



Making the merriness gentler for people with dementia

ADAM SMELTZ

DEC 13, 2021

6:00 AM

Even before the coronavirus pandemic, getting together with family and friends was often a challenge for people with dementia. For many, a stimulation deluge — a lot of different voices, foot traffic and moving around — tends to prove overwhelming.

But after 21 months of relative isolation, many with dementia face an especially jarring re-entry to social life as holiday celebrations return this winter, clinicians warn.

To limit discomfort and anxiety — for both dementia patients and their regular caregivers — experts encourage families to think through events ahead of time, temper the size of gatherings, and consider amending traditions for minimal confusion and chaos.

Such steps can help patients better enjoy the occasion and the warm memories that the holidays can conjure, said Sara Murphy, vice president

of programs and services for the greater Pennsylvania chapter of the Alzheimer's Association.

"I always recommend for family members during the holidays to create moments of joy," Ms. Murphy said, encouraging families to "be in the moment with their loved ones during this holiday season."

Visitors, especially unfamiliar ones, can be confusing or alarming to someone with dementia, Ms. Murphy added. While there is no universal size limit for gatherings, she recommended that families plan together, be attuned to what the relative is going through, and recognize that the person's crowd thresholds or other trigger points can change as disease advances.

Likewise, Ms. Murphy said, people with dementia may need extra support after a gathering if it leaves them confused. Before visits, caregivers can prepare visitors for any changes in personality and other cognitive developments since the last in-person encounter, said Dr. Riddhi Patira, who specializes in memory and cognitive disorders neurology at UPMC.

Once they arrive, visitors shouldn't accost patients with questions about how they've changed, she said. That can throw off people with dementia and leave them uncertain about what to say.

"We should avoid that kind of confrontation," which can lead to an awkward quiet, Dr. Patira said. "Open communication with caregivers is important so we can avoid that kind of silence on both sides."

Especially for those who haven't seen a relative with dementia in more than six months, the primary caregiver should explain specifically how the disease has progressed and what they can expect at the dinner table, said Dr. Daniel DiCola, an Excelsa Health family physician. A patient's physical appearance, verbal filters, and abilities to eat and control bodily functions, for instance, can shift quickly, he said.

When it comes to talking directly with a patient about dementia's effects, Peter Storkerson, 74, of O'Hara, who is diagnosed with two neurological syndromes, suggested thoughtful timing.

Mr. Storkerson said he thought patients "would probably be very happy to talk" about those questions, but that a holiday gathering might not be the right place to do it.

He and his wife, Elzbieta Kazmierczak, 62, had holiday visits with family in November to escape the bigger gatherings later in the year, she said.

“We didn’t want to be in the middle of celebrations that are noisy. It’s a different mood, and it’s too much going on — there’s so much stimulation,” Ms. Kazmierczak said. “It’s very difficult, then, to recover from it for Peter.”

For those environments with more commotion, Mr. Storkerson recommended identifying a less-loud space where a person with dementia might go “off to the side and recoup” — an idea echoed by doctors.

Another tip: If the person with dementia is able to communicate and engage, ask directly what holiday plans would be most welcome, Ms. Kazmierczak said.

“They’ll tell you, ‘I don’t like this or that or something else,’” or “‘I can’t stand the light,’” she said. “Someone should watch facial and body expressions to say now is the time they might want to take a break.”

As part of limiting disruptive or confusing stimuli, families might avoid rearranging the home, including furniture, and steer clear of blinking lights, real candles, loud music and Christmas ornaments that could be mistaken for food, Dr. DiCola said.

People with dementia often “need a quiet, sedate environment to function” well, he said. Shorter gatherings earlier in the day tend to be most helpful, and prevent “sundowning,” or the worsening of confusion later in the day, Dr. DiCola added. Patients tend to do better, too, if they’re in one place and not taken from home to home, he said.

He also encouraged standard practices to prevent spreading COVID-19, which can be especially dangerous for the elderly. Those practices include vaccination, smaller gatherings and assigning one person to serve dinner rather than organizing a buffet-style meal.

At his Westmoreland County home, Dr. DiCola said, his family celebrated Thanksgiving with two gatherings in order to decrease their size. In Latrobe, Brian Musick’s family keeps daily routines largely intact over the holiday season for his mother, Joan, 90, who is diagnosed with Lewy body dementia.

“We still put up a tree inside for her, and I still decorate outside,” said Mr. Musick, 64, who lives adjacent to her. “We felt it helped keep that intact, that she understands the holidays.”

His thinking: As she’s still living in her house of more than 60 years, “why not keep it like a normal home?”

Consistency is also a staple for Sara Belt, 56, of Unity. Diagnosed with early-onset Alzheimer’s in 2018, she’s a congressional ambassador for the Alzheimer’s Association, lobbying lawmakers for the nonprofit organization.

“I think it’s very important to stay social with your friends,” said Mrs. Belt, a former teacher. Her husband, Don Belt, 74, called socialization among the best non-medical activities for Alzheimer’s patients.

The couple spread their family Thanksgiving festivities across three days. They said such deliberate interaction is a key in their routine together.

“She loves it — because it feels good to her,” Mr. Belt said. “As long as [people] know she has Alzheimer’s and they’re willing to be patient, it becomes very positive.”

Doctors said social engagement has known health benefits, although the pandemic has complicated the interaction. Recalling old memories and making new ones over the holidays can be a form of therapy, “but everything has to be in moderation,” Dr. Patira said.

Social activity “has to be a routine and a structure,” she said. “It can’t be just one day the entire year” to spark a health benefit. “Putting it all on the holidays might not be the best idea.”

Questions or concerns about how someone might react to specific trips or other events are best addressed with the person’s doctor, she said.

Clinicians also emphasized the role of caregivers and the relief they could use over the holidays. Relatives can help them prep for celebrations in part by contributing food or perhaps by simplifying the entire affair, Dr. DiCola said.

“We need to make sure the other family members support that caregiver and make sure the caregivers know it’s OK to ask for help,” he said.

“Caregiving is so stressful. You add that on to a holiday celebration — and we want to be very supportive of them at this time.”

Anxiety has spiked for caregivers particularly during the pandemic as they worry over patient safety, said Ms. Murphy, of the Alzheimer’s Association. To support them, the Pennsylvania chapter is helping to host a Virtual Dementia Caregiver Symposium from 10 a.m. to 2 p.m. Dec. 14.

The free program on Zoom — accessible to anyone in the state — will include a focus on caregiving skills, practical tips and community-based resources. Registration is available at <https://action.alz.org/mtg/77357311>; more information is available through the association’s help line at 800-272-3900.

“Caregivers need to be able to have an outlet to talk with someone” about their challenges, Ms. Murphy said. “This has been such an isolating time — People need to be aware that there is support.”

Adam Smeltz is a freelance contributor and former city hall reporter for the Post-Gazette. He can be reached at asmeltz@gmail.com.

First Published December 13, 2021, 6:00am