

## December 2017 Alzheimer's Talks

Welcome to Alzheimer's Talks, a free monthly teleconference presented by UsAgainstAlzheimer's. This is George Vradenburg, chairman and co-founder of UsAgainstAlzheimer's, and I'm so glad that you could join us today.

I'd like to provide you with just a couple of quick updates and then will introduce our guest, Lakelyn Hogan from Home Instead.

Yesterday, UsAgainstAlzheimer's released a new report with the [USC Edward R. Roybal Institute on Aging](#). This first-of-its-kind analysis shows that one out of six millennial caregivers cares for someone with dementia. With the prevalence of Alzheimer's disease and other dementias expected to triple by 2050, more millennials and young Americans are expected to face caregiving responsibilities in the future. The [full report](#) is available on our website, [www.UsAgainstAlheimers.org](http://www.UsAgainstAlheimers.org). The report will give you more information on the caregiving activities that young people are performing, how those activities interfere with their workforce participation, and policy and programmatic recommendations to address these challenges. Recognizing that Alzheimer's is an urgent economic and public health issue impacting families across all generations, [we launched yesterday the Youth Against Alzheimer's Coalition](#), with the Youth Against Movement Against Alzheimer's and other youth-serving organizations.

Another major news item in the last week is that the U.S. Postal Service just debuted, last Thursday, an [Alzheimer's semi-postal stamp](#). This has been a long advocacy effort led by UsAgainstAlzheimer's advocates Lynda Everman and Kathy Siggins. The funds raised by this stamp will support research at NIH, so I encourage you to [buy some stamps](#) and share with your friends. Get off e-mail. Send your letters, your Christmas cards, your Hanukkah cards, your Kwanzaa cards, with a stamp—an Alzheimer's stamp.

Now, let me introduce Lakelyn Hogan. I'm so happy that Lakelyn has joined us today. She's a gerontologist and caregiver advocate at Home Instead Senior Care. In this role, Lakelyn educates professionals, families and communities on issues that older adults face. Lakelyn has a master's degree in Social Gerontology as well as a master's in Business Administration, and she is currently pursuing a doctorate at the University of Nebraska Omaha, where she is studying social gerontology. She has worked on special projects for the University of Nebraska Omaha's Department of Gerontology, the Douglas County Older Adult Mental Health Coalition and the local Area Agency on Aging. She has a true passion for helping others, especially aging adults and their families. Lakelyn and Home Instead have been great partners with UsAgainstAlzheimer's across a wide number of areas. If you don't already receive the great e-mails that Lakelyn sends out, I highly encourage you to go to [www.HelpForAlzheimersFamilies.com](http://www.HelpForAlzheimersFamilies.com) and sign up. That's [www.HelpForAlzheimersFamilies.com](http://www.HelpForAlzheimersFamilies.com). She offers very concrete tips and suggestions based upon questions from readers.

Today we are lucky enough to have Lakelyn for the next hour, when she will discuss how to make the holidays more enjoyable for someone with Alzheimer's disease, discuss what to watch for when visiting older relatives, and answer your questions. So, if you have a question during the call, please press \*3 on your phone. That's \*3, not #3. By pressing \*3 you will be placed into a question queue. Please have your questions ready to share briefly with a member of our staff, or if you are listening to us online, you can type your question in the box, and we will get to as many questions as possible today. Just for your information, we have over 500 people registered today from 48 states and three countries—Austria, Belgium and Canada —so obviously the interest in this topic is widespread, deep and international.

Thank you so much for joining us today, Lakelyn. We look forward to your comments.

**Lakelyn:** Thank you so much for having me. It's a true honor, and I'm excited to address everyone's questions and offer up some tips and advice here today. So thanks for having me.

**George:** So, if you could go ahead, Lakelyn, and just describe what Home Instead does, what Home Instead is, and how you work.

**Lakelyn:** I would be happy to. Home Instead Senior Care is the world's largest provider of home care services. We're in 12 countries and have about 1200 locations worldwide, so I was excited to hear that there are some international participants on this call since our organization does have an international footprint. The services we provide are very personalized, and our goal is to enhance the lives of aging adults and their families by keeping them safe and independent, wherever they call home.

