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Celebrating Dementia Friendsgiving

A Holiday Guide brought to you by

Dementia Friendly America











Dementia Friendsgiving:A Holiday for All of Us

The holidays can be especially challenging for people living with dementia and their caregivers, families, and communities. When families and friends make plans to gather, they often have concerns about including a loved one living with dementia because they don't know how to make it a joyful event for everyone. These concerns often lead to family conflict, isolation of loved ones, and disruption of cherished holiday traditions. Just like a regular Friendsgiving or Thanksgiving celebration, Dementia Friendsgiving is a holiday gathering of community, friends, chosen family,

What Is Dementia?

Dementia is the name for a collection of symptoms that include memory loss, mood changes, and problems with communication and reasoning. These symptoms are brought about by a number of diseases that cause changes in the brain. The most common is Alzheimer's disease.

About 10 million Americans live with dementia. It may be harder for them to do certain things, but with the right support and know-how, it's possible for someone with dementia to live well with a good quality of life. Despite this, the stigma and lack of understanding surrounding dementia often leave people living with dementia and their care partners socially isolated and unsupported.

and/or birth family. The difference is that a Dementia Friendsgiving has been adapted so that people living with dementia and their care partners can join and participate in a way that's meaningful for them and their family and friends.

This toolkit was developed by <u>Dementia</u>
<u>Friendly America</u> (**DFA**), which fosters
community support for people living with
dementia and their care partners so they
can safely remain in and engage with their
community. DFA is a program of <u>USAging</u>.

We hope you will use this toolkit as a guide for reclaiming the holidays for your close

friends and family at home or reducing social isolation for a larger group out in your community.

A great way to start is by completing a free, online <u>Dementia Friends session</u>. This will give you a foundation in dementia and the needs of people who live (and can thrive!) with it.

Welcome to the dementia-friendly movement! We're so glad you're joining us.





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Hosting Dementia Friendsgiving in Your Home (for close friends and family)

Adapting important holiday traditions to account for changes in your family and friend groups may feel daunting at first, but some relatively simple changes

Each person's dementia is different.

Symptoms change over time and may even change at different times throughout the day. We offer the ideas in this toolkit as general guidelines for planning your Dementia Friendsgiving but suggest you attune to and prioritize the specific needs of your person living with dementia. If they have a partner or caregiver, run your plan by them and make sure they think it fits.

Use what works and change what doesn't!

can help you include family or friends living with dementia in a way that's meaningful for everyone.

Before you start planning, we recommend completing DFA's free, online <u>Dementia Friends</u> <u>session</u>. It takes about an hour and will give you an important foundation in dementia and the needs of people who live (and can thrive!) with it.

Start by deciding whether to adapt an existing holiday gathering or host an additional dementia-friendly holiday gathering. If you

usually host a small group for the holiday, it may be relatively simple to make that a dementia-friendly gathering. If you usually have a large, boisterous crowd, we recommend either:

- Starting your event with a smaller dementia-friendly gathering of the people closest to your person living with dementia and their care partner.
- Hosting a separate, smaller dementia-friendly gathering in addition to your usual larger gathering.

As you plan, here are some ideas to keep in mind:

Guests

- Let your guests know in advance that this will be a dementia-friendly holiday gathering.
- Share the free <u>Dementia Friends session</u> and <u>Dementia-Friendly</u>
 Communication Tips (page 9 of this toolkit) with guests in advance.



- Ask one or two guests to help you watch for signs of stress or fatigue in your person living with dementia.
- Keep the guest list relatively small. Large, noisy crowds can be overwhelming.

Timing

- Schedule your gathering to accommodate the rhythms of the person living with dementia. Keep the meal time close to their normal routine, especially if sundowning is a concern.
- An all-day affair may be too much. Plan for a meal and one or two activities.
- Prepare to be flexible. Your person living with dementia may need to leave early or arrive late.

Dining

- If your person living with dementia has mobility challenges:
 - Prepare food that's easy to eat and not too messy. Finger foods like mini quiches, sliders, veggie sticks, or hand pies are simple options.
 - o Provide lightweight, easy-grip cutlery.
- Offer to prepare a plate for the person living dementia. For some, serving smaller portions at a time can prevent overwhelm.
- Seat the person near a care partner or supportive friend/family members. If you know they need quiet/calm, a seat near the end of the table may be most comfortable for them. Others may appreciate being in the middle, surrounded by loved ones.
- Turn down background music during the meal to reduce sensory overload.



Environment

- Designate a quiet/sensory room (or a corner if there's not a separate room available) where the person living with dementia can rest if things get too stimulating. Have soft lighting, a comfortable chair, a cozy blanket and pillows, and some sensory items like plush fidgets or weighted lap pads. Offer headphones if music would help.
- Some of the comfort and sensory items above can be made available in the main gathering space, as well.
- Avoid harsh lighting and highly reflective surfaces when possible.
- Clearly label the ways to and from (both into and out of) key areas like the dining room, quiet room, and bathroom.
- Play music the person living with dementia will enjoy, like hits from their younger years or family favorites.
- Pass out name tags with clearly printed, high-contrast writing to make group mingling easier for everyone.

