

CHILDREN, TEENS AND DEMENTIA

Finding out that someone close to you has dementia and coping with the ongoing illness can be distressing for anyone. But children and teenagers can find it particularly difficult. It is natural to want to protect them from upsetting and confusing situations. However, experts say that it is important to explain to children and teens what is going on.

- Children/teens are often aware of others' emotions and tensions, even when they don't know the cause. It is reassuring for them to understand what the problem is.
- Although the news may be distressing, children and teens may find it a relief to know that the person's behaviour is part of an illness and not done on purpose or as a result of something the child/teen has done.
- It can be more upsetting for the child/teen to find out later that something has been kept from them than to cope with the truth at the time, however upsetting the truth may be.

When dealing with dementia, children and teens may feel:

Sadness at what is happening to someone they love.

Fear or anxiety about what will happen to the person in the future.

Irritation or boredom at hearing the same stories and questions over and over again, perhaps mixed with guilt for feeling this way.

Embarrassment at being seen with the person with dementia.

Confusion about “role reversal” - having to be responsible for someone who in the past was responsible for them.

Loss – the person with dementia doesn't seem to be the same person as before and it isn't possible to communicate with them in the same way as in the past.

Anger or rejection if other family members seem to have less time for the child/teen as a result of caring for the person with dementia.

What you can do to help children and teens cope

- Be as honest as you can in talking about the illness. Use clear, simple explanations. Give practical examples of changes they may witness and the causes of those changes.
- Provide age-appropriate information through pamphlets, books, or the internet. Encourage your children or teens to do some research with you or on their own.
- Lessen fear of the future. Children and teens may be fearful of developing dementia in the future, or that their parents might develop it. Reassure them that dementia cannot be “caught”.
- Be patient. You may have to repeat your explanations and provide answers to evolving questions.
- Answer all questions in a calm and non-judgemental manner.
- Keep the lines of communication open. Listen to concerns.

Alzheimer Society of BC Provincial Office

300 - 828 West 8th Ave.

T: 604.681.6530

www.alzheimerbc.org

Vancouver, B.C. V5Z 1E2

Toll-free: 1-800.667.3742

info@alzheimerbc.org

Page 2 of 7

- Be reassuring, offer comfort, and tell the child/teen that you are there to help them deal with this.
- Try to alleviate guilt. Sometimes children/teens may believe that they are responsible for the illness. Explain that the person is sick and that it is nobody's fault.
- Let child/teen know that their feelings are normal.
- Spend quality time together.
- Allow children/teens to spend time by themselves or with their friends.

Communication tips to share with children and teens

- Speak clearly.
- Use a gentle tone of voice.
- Smile. Emphasize facial expressions, body language, and hand gestures.
- Maintain eye contact.
- Approach the person from the front.
- Hug or gently touch the person on the arm to connect.
- Use the person's name to get their attention.
- Tell them your name if they cannot remember.

Alzheimer Society of BC Provincial Office

300 - 828 West 8th Ave.

T: 604.681.6530

www.alzheimerbc.org

Vancouver, B.C. V5Z 1E2

Toll-free: 1-800.667.3742

info@alzheimerbc.org

Page 3 of 7

Involving children and teens with the person with dementia

- Emphasize that simply spending time with the person and showing them love and affection is the most important thing they can do.
- If appropriate, involve children/teens in assisting with care and/or activities for the person with dementia. This can help make the situation seem more normal for them and may ensure they don't feel shut out. Be careful not to give them too much responsibility or let it take up too much of their time. It is important that children and teens are able to continue with their normal lives.
- Try to ensure that the time they spend with the person is enjoyable.
- Make sure that children/teens know that you appreciate their efforts and help them see how their involvement benefits the person.
- Take photographs of the child/teen with the person to remind them (and you) that there can still be good times.
- Don't leave children/teens in charge of the person, even briefly, unless you are confident that they are able to cope with any situation that may arise.

