

NAVIGATING THE HOLIDAYS

when a loved one has dementia

The holidays are often filled with sharing, laughter and memories. But they can also bring stress, disappointment or sadness, particularly for families affected by dementia. Preparing ahead of time can help.

Adjust expectations

- The stress of caregiving responsibilities plus holiday traditions can take a toll. During this time of year, it is especially important that you take care of yourself - mentally, physically and emotionally.
- Communicate realistic expectations about what you can and cannot do. Sometimes this can create a sense of loss if you have to give up a role you always had, such as making the turkey, brisket or sweet potato pie, but think of it as a chance for another family member to start a new tradition.
- Have a conversation with family beforehand about changes they might notice in the person living with dementia.
- Some people living with Alzheimer's become confused or agitated in the evenings (this is known as "sundowning"). Consider celebrating earlier in the day to work around this, or make other arrangements.

Adapt gift giving

- Provide people with suggestions for useful and enjoyable gifts for the person, such as an identification bracelet or membership in a wandering response service. Or, suggest comfortable, easy-to-remove clothing; favorite music; photo albums of family and friends; or favorite treats.
- » Advise people not to give gifts such as dangerous tools or instruments, utensils, challenging board games, complicates electronic equipment or pets.
- Depending on their abilities and preferences, involve the person in gift giving. For example, someone who once enjoyed baking may enjoy helping to make cookies and pack them in tins or boxes. Or you may want to buy the gift so that the person can wrap it.
- Suggest to friends and family that they get you gift certificates or something that will help make things easier, like house cleaning; lawn or home maintenance; laundry services; restaurants or food delivery gift cards.

Familiarize others with the situation

- The holidays are full of emotions, so it can help to let friends and family members know what to expect. If the person is in the early stages of dementia, relatives and friends might not notice any changes. If the person is experiencing moderate or severe symptoms, though, there may be significant changes since their last interactions with some family members.
- Make sure friends and family understand that changes in behavior and memory are caused by the disease and not the person. People can help with communication by being patient, not interrupting or correcting, and giving the person time to finish their thoughts.
- You may find it easier to share changes in a letter or email that can be sent to multiple people. You can find an example letter on the next page.

Involve the person living with dementia

- Ask them to help prepare food, wrap packages, decorate or set the table.
- » Avoid using candies, artificial fruits and vegetables as decorations because the person with dementia might confuse them with real food. Lots or blinking lights may also confuse the person.
- When making holiday plans, consider what will be most comfortable and enjoyable for the person living with dementia. Maintain the person's normal routine as much as possible so that holiday preparations don't become disruptive or confusing.
- Focus on the things that bring happiness and let go of activities that seem overwhelming, stressful or too risky. Taking on too many tasks can wear on both of you.
- » Build on traditions and memories while experimenting with new traditions that might be less stressful or a better fit with your caregiving responsibilities, such as watching seasonal movies together.

Example email to send to friends and family before the holidays

"I'm writing to let you know how things are going at our house. While we're looking forward to the holidays, we thought it might be helpful if you understood our current situation in advance.

You may notice that [the person living with dementia] has changed since you last saw them. Among the changes you may notice are [memory lapses; difficulty finding the right word; taking longer to respond; trouble with familiar tasks; misplacing items; problems remembering names or calling people by the wrong name]. I've enclosed a picture so you know how [PLWD] looks now. Because [PLWD] sometimes has problems remembering and thinking clearly, their behavior is a little unpredictable.

Please understand that [PLWD] may not remember who you are and may confuse you with someone else. Please don't feel offended by this. They appreciate your time with us and so do we. Please treat [PLWD] as you would any person. A warm smile will be appreciated more than you know. You can find some resources on communicating with somebody with dementia at alz.org/help-support/resources.

We would ask that you call when you're nearby so we can prepare for your arrival. With your help and support, we can create a holiday memory that we'll all treasure."

Communication tips



- Do not try to reason.
- · Do not arque.
- Do not confront.
- Do not remind them that they forget.
- Do not question their recent memory.
- Do not take it personally.



- · Give short, one sentence explanations.
- · Repeat instructions or sentences.
- Allow plenty of time for comprehension.
- Agree with them and redirect them to another subject or activity.
- Accept the blame when something is wrong (even if it is a fantasy)
- Leave the room, if necessary, to avoid confrontations.
- Respond to the feelings rather than the words they say.
- Be patient, cheerful and reassuring.
 Go with the flow.
- Elevate your level of generosity and graciousness.
- Stay in the present and be mindful.
 Take time to care for yourself.

REMEMBER

- They are not crazy or lazy. They are saying and doing things that are normal for a person with dementia. If they were doing or saying things to deliberately aggravate you, they would have a different diagnosis.
- Their reality is now different than yours, and you cannot change them. You cannot control the disease. You can only control your reaction to their symptoms.
- They cannot remember and they cannot remember that they can't remember. They will ask the same question over and over - thinking it is the first time they have asked it.
- They are likely frightened and confused all the time. Each person reacts differently to fear. They may become passive, hostile, angry, uncooperative, agitated, verbally or physically combative. Their anxiety may compel them to shadow you. They cannot remember your reassurances, so you will have to repeat them.

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