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***In Touch* for Caregivers** electronic version

Help us reduce our costs by choosing to access *In Touch* via our website www.alzheimerbc.org. Just click on **Newsletters**. If you are currently receiving a mail copy of *In Touch* and would like to subscribe to the e-newsletter, please email us at info@alzheimerbc.org.

Maintaining the Spirit



Quality of life is defined as a person's sense of well-being that stems from satisfaction with areas of life that are important to them. Every person is unique, with individual values determining what is meaningful and how well-being can be

accomplished. Caring for a loved one with Alzheimer's disease or a related dementia often presents challenges that impact one's quality of life and overall spirit. This issue of *In Touch* will explore how caregivers can continue to experience joy and nurture their spirit as they cope with this disease.

Spirit and the Healthy Brain



have a life-threatening illness, you still retain the ability to influence many things like your relationships with family and friends, and your ability to enjoy what you are doing in the present moment.

When it comes to maintaining your spirit, there are six areas to focus on:

Healthy brains need purpose, perspective, and social connections. To improve your spirit, you need to believe in your ability to influence your own life and its outcomes! A sense of optimism and a positive outlook are really important; optimistic people have been found to live longer and to be less likely to develop dementia. Even if you

Stay Active Productive people tend to live longer and be more contented - both of which appear to reduce their risk of developing dementia. Hobbies, community and church groups are excellent ways to stay active and engaged.

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Maintaining the Spirit

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Nurture Your Spirit

People who develop or maintain a spiritual dimension to their lives -

through meditation, prayer, and spending time in nature - tend to have a more positive outlook. Also, the resulting calmness is restful and a good counter-balance to the business and stress of daily life.

Keep your Sense of Humour

Humour - especially appreciating, remembering, and telling jokes - can be a wonderful form of brain training, and it helps to lift the spirit. It can also significantly increase your level of hope, reduce pain, reduce stress, lower blood pressure, and increase a sense of well-being, all of which will help improve your mental fitness.



Build Solid Friendships

It is vital to maintain good social connections.

Many activities like dancing, chess, playing cards, and Scrabble combine brain stimulation with socializing and are good ways to interact with others and make friends. Studies have found that friends are even more valuable for quality social connections than family members. This is especially good news for people who don't have strong family relationships, or whose families live at a distance.

Treat Depression

Depression, and its close relative *anxiety*, rob life of pleasure and peace of mind. The benefits of overcoming anxiety and depression will impact you over the long term, and provide relief from suffering in the present. When you are anxious and depressed, your world shrinks and you withdraw from others. Long-term depression and chronic stress can have a lasting negative impact on brain health and memory, and may increase your risk of developing dementia. A handout that explains the symptoms and treatment options for depression can be found at www.healthservices.gov.bc.ca/gpac/pdf/depression_pg.pdf.

Alternative treatments such as acupuncture, and some spiritual and naturopathic remedies, have also been effective for some people. If you are concerned about depression, discuss your situation with your physician.

Spirituality involves a lifelong commitment involving your past, present, and future. The ability to be comfortable with all three time periods is a key to our spirit and emotional well-being.

Power of the past, present and future

Remembering where we have been, who we have known, life events, and all we have learned from life experiences, gives our life both substance and anchoring. Capture these memories so you can share them with future generations and, so you can look back when you want to. The Alzheimer Society of B.C. has launched a new interactive website

called Memory Bank – a space where people can share their inspiring stories, memories, and ideas. We believe it is crucial that the loss of memory associated with Alzheimer's disease does not mean the permanent loss of personal stories that help weave the fabric of our society - stories of love, family, struggle, survival, and triumph. Visit Memory Bank at www.thememorybank.ca.



Being fully aware of each precious moment of life ensures that we are open to the opportunities of the here and now. Being mindful increases focus and concentration, reduces forgetfulness, and lowers the amount of stress we experience. Meditation and the conscious practice of focusing on what we are doing in the present are important skills to develop.

Optimism is associated with greater mental and physical well-being and longer life. Optimists are happier, healthier and live longer. The ability to face the future - and project into the future - is a key part of mental fitness. This important ability can be eroded by poor mental and emotional fitness. Always have a plan for something that you can look forward to, and always treat depression - which will rob you of the ability to look forward with optimism.

Go to our website www.alzheimerbc.org/healthy_brain.php to print the Healthy Brain worksheet, or contact your local Resource Centre.



A Musical Eye-Opener

Music is the medicine of the breaking heart.

Alfred William Hunt

My father had been diagnosed with dementia and lived in a nursing home. He became ill enough to be admitted to the hospital, so I stayed with him. He was confused and rarely spoke, but that didn't keep me from chatting away, trying to communicate with him.

