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This is what it's like to care for someone with dementia

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- Dementia-causing diseases are on the rise.

- Many people with dementia are looked after by friends and family members, known as informal caregivers.
- Someone with dementia needs help with everyday tasks.
- So being a caregiver is a 24/7 job.
- But it's important carers take time for themselves, otherwise they burn out.

Many countries have an aging population, and diseases that cause dementia are on the rise. [Dementia is an umbrella term](#) given to the symptoms caused by various diseases - most commonly Alzheimer's - and 152 million people are expected to suffer with it by 2050, [according to the charity Alzheimer's Research UK](#).

Diane Darby Beach, a doctor with Right at Home's Cognitive Support Program, told Business Insider most people with dementia are taken care of for the entirety of their disease at home with their family or friends.

"The burden of the care falls to these, what we call, informal caregivers," she said. "Family and friends who don't necessarily have any training in it, and are just kind of thrown into this situation. And for some, it's almost unmanageable - it's very, very difficult."

Someone with dementia needs help with everyday tasks. In the early stages of dementia, most people are able to enjoy their life as they did before their diagnosis. But over time, symptoms get worse, and they tend to get more forgetful, distressed, and confused, meaning they require more care.

[According to the National Health Service website](#), some of the tasks someone recently diagnosed with dementia might be grateful for are shopping, laying the table, gardening, and taking the dog for a walk.

Memory aids, such as signs of cupboards and doors, can help the person remember where certain rooms are, or where to look for bowls and cups.

But as time goes by, dementia can affect the person's personality, ability to do anything themselves, and how they communicate. This means carers have to adjust how they talk to the person they look after.

The best way of not causing further distress to the person with dementia is to adjust to their reality, Darby Beach said. For instance, if someone is trying to pack their things to go to work or school, you shouldn't focus too much on trying to tell them they retired over a decade ago.

"We're not going to talk them out of their reality because that's only going to cause them frustration, so we meet them where they are," she said. "If Sally is a school teacher in this moment, then she's a school teacher. We never ever argue or try to reason with the person with dementia because the brain's reasoning centers, the abstract thinking, has been thrown."



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Rather than trying to convince Sally she is in an assisted living community, which may confuse and alarm her, her carer can tell her it's a Saturday, and there's no school today.

"That's what's hardest for families, because if you take an adult child with their parent, they've always reasoned with them... but it doesn't work anymore," said Darby Beach. "Don't expect them to be who they were, but find out where they are and what they can still do and organize activities and conversations around that."

Carers have to reframe and simplify the world for the person they're caring for into an environment they can handle.

"I'm talking one of the two steps at a time," said Darby Beach. "It's being in the moment with that person, and not trying to think too far in the future."

A surprise for caregivers is that it's a 24/7 job, and every day is different, Darby Beach said. They need to be really flexible and patient because something that worked today may not work tomorrow.

"The disease is so all over the place," she said. "One day a person with the disease can have a very good day where they're able to manage, and the next day they're not."

Sometimes dementia doesn't impair someone's memory and functions until it's very advanced - but it does affect vision. Laura Phipps, the head of communications and engagement at Alzheimer's Research UK [told Business Insider](#) that some types of dementia only affect sight and perception, which is the type English author Terry Pratchett had.

"One thing people often tell us about is that puddles on the ground can look like holes because there are issues with... depth perception and color perception," said Phipps. "You know when you go into a shop and they... have those big black mats in front of the door... for some people with dementia that looks like a massive abyss."

In this situation, reframing their environment may be as simple as going to a store that doesn't have those kind of mats. Phipps said a lot of the time, people with dementia can't make the judgment because their brain isn't working at 100%.

"There are big impacts on how people can live but people don't realize them," she said. "It may just be a really small thing that causes someone to be anxious, but if they can't articulate that you can't change it."

That's why there's a big movement for understanding why people with dementia are acting aggressive or agitated. There's a good chance it's something to do with their environment - the lighting, the way shadows are cast, or the floor - that could be causing their anxiety.



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Caring for someone with dementia is tough. If the carer is someone close, they may feel like the person they loved is being washed away and replaced by someone they don't recognize. Their world also gets smaller and smaller as they realize they don't have time for everything they used to before becoming a carer.

It's also like going through grief, as the person they care for slips away. As their loved one deteriorates and they start to lose their abilities, the caregiver is simultaneously caring for them and battling their own sadness that they aren't fully there anymore.

"The person eventually becomes a shell of who they were," said Darby Beach. "They are there in body, but the relationship is gone, the memories are gone, and that's hard on caregivers."

She said it's really important for carers to take care of themselves first. In her work, and from personal experience, she knows how draining it can be to care for someone else full time. And there's no way you can do that properly if you're completely burned out.

She said it's like when flight attendants are reading out the safety instructions on a plane, and they tell you to put on your own oxygen mask before helping anyone else. Carers are likely to feel guilty if they make time for themselves and leave their loved one with someone else for a few hours. But ultimately it's just one of the roller-coaster of emotions they'll feel, and it's better to minimize them wherever they can.

"It's OK be angry, it's OK to be frustrated, it's OK to not handle a particular situation exactly the right way," she said. "They need to forgive themselves and not be so hard on themselves, because the family caregivers are really tough on themselves."

Darby Beach said there are also a lot of good things that come out of being a carer. There is a great deal of stress that comes with the territory, but there will be moments where they're thankful they're around.

For example, carers can also stimulate old memories and conversations with their loved one by bringing props that remind the person with dementia



of their past. Someone who used to love cooking might not be able to eat solid food anymore, but they still have a sense of smell, so you could bake some bread. Or someone who used to love riding horses might like to see a saddle and talk about what it was like.

"Something like that can remind them of that interest ... and spur those memories and that connection," said Darby Beach.

"It's what's called person-centered care, and that really means knowing that person. The more that we know about somebody, the more information we have to be able to validate that person's [feelings and memories] and redirect them... So they're not all bad moments."

She added that she's seen families grow closer because of the time they spend together as carers.

"It's tough but there are also a lot of good things that come out of it," she said. "They do have that sense of satisfaction that they really were there to the end and helped their loved one, and they get closer. So they're not all bad moments."