

Caring for someone with dementia

Since actor Bruce Willis revealed a [frontotemporal dementia diagnosis](#), his family and friends have rallied around him to provide the best care.

There have been highs, like a small celebration of Willis' 68th birthday. And there have been lows, like when Willis' wife Emma urged fans and paparazzi not to yell at him in public to avoid overstimulating him.

It's all part of the massive task of caring for someone with dementia.

Medicinal treatment

[Courtney McFarlin, PA](#), is a primary care provider at OSF HealthCare who specializes in geriatrics. She says people with dementia can have issues speaking, articulating words, thinking and with compulsivity. They also may lack awareness of these problems. Medications known as selective serotonin reuptake inhibitors (SSRI for short) can help.

"Those are actually antidepressants, but they can help with some of the behavioral issues we see in patients with frontotemporal dementia," McFarlin says. "Sometimes we have to incorporate antipsychotics into the treatment regimen."

There's no cure for frontotemporal dementia, McFarlin says, so these medicines treat the disease as it comes, rather than try to slow it down or stop it.

Appointments with a neurologist, social worker, physical therapist, speech therapist and a behavioral health provider will go hand in hand.

What caregivers can expect

McFarlin says caregivers for people with dementia should be at every appointment so they can talk about how things are going. They should also understand that it's not an 8 a.m. to 8 p.m. job.

"People with dementia can have sundowning, getting up in the middle of the night and wandering around. They can have sleeplessness and other behavioral issues that are worse at night."

In other words, it's a team effort.

"The family could hire someone to come in a few hours a day or a few days a week to give them a break," McFarlin suggests. "Or if it's a family of multiple siblings, they can take turns."

"We try to make sure caregivers are also being cared for," she adds. "Getting adequate rest and making sure their emotional needs are also met."

Check with your health care provider or with groups in your community to see if there are caregiver support groups.

Living arrangements

McFarlin suggests letting someone with dementia live at home as long as possible. It's the environment they know, it comes with a sense of freedom and changing their living setting can actually cause a flare up in dementia symptoms. But a time may come when the person needs care that family can't provide. This could be a sophisticated level of care or round-the-clock help.

There are different types of senior living facilities. Independent living allows the person to, as the name suggests, live independently. They can mostly take care of themselves. Assisted living usually means you still have a private living space, but you have a helper (a nurse, for example) who stops by as needed. You may also eat in a shared space. Long term care facilities are for people who need care most or all of the time. Some long-term care facilities have memory care units to serve people with severe dementia.

"These people may have a lot of behavior problems or do a lot of wandering," McFarlin says. "The memory care centers are typically on a lockdown status. There are a lot of door alarms and bed alarms to make sure they're safe, not a fall risk and they don't leave the facility."

End-of-life discussions

There's no way around it. Talking with a loved one about advance directives, funeral arrangements and other end-of-life matters is difficult. But McFarlin says dementia, unlike a fast-acting disease, presents a silver lining. Its slower, progressive nature allows someone time to adjust to the new normal and think about end-of-life issues. Your provider can link you with care managers to help with the conversation. A person may go on [hospice](#), where someone typically with six months or less to live focuses on comfort care and not curative care.

"If you have the conversation the right way and give the person the resources they need, it can make a sad time less stressful," McFarlin says.