So we assist with independent activities of daily living—which includes things such as light housekeeping, meal preparation, medication reminders, transportation—and then also those more personalized services, such as bathing, grooming, restroom assistance and those types of things. Our caregivers are professionally trained, so our offices hire professional caregivers to send them into the homes to provide these needed services. We also provide a specialized Alzheimer's training to our caregivers because we know that people living with Alzheimer's disease and other dementias have some differing needs beyond our average clients'. So, we understand the needs of a person living with dementia and their families, and we work to personalize their care plan to meet those needs.

In addition to providing our home care services, we are very passionate about providing free public education on a variety of aging issues, especially related to Alzheimer's disease and dementia. As George mentioned, we have a great website, [www.HelpForAlzheimersFamilies.com](http://www.HelpForAlzheimersFamilies.com), where families can go for resources, expert advice, free online training, and that sort of thing. So, that's Home Instead in a snapshot and how we're related to Alzheimer's and dementia.

**George:** So let me ask you, the holidays are coming up. These are sometimes tricky, difficult and eye-opening for those who might have a person in the family that either is beginning to experience Alzheimer's or has Alzheimer's. Tell us how you advise these families to cope with the holidays.

**Lakelyn:** We know that this time of year, the holiday season, is full of hustle and bustle. It can be stressful for all of us, really, but in particular it can be stressful for families like you said, George, who have someone in their family, a loved one, with dementia or Alzheimer's disease. It can sometimes be difficult to look forward to the holidays when a beloved family member is not him/herself or is displaying difficult or unusual behaviors due to their dementia or Alzheimer's disease. Memories of better times might surface as we're reminded of what's been lost or what's changed in our loved ones, and, at a time when we feel we should be happy, instead, families might find themselves stressing. They might find feelings of disappointment and sadness that surface at this time. While I want to definitely keep this a positive conversation—because there's a lot of great tips out there and resources that I'm going to share with you that can make the holidays enjoyable—I do want to recognize that caregivers are feeling this rollercoaster of emotions that come with caregiving in general, but particularly at this time of year we see those emotions bubble to the surface. So I want family caregivers and care partners to realize these feelings that they're feeling are completely normal, and it's okay to have these feelings, but at the same time it's still very possible to find joy in the holiday season and involve your loved one with dementia or Alzheimer's in the festivities. So today I'm going to share some tips on how to reduce the stresses of caregiving over the holidays and really make it more enjoyable for the entire family—the person living with the disease and their care partners.

So I'm going to start with a high-level overview of some general tips, and I know we're going to open up those phone lines for questions in a little bit. So I pulled together some of the top topics as they relate to the holidays that I get asked about most frequently.

For starters, I always encourage care partners and families to involve their loved one in the holiday festivities the best that they can. Families should recognize that they may need to modify activities or traditions according to the abilities of their loved ones. We know that traditions are so important to families, but it can be stressful to carry on some of the traditions, especially hosting duties. So we need to keep in mind our loved ones' limitations, and, at the same time, try to modify these family gatherings and activities so that they can still participate and feel involved in the holiday celebrations and traditions.

I have a couple of examples. I'd like to paint this picture a bit, of how we can modify some activities or traditions that families might have. For example, if your mother who's maybe living with dementia has always cooked and hosted the holiday meal, perhaps families could consider adjusting that tradition. Maybe Mom still hosts, but everyone chips in to cook, so that she doesn't have to do that anymore. Or, if the dad, the father figure of the family, always used to hang the Christmas lights and decorate outdoors every year, perhaps this time the family chips in, and Dad can still help untangle the lights and participate, but a different family member maybe climbs the ladder, or the family can find easier areas of the home to decorate—maybe bushes, railings, something a little closer to the ground.

If Aunt Sally used to bake cookies every year, but maybe she's having trouble remembering the ingredients, remembering how to bake cookies, somebody could join her in the cookie-baking. Have her still stir the bowl, dump the ingredients in, but maybe somebody else helps with the measuring, helps with taking the pans in and out of the oven, so that way she's still participating.

