

In Touch

newsletter for caregivers

Alzheimer Society
BRITISH COLUMBIA

September 2008

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In Touch for Caregivers » electronic version «

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Managing Awkward Times

Caring for someone with Alzheimer's disease or a related dementia requires a great deal of courage and understanding. Caregivers deal with a wide variety of challenges, from overcoming emotional grief to making complex financial and health care decisions. This issue of *In Touch* will focus on the particular challenge of awkward situations. Feelings of embarrassment, or not knowing how to handle things, are common throughout the disease as new situations are presented. The following is a discussion of several circumstances which some individuals may find awkward.



Talking to Children about Alzheimer's Disease

When a grandparent or other loved one is diagnosed with dementia, it can be the children of the family who are most affected. Adults are capable of understanding the disease, its symptoms and what to expect. Parents and other relatives need to pass along this knowledge - in an age-appropriate way - to children who will be impacted.

Breaking the News

At any age, children can sense problems and stress in their environment, so it's important to address any concerns before they make the wrong assumption.

The conversation will differ depending on the child's age. For younger children, you don't



necessarily need to use the term *Alzheimer's disease*. Instead, talk about how the child's loved one is sick, will have trouble remembering things and might sometimes be confused. Be sure to mention that their loved one will probably get sicker and that it's important for the family to help out. Depending on their level of understanding, try to prepare them for the changes they'll (Continued on page 2)

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(Talking to Children Continued from page 1)

see in their loved one.

Teenagers, who are more capable of understanding the diagnosis, should hear more details, such as how long their loved one may live with the disease and what are treatment options. Talk to them before inviting a loved one to move in for full-time care. While parents might not always abide by teens' opinions, it's important that everyone's voice be heard.

Reassure children that Alzheimer's disease is not infectious. If the loved one was diagnosed before age 65, talk to older teens about the possibility that the disease is inherited. If early-onset Alzheimer's disease has affected several immediate relatives, the family might consider genetic testing for the disease.

Continue to talk to children and teens about the time when the disease will progress to the point where their loved one no longer recognizes them. Acknowledge their feelings and assure the person still loves them and still appreciates their visits. Allow them to grieve this loss, and don't force them to continue visiting if they are truly uncomfortable.

Emotions and Reactions

Children can experience a variety of emotions relating to their loved one's condition, but they might not volunteer their feelings. In some cases, parents might need to anticipate these emotions and be proactive about initiating a conversation.

These emotions can include:

- Fear that parents, other relatives or they themselves might be diagnosed with the disease
- Anxiety, sadness, or fear regarding changes in their loved one's behavior or personality
- Frustration over having to say things many times or needing to repeatedly identify themselves
- Remorse over acting frustrated or guilt about not having the disease themselves
- Self-consciousness about being in public with their loved one or, if the loved one lives with the family, feeling ashamed of their living situation

Remember, kids and teenagers don't always express their emotions in the same ways that adults do. Instead of talking about their fears, worries, and guilt, they might exhibit behavioral problems, be distracted from



schoolwork, avoid interaction with the family, and even complain about physical ailments. If this occurs, try having another conversation; if necessary, ask a trusted teacher, another adult or a school counselor to sit in on it.

Parenting Strategies

Offer continuous support to children while they cope with their loved one's disease. It's important to allow them to express themselves, to avoid judging their feelings and to answer all of their questions as honestly as possible. For more help, visit the Alzheimer's Association website for kids and teens (www.alz.org).

It can also be helpful to engage the children in family-related activities, such as making a family tree or looking at old photographs. These activities can help children feel connected to their loved one.

Parents or guardians can also engage children in making a memory book for their loved one. Memory books, which have been shown to ease behavioral symptoms in people with Alzheimer's disease, usually consist of family photos and other memorabilia. The book can help a loved one with Alzheimer's disease reconnect with memories. Children can also write a letter or draw a picture for their loved one to be included in the book. ☞

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Contact your local resource centre for an information sheet for children or teens. You can also help your children create memory boxes online at the Memory Bank website. Your memory boxes can include journal entries, photos, audio or video clips. Visit www.thememorybank.ca.