Alzheimer Society of BC Provincial Office

300 - 828 West 8th Ave.

T: 604.681.6530

www.alzheimerbc.org

Vancouver, B.C. V5Z 1E2

Toll-free: 1-800.667.3742

info@alzheimerbc.org

Page 4 of 7

Suggested activities children and teens can do with the person with dementia

- Go for a walk.
- Play a simple game or work on a puzzle.
- Make a scrapbook or a “memory box”.
- Look at photographs.
- Listen to music together.
- Read stories or the newspaper.
- Cook or bake using a simple recipe. Be careful of sharp objects and potentially dangerous situations.
- Fold laundry, sweep the floor, clip coupons, or do other simple chores.
- Reminisce about the past.

Signs that children and teens may be having difficulty coping

Anxiety-related symptoms: nightmares, sleeping difficulties, attention-seeking or disruptive behaviour, or unexplainable aches and pains.

- The child/teen may need more support. Make sure you give them plenty of time to talk things through. If you're worried, you may want to consider talking to their school counselor, other therapists, or your GP.

School work is deteriorating. Children/teens who are upset often find it harder to concentrate and school work may suffer.

- If this is the case, have a word with your child's teacher so they are aware of the situation. Offer extra help with homework.

Appears totally unaffected. If the child/teen seems uncharacteristically disinterested in the situation or unusually cheerful, they may be bottling things up or putting on a brave face.

- Encourage them to talk about the situation and express their feelings. Share some of your feelings about what is happening.

Being sad and weepy. Some children/teens respond by feeling very upset and may need a great deal of attention over a long period of time.

- Try to give them some time each day to talk things over.

Retreating from the situation. Older children and teens may withdraw into themselves, spending extra time in their rooms or staying out more than usual.

- They may feel embarrassed talking about their feelings or think that you won't understand. They need to know that you love them and are willing to listen. Show that you are available to talk by spending time together.

References:

- Alzheimer Association (USA). (2010). Retrieved from <http://www.alz.org>
- Alzheimer Society of B.C. (2010). Retrieved from <http://www.alzheimerbc.org>
- Alzheimer Society of Canada. (2010). Retrieved from <http://www.alzheimer.ca>
- Alzheimer's Australia, Living with Dementia (AUS). (2010). Retrieved from <http://www.alzheimers.org.au/default.aspx>
- Alzheimer's Home Companion. (1999-2004). Eymann Publications
- Alzheimer's Society (UK). (2010). Retrieved from <http://alzheimers.org.uk>
- Dementia Guide, Helping People Affected by Dementia. (2010). Retrieved from <http://www.dementiaguide.com/sitemap>
- Family Caregivers Alliance, National Centre on Caregiving. (2008). *Practical Tools and Resources for Caregivers*. San Francisco, CA: Family Caregiver Alliance.
- Family Caregivers Alliance, National Centre on Caregiving. (2010). Retrieved from <http://www.caregiver.org/caregiver/jsp/home.jsp>
- Fisher Centre for Alzheimer's Research Foundation. (2010). Retrieved from <http://www.alzinfo.org>
- MAREP, Murray Alzheimer Research and Education Program. (2010). Retrieved from <http://marep.uwaterloo.ca>
- McCann-Beranger, Judith. (2000). *A Caregiver Guide to Alzheimer Disease and Other Dementia*. Alzheimer Society of Canada.
- Robinson, Anne. Spencer, Beth. & White, Laurie. (2005). Ypsilanti, MN: *Understanding Difficult Behaviours*. Eastern Michigan University.
- US. National Institute on Aging. (2010). Retrieved from <http://www.nia.nih.gov/Alzheimers>

Alzheimer Society of BC Provincial Office

300 - 828 West 8th Ave.

T: 604.681.6530

www.alzheimerbc.org

Vancouver, B.C. V5Z 1E2

Toll-free: 1-800.667.3742

info@alzheimerbc.org

Page 7 of 7