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Holiday Issue

The holidays can be an overwhelming time for many people. This is particularly true when you are caring for a person with dementia. This issue is a collection of previous *In Touch* articles that caregivers may find helpful as they navigate the joys and pitfalls of the holiday season.



Families and Holiday Celebrations

by Eva Neufeld



The winter holiday season can be an exciting time of the year. Families will often arrange multiple gatherings to celebrate, although sometimes these family gatherings can pose special dilemmas for persons with memory loss and their family caregivers. However, with some adjustments to traditional holiday festivities, people with dementia and their families can enjoy what the season has to offer, creating new memories to savor.

As the holidays approach, it is only natural to want to change or decorate the house to mark the celebration. However, dramatically changing the environment or changing a routine can cause the person with dementia to feel anxious. Consider your family member's response to the physical environment to determine whether the change is appropriate. Though it may be difficult to vary long-held traditions, be prepared to let go of expectations of how things "should be" if those traditions are causing anxiety and/or discomfort.

Visiting with friends or family away from home during the holidays may also cause anxiety for people with dementia. In a different home or environment they may not know what is expected of them. Not knowing what to do or when/how to do it, the person may want to leave.

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Families and Holiday Celebrations continued from page 1

Among a large group of people, many people with dementia feel confused and uncomfortable. Since it is difficult to anticipate what the person will be able to handle, consider alternate plans for these kinds of special occasions. For instance, one consideration may be to hold family gatherings at the home of the person with dementia, which would allow them to remain in familiar surroundings. In circumstances where there are too many people around at one time, the person would be able to go to their bedroom or to a private space to be alone and regain a sense of control. Similarly, families may want to scale down the size of their gatherings and arrange for individual visits rather than having everyone over at one time. Family visits can be scheduled every few days as opposed to visiting one right after the other.

Some family members, both immediate and extended, may not understand the need for changes to holiday traditions, due to a lack of understanding and/or experience with Alzheimer's disease. The primary caregiver may have to make a stand for the modified celebrations. However, once family members become familiar with the altered arrangements, the personal connections that can result (e.g. smaller, more intimate family gatherings) can become a true gift and a newly celebrated tradition for everyone.

Families are often motivated to bring relatives with dementia home from care facilities for holidays out of fear that they will feel neglected if they do not. It is important to remember that people with dementia may not have the same expectations of holiday celebrations as they once did, and taking them out of the facility may reflect our own need to recreate holidays as they used to be. Whether to bring a family member with dementia home for the holidays is a difficult decision and depends on the individual. Consider whether he or she would benefit from being at home, or would the change in routine and environment be too difficult to handle? Consider what approach to use when it is time to bring the person back to the care facility, since the person may not want to return after being at home for a few days.

The holidays need not be a stressful time for families caring for a person with dementia. These long-held traditions may be an excellent opportunity for sharing stories and reminiscence. Although the person may no longer be able to handle cooking an elaborate traditional meal, they may still be able to wash vegetables, taste familiar foods, and talk about a favourite meal or holiday memory. By surrounding them with things that trigger their five senses (e.g. seeing, hearing, smelling, tasting, and touching), you will be sparking their long-term memory. If your family anticipates adjustments to your holiday celebrations this year, consider which traditions can be kept and which need to be modified based on the positive (and negative) responses of the person with dementia.



Having opportunities for reminiscence can bring families closer together and make the holidays more meaningful and memorable for everyone. ♦

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DEMENTIA HELPLINE

Alzheimer Society
BRITISH COLUMBIA

1-800-936-6033
(Lower Mainland 604-681-8651)

Helping people with dementia, their friends, and their family members to build the confidence to maintain quality of life when facing dementia.



Holiday Gifts

by Amy Bath

The holiday season between November and January can be a stressful time for almost everyone and can be a particularly overwhelming time for caregivers.

Choosing gifts for someone with dementia may seem like one more challenge during the holiday season. Fortunately, simple, useful and practical gifts are best. When giving gifts to someone with dementia, you need to consider the symptoms that the person is experiencing, as well as their personal safety. Think twice before giving gifts the person might find confusing or frustrating or that might pose a safety risk (e.g. a difficult puzzle, a complicated piece of clothing, electronic equipment, tools, utensils, pets). You may want to prepare a list of gift ideas and give the list to family and friends.

