

Preparing for Family Gatherings – Holidays with a Person with Alzheimer's



by Jill Lorentz



For most families, the holidays are filled with opportunities for togetherness, sharing laughter and memories. For people caring for the 100,000 Coloradoans with Alzheimer's disease, the holidays can also be filled with stress, disappointment and sadness. Because of the changes caused by Alzheimer's, families as well as the person with the disease, may feel a special sense of loss during the holidays. Caregivers may also feel overwhelmed by trying to maintain holiday traditions while providing care. In addition, there may be some hesitation about inviting family and friends over to share the holiday for fear they will be uncomfortable with the changes they see in the person with the disease.

Here are some suggestions for creating happy, contented and memorable holidays from people caring for someone in the early stages of Alzheimer's:

Don't feel compelled to hang onto established family traditions if they are no longer practical. Be willing to substitute or start a new activity that may become a tradition. One thing I did in years past was to put gifts in bags instead of wrapping them. This saved me lots of time. I collect bags from year to year so this also recycles. By using bags you could help the person with dementia feel part of the festivities.

Preparing Family and Friends:

Familiarize friends and family with changes in behavior and appearance that they may notice in your loved one. Give them tips for communicating and how to watch for increased anxiety or situations that might cause frustration and methods for helping calm your loved one down.

Familiarize others with the situation

The holidays are full of emotions, so it can help to let guests know what to expect before they arrive.

If the person is in the early stages of Alzheimer's, relatives and friends might not notice any changes. But the person with dementia may have trouble following conversation or tend to

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repeat him- or herself. Family can help with communication by being patient, not interrupting or correcting, and giving the person time to finish his or her thoughts.

If the person is in the middle or late stages of Alzheimer's, there may be significant changes in cognitive abilities since the last time an out-of-town friend or relative has visited. These changes can be hard to accept. Make sure visitors understand that changes in behavior and memory are caused by the disease and not the person.

You may find this easier to share changes in a letter or email that can be sent to multiple recipients. Here are some examples:

>> "I'm writing to let you know how things are going at our house. While we're looking forward to your visit, we thought it might be helpful if you understood our current situation before you arrive.

>> "You may notice that	has changed since you last saw him/her. Among the
changes you may notice are	<u>.</u> .

>> "Because ____ sometimes has problems remembering and thinking clearly, his/ her behavior is a little unpredictable.

>> "Please understand that ___ may not remember who you are and may confuse you with someone else. Please don't feel offended by this. He/she appreciates your being with us and so do I."

Adjust expectations

The Gift of Perspective

The stress of caregiving layered with holiday traditions can take a toll

Call a meeting to discuss upcoming plans.

The stress of caregiving responsibilities layered with holiday traditions can take a toll.

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Invite family and friends to a face-to-face meeting, or if geography is an obstacle, set up a telephone conference call. Make sure everyone understands your caregiving situation and has realistic expectations about what you can do. Be honest about any limitations or needs, such as keeping a daily routine.

Be good to yourself.

Give yourself permission to do only what you can reasonably manage. If you've always invited 15 to 20 people to your home, consider paring it down to a few guests for a simple meal. Let others contribute. Have a potluck dinner or ask them to host at their home. You also may want to consider breaking large gatherings up into smaller visits of two or three people at a time to keep the person with Alzheimer's and yourself from getting overtired.

Do a variation on a theme.

If evening confusion and agitation are a problem, consider changing a holiday dinner into a holiday lunch or brunch. If you do keep the celebration at night, keep the room well-lit and try to avoid any known triggers.

Involve the person with dementia

Build on past traditions and memories.

Focus on activities that are meaningful to the person with dementia. Your family member may find comfort in singing old holiday songs or looking through old photo albums.

Involve the person in holiday preparation.

As the person's abilities allow, invite him or her to help you prepare food, wrap packages, help decorate or set the table. This could be as simple as having the person measure an ingredient or hand decorations to you as you put them up. (Be careful with decoration choices. Blinking lights may confuse or scare a person with dementia, and decoration choices.)

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tions that look like food could be mistaken as edible.)

Maintain a normal routine.

Sticking to the person's normal routine will help keep the holidays from becoming disruptive or confusing. Plan time for breaks and rest.

Adapt gift giving

Reduce post-holiday stress.

Arrange for respite care so you can enjoy a movie or lunch with a friend.

Encourage safe and useful gifts for the person with dementia.

Diminishing capacity may make some gifts unusable or even dangerous to a person with dementia. If someone asks for gift ideas, suggest items the person with dementia needs or can easily enjoy. Ideas include: comfortable clothing, audiotapes of favorite music, videos and photo albums.

Put respite care on your wish list.

If friends or family ask what you would like for a gift, suggest a gift certificate or something that will help you take care of yourself as you care for your loved one. This could be a cleaning or household chore service, an offer to provide respite care, or something that provides you with a bit of rest and relaxation.

Ask if they might put their name on a calendar and make routine weekly, bi monthly or monthly visits for an hour or two at a time. Have some activities planned that would provide meaningful engagement for your loved one.

