



TRANSCRIPT

Planning Events

Over the years I have seen that one of the biggest challenges in caregiving is that many family members and friends do not fully understand that their loved one is changing. They will not or cannot accept that modifications need to be made to help their loved one remain comfortable and engaged. And that these adaptations are made not once or twice, but constantly as the person moves through the disease process.

Here's an example:

For the past 20 years Brenda's entire family of 14 adult children and grandchildren would celebrate Mom's birthday every year with dinner at a well-known and lovely restaurant in Half Moon Bay. The issue was that getting there required a 45-minute drive on a twisty two-lane highway over a mountain pass. Mom has had Alzheimer's for five years, now is in moderate stage, and has a diminished threshold for stress. Brenda, her daughter, has been taking care of Mom in Brenda's home for three years.

Last year the dinner worked out, but then Brenda noticed how hard it was on her mom and that she was exhausted, more confused, and restless for a few days after. She shared this with her family, but all they saw was Mom smiling in the photos with her cake. They didn't understand or accept that there were consequences afterwards.

Brenda was a member of my dementia support group, and I suggested to her that some simple modifications likely would make this year's celebration work for Mom. For example, making it a lunch celebration instead of dinner. Mom has been more confused and agitated this past year after dark. This is called sundowning and is quite common. Or picking a different restaurant that was closer to home and didn't require the windy road. Perhaps making it a smaller gathering, or shorter in length. Family felt that Brenda was being overprotective and wouldn't budge on the details.

The predictable result was that the moment Mom arrived, she was asking to go home. She said she didn't know where she was, didn't recognize some of the family members, and had an accident on the way to the bathroom. She was on her way home with Brenda in less than 30 minutes. No smiling photos this year.

Family being open and willing to modify gatherings and celebrations is key to assisting a person living with dementia to be able to continue with many of the same activities and traditions they have always enjoyed.

Another family I know had a tradition of taking Dad to an annual concert, in the winter, for the holidays. Family did not fully appreciate that Dad was now physically weaker and more uncomfortable in cold temperatures. Dad grew up in Michigan, they said, and he was tough. But now he was 86, had mild dementia, and shuffled his feet. His family did not plan for the long walk to the venue from the parking lot and the cold temperature. As a result, after the concert, Dad refused to leave the warm venue. The concert emptied out but Dad refused to go out the door and started to shout every time his son took his arm to lead him outside.

Some accommodations that would have helped would have been to take him to a matinee. Or put him in a wheelchair with a blanket. Even if he had refused the wheelchair going in, when it was light and warmer outside, he likely would have welcomed it when leaving. Pulling the car to the closest possible place when leaving would have helped as well.

Some tips for gatherings to make things easier, including less fuss:

A tired caregiver can be a cranky caregiver. Be willing to forgo some of the events and focus on the most important ones. Ask other family members to host, and leave when your loved one is getting tired or agitated.

Plan smaller gatherings. Spread them out over time. Providing a quiet place to rest in the home is a good idea. I had a family go into the den to visit Grandpa two at a time. Soft music that he liked was playing, and there was soft lighting and less commotion. During the meal they were all together.

Don't ask questions such as "Do you remember me?" Give them space. Listen. If they say "I don't know" or "I don't remember" regarding the family trip to Hawaii five years ago, then provide some details. Or change the subject. Listen to the pitch of their voice. Stressed people often have higher pitches. Watch their body language, their facial expression. Many people with dementia, when stressed, have a more difficult time with complete thoughts or sentences. Know your person or rely on those who are spending the most time with them to provide guidance.

Ultimately it is not about you, it is about them.

I taught a class through the Alzheimer's Association called The Savvy Caregiver. It was a wonderful six-week course. Part of the course was to pick something that was getting difficult or concerning regarding caregiving, so we could all process it, and provide feedback and options that the person had not yet fully considered. I loved doing this, as the participants were open to new ways of thinking and making needed changes to make life better.

In class, Ray shared that in two weeks was the annual Rotary dinner. He and his wife had been very involved for over 20 years, both were very social, loved getting dressed up, and this gala was the event of the year. His wife now had moderate dementia and got confused and anxious when away from him. He shared that he just could not go with her and would not go without her. This was yet another loss due to his wife's dementia. We brainstormed on how he could go by changing his expectations of the event.

This is what we suggested and he agreed to do. He should skip the business meeting before the event.

Go with her and arrange for women at the event, her friends that knew her well and understood her confusion, to take her to the restroom and visit with her if he was occupied talking to his male friends. This meant he would not have to be hypervigilant and could relax a bit and enjoy himself. If she began to worry about where he was, the ladies would escort her to where he was. During the meal he coached these friends to slow down, include her in the conversation, and be sure not to quiz her but offer information. This last part is crucial: He should make plans to leave early, if needed. Avoid putting her on the spot. Tell others that *he* was feeling tired, not making it about her.

When we checked in with him during the next class, we were thrilled to hear it was a resounding success. Both had a wonderful time, and he brought photos to share with the class. His wife looked radiant.

If we are open to making modifications to gatherings and celebrations and setting reasonable expectations, we provide more opportunities for the person living with dementia and their family to enjoy the precious time they have together.

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