One day, I ran out of things to say, so I decided to sing. Unfortunately, I inherited my daddy's musical ability. Neither of us could carry a tune in a bucket. I crooned, "I love you. You love me. We're a great big family."

Daddy opened his eyes, turned and looked at me. For the first time in days, he spoke. "I love you too, honey," he said. "But you don't have to sing about it."

Nancy B. Gibbs

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Celebrating the Holidays



The holiday season can be an exciting time of the year. Families and friends will often arrange gatherings to celebrate, although family gatherings can pose special dilemmas for persons with dementia and their family caregivers. Because people with dementia need to have some structure and routine in their lives, the changes and excitement that are associated with the holiday season often raise their level of stress, causing insecurity, disorientation, and distress. The more the dementia has progressed, the more this is evident.

Managing stress for the caregiver and the person with dementia is key to a relaxing and enjoyable holiday season. Below are some tips that can help to relieve some of the anxiety associated with the holidays.

Pick and choose family traditions

- Do not attempt to maintain all the holiday season traditions. This will be too stressful for the person with dementia and likely too stressful for you as well.

- Pick and choose the tradition(s) that you want to keep and adapt them to fit your current situation. For example, the person with dementia does not have to carve the turkey, even though it may be traditional for him or her to do so. The pressure of remembering how to carve the turkey and the lack of dexterity to effectively do it, could end up being more humiliating and distressing for the person with dementia than it is enjoyable.

Start new traditions

- As the caregiver, you know what is likely to cause the least stress. You might have to take the lead on this and explain to your family why you are changing the tradition this year. This year, make new traditions that will be less stressful for everyone.
- Usually less is more for people with dementia: fewer people, less noise, less commotion. Have one or two small get-togethers instead of one big overwhelming reunion.
- Shorter visits are usually better.
- To reduce stress, spread the holiday celebration and visits over several days or even weeks, instead of having all the celebration concentrated into two intense days.
- Remember that people with dementia usually do better

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“There’s my man,” my mother says to the nurse, beaming at my father. He has been out of the room for five minutes, but Mom greets him like it has been days.

Shyly, my father comes up to her and takes her hand. They look at each other.

“Fifty-two years married,” my father tells the nurse, as she checks the IV.

She shakes her head. “And still in love,” she marvels. She adjusts her blond ponytail, pulls the stethoscope out of the pocket of her smock and leans to listen to Mom’s heart.

“Your main man, huh?” she says to Mom.

Mom smiles, making a noise right out of a Donald Duck cartoon. Then Mom picks up a corner of her hospital gown and tugs at it. She pleats it into little sections and tugs again. “Well you so and so,” she says to the gown. “If you aren’t going to cooperate, you can’t come with me.”

I hand her a blanket. “Here,” I say. She stares into the blanket like there’s a child cradled inside. “What a sweet baby,” she says. “I love you, baby.”

I look at Dad, who shrugs and smiles.

Maybe this is the lesson we are all to learn eventually. In the end,

Love in the Land of Dementia

by Deborah Shouse

only love is left.

With Mom’s advancing Alzheimer’s, much has been lost. Rising up and sitting down are complicated feats of gymnastic proportion. All foodstuffs are foreign substances. Dressing, conversing, bathing, teeth brushing – all the events of everyday life – are neatly erased from Mom’s scope.

But when my Dad walks in, for a moment, she remembers this is her husband. For those seconds, happiness floods her.

“I wish I had a relationship like you two have,” the evening nurse says wistfully. She’s a thin vigorous brunette from Dubuque, Iowa. She’s already been through two husbands, she tells us as she gently wraps the blood pressure cuff around Mom’s arm. “Neither one of them was worth the polish on my toenails,” she says.

My parents don’t have the perfect romance. Most of the time he has to stand right in front of her to talk. Most of the time Mom’s her own entertainment center, bouncing off his words but not truly interacting with him.

But when he first enters the room, light fills her face. Her eyes are luminous and her silvery hair seems to glow. The distracted, anxious look leaves her and there’s an angel purity to her expression. For that moment, she is present and filled with only love.

All who see this look – the certified nurse’s aid, the registered

nurse, the lab tech, and the social worker – all look with awe and envy. They coo and sigh. “Ahhh,” they murmur, “that’s the way it is supposed to be.”

Even the doctor looks up from his clipboard, as if there’s been an alien sighting. When he continues his charting, I wonder if he will write, “Patient exhibits symptoms of deep dementia and signs of true love.” I wonder how far apart these two conditions are.

“I want you to kill me if I ever have to go into a nursing home,” my mother used to say, when she was about my age. “I want to die if I lose my mind.”

According to her diagnosis, my mother has officially “lost her mind.” She came to the hospital from an assisted living facility. The “worst,” as she then envisioned it, has happened.