Some good gift ideas:

- Jewellery (e.g. an ID bracelet)
- Games that stimulate but do not depend on short-term memory alone (e.g. dominoes, Snakes & Ladders)
- Membership or passes to fitness activities
- Comfortable walking shoes
- Gift Certificates (e.g. dinner or breakfast in a restaurant)
- Simple, comfy and easy-to-remove clothing
- Favourite music: you could make a mixed CD of music the person used to enjoy. This would help him/her reminisce and gain feelings of familiarity. Music is closely connected to memory.
- A box of costume jewellery to sort through.

- Home videos are a great creative gift. You could include both old and current videos, or combine several into a "Highlights" video.
- Photo albums, scrapbooks, or collages that display the person's life visually.
- Picture books of movie stars, historical events or nature.
- Materials to sort, such as cards, keys or beads. Yarn or fabric to sort is also good - sorting is an activity that stimulates the sense of touch, and is an activity people tend to enjoy as their dementia progresses.

For the person in the late stages of dementia:

- Hand / body lotions
- Knee warmer or lap blanket to conserve heat and reduce symptoms of poor circulation
- Recordings of favourite music
- A soft cuddle object

Do not neglect yourself. If people ask you what you would like, suggest gift certificates for take-out restaurants, cleaning service, or a massage, pedicure, or hairstyling. A great present for a caregiver is a made-up "coupon" for a day off or free afternoon, so that you can relax and enjoy the holiday season. Aim to make your life a bit easier. You deserve it!

While the holiday season can be stressful, it is also an opportunity for togetherness, excitement, laughter and memories. Like other traditions, try to adapt gift giving to make the season less hectic and a little more relaxing. ♦

Adapted from www.egyptianaaa.org and www.alzla.org/dementia/holidays.html

The Holiday Checklist

Adapted from Thanatos Magazine, Fall 1994

On this page, **underline** *what you would traditionally do* and then **circle** *what you want to do this year*. Share this with your family and have them do one of their own and compare notes. Consider whether this is a good time to make some changes that benefit you and help restore your health and well-being.

Cards

Mail as usual
Shorten your list
Include a 'Holiday Letter'
Elect to skip this year

Shopping

Shop as usual
Give cash instead of gifts
Ask for help
Shop early
Make your gifts
Give baked goods
Ask for help wrapping gifts
Do not exchange gifts now but perhaps later
Before shopping, make a list of gifts

Decorations

Decorate as usual
Ask for help
Let others do it
Make changes; e.g. an artificial tree instead of a real one, an electric menorah instead of candles
Have a special decoration for your family member
Eliminate some or all decorations

Holiday Dinner

Prepare as usual
Eat with the person with dementia at new residence
Go out for dinner
Invite friends over
Eat alone
Change time of dinner
Change routine of dinner (e.g. go to a buffet)
Change location of dinner, eat in a different room
Ask for help

Holiday Music

Enjoy as usual
Avoid turning on the radio
Shop early before the stores have holiday music on
Listen to it, have a good cry and allow yourself to feel sad

Traditions

Keep the old traditions
Attend holiday parties
Don't attend holiday parties
Go to an entirely new place
Bake the usual holiday foods
Buy the usual holiday foods
Bake, but modify what you would usually do
Attend religious services
Do not attend religious services
Attend religious services but at a different time
Attend a different place of worship
Visit family member at new residence
Spend quiet time alone
If appropriate, visit cemetery
Have a New Year's party
Open gifts early
Open gifts on usual day

Post Holiday and New Year's Day

Spend as usual
Remove decorations early
Go out of town
Avoid New Year's party
Attend a New Year's party
Spend time with only a few friends
Write in your journal your hopes for the new year
Go to a movie
Go to bed early

Visiting Tips



Before visiting, check the physical and mental condition of the person with dementia. The more you know, the more comfortable you will feel.

When visiting, it is the moments shared together that count, not what the person may or may not remember afterwards. Whether able to participate or not, being with company and involved in conversations is valuable. If the same question is repeated several times, graciously answer; the question or answer may have been forgotten because of the disease. Reminiscing about shared memories as well as daily events can enable the person to feel that they're still important to others.

Sharing time matters more than what is said or understood. Be prepared for potentially embarrassing or unusual behaviour as the person may be confused and won't remember what is polite or expected. Remember, the disease can cause challenging behaviour, so don't take criticism or accusations personally.

Quiet and simple activities are often the best and "just being there" is a gift. You don't have to feel that you always need to be "doing something". If you're not feeling well, avoid visiting out of a sense of duty; influenza and pneumonia can be real threats to older adults. Avoid unnecessary stress and fatigue for everyone by keeping visits short. As the person's routine may be disrupted when visiting, you may want to leave if the person becomes restless.

