

Holiday Tips for the Caregiver

General Planning for the Holidays

Preparation for the holidays can be stressful and tiring even under the best of circumstances. For families and caregivers of people with dementia (PWD), the holidays can often be extra difficult. However, with some planning and considerations, the holidays can still be a great source of pleasure. Traditional holiday activities, which your family has enjoyed throughout the years, may have to be changed to some degree. When preparing for Christmas, make sure you set your limits early, stick to them and be clear about them with others. You do not have to live up to the expectations of friends or relatives.

The following are some tips and information which may help whilst you plan for Christmas.

Preparing Yourself, the Caregiver

It is very normal for caregivers to feel overwhelmed in their effort to maintain holiday traditions, as well as, caring for the PWD. Caregivers often feel hesitant to engage in traditional celebrations for fear that others will react negatively to the changed behaviour of the PWD. If you're feeling guilty, angry, frustrated, or trapped before, during or after holiday celebrations, it may help to know that these feelings are normal and that you're not alone. Here are some suggestions that may help to ease the burden of caregiving and make your holiday a happy and memorable occasion.

- Try celebrating over a lunch or brunch, rather than an evening meal. For some people with dementia, afternoons and evenings can be a very restless period which will only be exacerbated if there are many people around or if the PWD is in an unfamiliar environment.

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- Prepare for stress. Leading up to Christmas, arrange additional days at a respite centre or for someone to provide in-home care for your loved one. This will allow you to complete your shopping or tasks, as well as, give you a chance to relax before Christmas day.
- Do not do everything yourself. Arrange to celebrate at a different house or, ask guests to bring a plate of food. Remember, taking on too many tasks will only cause stress, fatigue and frustration, for yourself and your loved one.
- Give yourself a balance between solitude with sociability. Solitude can renew your strength. Being with people you care about can be equally important.
- Set aside "letting go" time. Christmas often brings about a mourning period where you reflect on the things you no longer have. Acknowledge your grief and loss, it's natural and normal. Set aside time to reflect on the life you once had, as well as, the positive experiences yet to come.
- Talk about dementia! Out of love, family and friends will often be reluctant to mention the changes in your loved one because (a) they do not know how to raise the subject and/or (b) they don't want you to get

upset. It is important that people understand your role, your life and what is happening to the PWD. Break the ice by bringing it up yourself.

Preparing the person with Dementia

Unexpected gatherings and celebrations can be overwhelming for a person with dementia and can cause increased frustration and agitation. Therefore, it is important to involve the PWD in safe, manageable activities to help prepare them for the holiday season. Involve your loved one in preparing food, selecting wrapper paper, wrapping gifts, hanging decorations or setting the table. Where possible, maintain the person's normal routine so that Christmas planning does not become disruptive or confusing. Try to find a balance between daily activities, Christmas tasks and adequate rest so that both of you do not end up exhausted.

It is important to remember that large gatherings can often be a trigger for PWD and lead to increased confusion, frustration and agitation. The PWD may not be able to tell you they are overwhelmed or need a rest so, the frustration they are experiencing is often exhibited through other behaviours. In order to minimise unsettling behaviours, try to avoid:

- Crowds of people (especially as they may expect the PWD to remember them).
- Noise, loud conversations and/or loud music (especially if they are all occurring at once!).
- Changes in light intensity (too bright or too dark).
- Over indulgence in rich foods or drinks (including alcohol).
- Changes to regular routines and sleep patterns.

Preparing the Guests

It is important that guests are made aware your loved one has dementia. Try and inform guests as early as possible to avoid challenging conversations on the day of the event. Explain that your loved one has a memory loss and may not remember people or faces. Explain that your loved one may ask the same questions repeatedly and this requires patience. Explain that the PWD may not know what is expected and acceptable and therefore, may display some unusual behaviours. Give examples of the unusual behaviours as some guests may not have previously shared time with a person with dementia.

Often, a long time has passed since family members have seen your loved one or, this could be the first time they have seen the PWD since

the diagnosis. Let your guest know that the visit may be emotionally difficult, especially if the PWD does not remember the guest. Explain that memory loss is a result of the disease and it is not intentional or personal. Emphasise to your guests that what is important is the meaningfulness of the moment spent together and not what the person remembers.

For most families, holidays are filled with opportunities for togetherness, sharing, laughter, and memories. But holidays can also be filled with stress, disappointment, and sadness. Because of the changes he or she has experienced, the person with dementia (and their carer) may feel a special sense of loss during holiday seasons. This loss may be made more apparent as guests may not know how to interact with a PWD. Reiterate to guests that your loved one still needs and enjoys conversation, laughter, physical touch and eye contact, even if the PWD is unable to communicate.

Remember ...

As a caregiver, Christmas can be a difficult time of year. It is important to take care of yourself during this time and resist the pressure to do things the way others might expect you to. Set firm boundaries and expectations for your family and friends and remember, you cannot control the progression of dementia or protect the PWD from the



distress or confusion that may occur. You can however, prepare yourself and prepare your guests, as well as, give yourself permission to enjoy the celebration and enjoy the time spent making new memories.

**Help and assistance is available.
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contact Alzheimer's Queensland
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