Gift-wrapping is another great area where families can involve their loved ones in holiday festivities. Families could offer their loved ones simple choices—that's a great suggestion around the holiday times. So if you're wrapping gifts, you could ask for their opinion: should we use the red bow or green bow, could you help me hold the paper down here while I tape it, that sort of thing. Again, keep them involved in the activities,

but modify those traditions so they can still participate and feel very much a part of the celebrations.

Another thing to keep in mind over the holidays is the person's daily routine. This time of year, of course, can be hectic, and we know that people living with Alzheimer's disease or dementia really benefit from a routine. And they get used to that daily routine. If families can keep that routine the best that they can, it will make things go more smoothly. If families can rearrange their gathering around that daily schedule, it can really help make it more enjoyable. For example, if the person is most alert in the morning—maybe that's when they have more clear conversations and less agitation—perhaps have a holiday brunch gathering instead of a late lunch or dinner. If the person typically eats at a certain time, perhaps the family makes sure that the meal happens around their typical meal time, to help keep that routine. That will really help with the stresses of the holidays.

Another thing it's important for families to remember is they need to be prepared and be flexible over the holiday season. If you're taking your loved one outside of the home for a gathering, be sure that you're prepared. If the person has a routine of napping every day at one o'clock, you might want to check with the host of the location you're going to, to see if there's a place where they can have some down time, some quiet time around one p.m.—maybe it's a bedroom or a smaller area of the environment—again, just so that person can stay in their routine.

Another way you can be prepared is, if the individual has certain comforts that they enjoy—maybe a certain type of music, snack, or activity—perhaps bring that along to the family gathering or holiday celebration. If the person gets a little agitated or frustrated, you can bring out that comfort to try to soothe them and maybe remove them to a quieter area of the gathering.

As you're preparing to leave the home or get ready for the next day's holiday activity, make sure you allow yourself plenty of time. As we're rushing about during this holiday

season, sometimes we have to be flexible. If we're able to give ourselves plenty of time, to get washed up for the holiday gathering and get everything we need in the car, having that extra buffer of time can be a blessing at this crazy time of year. So, being prepared—that's another tip that family members can take away from today's chat.

Then, one great thing about the holidays is that it's a time for all of us to really reminisce. It's a great time of year to dust off the old photo albums and share holiday memories. You can ask all sorts of questions about favorite gifts that they received as a child or ask them how their house was decorated for Christmas or Hanukkah when they were young. You can talk about favorite family recipes; if they are able, you could make those recipes together. Holiday music this time of year brings back so many memories. You can pull out the old Bing Crosby Christmas songs or whatnot; it really can bring out those happy memories and open up conversations. You can talk about time spent caroling, or ice skating on Christmas Day, and use the opportunity to document some of these special stories—on paper or record a video of your loved one. It's a great time of year to reminisce, tell stories and capture that loved one's past, preserving those memories. It can truly be a gift to learn new things about your loved one's past as you reminisce.

Another tip is to utilize the senses of the season. I say this because some, especially those that are in the later stages of Alzheimer's disease, might have lost their ability to communicate. That suggestion I gave to reminisce about the holidays—they might not be able to share, verbally, those memories and traditions. But, if we can use the senses, we can still bring that person back, in their mind. They might not be able to verbalize it, but we can bring those feelings of warmth and joy of the holidays through the senses.

I want to give some examples. Our sense of sound: you can play holiday music, which can be comforting, or you can read religious texts—perhaps tell the story of Hanukkah or Christmas, that sort of thing. We can use the sights of the holidays, such as holiday decor, the lights and perhaps old movies that people once enjoyed, like *Miracle on 34th Street* or *White Christmas*. Of course, the smells and the tastes of the holidays can

really invoke some strong memories and happy feelings. Maybe it's cooking a traditional meal or dessert. If they aren't able to eat solid foods or partake in the meal itself, there are so many wonderful candles that smell like sugar cookies or cinnamon apple and those sorts of things. You can use that aromatherapy to bring out those yummy smells of the season.

Then our sense of touch—we can use that as well to bring back memories. Maybe gather ornaments, pine cones, soft fabrics, garlands, a dreidel or other festive items, and let them feel those items. Those can be opportunities to story-tell. If that individual with Alzheimer's or dementia, they're not able to tell a story, maybe you share with them your favorite memories of putting up the Christmas tree with them or decorating for Hanukah or Kwanzaa with them. They will be able to listen to that story. They may not be able to verbalize it, but these things can really bring back those memories of joy. So don't hesitate, families, to use the senses of the season to really evoke those joyous feelings.

