

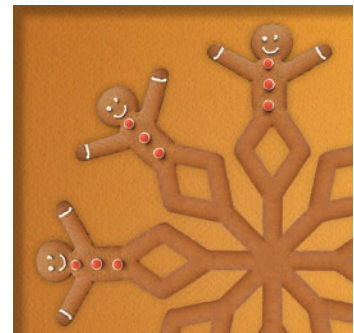
Holiday Hints for Caregivers

(Adapted and taken from the NIA – the National Institute of Aging)

Holidays can be meaningful, enriching times for both the person with PSP, CBD, MSA, or related diseases and his or her family. Maintaining or adapting family rituals and traditions helps all

family members feel a sense of belonging and family identity. For a person with one of these diseases, this link with a familiar past is reassuring.

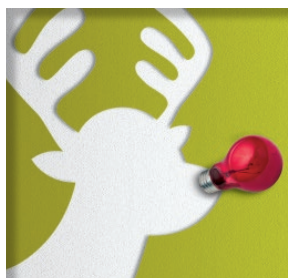
However, when celebrations, special events, or holidays include many people, this can cause confusion and anxiety for a person with PSP, CBD, or MSA. He or she may find some situations easier and more pleasurable than others. The tips below can help you and your loved one visit and reconnect with family, friends, and neighbors during holidays.



Finding the Right Balance

Many caregivers have mixed feelings about holidays. They may have happy memories of the past, but they also may worry about the extra demands that holidays make on their time and energy. Here are some ways to balance doing many holiday-related activities while taking care of your own needs and those of the person with PSP, CBD, MSA, or related diseases:

- Celebrate holidays that are important to you. Include the person with PSP, CBD, MSA, or related diseases as much as possible.
- Set your own limits, and be clear about them with others. You do not have to live up to the expectations of friends or relatives. Your situation is different now.
- Involve your loved one in simple holiday preparations, or have him or her observe your preparations. Observing you will familiarize him or her with the upcoming festivities. Participating with you may give the person the pleasure of helping and the fun of anticipating and reminiscing.



- Consider simplifying your holidays around the home. For example, rather than cooking an elaborate dinner, invite family and friends for a potluck. Instead of elaborate decorations, consider choosing a few select items.
- Encourage friends and family to visit even if it's difficult. Limit the number of visitors at any one time, or have a few people visit quietly with the person in a separate room. Plan visits when the person usually is at his or her best.
- Prepare quiet distractions to use, such as a family photo album, if your loved one becomes upset or overstimulated.

- Make sure there is a space where the person can rest when he or she goes to larger gatherings.
- Try to avoid situations that may confuse or frustrate your loved one, such as crowds, changes in routine, and strange places. Also, try to stay away from noise, loud conversations, loud music, lighting that is too bright or too dark, and having too much rich food or drink (especially alcohol).
- Find time for holiday activities you like to do. If you receive invitations to celebrations that your loved one cannot attend, go yourself. Ask a friend or family member to spend time with the person while you're out.



Holiday Home Safety Tips

Holiday decorations, such as Christmas trees, lights, or menorahs, should be secured so that they do not fall or catch on fire. Anything flammable should be monitored at all times, and extra precautions should be taken so that lights or anything breakable are fixed firmly. Candles should never be lit without supervision. When not in use, they should be put away. Also, try to avoid clutter, especially in walkways, during the holidays.

Preparing Guests

Explain to guests the type of symptoms of your loved one. Give examples of unusual behaviors that may take place such as incontinence, eating food with fingers, loud coughing, speech problems, and cognitive issues. If this is the first visit since your loved one became severely impaired, tell guests that the visit may be painful watching the difficulties in movements and cognition.

- Explain that the staring gaze is result of the disease and is not intentional. Ask visitors to bend down, so that patients can actually see them.
- Stress that the meaningfulness of the moment together matters more than what the person remembers or can express.
- Explain that touch is very important to patients. PSP, CBD, MSA, and related disorders are not contagious.



CurePSP wishes all of our patients and their caregivers and friends a very happy holiday season.

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