hope to navigate your condition. As time passes, you may need support handling the complex changes that come with the diagnosis, and you'll want those closest to you by your side.

Remember, it may take your family and friends some time to cope with the idea of you living with this new set of challenges. For some, learning what to expect can help them understand that it is still entirely possible to live well despite your diagnosis.

## *The following tips can help you stay connected and continuing to make new friends while navigating this life change:*

- Tell people that you want to stay connected.
- Share the changes you are experiencing.
- Be open about how the changes are affecting you.
- Invite questions about your experience.
- Keep in touch in different ways (e.g. in-person, mail, phone, video calling).
- Join a support group online or in person.
- Continue doing the things you love.



The best thing you can do for your overall health and well-being is to stay engaged. Whether living with cognitive change or not, your social connections will help protect your brain because every unique social interaction you engage in forces the brain to create new pathways for information delivery.

Therefore, continue to do the things that bring you purpose and joy with the people you love, as much as you can. Your brain will thank you for it!



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tailored just for you.