Activities

- Plan activities everyone can do together, whether or not they are living with dementia. Examples include:
 - Decorating cookies or ornaments.
 - Sorting change. Ask everyone to bring all their spare change. Sort it, count it, and donate to a good cause!
 - Sensory boxes with seasonal items to explore and discuss (smooth pinecones, soft scarves, cinnamon sticks for smell).
 - Ask everyone to share a favorite holiday memory or something they'd like to do for a future holiday.



- Any open-ended question with no right or wrong answer can be an inviting place to start a conversation. TimeSlips calls these "beautiful questions."
 - To hear how one of these conversations might go, listen to Sam Goodrich from TimeSlips talk to her Aunt Eleanor Guilbert about the question "How do you give thanks?"
 - You can also <u>watch this short explanation</u> of beautiful questions from PBS.
 - Come up with your own beautiful questions, or <u>choose from this list</u> in the TimeSlips Creativity Center. (In the "All Categories" drop down menu, select "Ask A Beautiful Question" and click the Submit button.)

Last But Not Least

Have fun! When you do your best to act with kindness and be flexible when things don't go as planned, the details don't matter nearly as much as the fact that you're bringing your family and friends together again, reducing social isolation, and taking part in a new way of connecting and creating meaning.



Hosting Dementia Friendsgiving in Your Community

Before planning a Dementia Friendsgiving in your community, we recommend these first steps:

- Find out if there are Memory Cafes in your immediate area. If there are, reach out to the host and ask if they would be willing partner with you to create a Dementia Friendsgiving through their cafe. They will have experience and resources that will benefit your event. If there is no Memory Cafe that you can partner with, use this guide to host a Dementia Friendsgiving on your own.
- You can also <u>create a free Memory Cafe account</u> to access more detailed training on hosting dementia-friendly events.
- Complete DFA's free, online <u>Dementia Friends session</u> to become a Dementia Friend. This will give you an important foundation in dementia and the needs of people who live (and can thrive!) with it. **Be sure to share this resource** with your volunteers and attendees before the event, and encourage them to become Dementia Friends, as well!

When hosting a Dementia Friendsgiving, be guided by the following principles:

- Plan with social connection in mind. This isn't an educational event or a sales pitch; it's a chance to reduce social isolation and create meaningful experiences.
- Choose activities everyone can participate in, no matter how mild or significant their symptoms are.
- Go with the flow. Read the room and be ready to pivot if what you've planned isn't working – or if something new emerges that feels alive for most people in the room.

Thoughts on who should attend

 Invite dyads: one person living with dementia and their care partner. That way, there's always someone who knows each person living with dementia, and caregivers get to enjoy the event as well!



- If this is your first event like this, plan to keep it small—a maximum of 10 dyads—so it's easier to keep the event relatively calm and manageable.
 Consider asking dyads to RSVP (and capping the number) so you know exactly how many people might be there.
- You do not need to confirm that people have dementia, or even which person
 in a dyad is the care partner and which is the person living with dementia. This
 way, you can include people who have not been diagnosed, are not aware of
 their diagnosis, or are not comfortable talking about it.
- Find attendees by reaching out to in-person establishments like senior centers and churches and by posting online in neighborhood groups on Facebook or Nextdoor.
- You'll also need trusted volunteers at the event! Be sure to have some extra help on hand. Share the free <u>Dementia Friends session</u> and <u>Dementia-</u> <u>Friendly Communication Tips (page 9 of this toolkit)</u> with volunteers in advance.

Location, location, location

- When selecting a place for your Dementia Friendsgiving, consider accessibility
 of all kinds:
 - Parking and public transportation routes
 - Physical access to the building, bathrooms, and ideally a separate quiet room or area
 - Rooms you're allowed to rearrange for the comfort of participants and to facilitate activities
 - Good lighting and acoustics
 - o No highly reflective surfaces or distracting décor
- Consider free or low-cost locations designed for people of all ages and abilities:
 libraries, community centers, church basements or classrooms, etc.
- Be sure you're allowed to bring food!



Setting up the space

- Have clear signage directing people into *and out of* the right rooms (event room, bathroom, quiet/sensory space, etc.)
- Distribute name tags and bold markers for writing names on them.
- Offer a quiet room or area in case someone gets overstimulated.
- Provide sensory comfort items like soft blankets, weighted lap pads, plush fidget toys, LED candles, etc. (Google "sensory items for people with dementia" for more ideas.)
- Make room for food and drinks! It's Thanksgiving, after all.
 - Serve simple variations on traditional Thanksgiving foods. If that's too difficult, familiar foods from the cultures of your participants are always a hit.
 - Offer food that's easy to eat and not too messy, as some attendees may have mobility challenges.