And then, we just want to cherish the time that we have with one another over these holiday seasons. A diagnosis of Alzheimer's or dementia can really send families into a spiral of emotions. For some families it might bring them closer together. For others it could cause some conflict or strife.

If we can use this time during the holidays to really enjoy each other's company, we can use this time to talk—maybe families can use it as a family meeting, to talk about chipping in more, to help out the primary care partner with different activities or tasks that need to be done for that loved one. If the person with dementia is still able to share their wishes, this would be a great time to have those conversations with loved ones about, if they got to a point where they needed personal care assistance, what that would look like, what the best scenario would be in that person's mind, and what their wishes would be. It might be a time for forgiveness and healing for families where there might once have been conflict. So just cherish this time of year, because it is such a

special time of year. While it does come with a lot of different emotions, it can really be a great time to get together.

I know that a lot of families might be thinking: Well, I've had a feeling that my loved one is displaying some cognitive issues, is there anything I should be looking out for, when I go home for the holidays—anything that I should pay close attention to? When we're home for the holidays, a lot of times, we're with family for extended periods of time. You might be able to pick up on more of their daily routines. Some things to keep your eye out for are the condition of the home—if your loved one always kept a very tidy house and things seem a little out of order or there are bills piling up and the cleanliness of the house just isn't what it used to be, that could be a sign. If you're eating your holiday meal and the recipe doesn't taste quite right, maybe there are some cognitive issues in remembering those recipes or abilities to cook in the kitchen. If the loved one is still driving, the condition of the car can be an indicator—bumps or scrapes on the car might be something to look out for. Also medications—if you're seeing pill bottles everywhere, looking like maybe medications aren't being taken properly, that could be a sign that there's something going on. And the physical appearance of the person—if the person's personal hygiene isn't quite what it used to be, that could be another sign that there might be an issue, in addition to forgetfulness and those types of things.

So those are some kind of general tips for how families can better enjoy the holidays. Really, the ultimate goal is to still engage the loved one or person with Alzheimer's or dementia in the holiday festivities. Socialization is so important for all of us, and while we're engaging that person in those activities, we just need to remember to be prepared, be flexible and be accommodating to that person's needs and their daily routine, and it will really make the entire holiday season that much more enjoyable for everyone involved—for the person living with the disease, for the family and for the care partner.

I know we have probably some questions that will come in on the topic of holidays with our family members or loved ones with dementia, but I just wanted to kick it off with a few general tips. I'm happy to answer any other questions that come in today.

**George:** Lakelyn, that was terrific. I want to come to your house for the holidays!

**Lakelyn:** You're always welcome, George.

**George:** What does a family member do, who may detect some warning signs, some of the things that you discussed near the end of that introduction? What do you do if you see some of those warning signs?

**Lakelyn:** That's a great question. This is a question I get asked quite frequently. If you are noticing some of the signs, you might approach your loved one and ask them if they themselves are noticing any changes. They might be willing to say, yeah, actually, I've been more forgetful lately and I'm a little concerned. If that's the case, the next step would be to schedule an appointment with their physician to talk about these changes that they're noticing in cognition. If they're not so receptive, which we know can be the case, if the family is able to reach out to the medical care provider and express their concerns, then, perhaps at the next doctor's visit or the next checkup, they can bring up cognition as a topic of that visit. But if there are some extreme concerns, a lot of times, a general practitioner will recommend that the family goes to have a more formal cognitive evaluation. Those are some quick tips if they're noticing these cognitive changes. If one child is noticing it or one family member, they might want to talk with other family members who see them routinely, to see if they're noticing some of the same cognitive impairments or some of the same changes in the home—or they might even have seen additional changes that are present.