Tips for Dealing with Changes in Sexual Behaviour

Dementia does not change the need for love and affection, but it can affect a person's interest in sex, either increasing or decreasing it. Inappropriate sexual behaviour might also become a problem.

Sometimes what we consider to be an inappropriate sexual behaviour has no sexual connotation for the person with dementia. For example, if the person with dementia seems to be rubbing their genitalia, it might be because they need to go to the bathroom, or their clothing is too tight, or they have a genital or urinary infection.

Here are some tips to deal with inappropriate behaviours:

- Stay calm; do not blow the situation out of proportion, because the person with dementia probably does not understand why there is a problem. Keep in mind that they have less control over their needs and urges due to changes in the brain.
- Ignore the behaviour, if it is appropriate to do so.
- Distract or redirect the person with an activity; a person with dementia who is bored or under-stimulated, might masturbate as a distraction.
- (If sexuality is becoming an obsession due to changes in the brain) redirect the sexual energy of the person with dementia with an activity, such as going for a walk. If they are constantly initiating sexual advances because they cannot remember just having sex, reassure them that you just had a lovely time together and propose going to an environment non-conductive to intimacy (such as a public place).
- Provide privacy for the person if they are in a public area.
- Leave the situation, if appropriate. Take a break and come back later.
- Give the person with dementia something to hold or manipulate, if they are touching themselves or another in an inappropriate way. The person might have a need to manipulate things, or may just be bored.
- Comfort the person. They might be anxious or fearful and may be using sexual outlets as a way to get comfort and feel more secure.
- Gently touch or hug the person in a way that will not be perceived as sexual. What we perceive as a sexual behaviour might be an attempt to connect, give or display affection.
- Offer a body-pillow to cuddle in bed (if the person goes into other people's beds at night). A stuffed animal or a hot-water bottle wrapped in a towel can also provide comfort and satisfy the need to feel a warm body; a pet lying at the foot of the bed can also provide companionship).
- Adapt the environment to the situation. It is often easier to change something in the environment of the person with dementia. For example:
 - If someone is exposing their genitalia, consider pants with no zipper, pants with suspenders, or overalls.
 - Wearing an apron with pockets filled with interesting objects to touch might divert someone from touching themselves or at least allow them to do so more discreetly.
- Putting a pillow on someone's lap can provide a barrier between their hands and their genitalia.
- Wearing an athletic cup might prevent a man from grabbing his genitalia.
- Wearing a bracelet with small bells might distract a woman from masturbating.
- Do not take it personally; you are not responsible for the inappropriate behaviour of the person with dementia. The behaviour is a consequence of the illness and is not a reflection on you.
- Consult your physician; the side effects of some medications will decrease sexual desire, or cause impotency. If your partner with dementia is becoming aggressive in their sexual relationship with you, and if non-medical interventions are ineffective, consider talking to your physician, who might prescribe medications to decrease the libido.
- Check for signs of depression. People suffering from depression often lose interest in sexual intimacy. ☞



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From the Alzheimer Society of B.C.

Alzheimer's disease: Causes of Fecal Incontinence

Fecal incontinence is a common condition that can occur at any stage in Alzheimer's disease. It is stigmatizing, embarrassing and causes misery to both the person with Alzheimer's and their caregiver. In this article we look at the possible causes of fecal incontinence.

Fecal incontinence is a symptom not a disease. Before you can think about treatment, you need to determine the cause. Always remember just because someone has Alzheimer's it does not mean that they cannot get sick too!

Causes of fecal incontinence include:

Diet

Diet should be rich in fiber but not to the point where it causes diarrhea. A balanced diet is important to maintain healthy and efficient bowel movement. As the body ages it can become more sensitive to certain foods. Good observation skills and monitoring the effect of diet on an individual can help avoid problems.

Medication side effects

Fecal incontinence may be the result of side effects from medication. Constipation, diarrhea and/or an upset digestive system can be side effects. Gastrointestinal and stomach upsets are common to many drugs. Do not stop taking the prescribed drug unless your doctor tells you it is OK. Seek his or her advice quickly. Fecal incontinence has many causes, and can be life threatening. The

doctor can decide if tests are needed to determine the cause or may decide to prescribe another type of medication. It is important to seek help so that the person does not suffer or get sicker.