Holding the event

- Eat at a communal table or tables so attendees can socialize with each other.
- Designate time for movement. Lead stretches that can be done sitting down and/or play music that will inspire your attendees to dance!
- Break into small groups and collectively answer beautiful questions. These are open-ended questions with no right or wrong answers that help people be themselves and connect with others.
 - For an example of how one of these discussions might go, listen to Sam Goodrich from TimeSlips talk to her Aunt Eleanor Guilbert about the question "How do you give thanks?"
 - Watch this short explanation of beautiful questions from PBS.
 - Come up with your own beautiful questions, or <u>choose from this list</u> in the TimeSlips Creativity Center. (In the "All Categories" drop down menu, select "Ask A Beautiful Question" and click the Submit button.)



Up Next

If you're inspired after hosting this event, consider building on your experience by starting a <u>Memory Cafe</u> that meets regularly!



Dementia-Friendly Communication Tips (Share these with attendees in advance!)

Communication and connection are central to great holiday experiences.

Communicating with a person living with dementia requires patience, understanding, and good listening skills. You may notice that a person living with dementia may:

- Use familiar words repeatedly
- Invent new words to describe familiar objects
- Easily lose their train of thought
- Revert to a first (or birth) language
- Have difficulty organizing words logically
- Respond with unexpected behaviors

Even so, exchanging ideas, wishes, and feelings is a basic human need! Some tips for communicating with people living with dementia:

- Treat the person with dignity and respect. Avoid talking past the person as if they aren't there.
- Be aware of your own feelings. Your tone of voice may communicate your attitude. Use positive, friendly facial expressions.
- Be patient and supportive. Let the person know that you are listening and trying to understand. Show that you care about what he or she is saying and be careful not to interrupt. It may take the person up to 20 seconds to take in what you have said and get out their response.
- Offer comfort and reassurance. If they become frustrated or insecure, reassure them that it's okay and encourage the person to continue.
- Avoid criticizing or correcting. Don't tell the person what he or she is saying is incorrect. Instead, listen and try to find the meaning in what is being said.



- Avoid arguing. If the person says something you don't agree with, let it be.
 Arguing usually only makes things worse and often increases agitation for the person living with dementia.
- Encourage nonverbal communication and give visual cues. If you don't understand what is being said, ask the person to point or gesture. You can also point or touch an item you want the person to use.
- When approaching and starting a conversation, come from the front, identify
 yourself, and keep good eye contact. If the person is seated or reclined, go
 down to that level.
- Provide a statement rather than ask a question. For example, say "The bathroom is right here," instead of asking, "Do you need to use the bathroom?"
- Avoid confusing and vague statements about something you want the person to do. Instead:
 - Speak directly. For example, "Please come here. Your dinner is ready."
 - Name an object or place. For example, rather than "Here it is" say "Here is your coat."
- Turn negatives into positives. Instead of saying, "Don't go there," say, "Let's go here."
- Avoid quizzing. Reminiscing may be healthy, but avoid asking, "Do you remember when?"
- Remember that unexpected behaviors are often a form of communication. You
 might notice that the person does not respond to you, or they may respond by
 pushing you away, crying, or making sounds. If a person can no longer tell you
 it hurts to sit in a particular chair, they may refuse to approach it. If everyone is
 moving quickly and the room is loud, a person who can't tell you to calm down
 may cry.



Focus on creative conversations. A person may not be able to remember what
they did yesterday, but they can have fun describing a dream vacation, making
up stories about people walking outside, or telling you what they think about
the fashion choices in a magazine.

More than Meets the Eye

Above all, remember that there's more to a person than their dementia! Although they may lose certain capabilities and need to communicate in new ways, they retain many of their emotions and instincts to connect, care, and sense respect from others. For example, even if a person living with dementia cannot remember your name, they can remember feelings of love and comfort from a supportive visit. Similarly, they would remember feelings of anger and hurt from an argument.



Additional Resources

TimeSlips Training for Friends and Family

Our friends at TimeSlips offer a free, self-paced training to help family and friends of people living with dementia connect in new, joyful ways.

How's Your Mom? (This American Life)

Janelle Taylor shares beautifully about how she connects with her mother, who has dementia.

Video: Storytelling soothes seniors with dementia (TODAY Show)

<u>Video: Storytelling helping memory care patients</u> (YouTube)

Learn about TimeSlips creative storytelling techniques from these videos.

Communicating and Dementia (Alzheimer's Society)

This fantastic explainer covers how dementia affects communication, plus how to (and how not to) talk to people living with dementia.

Words Matter (Dementia Action Alliance)

How to talk about dementia (Dementia Australia)

Dementia words matter: Guidelines on language about dementia (Dementia

Engagement & Empowerment Project)

These guides cover constructive and productive ways to talk about dementia and the people living with it.

<u>Dementia Friendly Physical Environments Checklist</u> (Dementia Action Alliance)

This list describes small changes that make big improvements to accessibility for people living with dementia.

About Dementia Friendly America (DFA)

DFA envisions an America where individuals living with dementia and their care partners can live, engage, and thrive in their communities. We are a national network of communities, organizations, and individuals seeking to ensure that communities across the U.S. are equipped to support people living with dementia and their care partners. Learn more about our work at defamerica.org. DFA is a program of USAging.