A lot of times, we have long distance caregivers--people aren't staying put, or they're moving halfway across the country—and their loved ones might be miles away. So the holiday season is really when, at Home Instead, we get a high volume of calls because

people have been home to see their loved ones. They have some concerns and then give us a call to see if there's anything we can do to help. So we know that the holidays are a time when people start to take notice of these things because they are with their loved ones for an extended period of time. Often we hear, "Well, I talk to them on the phone and everything sounded okay, but then I showed up at their home, and it was a totally different story." So, getting your eyes in their environment and a glimpse into their world can be eye-opening for families and for care partners.

**George:** What can Home Instead do when you get those calls at Christmas time? You may have a professional caregiver in the home, or you may not, so what can you do when you get those calls?

**Lakelyn:** When we get calls like that, we usually dig deeper into why, what prompted them to call us, asking what kinds of things they are noticing. Then we'll set up what we call a care consult if they're not already a client of ours. We'll go into the home, sit down with this family and go over their daily routine and various aspects of their life, to see where they might need a little extra support. Perhaps it is medication management: we'd make some recommendations like ways they can set up a medication set or connect with a company that can sort the medication for them. If it's problems with personal hygiene: maybe the root cause is they're afraid to shower alone because they live alone, and maybe they've had a fall or a near fall; then we can go in and provide support. We can be there while they bathe or assist in that process to ensure that they're keeping up with daily hygiene and that sort of thing, and preventing falls, which we know can be very risky in causing further health-related issues. Falls are one of the top reasons that people of older age are hospitalized. We go in, dig deeper into the situation and see where we can be supportive and then bring in other resources as needed.

**George:** One hears a lot of anecdotes about a person coming home at holiday time and seeing signs of cognitive impairment, but the spouse of the loved one who may be experiencing those signs is resisting the idea that there's any problem, denying the

problem and saying they're fine, they're just a little tired or other things. How do you advise families to deal with this, the infrequent returning relatives who are seeing signs and the relative who's always present denying them?

**Lakelyn:** That is a really tough situation, and it's probably more common than we even hear. Especially if the individual does live with them every day, they might not see the more drastic change in the individual as a long-distance relative might. They would be more accustomed to seeing them on a day-to-day basis, so they're more likely to be compensating like you mentioned, George—picking up the slack, where there's cognitive impairment of the other one. That is a really challenging situation.

The concerned relative can make a suggestion to see a specialist or a geriatric physician who could possibly do some cognitive screening. I know Medicare has recently passed or now allows physicians, or reimburses physicians, for cognitive screening. So the family member could suggest that or even make a call to the physician to say, "I've noticed some concerns, and is it a possibility to do cognitive screening the next time my loved one comes in?" But, you're right, George, that is a situation that happens every so often.

Another suggestion could be to offer that caregiver some respite. Perhaps offer to stay with them for a weekend to get a better understanding of everything that's going on in the home, to see that loved one without their spouse or whoever is living with them, and to get a better feel for those cognitive impairments. If you have this opportunity to stay with them for an extended period of time, to document or make a journal of everything you're noticing, to have written proof if you will, then you can reach out later to the physician and provide a more detailed assessment of the different things you're noticing. We do find that, in some situations, memory loss or cognitive issues could be due to something other than dementia. It could be a combination of medications that's causing a memory loss, or if it's a sudden cognitive change, it could be due to some sort of infection, like a urinary tract infection. So it's important that we get our loved ones to get some sort of assessment, to rule out any other reasons that might be appear to

be cognitive impairment. Then get the family the needed support, so that the loved one can continue to live independently in their environment.

**George:** Great advice. Just a reminder, to those on the call, if you have a question, press \*3 on your phone and get into a question queue and we'll put it to Lakelyn. We do have a question coming in online from Barbara Seacrest from Oregon asking, whether they should print up a note to add to the loved one's Christmas cards and have their loved one try to sign the cards. Is that, do you think, a good idea?

**Lakelyn:** That is a good question, and Barbara, thank you so much for writing that in, because I'm sure that other people out there have similar questions. We know that Christmas cards are a tradition that many people have participated in over the course of their lives. So, trying to maintain traditions and keep your loved one engaged in those traditions—especially if it's something that brought your mom joy—Barbara, I'm sure putting together the Christmas cards, picking out the cards and sending them out was something that she really enjoyed. If you can modify that activity so she can still participate, maybe she can help pick out the card and, if she is able to still sign the card, have her still engage in that part, and maybe you break it up into smaller amounts of cards that she signs throughout the day or the week—maybe five here, five there.