Mental state

Emotional states and behavior can affect the way the body responds. You will know when you are anxious that it can affect your toilet habits! It is, of course, the same for anyone with dementia such as Alzheimer's disease. Fecal incontinence can result from organic dementia and confusion disorders such as those present as a result of medication, mental illness that includes depression and mania.

Disease

Fecal incontinence can occur because of disease or conditions. The range shows how important it can be to get fecal incontinence diagnosed properly. Causes include:

- Muscular weakness due to disease, surgery, injury.
- Congenital rectal and anal abnormalities even with surgical intervention can persist into adulthood.
- Surgical trauma. Some conditions that can be treated surgically may occasionally result in fecal incontinence, for example haemorrhoidectomy (piles), the treatment for anal fistula, and some outdated treatments such as manual dilatation.



- Trauma. Injury to the anus and rectum due to accident or sexual practices.
- Severe diarrhea (persistent or intermittent) may be due to infection, irritable bowel, side effects of medication, diseases of the bowel such as ulcerative colitis, Crohn's disease, Diverticulitis, cancer, radiotherapy.
- Disorders of the lower bowel due to cancer, anal fistula, hemorrhoids.
- Disorders of the nervous system. These can include multiple sclerosis, effects of a stroke, spinal cord injury, diseases affecting the brain such as cancer, structural abnormalities, as well as dementia.

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(Incontinence continued from page 4)

Constipation or fecal impaction

Fecal incontinence can be due to or exacerbated by constipation or fecal impaction. Constipation may mean the patient is passing feces more regularly and unpredictably. Dealing effectively with the constipation may well return the person to a more regular pattern of bowel habits once the constipation is cured.

Fecal impaction, where the bowel becomes filled with hard feces can cause a lot of problems and is quite common in the bed bound. The result is uncomfortable, painful and can cause the person's mental state to deteriorate dramatically. Overflow diarrhea can also occur making for even more problems. Making a note of bowel habits will avoid impaction. Once impaction occurs, a doctor should be consulted on cause and an enema is the usual treatment, depending on the cause and the individual's medical history.

Fecal incontinence and urgent medical attention

Always seek urgent help if you or someone with Alzheimer's has any of the following signs and symptoms:

- Pain in the rectum
- Bleeding from the rectum
- Changes in bowel habits
- Diarrhea that lasts more than a day or two
- Dark or black stools
- Unexplained weight loss
- Feeling your bowel is never completely empty ☞

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Bathing Tips



Bathing is one of the most intimate types of personal care. Depending on your comfort level, it can be an awkward task for you as the caregiver, especially if you are the son or daughter. For the person with dementia, this type of intimate care can signify a loss of privacy and independence.

It is humiliating for some people to be bathed or even to be reminded to take a bath or a shower. This could be one of many reasons why the person with dementia refuses to bathe.

With any difficult behaviour, it is important to find the source of the problem in order to solve it. Bathing is no exception. Changes in a person's behaviour could be related to the disease process. For example, because of changes within the brain, the sensation of cold and warm, or the feeling of water itself might change. In other cases, the person with dementia may have forgotten the necessary steps to take a bath or a shower, or may have forgotten the purpose of bathing or good hygiene. Whatever the reason for this resistance, it is important to be sensitive and tactful and to preserve the dignity of the person with dementia.

Below are some suggestions that can help make bathing easier:

- Evaluate the best day and best time for bathing; consider the person's former bathing habits.
- Use the person's own words around bathing. Some people have little sayings that they used in the past about bathing or getting dressed, such as "getting ready to face the day" or "freshen up." Giving them their words back might prompt self-care behaviour.
- Make the bathroom warm and inviting by playing their favourite music and providing adequate lighting, especially in the evening.
- Use coloured bubble bath or a coloured bath mat to make it easier to judge the depth of the water (avoid dark coloured mats -- it could give the impression of a hole). Lay a towel or a strip of coloured tape on the edge of the tub to make it stand out.
- Consider using a hand-held spray attachment on a flexible hose. It makes rinsing and washing hair much easier.
- Adjust the water level to the person's preference. Some people can only tolerate a few inches of water in the bathtub.
- Avoid making the person wait or become tired while you are preparing the bath. Prepare the bath ahead of time (this may be a good idea as the sound of water running in the bathtub may feel overwhelming or too loud). Lay out the soap, washcloth, shampoo, towels, and have water in the tub.

