



WELCOME !

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The ALS Association

National Office-Care Services

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Maintaining Family Celebrations During a Journey with ALS

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MAINTAINING FAMILY CELEBRATIONS DURING A JOURNEY WITH ALS

Alabama Lifespan Respite

For many caregivers and care recipients the holiday season gives rise to stress, frustration and anger, instead of peace and good will.

Caregivers may feel resentful towards other family members who they feel have not offered enough assistance. Caregivers and their loved ones may feel that they will not be able to participate as fully as they would like in family gatherings, causing stress and sadness. Already feeling overwhelmed with daily life, stressed-out caregivers and loved ones may view traditional holiday preparations as more of a drain of precious energy than a joy.





Keep in mind that the holidays can, in fact, provide unique opportunities to seek better communication, connection and support from family and friends.

Focus on what is most meaningful

As much as we'd like to create the perfect holiday experience, remember that perfection is not the goal of the holidays — meaning and joy are. There are many factors we can't control when it comes to our loved ones' health and abilities, so adjust your view of a successful holiday. Talk about prioritizing the holiday activities that hold the deepest meaning. Focus on what feels necessary to produce a holiday feeling and create good memories.

Simplify your holiday activities

If going all out for the holidays will push you over the edge this year, remember that it doesn't have to be all or nothing. If you can't put out all of your decorations, choose a few items that are most significant. You might ask a friend to decorate, or pay someone to do so; you can always rearrange decorations once they are out. If going to all religious services feels like too much, choose one service that means the most. If sending greeting cards is too time-consuming, try sending e-greetings. Many family caregivers also adjust the location of celebrations or postpone holiday travel to accommodate loved ones in their care.

Start new traditions

Instead of focusing on losses and what you and/or your loved ones aren't able to do, try doing something new. If your loved one has trouble getting around, drive through a holiday light display or watch a holiday concert on TV. If you can't make it to a holiday gathering, have a video chat. Is your loved ones unable to participate in decorating this year? Invite a friend over to help, with your loved one nearby to watch and cheer you on. Start a home holiday movie night tradition — or watch old home movies so everyone can participate.

Adjust meals

Food is a big part of many holidays, so it's especially difficult to think about changing mealtime traditions. Traditional meals aren't always an option for someone with ALS but they also require a lot of time, money and coordination. So rather than canceling holiday meals entirely learn to make adjustments like these:

- Simplify the menu. Try fewer side dishes or one dessert instead of three.
- Split up the grocery shopping and cooking among other family members and guests. There's nothing wrong with a potluck.
- Pay someone to cook meals at your house ahead of time or on the holiday.
- Replace a big meal time with quality time in the scenario of your loved one not being able to join in meal time.
- Eat at someone else's home, or at a restaurant.

Anticipate holiday hot buttons

Are there holiday activities or toxic relatives that trigger stress or unhappy memories? Perhaps feelings of grief or loss overcome you at certain times of the day. Do unhelpful relatives arrive for the holidays and criticize your caregiving? Maybe old family issues inevitably flare up at gatherings. It may be best to limit your exposure to — or even avoid — certain places, events, conversations or people. If you can't do that, prepare yourself. Minimize the drama; don't try to resolve problems over the holidays. Instead, try short encounters and develop quick exit strategies. Mentally put yourself in a protective bubble, letting negative energy bounce off without hurting, annoying or distressing you.

Mind your mindset

Negative thinking actually activates your body's stress response, so steer your mind to the positives when you start down that slippery slope. Try to stay mindful, concentrating on the present moment. Think about what you *can* accomplish instead of what isn't getting done; celebrate what your loved ones *can* do, rather than dwelling on what they can no longer participate in; revel in the holiday joys you experience instead of focusing on those you bypass; appreciate the help you are receiving rather than resenting those who aren't supportive.

Keep self-care at the top of the list

As caregivers, you give and give, and during the holidays you give even more. All that giving can leave you running on empty, with high stress levels or even full-on burnout. Be aware of emotional ups and downs, fatigue, foggy thinking, inability to sit still or the opposite — feeling frozen and unable to get anything done. These red flags have to be dealt with, but when we're busy it's easy to let self-care slip — just when we need it most. Find ways to fill your tank. Be aware of unhealthy coping skills, like overeating or drinking too much. Get outside for some mood-elevating vitamin D from sunlight, or consider therapeutic lighting if you suffer from Seasonal Affective Disorder. Care recipients also get overlooked when it comes to the emotions they're dealing with. Those dealing with a terminal diagnosis still require self care, whether that be alone time, or trying to maintain an activity they have always loved to do.

Connect with other caregivers and those affected by ALS

Other caregivers and those with a ALS diagnosis are feeling many of the same emotions you are, even when others don't understand. Connect to share your feelings and get tips for holiday survival. If it's difficult to get to a support group try [online message boards](#), virtual support groups or social media groups.

Ask for help

Even if you don't normally do so, the holidays are a great time to get some extra help — even a few hours can be a huge relief. Family and friends can help with holiday preparations. Someone can complete items on your holiday to-do list or handle personal things like organizing mail or running errands. Get someone to clean the house or catch up on laundry. Ask family and friends to help with direct care for your loved ones, or try [community resources](#) like adult day care centers, in-home or facility-based respite care, or paid home health aides/caregivers.

Remember, you'll be happier if you can go with the flow and expect that there will be some delays, a crisis or two and maybe some disappointments.



After the holidays, write a thank you note to family members or friends who spent time with you and your loved one. Emphasize the positive impact their visit or brief time spent with your loved one had on them. This may reinforce positive feelings from their visit and diminish any discomfort they experienced. They may then be more encouraged to visit again or be more supportive of your efforts.



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