Does she want to die? I wonder, as I watch Mom pick at the lint on her blanket. She is not “herself;” she is not the mother I have known and the wife Dad has loved. But despite all the losses she is still someone well worth being around. Her greatness remains in this simple gift she shows us: when all of the ordinary things are gone, the spirit can still remain. Love doesn’t necessarily conquer anything or all, but it can outlast the rational parts of life.

Tomorrow, everything could change. My Dad could walk in and Mom might not ever look up from her pleating, plucking and picking. »

Maintaining the Spirit

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She might stare at him like she sometimes stares at me, knowing he's a nice person, but not knowing just who he is.

But we no longer think of tomorrow. We are happy at the fact that Mom laughs, even if it's at a bowl of vanilla pudding. We are thrilled with the fact that she talks, even if she's addressing invisible children in language that makes Pig Latin seem scholarly. And we are awed by the fact that she loves.

"So where's your husband?" the nurse's aide says, as she organizes Mom's dinner tray.

Mom doesn't answer: she examines the pink plastic arm bracelet on her left wrist.

"Let's scoot up in the bed," the aide says. Mom doesn't move. She fiddles with the plastic.

Then Dad walks into the room. He stops in front of the bed. Mom stops fiddling. She looks at him and smiles. "My husband," she says in an awestruck voice. "My husband's here," she says to the nurse and to me.

"That's right," Dad says. I hear the joy and anguish in his voice. I hear the depth of his grief and the strength of his love.

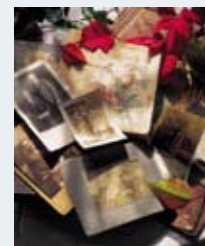
You can also check out *Love in the Land of Dementia: Finding Hope in the Caregiver's Journey*. For more information, visit www.TheCreativityConnection.com.

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(Celebrating the Holidays continued from page 3)

earlier in the day, so schedule visits and activities accordingly. Consider a brunch or a luncheon celebration instead of the traditional dinner event.

- If your family gathering involves a large number of people, try to have a quiet room where the person can sit and be visited one-on-one or with only a few family members at a time.
- Schedule time and space where the person can rest while family is visiting.
- Reminiscing about the past is an enjoyable activity as family and friends get together. Consider using tangible things like photos, videos, music, stories, toys or even a piece of fabric from the past as tools to help the person with dementia reminisce about the old days.



Involve the person with dementia

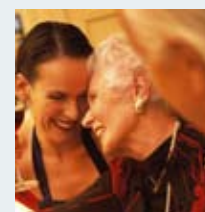
- Involve the person with activities. Focus on their remaining strengths in order to make them feel like a contributing member of the group. For example ask for their help in setting the table, putting gifts in Christmas bags or putting the bows on all of the gifts.

Have your guests help you

- Share the load with family and friends. Ask some of your guests to do an activity with the person with dementia, or simply spend time with him or her while you are doing something else or just taking a break.

Prepare your guests

- Inform your guests about the person's condition and what to expect and what they should or should not do.
- For example, your guests should be prepared to be patient when waiting for an answer from the person with dementia. They will likely have to repeat questions or answers several times.
- Help them understand that facial expression, body language and tone of voice will be a big part of communicating.
- Remind them to introduce themselves as they greet the person with dementia. You could also use easy to read nametags or place cards.



You may want to send some literature about dementia to your guests. Contact your local resource centre or for more information call 1-800-667-3742. You can also direct them to the Alzheimer Society of B.C. website at www.alzheimerbc.org.

Maintaining the Spirit



Taking Care of Yourself

Excerpt from *Creating Moments of Joy* by Jolene Brackey

You need to take care of yourself before you can take care of someone else. No matter what your situation, start now and get involved with your own life once again. Take time to do the things you love to do, be with people who make you feel good and pamper – no, better yet – spoil yourself as often as possible.

Just as we need to relieve stress for a person with dementia, you need to find ways to relieve stress in your own life. It is proven that stress adversely affects brain functioning. Reducing stress helps us function better. Even when you don't feel like it, smile, because just smiling lifts your spirit and relieves stress. Exercising is a great way to relieve stress and increase blood flow to the brain. Meditating 20 minutes in the morning and at night will help you relax. Of course, eat good foods, lower your fat intake, and drink lots of water (six cups a day). Get lots of rest!!! If the person is having fragmented sleeping patterns and waking up in the middle of the night for a couple of hours, you need to sleep when the person sleeps. This might mean napping at 10:00 in the morning.

Of most importance, take time off from caregiving – at least two days a week. I hear many reasons why people feel like they can't take time off. The fact is if you don't take care of yourself first, you will soon be less healthy than the person with dementia.