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(Bathing tips continued from page 5)

- Pull the blinds down and close the door to create a sense of privacy.
- Respect the need for modesty: allow the person to bathe in underwear, a bathing suit, or wrapped in a towel.
- Allow the person to do as much of the washing as possible.
- Simplify the task by giving one instruction at a time.
- Let the person feel the water before getting into the tub, or gently pour water over the hands to reassure the person that the water is not too cold or too hot. This might also help remove some of the fear associated with water itself.
- Make bathing a positive experience by praising the person's accomplishments.
- Make sure the person's hands are occupied by providing a washcloth.
- If washing hair is part of the problem, separate hair washing from bath time. Try shampoos that don't require water.
- Try a no-rinse soap to shorten the time in the shower.
- Try a sponge bath at the sink, especially if the person has mobility problems.
- For people who are very resistant, consider washing a body part each day rather than the whole body every second or third day.
- If the person regularly refuses to take a bath, escort him/her to the bathroom before raising the subject.
- Cover the mirror if the person no longer recognizes his or her own reflection.
- Use a quiet and calm, matter-of-fact approach. For example: "Mother your bath is ready."
- Offer the person some choices. For example: "Would you like to take a bath now or before going to bed?"
- Offer a 'reward' such as a favourite food or activity.
- Arrange to have another individual, with whom the person is comfortable, help with bathing.
- Enlist the help of your doctor or someone that the person respects to give bathing instructions, or have bathing instruction on a doctor's pad.

On some days, these ideas will make bathing easier. On other days, you may decide that a sponge bath will be sufficient or even no bath is the best option. It's true most of us like to bathe or shower often and prefer that the person we are caring for does as well. It is important to remember that you are doing the best you can. ✂

For more information, you can request a fact sheet on bathing from your local resource centre or e-mail: info@alzheimercbc.org. The tips above are provided by the Alzheimer Society of B.C.

I Want To Go Home

Excerpt from *Creating Moments of Joy* by Jolene Brackey

What if you were in a restaurant or at someone's house who you didn't know and said, "I want to go home," and they replied, "No, you live here now. This is your home. I am going to do your hair and we are going to play bingo. This is your home."

Wouldn't that make you feel scared, angry and frustrated? You would want to dart out the back door as soon as these people turned their backs.

Well, that is exactly how a person with dementia feels. Now let's change the response to, "Oh, please stay for dessert." We can all stay somewhere just a little bit longer (especially for dessert).

When the person says, "I want to go home," give them a reason to stay just a little bit longer and give them the hope that they can still go home. They can live in a place for two years and think it has been one day. This is why this answer works. A typical day might look like this:

When they wake up in the morning, they say, "I want to go home."

Your response, "Let's get dressed first."

"I want to go home."

"But we are having bacon and eggs for breakfast. Just stay for breakfast."

"I want to go home."

"Let me do your hair before you go."

"I want to go home."

"We are going to have devotions soon."

"I want to go home."

"The church ladies have made us roast beef and mashed potatoes."

(Triggers three responses: The food is (continued on page 7)

(I Want To Go Home continued from page 6)

good, the food is free, and it would be rude if they left).

"I want to go home."

"But we are going to sing this afternoon. I love your alto voice."

Now men are much more difficult to get to stay. So when a man wants to leave, you need to become the damsel in distress. "Would you mind moving this really big box?" When the man gets up, take his arm and don't be surprised while you are walking down the hall if he thinks, "Dang... Where did I find this woman?" Walking with you down the hall is a moment of joy. When you get to the box and he picks it up, the key words to say are, "You are sooooo strong."

Another suggestion is to figure out what he would be good at fixing. What was his occupation? Then he needs to "help you" later that day.

