Romance outside a relationship: Seeking intimacy with others when a spouse or partner has dementia

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June 16, 2022

By Stephanie Bouchard

Lino Darchun began "practice dating" two years after his wife, Sydnee, was diagnosed with younger-onset Alzheimer's disease. "I would ask a woman out for lunch or dinner just to have the experience of sitting with a woman and talking intelligently," says Darchun, who lived most of his life in Chicago before retiring to Florida.

Darchun continued to date other women while his wife was alive yet progressively succumbing to Alzheimer's disease. He did so with "great fear and trepidation," but says he felt he had to do it. At the time, he was 61 years old, and he worried that loneliness would kill him.

The effects of loneliness are well known today: increased risk of heart disease, stroke, and death, and higher rates of depression, anxiety, and suicide. For spouses or partners of those with Alzheimer's disease, loneliness is often a fact of life.

In fact, in one survey, almost two-thirds of 1,195 caregivers for people with dementia said they were lonely, with 18% saying they were severely lonely, according to a study published in the journal *Aging and Mental Health* in April 2020.

For some of those caregivers, developing new romantic relationships creates a lifeline. While they still love their spouse or partner, their loved one may not be able to speak or carry out basic functions, such as feeding themselves or using the

toilet. This may leave their partner conflicted — in love but craving an intimate relationship with another adult.

Lost in diagnosis

In 2002, Darchun's wife was 58 years old. A senior American Airlines flight attendant from Chicago, she loved her job working overnight flights to Europe. She was healthy and active when she started acting out of character. Darchun, 59, a busy and successful real estate broker, reasoned the oddities away until her coworkers shared their concerns.

Testing and a consultation with a neurologist revealed Alzheimer's disease — a diagnosis that left Darchun and his wife stunned. They had no idea what was ahead of them.

"As a caregiver for my wife, I didn't know what the hell I was doing, and I didn't know what was going to happen. I have to admit to being frightened," says Darchun, who is now 80 and living in Miami. "I loved my wife very, very much, and we had a very good, healthy relationship."

But as her disease progressed, the couple's emotional and sexual intimacy gradually ceased. "There reached a time when I felt to ask for sex or to make sexual moves was taking advantage of her," he says.

Eventually, after struggling with the emotional turmoil of loving his wife but needing intimacy, Darchun slowly moved out of practice dating and into real relationships that included sex. "It made me realize I was still desirable, that I still had value to a person of the opposite sex," he says. "That shored me up and helped make life more tolerable."

Respecting relationships

Alzheimer's is a disease of the brain that impacts many areas of thinking. Its progression can last from years to decades. "As this disease progresses to moderate and severe stages, it changes the landscapes of relationships," says caregiving and geriatric medicine specialist Shellie Williams, MD, at <u>University of Chicago</u>

Medicine.

Unless someone has cared for a person with Alzheimer's disease, it is difficult to fully grasp how deeply the experience impacts spousal or partner caregivers, Williams says. "There are different levels of grief that go along with this illness. That's why it's so important to create buffers of joy so that you are not living in constant grief."

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It's important for caregivers to be respectful of the relationship they've had with their spouse or partner but also to be honest with themselves about their needs. "You cannot be there for someone else who you love if you're not meeting your own needs," Williams says.

New romantic relationships offer a way to ease loneliness and stress while bringing a measure of happiness into caregivers' lives. But dating is also a complex and emotionally fraught option, says Ellen Carbonell, LCSW, assistant professor in the department of social work at <u>Rush University's College of Health Sciences</u>. Supportive therapy can help people "identify the components, sort through the associated feelings, and come to terms with it for themselves," she says.

Communicating changes

Once caregivers have settled on the role of a new relationship in their lives, they then have to weigh how, or whether, to tell friends and family members.

Such news may bring on others' emotions and judgments.

"I think the more open people can be about what they're doing, the better. It's not a luxury that everybody has, though," Carbonell says.

"It's a big risk to introduce this kind of thing into what's going on in the family, because people close to those involved may have very strong feelings about the situation," she says. "The more it can be approached in an empathic way — keeping everyone's feelings in mind — the better. But that doesn't mean you can expect that everyone's going to understand."

Plan ahead, and think about what you'll do if others don't accept your new direction, she says.

A lack of understanding from some family and friends motivated Darchun to keep his dating life private. "They didn't understand or accept the fact that she was that much in decline," he says. "There were people for years who said, 'Don't you worry, Lino. She's going to get better.' No one knows the decline of dementia unless they experience it for themselves."

Sydnee died in 2015. Darchun has never remarried but still dates and maintains an active sex life. Not a day goes by, he says, when he doesn't think about his wife and their love for each other.