



Celebrating the festive season with someone who has dementia

Introduction

The festive season is something most of us look forward to. With excitement and expectations running high, special meals to be prepared, gifts to be bought and guests to entertain, it can be a stressful time. For people with dementia and their partners and families, there is the additional challenge of coping with the disruption of established routines, of dealing with unfamiliar environments and of managing without the full complement of support services.

This information sheet is aimed at partners, families and friends of people with dementia, whether they are caring at home, planning for a visit from a person with dementia, or caring for a person who now lives in a care home.

Travelling

If you are planning on going away, please see information sheet IS9: *Travel and holidays* for information on travel by land, sea and air; insurance; health care abroad, etc.

Activities and family customs

Much of the festive season centres around family activities and customs that have been passed on from one generation to the next, as well as any religious celebrations. People can feel very disappointed if these customs are not maintained but it is important to be realistic and not to have too high expectations of the holidays.

Even if the person with dementia is unable to join in to the same extent, there are still many things that you can do together such as:

- go to religious services

- decorate the Christmas tree or put up simple decorations
- sing favourite songs or listen to traditional holiday music
- go for a walk
- watch a favourite film.

The person with dementia may also like to play a part in preparing for any celebrations – helping with preparing meals, doing dishes, light housework, etc. But it is important to consider the person's safety – see section on *Safety first* below.

Preparation

To make the holidays as stress free as possible it is important to prepare ahead. This preparation should not just include practical details, although these are important; it should also include emotional preparation.

It is important to be realistic about what is manageable both for the person with dementia and you as carer. What adjustments are needed to make the holidays as stress-free as possible? Do you need to entertain as lavishly as you have always done or could you produce simpler meals or ask friends and family to bring along a dish? Would it be better to have just one or two visitors rather than a houseful, particularly if the person with dementia finds it hard to cope with lots of people and noise? Do you need to celebrate at all or would you prefer just to have a quiet time at home, particularly if the person you care for no longer recognises that it is the festive season?

If other family and friends will be visiting, you may wish to prepare them for particular kinds of behaviour such as unusual eating habits or

reactions. People may need to be asked to introduce themselves rather than assume that the person will remember them. It can also help if they explain their relationship to the person if he or she doesn't seem to recognise the visitor.

The following sections look at some of the practical considerations.

Safety first

Whether you are caring for a person with dementia at home or having them to visit, you should, depending on how advanced their dementia is:

- remove trip hazards such as trailing cords or extension cables, clutter, rumped rugs
- consider lighting levels. If the light is poor, there is a greater risk of falls and trips; people in later stages of dementia may also get confused and mistake shadows for strangers or some kind of threat
- lock away medicines and dangerous household chemicals
- avoid having poisonous plants or berries in the house such as holly or mistletoe berries
- exercise caution with electrical appliances
- fit a fireguard
- be careful about knives and other sharp objects.

Overnight stays

If you are having someone with dementia to stay with you, or are at home but may be distracted by visitors, you should ensure that external doors are kept closed, perhaps even locked. This is especially important if the person with dementia is likely to get up in the night. But make sure that people can get out in an emergency.

If the person with dementia is in an unfamiliar environment you should leave a hall light on so that the bathroom can be found, and stairs are clearly visible. It can be useful to stick labels or symbols on doors to assist with orientation and help the person with dementia

feel at home. You should also find out well in advance if there are any appliances or aids they will need, such as special cutlery, cups, or continence aids.

In the later stages of dementia, some people cannot recognise their own reflection, and thinking they see a stranger, become alarmed. Mirrors can be covered but you should check for other shiny surfaces and make sure that curtains are pulled before darkness outside and light inside make windows reflective.

Food and drink

Food has an important role in traditional festive celebrations. The most important thing is not to overwhelm the person with dementia. Try to find out if they would rather eat by themselves, rather than be distracted by other people, and what sort of appetite they have. Ask in advance what sort of food best suits the person with dementia; they might prefer finger food or light meals; they might like combinations of food which seem peculiar; they might prefer to eat outwith normal mealtimes. Consider using an insulated plate if you find that the person with dementia is a slow eater.

Sometimes, people with dementia find it hard to make out the food on their plate or are unable to see the plate on a table. Using a plate which contrasts with the colour of the food will make it seem more appealing and easier to see. Consider how easy it is to see the plate on the table surface or tablecloth you are using. A white plate on a white tablecloth will be harder to see, for example.

The person with dementia may enjoy a glass of wine with their meal or a celebratory whisky or sherry, but alcohol should be consumed in moderation or perhaps not at all. People with alcohol-related dementia should avoid alcohol. Some people may be unable to drink alcohol because of medication they are taking or because they have a health condition which makes them more susceptible to the effects of alcohol.