When the person lives in a care facility

A holiday is still a holiday whether it is celebrated at home or at a care facility. Here are some ways to celebrate together:

Consider joining your loved one in any facility-planned holiday activities

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Bring a favorite holiday food to share

Sing holiday songs and ask if other residents can join in

Read a favorite holiday story or poem out loud

Help the staff decorate the community for the holidays.

Help the activities staff or your loved one to create crafts that are simple like cards or pine cone art, paper crafts and such.

Take some holiday cards to your loved one and ask them to mark or try to sign them and send them out to relatives and friends.

String fruit loops or cheerios on string to make necklaces, which could be a gift from your loved one.

Preparing Family and Friends:

Familiarize friends and family with changes in behavior and appearance that they may notice in your loved one. Give them tips for communicating and how to watch for increased anxiety or situations that might cause frustration and methods for helping calm your loved one down.

Communication Tips:

Communicating with a person affected by Alzheimer's disease requires patience and understanding. First and foremost, you must be a good listener. When helping the person communicate:

- Be patient and supportive
- Show your interest by maintaining eye contact
- Offer comfort and reassurance

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- Give him/her time
- Avoid criticizing or correcting.
- Don't argue. Arguing often only makes things worse
- Offer a guess if he/she is struggling to find a word
- Focus on feelings, not facts
- Limit distractions
- Encourage him/her to communicate nonverbally

Some additional ideas:

- Be calm and supportive
- Focus on feelings, not facts
- Pay attention to tone of voice, yours and his/hers
- identify yourself and address the person by name
- Speak slowly and clearly
- Use short, simple and familiar words
- Ask one question (yes or no) at a time and...
- Allow enough time for a response
- Use nonverbal communication such as pointing and touching
- Offer assistance as needed
- Don't talk about the person as if he/she was not there
- Have patience, flexibility and understanding

Time Your Celebrations:

Celebrate early in the day to reduce the likelihood of — Sundowner Syndrome (evening confusion)

- Have a holiday lunch rather than a dinner
- Serve sparkling apple juice or nonalcoholic beer or wine
- Keep the lights on to keep the room bright and the television off

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Embracing New Traditions:

- Ask everyone to wear a name tag. Make a game/craft out of it.
- Make sure everyone understands your caregiving situation and understands what works and what doesn't
- Run through celebrations and rituals of years gone by and determine which of these to continue and what new traditions may be initiated
- Set limits as to what you are able to do and what is not possible for you and your loved one
- Consider holding a simpler gathering with fewer people
- Discuss having a potluck dinner or ask others to host the holiday at their home
- Look for ways to simplify shopping and gift-giving
- Ask other for help with those extra holiday tasks or errands

Gift Giving Ideas for the Caregiver

- Book or magazine subscription
- Gift certificate from a favorite store or day spa for a massage
- Something the household budget might not allow (massage, spa treatment, etc.)
- A supply of frozen and dated home-made meals
- Regular visits to the loved one in a long-term care facility
- Safety/assistive devices (e.g. exit alarms, hand-held shower, safety knobs)
- Your time (e.g., stay at the home so the caregiver can attend a support group meeting, a movie, a day spa)
- A coupon for coffee or a movie with a friend

Ideas for the Person with Alzheimer's

- Sneakers with Velcro or easy care clothing
- Tickets to a ball game, circus or concert (for those in the early stages of the disease)
- Music CDs

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- Books with large pictures and few words
- Photo albums with pictures of children at different stages
- Modeling clay, watercolor paints
- Short car trips
- Simple and familiar games (early stage)
- A visit with your pet
- Your attention, company and hugs
- Pass to a State or National Park
- Seasonal pass to the zoo or membership at a local museum

Items to help make dressing a little easier:

- Easy-to-remove clothing in comfortable, machine washable fabrics
- A jogging suit that pulls on or has Velcro fastenings
- A brightly colored cardigan sweater
- Slip-on shoes/slippers with Velcro closing
- Slipper socks with non-skid soles
- Leg warmers
- Clips to attach gloves to a coat
- Yak tracks or other nonslip shoe covers
- Invite children to visit only briefly or hold events that are adults only.
- Consider multiple small holiday meals with fewer people.
- Make nametags for everyone attending
- Ask adult children to rotate buddying up with the person struggling with memory loss. They can help monitor anxiety, overstimulation and tiredness as well as triggers for wander-ing, a risk if no one has been specifically tasked with staying close to the person with the disease.
- Bring a special dinner to the assisted living or care facility in-stead of taking the person with the disease out to a crowded restaurant.

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• Have a quiet room so the person with dementia can relax or visit quietly with one or two people.

Holiday Decorations

- Remove all poisonous holiday decorations such as live poin-settias and mistletoe.
- Avoid accidental poisoning by substituting fake plants for the real thing or putting live plants far out of reach.
- Use flame-retardant artificial trees; if using cut trees, keep water reservoir full.
- Do not decorate with candles even if you never intend to light them.
- Maintain the normal paths and walkways as much as possible to avoid fall risks.

Quiet Time:

Plan for some quiet-time activities.

- Have a favorite DVD, CD, or record on hand
- Be prepared with some simple repetitive activity to maintain calmness: cracking nuts, folding napkins, or shelling peas
- Leave time to allow yourself and your loved one to take a walk
- Keep photo albums handy go through them together