Begin new rituals at home or in a care facility. Develop a ritual that you feel comfortable with and which honours the person with dementia. For example, acknowledge the person in a prayer or blessing; include a dish that the individual prepared in the past and provide others with the recipe; look over photographs and tell others about those times.

Choose to celebrate a spiritual aspect of the holiday. Visiting or reaching out to others who are not a part of your family or circle of friends can be a surprisingly healing experience. It gives meaning to the holiday sentiment, "It is more blessed to give than to receive." ♦

Adapted from *Holiday Visiting Tips: A Message for the Faith Community and Friends of Alzheimer's Families*, by Edna L. Ballard, MSW, ACSW and J. Whitney Little, *The Caregiver Newsletter of the Duke Family Support Program - Center for the Study of Aging*, Duke University Medical Center, Durham, NC, Oct-Nov 2005

Seasonal Safety

With the holidays approaching, there are a number of things to keep in mind when caring for a person with dementia. Below is a checklist of things to help maintain safety during the holiday season.

Things to consider avoiding:

- small ornaments or other items that might be accidentally eaten and cause choking
- lighted candles
- breakable ornaments
- hard candy
- plastic fruit decorations or anything that resembles something edible
- noise and crowds
- blinking lights – they can be very distracting
- alcoholic beverages
- poisonous plants such as mistletoe

Other precautions:

- Make sure tree lights and other electrical decorations are only turned on when someone else is in the room.
- Exercise caution when using space heaters.
- Do not leave the person alone around an open fire/fireplace.
- Consider using ribbon or coloured string instead of the usual sharp hooks used for hanging ornaments.
- Make sure that you and the person with dementia eat healthy meals.
- Avoid rearranging furniture when you're decorating; minimize clutter.
- Secure all extension cords to avoid potential tripping hazards.
- Keep a spare key outside.
- Try to have a quiet space available where the person with dementia can rest, be alone, or spend time with fewer people. ♦

Surviving the Holidays

originally published *In Touch*, December 2003



For most families, regardless of faith or culture, holidays are a time of joy and togetherness, a time for celebrating, sharing and enjoying one another's company. Holidays can also be stressful, even at the best of times. When you're caring for a person with dementia, the holiday season can be especially difficult for all kinds of reasons.

Typical stressors at this time of year include:

- Dealing with the memories of past holidays, and the unexpected feelings and emotions these memories cause.
- Feeling overwhelmed with maintaining holiday traditions while trying to keep up with caregiving responsibilities.
- Dealing with visitors who don't feel comfortable relating to a person with dementia.
- Expecting too much of yourself or others.
- Trying to live up to others' expectations.
- Feeling guilty for not being able to get into the holiday spirit.

The person you're caring for may also have a difficult time coping with the holiday season. Perhaps he or she feels a particular sense of loss at this time of year or finds the disruption in routine caused by holiday activities distressing.

What can you do to survive the holiday season?

Adjust expectations

Talk to family members and friends to make sure they understand your situation and that their expectations are realistic.

Prepare them for the changes they will notice, and let them know that the person may behave in unpredictable ways. For example, he or she may ask the same question over and over, or may become agitated if there is too much sensory stimulation.

Remind family and friends that the person may have trouble remembering names and faces, and suggest they introduce themselves.

Perhaps as a group you can all make plans to adapt your traditional activities to suit the needs of your family member with dementia.

Minimize holiday stress

This is obviously much easier said than done. However, there are things you can do to help yourself get through the holiday season more smoothly.



- Give yourself permission to take a break. You deserve it. Remind yourself that you can only provide good care if you're taking good care of yourself.
- Look after yourself. Eat healthily, get as much sleep as you can, and try to get some exercise.
- When family members offer to help, accept. If they don't offer, don't be afraid to ask.
- Set realistic goals and expectations.
- Be selective. Pick and choose the holiday activities and traditions that mean the most to you and to your family member. Don't try to do it all.
- Keep it simple. Try to do all your gift shopping in one store, attend the smaller family gatherings, invite only a few guests at a time, use paper plates to make clean-up easier.
- Slow down.
- Give yourself permission to enjoy the holidays. Spend time with your friends and family, even if the person you're caring for can't participate.
- Keep to your regular routine as much as possible.
- Recognize that you may feel lonely, angry, sad or disappointed before, during and after the holidays. These feelings are normal, and they don't mean you love the person with dementia any less. »

(*Surviving the Holidays* continued from page 6)

Involve the person with dementia

When you can, involve the person in the holiday preparations. You know best what activities he or she is capable of and interested in. Try doing some of the following activities together:

- Reading the cards you receive and reminiscing about the senders
- Wrapping presents
- Hanging decorations
- Preparing food
- Packing cookies in tins for gifts
- Listening to music and singing holiday songs
- Driving around in the evening to look at the holiday lights. ♦

Thankful

by Penelope Hutchison



My father has Alzheimer's and he is no longer the man I cherished as a girl. He stares out the window for hours at a time, looking at nothing, his thoughts blank.