This lady from New Jersey told me how her husband loved to fix the vacuum but every time he fixed it, she had to spend \$120 to get it fixed. So she would hide it in the closet or in the basement. That just made him more upset because he couldn't find the vacuum. I suggested getting three vacuums from Goodwill; put one in every room and let him fix till his heart is content. You can't take away an obsession. You need to saturate obsessions.

To get a man to want to stay, it may only take three statements. "You are soooo strong." "You are soooo smart." And the last one, "You are sooooo handsome." Don't forget to wink. Men need to be needed in order to want to stay. ☺

(For more information on the book, *Creating Moments of Joy* check out www.enhancedmoments.com).

Some people find that explaining their loved one's behavior to other people often alleviates an awkward situation. Once people have an explanation as to why a person is behaving in a way that is unusual, people tend to relax. Below is a sample card that you can use to defuse a potentially awkward situation. You can contact the Alzheimer Society of B.C. for other versions.



Please be patient
and compassionate.
My companion has
Alzheimer's disease.



September 18, 2008

Coffee Break is an event where people gather over a cup of coffee at home or at work, and make a donation to the Alzheimer Society of B.C. The money raised stays in the community to help support local programs and services. Coffee Break 2007 raised over \$60,000 in British Columbia.

Location: Communities across B.C.

Contact Info: For more information or to find a Coffee Break event near you, visit our website at: www.alzheimerbc.org/coffee.php

Heads Up for Healthier Brains



Ever wondered what you can do to keep your brain fit? Join us for a presentation with Dr. Jonathan Schooler, professor of psychology specializing in memory, who will present helpful tips to keep our brains sharp as we age.

Admission is by donation to the Alzheimer Society of B.C. No registration is required. Seating is on a first-come, first-serve basis. The first 450 people will receive a free pedometer.

Thursday, October 9, 2008
7:00 - 9:30 pm (doors open at 6:30)
3456 Fraser Street
Glad Tidings Church, Vancouver

Hosted by

Alzheimer Society
BRITISH COLUMBIA

Vancouver Coastal Health

Notices and Announcements

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 for family. 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.



You can register online at: www.alzheimerbc.org. Click on 'Caregivers Can Learn from Home' at the bottom of the page. Then scroll down and find the workshop you are interested in. To register you will be directed to the Care-ring Voice website.

You can register by phone by calling toll free 1-866-396-2433, Monday to Friday 6:00 a.m. to 2:00 p.m. PST. Check our website for more information at: www.alzheimerbc.org.

Upcoming Tele-Workshops

Healthy Brain

Thursday, September 25, 2008
from 10am to 11am

Life After Diagnosis

Thursday, October 30, 2008
from 7pm to 8pm



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 the cure.

The Pathway to Healthy Brain Aging – Past, Present and Future Perspectives

is a public awareness event to launch the Atlas of Alzheimer's Disease. Author and internationally acclaimed authority on the disease, Dr. Howard Feldman and his Co-authors will discuss prevention, treatment and future research outcomes for the benefit of patients, caregivers, and the general public **Oct. 2, 2008, 7:00-8:30 P.M.** at Cordula and Günter Paetzold Health Education Centre Auditorium, VGH, Jim Pattison Pavilion, 1st Flr, 899 W. 12th Ave.

Alzheimer Society BRITISH COLUMBIA

Check www.alzheimerbc.org to find out more about our programs and services.

- Education programs:
 - The Dementia Series
 - Tele-Workshops
- Healthy Brain
- Information Services
- Support Groups for caregivers and people in the early stages of dementia
- Insight—a newsletter for and by people with dementia
- Memory Bank
www.thememorybank.ca
- Safely Home/B.C. Photo Registry
- Dementia Helpline

In Touch Publication Schedule

December 2008
Maintaining the Spirit

Health Line Services BC - A 24-hour line that puts you in touch with a Registered Nurse who will answer your questions about symptoms, health concerns, when to see a health professional, etc. Call 1-888-215-4700 or in Vancouver (604) 215-4700. Deaf and hearing impaired toll free province-wide 1-866-TTY-4700.

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.

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.