Because people's balance tends to get worse as they get older, even a small amount of alcohol may make people more unsteady on their feet and more likely to fall.

Check with the person's doctor if there are any foods which should be avoided or if there are any reasons why the person should not consume alcohol.

Medication

You should make sure that the person with dementia has their prescription(s) and enough medication to cover the holiday period. Pharmacies are required to provide holiday cover - see the telephone book, or consult your local pharmacist in advance to get details. If you are not the person's usual carer, speak to the person's carer or to their care manager for details of their medication.

Emergencies

All local authorities have an emergency social work service – the number is in the phone book or ask the Dementia Helpline (0808 808 3000) for the number for your area. You should also ensure that you have a number for the person with dementia's GP and that you know where the nearest accident and emergency unit is.

NHS 24 operates a 24-hour nurse advice and health information service providing confidential information for the general public, and further details of out-of-hours medical services in your area. The telephone number is *08454 24 24 24*.

Emotional needs

Inevitably, feelings are magnified when families come together over the holiday period. Just as the festive period may trigger happy memories, it may bring sadness at the thought of times past. Try to find positive things to focus on in the present and the future, rather than dwell on the past.

A person with dementia may feel guilt or

sadness if they perceive themselves to be an additional burden; adult children may feel guilty that they should be doing more to help their parents. These kinds of feelings are best discussed openly rather than allowed to fester. Try to have an honest discussion and to understand each other's perspectives. There is no easy fix but problems discussed honestly and openly have more chance of being resolved.

Dementia Helpline

Alzheimer Scotland's freephone Dementia Helpline is open 24 hours a day, every day, including the holiday period. As well as information and support they offer a confidential listening ear.

0808 808 3000

Closure of services

Many local authorities provide services throughout the festive period. Unfortunately, in some areas services may be reduced, or even withdrawn completely as workers take leave to spend time with their own families. It is important to find out in advance just where the gaps in service provision will occur, especially if the person with dementia is heavily reliant upon them.

Try to prioritise the areas to cover and enlist as much assistance as possible. Explain to family and friends how much difference even a little help can make, and break tasks down into realistic goals so that they are less overwhelming.

People in care homes

Partners and families often feel tremendous guilt that a loved one is being cared for away from home. Over the festive period, you may feel even more guilty that the person you care for can't join in the celebrations or you may miss them if you have usually spent that time together in the past.

You may be considering bringing the person home for the holidays. For some people with dementia, a change of environment can be

very stressful and can cause confusion or anxiety. You may have adjust your plans to make the visit workable and enjoyable for all concerned. So where you might usually have had lots of visitors, with lots of extra entertaining, you may want to keep things simpler and quieter. You could ask visitors to come in small groups and space out their visits so that the person with dementia isn't overwhelmed. Or you could ask visitors to come at a time when the person is likely to be at his or her best.

If you are particularly concerned about how you and the person with dementia might cope with a visit home, you might want to have a test visit shortly before the holiday to see how things work out.

If the person you care for can't come home, you can still make plans to share part of the celebrations with him or her. Ask the care home staff what they will be doing to help residents celebrate and if you can do anything to help. You might want to take along some home cooking or a special treat that you know the person will particularly enjoy.

You may be able to spend a large part of the day visiting the care home but you should try to ensure that the person with dementia isn't overwhelmed. Be realistic about your responsibility to yourself and to other family members.

Five festive tips for carers

Encourage napping: short days, rich food and lack of exercise can make people sleepy. Make sure there is a quiet place set aside for those who prefer to doze in a chair and remember, carers need naps too!

Get outside: if it's cold people tend to stay inside but this can cause restlessness. Wrap up warmly and get outside for a while, just to clear your head and breathe some fresh air.

Stay active: this is hardly likely to be a problem if you are catering for lots of family and friends, but if you are on your own caring for a person with dementia you should avoid becoming isolated. Make sure you have given yourself time to do some things which you enjoy whether this is sitting in peace listening to music and doing the crossword, or getting out for a brisk walk.

Watch your diet: alcohol is a prominent feature of the festive period and you should certainly enjoy a drink if you want to. Remember though that alcohol is a depressant and should be taken in moderation. Also, with so many rich, sweet festive foods on offer, you may find that your energy levels fluctuate. Treat yourself but try to maintain a healthy intake of vegetables and to get enough fluid.

Take time to talk: don't view the burden of care as a taboo subject. Family and friends, and indeed the person with dementia, may have issues they want to get off their chests but be reluctant to bother you with.

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