When it comes to printing up the note—and, Barbara, I'm not 100 percent sure if you're referring to just a general holiday greeting or a note updating loved ones on the cognitive change—the latter is a very touchy subject. If your mom is still able to voice her opinion, you could always ask her if that's something she'd be comfortable with. If it's more of a general greeting, a holiday greeting, I think that's a great idea to print it up for her. That way she doesn't have to write all the cards. She could just sign her name.

But printing up a note about her cognitive decline might be something very sensitive. If it's a card that just goes out to relatives and very close friends, that might be something she would be okay with. But if it's going to a big list of Christmas card recipients that she's had for years and years, she might not be okay with that or might feel nervous

about sending out that type of communication in a Christmas card. If she's able to have that conversation, I would engage her in that and see what her comfort level is, but I would certainly say if she loved putting those Christmas cards together, that you could still help her and maybe she's helping to put the stamps on and signing the cards in little amounts over the week or helping to seal the envelopes, and the care partner does the address labeling and that sort of thing, the more tedious tasks. That might be a way that we can modify that activity and engage her in it and still allow her to send out those Christmas greetings which could have brought her a lot of joy over the years.

Another great thing about Christmas cards—I don't know about any of you out there, but my mom and my grandma have saved their Christmas cards for, I don't know, the past 20 years. That could be another fun activity, to go through old Christmas cards or old holiday greeting cards from years past. Reminisce about them, read the notes from loved ones, look at the pictures and feel the texture of the cards. It's a way to still engage in that holiday activity in a way that meets her where she's at. Barbara, I hope that's helpful in answering your question.

**George:** I think that's a terrific tip. Frequently one hears, and I experienced this in my own family, that the different members of the family may have different roles in supporting a person with dementia. There's the spouse that's living with the loved one; there are children who may have different capacities to be helpful financially; there are different children who may have capacity for providing supplemental care or respite care; but there's also a fair amount of opportunity for family tension about whether someone's doing enough and whether everyone is contributing equally. I'm curious, how would you recommend a family work through this—obviously, individualized in terms of how families deal with this and what the situation is—but are there techniques? Are there services? Are there people who can help families negotiate relative contributions towards the care of a loved one with dementia?

**Lakelyn:** George, that is a very common question that we hear. The caregiving roles within a family structure can, like I mentioned earlier, bring the family closer together, or

they can create some ripples, some conflicts and strife within a family. What I think families need to recognize is that everyone involved in the care—all the children, the spouse, maybe some more extended family, neighbors—everyone has their own strengths and their own comfort levels with providing care to their loved ones. There might also be some deep-rooted family conflict that's causing maybe one child to step up more so than the other, or causing two children in particular to quarrel over the care of their loved one. So, when I talk with families, I may say we need to remember that the individual living with the disease is really at the center of the care. And everyone should be working towards the quality of life of that individual and towards helping to meet the needs. Families can, in the best-case scenario, pull together in a family meeting and assess the needs of their loved one and the strengths of everyone involved in the care. As you mentioned, George, some care partners might be able to contribute financially. Maybe there's a son who is in the financial world or that's his strong suit; perhaps he could take over the bill paying. If there's a relative who lives closely and has always been very close to that relative, maybe they are in charge of more hands-on day-to-day care, and a different relative who lives somewhat close by could come in to provide respite.

If families aren't able to come to an agreement on their own, a lot of communities have geriatric care managers who specialize in helping families navigate the care continuum and help them navigate different family dynamics. There's a website, [www.aginglifecare.org](http://www.aginglifecare.org), where you can search for a certified expert in your area. So there are people out there who can help mediate this process.

But just remember that the person who needs the care should be the central focus—their well-being and their wishes, if those wishes are known. We need to stay focused on that. Sometimes all it takes is to understand where everyone is coming from. Sometimes it takes a verbal conversation about how everyone has the individual with dementia and their best interests at heart, and then it will help everyone realize that they all want the same thing. They just need to come together to figure out how they can

best use their strengths, use their resources and use their talents, to provide that care for the individual.

