

# How to support someone with dementia—and feel better yourself

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Visiting a loved one with dementia can be tough, but there are ways to make the experience better for everyone involved, says a UAlberta expert in end-of-life care. Credit: University of Alberta

Visiting a loved one with dementia can feel frustrating, even hopeless, but there are ways to turn that precious time into a better experience, says a University of Alberta researcher.

"One of the hardest things for family and friends to see is the person

who is there physically, but who they are—that's not there anymore," said Wendy Duggleby, a leading researcher in the Faculty of Nursing who studies [end-of-life care](#), including [dementia](#).

"They may not know you at all, but other times they might smile or recognize you. Or they think you're someone else. You're losing that person over and over. It's like a continuous death and it can be distressing."

But it's still important to connect with that person in some way, even after they go into long-term care, she said. "That human interaction is huge, whether it's just a touch or talking to that person."

The key to what could be considered a positive visit is in not setting expectations, Duggleby added.

"Don't be worried about how you might find them when you visit; just being there can have a positive impact."

One study showed that trying to include non-verbal dementia patients in conversations—looking at that person when you speak and watching for non-verbal responses—reduced their feelings of confusion, Duggleby noted.

"You really are doing them a great kindness. You might see their facial expression relax, or they might move," she said.

But even if there isn't a visible response, it's important to realize that person could still be hearing you, she added.

## **Understanding the signals**

A common misunderstanding about dementia is that the person is

unaware of what's going on around them.

Brain diseases like Alzheimer's cause difficulties and delays in processing information, which is often mistaken for hearing loss. Peripheral vision can also deteriorate, which is why some patients, for instance, run their hands along a wall.

"These changes can be scary for them, so don't assume they can't understand, hear or see what's going on around them. They are not cut off from the world; it's just a different kind of processing," Duggleby said.

She added that a behavioural response can be mistaken for aggression, when the issue could instead be environmental. For example, a patient who starts screaming in fear when approaching a shower stall may in fact be scared of the bright light or tile lines.

"They are responding to stimuli in their surroundings," she explained.

And if they are confused about dates, places, events or people, don't correct them. "What's more important is that they are talking to you. It's the interaction that matters."

It's also important to be flexible about how a visit will go.

"There are good days and bad days for that person. If they don't seem to respond, plan for different ways to communicate."

Jogging happy memories is one of the best ways to do that.

"There's a misconception that the past will upset a dementia patient, but in fact it can be very calming and reassuring," Duggleby said. "Their short-term memory may be gone, causing confusion about where they

now are and the strangers surrounding them, but they still do have some long-term memory, and reminiscence—remembering good times—can be therapeutic. It brings endorphins to the brain, and that physiological response is good for all of us, including people with dementia."

Sharing old photos, listening or singing along to favourite music, even playing recordings of a friend or family member's voice, can offer comfort. Non-verbal gestures like a back rub or hairbrushing can also be soothing.

## **Don't be too hard on yourself**

It's natural to feel guilty about putting someone into care or to feel resentful about visiting, Duggleby noted.

"We do see that, by the time someone is admitted to long-term care, family and friends are burned out. They may feel pressure to visit every day, but they don't have to do that. Remember, the person has people caring for them, keeping them safe, and you need to find that balance," she said.

Learning about dementia can help people cope with visits they find stressful, as they witness their loved one changing.

"We've found in our research that those who actively seek knowledge and assistance to understand the disease have higher levels of hope and report better quality of life than those who use other coping mechanisms, such as taking one day at a time or connecting with other family members and friends," Duggleby said. "If you know what's happening, you can blame the disease and not the person."

She recommends exploring [My Tools 4 Care](#) and the [Alzheimer Society of Canada](#) as information sources. "You can have a whole different

feeling about visiting, a different relationship, and your expectations will be different."

[Connecting with hope](#)—one of Duggleby's main research areas—plays a big part in coping, she added.

"Everyday hope is about little things, day by day. It's a possibility for a better future within uncertainty. In stressful situations, our hopes become specific and the time frames change. Ask yourself in this moment, what could give you hope. It could be hope in knowing that pain medication will start working in a few minutes, or hope for our families, even though we are suffering. It's a positive emotion that makes us feel better physically and mentally, and that's how we improve our quality of life."

## **10 ways to connect with a person who has dementia**

1. Talk about topics that you know interest them.
2. Use props during a conversation. It's easier for the person to talk about something they can see.
3. Avoid asking open-ended questions to avoid frustrating the person, who may struggle to come up with an answer. Ask questions that invite yes or no answers.
4. For those who can't speak, acknowledge their body language or facial expressions so they feel included.
5. If the person is in long-term care, draw them into an activity that relates to their past interests. Someone who was an enthusiastic gardener, for instance, might enjoy caring for a plant.
6. Celebrate as many family occasions as possible with your loved one. "Several studies report that people with dementia consider family to be the most important part of their lives," Duggleby said.
7. Help them exercise their brain. It helps them engage more and reduces any feelings of uselessness. Good activities include

puzzles, games, quizzes, reading and hands-on tasks like folding clothes together.

8. Bring favourite foods for the person to enjoy. Familiar tastes and smells can bring back pleasant memories of mealtimes at home with [family](#).
9. Go down memory lane by asking them about their past. It provides meaningful conversation and can improve their mood and make them feel proud. Create a memory box of pictures and other small, favourite items they can keep with them.
10. Sing, dance or listen to music together. A favourite song can remind a person of happy times.

Provided by University of Alberta

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