Families need to work together to survive this disease. I've heard many stories how the oldest sibling is responsible for the parent. This journey cannot be done alone. Each sibling needs to play a role in taking care of a parent. Maybe the son handles the finances, the daughter sets up a schedule for when other relatives take care of the person.

Alzheimer's disease is understandably devastating to families. It creates tension and stress for even the most solid families. It's overwhelming when you are suddenly responsible for finances, the house, and for a person who is dependent on you for the most basic needs (eating, grooming, bathing, dressing). Many times, the

best solution is to find a good memory care community.

My brother came to visit me. My husband has Alzheimer's and I was obviously showing frustration, anger and resentment toward my husband. He looked at me and gave me advice that saved my life. "Let someone else take care of him for a while. Don't wait until your love turns to hate."

-wife in need

I strongly recommend you get involved in a support group and connect with someone who has already been through the journey you're embarking on. This group of support people will be able to relate to your frustrations, share the mistakes and solutions, and assure you that what is happening is normal. Seek help from others. It's not an option, it is a necessary step.

I sometimes make this journey sound like butterflies and cupcakes. That cannot be further from the true suffering and pain that is caused by Alzheimer's. But you are on this road, so you must get to your destination as safely as possible. Watch for signs to give yourself some direction, pull off the road, take a catnap whenever necessary, and accept help from others when something breaks down. In fact, take a couple of friends with you so they can drive when you get worn out. And last but not least, savor the moments of joy.

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

Suggested Websites

Care Exchange and Caregiver Forum

www.alzheimer.ca/english/forums/intro.htm

Family Caregiver Alliance

www.caregiver.org

Information that addresses the needs of individuals providing long term care at home; includes caregiving info and advice, along with fact sheets and a list of publications.

Butterfly Thoughts

by Brenda Firth



as fragile as a butterfly wing
as swiftly blown away
my memories take flight at times;
sail to some distant bay

yet, now and then they gently light
within my wooly head
and with a powdered fluttering
they bring me peace, instead

sweet memories

bring only joy

sad ones

bring only pain

my butterfly thoughts

don't tie me in knots...

they're here, then they're gone again

so if my mind seems far away
while yours is focused on me
don't make it a moment
that spoils your whole day...
let go - set your butterflies free

for I remember LOVE
and it may feed and fuel my soul,
I feel it in a smiling face
a caring word, a warm embrace

a hand in mine
showing me my way;
these are the memories
of each new day

and even if that memory
should simply flutter by...
I'll catch it...maybe...later
when it comes by butterfly

Love has many faces

Love is many things

It may flutter by on a Butterfly
Or come on Angel wings



Get Walking!

Sunday, January 25, 2009

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 25, 2009 in 17 communities in B.C.

Money raised will create awareness and support the more than 64,000 British Columbians who are living with Alzheimer's disease and dementia.

Come out and join this fun family event. For more information, call Angie Kok at 1-800-667-3742. You can also check out our website www.walkformemories.com



The Dementia Journey

Whether you have a formal diagnosis or are caring for a loved one with Alzheimer's disease or another form of dementia, it can often leave you feeling frustrated and afraid. Thanks to a partnership between the Alzheimer Society of B.C. and the BC provincial health authorities, new help is available. The Dementia Journey website has now expanded province-wide. Through the stories of real people, it supports those with dementia and loved ones as they experience their own dementia journey and links visitors to current information and to help plan the next steps of their lives. To find out more please visit www.dementiajourney.ca.



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.

University of Victoria  Centre on Aging

The Caregiver Appraisal Study, part of the Alzheimer Drug Therapy Initiative, is looking for caregivers and their family members from across B.C. to discuss their experiences with Alzheimer's medications: Aricept, Exelon, & Reminyl. All correspondence is confidential, and participation is voluntary. For more information, please call the University of Victoria's Centre on Aging toll-free at 1-866-511-2594.

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 by phone by calling toll free 1-866-396-2433, Monday to Friday from 6:00am to 2:00pm PST. For more information or to register online, go to www.alzheimerbc.org and click on "Caregivers Can Learn from Home" at the bottom of the page. Scroll down and find the workshop that you are interested in. To register, you will be directed to the Care-ring Voice website.

Upcoming Tele-Workshops

The Progression of Alzheimer's Disease

Thursday, January 29, 2009
from 7pm to 8pm

Interacting with People with Dementia

Thursday, February 26, 2008
from 10am to 11am

Alzheimer Society BRITISH COLUMBIA

For information about our programs and services, check out www.alzheimerbc.org.

- 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

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



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.

In Touch

Publication Schedule

March 2009:
Healthy Brain

June 2009:
Caregiving from a distance

September 2009:
Research Issue

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.