I walk up to him slowly, carefully, quietly, afraid to surprise him. He looks up at me from his chair, his eyes trying to register my identity. Thirty seconds, one minute passes, sometimes two before the flash of recognition alights and he smiles.

Each time I board the plane to return to my family home, I wonder how much more of him has disappeared. I know our days together as father and daughter are numbered. I am thankful for however many days are left that he can still be 'my dad'. ♦

Tele-Workshops



The Alzheimer Society of B.C., in partnership with Care-Ring Voice Network, offers free one-hour telephone/internet workshops for family caregivers, wherever they are in the province. They are particularly suited to caregivers who find it difficult to get out of their house to attend a workshop.

The tele-workshops are free. All you need is a phone. However, participants who also have access to high-speed internet will be able to follow along with the online presentation. During the tele-workshops, you can ask questions and also hear from other caregiver participants.

Register by calling toll-free 1-866-396-2433, Monday to Friday from 6 a.m. to 2 p.m. PST. For a list of tele-workshops or to register online, go to www.alzheimerbc.org and you will be directed to the Care-ring Voice website.

Upcoming Tele-Workshops

Please note, participation in the following workshops is limited to family caregivers who reside in B.C. and Yukon.

A Doctor's Insight into Assessment and Care for People with Dementia

Monday, November 30, 2009, at 7 p.m.

Featuring Dr. David Gayton, this informative live presentation will provide insights into the diagnosis and treatment of Alzheimer's disease and related dementias. Dr. Gayton will also discuss the management of behavioral and psychological symptoms of dementia.

The Balancing Act: Caregiver Self-Care

Thursday, December 10, 2009, at 7 p.m.

Family caregivers may not always recognize the stress they experience caring for a person with a complex brain disease. This workshop will help to focus on coping strategies and on finding balance.



Get Walking!

Sunday, January 31, 2010

www.walkformemories.com / 1.800.667.3742

Your few steps can make a difference! Come out and join the *Investors Group Walk for Memories* happening on Sunday, January 31, 2010, in 19 communities in B.C. Money raised will create awareness and support the more than 70,000 British Columbians who are living with Alzheimer's disease and related dementias.

Come out and join this fun family event. For more information, call Angie Kok at 1-800-667-3742 or go to www.walkformemories.com for more information.



Alzheimer Society BRITISH COLUMBIA

A total of 18 Alzheimer Resource Centres located throughout the province offer information, educational workshops, support groups and the opportunity to talk directly with a knowledgeable team member. Resource Centres also offer lending libraries, information packages with brochures and fact sheets, individual support by appointment, and referrals to community resources.

For more information on our services or to find a resource centre near you, call the Dementia Helpline toll-free at 1-800-936-6033 or in the Lower Mainland at 604-681-8651. You can also visit our website; click on In My Community or click on: www.alzheimerbc.org/In-My-Community.aspx

HealthLink BC - Call 811

Speak with a nurse about your symptoms, consult a pharmacist about your medication questions, or get healthy eating advice from a dietician. This service is free of charge and available 24 hours a day and 7 days a week. Simply dial 811 for health information and answers to non-emergency questions. Information is also available online at www.healthlinkbc.ca.

The Alzheimer Society of B.C. is committed to protecting the privacy of people whose personal information is collected and held by the Society and we adhere to all legislative requirements with respect to protecting privacy. If at any time you wish to have your name removed from this or another mailing, contact us by phone at 604-681-6530, toll free at 1-800-667-3742 or via email at info@alzheimerbc.org.



Call for Participants for Memory Training Research Study

- Who: Persons who have Alzheimer's disease and their family members
- What: To participate in a new memory training program
- Where: In your home and at your convenience
- When: For 6 weeks (2 one-hour sessions each week)

To learn more about our study or if you are interested in participating, please contact Jeff Small at 604-822-5798.



Our Vision

Our ultimate vision is to create a world without Alzheimer's disease and related dementia.

Our Mission

The Alzheimer Society of B.C. exists to alleviate the personal and social consequences of Alzheimer's disease and related dementias, to promote public awareness and to search for the causes and cures.