There's not a really one-size-fits-all solution to this type of family conflict, but there are strategies that families can use: maybe it's creating a matrix of the person's needs and then a list of everyone's strengths and divvy up based on that matrix. Having that conversation is so important, and maintaining communication throughout the care journey is also important for families. Make sure that everyone remains on the same page and everyone continues to keep the individual living with dementia at the center, focusing on their well-being and quality of life, which is so, so important, and it's important that everyone is on that same page.

**George:** We have a question here online from Celeste Miller. This goes to a slightly different emphasis from the one that you were just putting on holiday experiences, Lakelyn. It is on the person who's the caregiver. So this is from Celeste. Her question: "It seems that my loved one is possessive with my time and attention. The holidays seem to make this worse since I'm busier. Sometimes I feel smothered. Is it my imagination or does my husband purposely stand in front of the TV?" The question about the loved one, not the person with dementia, but the spouse or other loved one in the home—there is additional stress and strain on that person as well as the person with dementia at holiday time.

**Lakelyn:** There most certainly is that added layer of stress when you feel that your loved one—if you take two steps, they are taking two steps right behind you. Often, especially in a spousal caregiving relationship, we find that there becomes such an attachment, because they associate comfort and familiarity with their loved one. Celeste, in your situation, it's likely that your husband finds comfort knowing that you're close by. That might be one reason that he's kind of your shadow throughout the home and throughout the holiday season.

It's so important for families, especially earlier in the diagnosis, if possible, to get in the habit of some routine respite. Whether it's having a neighbor, a person from your faith community or a relative coming over to give you needed time away from your loved one, that can be so important. It allows the caregiver, the care partner, a chance to recharge their batteries. This time of year, it's probably a chance to get the holiday shopping done, to run your errands, go to your own doctor's appointments, get your hair done, go to the grocery store, or prepare the meal for the holiday gathering. If families can implement that type of respite care early on, it can get the individual living with dementia used to having other people providing care or other people in the home so the caregiver can hopefully avoid that overwhelming feeling of my "loved one is my shadow—I can't seem to do anything because they're always right there demanding my time and attention."

Celeste, I'm not sure if you have any one in your care circle or in your community who can come over to provide you with some needed respite on a regular basis. You may want to check with your local [Area Agencies on Aging](#). A lot of those types of organizations have a respite care program you can apply for—you can seek out respite care providers. Of course at Home Instead we can provide that type of respite as well, and many communities have services like that. Some might find that there are financial barriers to that. Again, those Area Agencies on Aging might be able to help with those financial barriers.

It's really an investment in the caregiver when you think about having respite care come into the home, because having that time away gives caregivers that chance to recharge, a chance to relax and get away from the caregiving situation even just for a few hours. That's so important because caregivers need to take care of themselves. They need to practice good self-care, so that they can continue to provide care to their loved one with Alzheimer's or dementia. We've seen too often, when caregivers neglect their own health and well-being, they end up ill or in the hospital, or they develop diseases or, in some extreme cases, pass away before their loved one because they're not taking care of themselves.

Also, Celeste, if you can find some activities that your loved one really enjoys even in the home, engaging them in those activities can hopefully give you a few minutes to get things done around the house, especially this busy holiday season. And actually our [HelpForAlzheimersFamilies.com](https://www.helpforalzheimersfamilies.com) website has some great tips and advice. There's also a free app you can download to your smartphone, where you type in keywords and it will pull up tips and advice for those particular situations. If you have difficulties finding certain activities your loved one enjoys, you can type in the word *activities* to that app, and it will pull up pages and pages of activity suggestions. It's kind of a community-based app, so people are contributing ideas that have worked with their loved one. I would encourage you to check that out for some additional advice.

That is something that can be challenging when you are living with the person with dementia. You can find that it's hard to get away, but, if you can, if it's possible to get that respite, it will make a world of difference and make you an even better caregiver and be able to care for your loved one even longer.

**George:** Let me ask, Lakelyn, and I don't mean to make this Home Instead-centric, but can Home Instead provide a professional caregiver just during the holidays, on a limited basis, for these more stressful situations, these more complicated situations?

**Lakelyn:** We certainly can. We create a very personalized care plan for each individual that we serve, so if families feel overwhelmed during the holiday season, they can reach out to their local office to talk with them about a care plan that will work best for them. If it happens to be just for this period of time, most offices can accommodate that. Then if the family finds that they really are enjoying respite—this time away—and the caregiver and your loved one are really connecting, then you can always extend this service. I would certainly encourage families who are considering some extra help or respite around the holidays, to reach out. At [HomeInstead.com](https://www.HomeInstead.com), you can put in your ZIP code to find the office nearest you. If you're an international listener, all of our international markets are at the very bottom of the page at [HomeInstead.com](https://www.HomeInstead.com), so you can get connected to the country closest to you to find out more information. Certainly this time

of year is especially stressful, so reach out to us, and we'll do our best to work with the family to personalize the care plan to their specific needs.

**George:** Would that include the ability to basically have a Home Instead caregiver come to your home once or twice a week and basically end up providing sort of a respite service for families?

**Lakelyn:** Exactly, yes. A majority of the clients we work with do set up some sort of regular schedule. Each of our offices is independently owned and operated, and they have varying minimums—it might be one visit a week for three hours is their minimum. You might reach out to your local office to find out if they have minimums. In most cases, where we're working in the client's home, we do have a regular cadence set up for care. That way the caregiver can continue to have that ongoing respite. We provide daily care for working professionals who need peace of mind while they're at work, and they have a Home Instead caregiver come in during the work day. Maybe it's on the weekends that they really need a break, and we can be there then. It's very personalized care plan to fit the needs of the individual living with dementia and the care partner.

**George:** One more question and then we have to wrap up. What is the one, or two or three, most frequent reasons that people reach out to get professional caregiving services from Home Instead? What triggers that desire on the part of a family?

**Lakelyn:** We often find that a major event is something that can trigger a call to us—perhaps it's a fall or perhaps a hospitalization. Also frequently, around the holiday times, when families go home and notice that their loved one is really not keeping up the house or they're really not comfortable driving any more, we can come in and provide that light housekeeping. We can come in and provide transportation. If individuals have a hospitalization, we can help with the transition home from the hospital or rehab setting. A lot of times it is that needed respite for the family caregiver. They're feeling a little overwhelmed. Perhaps they're not sleeping at night because their loved one is

wandering, so they'll have us do overnight visits with their loved one so that they can get that needed rest, that needed recharge to be the full-time daily caregiver.

There's really a variety of reasons that people pick up the phone or inquire online about services, but I would say those are some of the common themes that we hear. Especially when it comes to Alzheimer's and dementia, families notice these changes in their loved ones, and they call to find out if there's somebody out there who can help. We're able to provide respite and help these individuals with their daily activities. We can help them stay home and remain independent longer, because we're hopefully creating a safer environment. We help them take their medications, get their needed nutrition and hydration, and engage in activities or a little exercise. Those things can help an individual stay independent, at home, where most people want to be, for longer.

**George:** Lakelyn, this has really been interesting and I think very, very helpful to our listeners today, so I thank you for joining us. I hope this conversation was helpful to those who are listening and experiencing some of these tensions or opportunities during the holiday season with their loved one and families, who may be coping with a new environment with respect to a loved one with dementia.

If you would like to receive regular e-mails from Lakelyn and Home Instead, please visit [www.helpforalzheimersfamilies.com](http://www.helpforalzheimersfamilies.com). If you've not already joined UsAgainstAlzheimer's, please go to [www.UsAgainstAlzheimers.com](http://www.UsAgainstAlzheimers.com) and sign up. We'll send you a recap of this call, invitations to future calls, important updates and simple ways that you can get involved in this battle—this fight back, as former British Prime Minister David Cameron once put it, against Alzheimer's. I hope that you'll join us at UsAgainstAlzheimer's.

Thank you to everyone on the phone or online for participating today. We'll soon have a copy of the recording and a transcript on our website for you to share with your friends. Thank you for joining us today, Lakelyn Hogan, for your excellent discussion about dealing with Alzheimer's and taking advantage of the holidays with your loved one. Have a good afternoon, Lakelyn and everyone on the line.