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A Changing Melody

A forum specifically designed for persons living with memory loss.

A Changing Melody was conceived out of the need to develop meaningful partnerships between persons with dementia, their families and all others involved in dementia care and support – partnerships that value the diverse expertise, perspectives, and experiences of all involved in dementia care. Planning for the forum was guided by research that demonstrated that persons with dementia can learn and adjust to their illness, contribute to their own care and live meaningful lives if provided with adequate information, resources and support.

The motivation for naming the forum *A Changing Melody* came from a story shared by a person with dementia, Jim Agnew, during one of the initial planning committee meetings. Jim had heard an account of violinist Itzhak Perlman and his inspirational performance at the Lincoln Center in New York City. Perlman is a world renowned musician, who overcame polio as a child and now walks with crutches. It has been told that at a 1995 performance, just as he finished the first few bars in his recital, one of the strings on his violin broke. To everyone's amazement, and without fixing the string, Perlman closed his eyes and continued to play, changing and recomposing the piece as he went. At the end of his performance, the audience rose to their feet to show their gratitude for his persistence, and after brushing the sweat from his brow, Perlman said to the audience, 'You know, sometimes it is the artist's task to find out how much music he can still make with what he has left'.

This story really resonated with Jim and he used the story as a metaphor for his own life. He told the planning committee that although he faced many challenges in his life as a result of his diagnosis of dementia, he still could make 'beautiful music'. Although life was certainly changing, he, and others like him, could continue to live meaningful lives despite dementia. Although the music continues, the melody changes as persons with dementia learn how to adjust to living with the illness. The story of Itzhak Perlman inspired Jim to focus on his abilities and not his deficits and to adapt to the challenges he had been presented in life. His recounting of the story also inspired others on the planning committee. Based on this story, the committee opted to name the forum *A Changing Melody* to reflect the idea that life can still be beautiful even when faced with challenges.



Dr. Phill

Well-known in the Niagara Region, Dr. Phillip O'Reilly currently sits on the board of the Alzheimer Society of Niagara Region. He is also offering his medical expertise to answer any questions you may have about Alzheimer's disease and related dementias.

If you have a question for our very own Dr. Phill, please see the last page for how you can contact us.



Dear Doctor Phill,

Since my diagnosis of dementia, my relationship with my wife has changed. We no longer engage in our normal spousal relations. I feel like I have lost a piece of our marriage. What can I do?

Your question is one which has been asked many times by my patients. Your term, 'Spousal Relations', can take on several meanings – from discussing family issues (including the diagnosis), to decision-making, to intimacy. Each can be significantly impacted following a diagnosis of dementia.

I have found that the major underlying problem is the lack of communication after a painful diagnosis is given. Often, spouses believe that they are protecting one another from feeling distress when they avoid talking not only about the diagnosis, but also what it means for them and how they can plan ahead. The reality is, however, that each then suffers his or her own distress, in silence, much like it seems you are doing now. You are denying yourselves the opportunity of that vital, mutual support and understanding.

I would encourage you to talk to your wife about how you are feeling. You may find that she just didn't know how, or was maybe afraid, to approach the subject. If it is too difficult for the two of you to sort it out on your own, then arrange to meet with your doctor/pastor. They may be able to give you both the support and guidance to work it through or suggest someone who can.

It is important for you both to continue to live life to the fullest despite your diagnosis. The words may not come as easily as they once did and decision-making may be a bit more challenging, but your feelings are very much intact and you can still share those wonderful moments of affection and intimacy. The key is to: Communicate! Communicate! Communicate!

All the best,

Dr. Phill



Exerpts from “Ten Ways to Beat the Winter Blues”

By Nicole Nichols

The “winter blues” are characterized by the mild depression, lack of motivation, and low energy that many people experience during this cold season. Luckily, there is a lot you can do to both prevent the blues and to get yourself back to normal if they are already here.

- 1. Exercise:** Exercise relieves the stresses of life, giving you more energy throughout the day. Exercise helps your mind by releasing those “feel good chemicals” that improve your mood.
- 2. Eat a Healthy Diet:** Avoid refined and processed foods (white breads, rice, and sugar). These foods can zap your energy levels and affect your mood. Try to incorporate more complex carbohydrates (whole wheat breads, brown rice, veggies, and fruit) and make sure you stay hydrated.
- 3. Get Some Sun:** The sun provides us with Vitamin D and also improves your mood. Try to spend a little more time outdoors, keep your shades up during the day, and change your light bulb to “full spectrum” bulbs. Similar to exercise, sunlight exposure releases neurotransmitters in the brain that affect our mood.
- 4. Act on Your Resolutions:** Studies show a strong link between healthy behaviors and depression. So stick to your commitment of not smoking, or getting more exercise.
- 5. Treat Yourself:** Having something to look forward to can keep anyone motivated. Plan something exciting, it will improve your mood.
- 6. Relax:** Everyone needs some time off. Try to spend a few minutes each day doing nothing!
- 7. Embrace the Season:** Instead of avoiding the snow- look for the best that it has to offer! Bundle up and go for a walk when the weather permits, head to the skating rink or toboggan hill to watch the kids.
- 8. Get Social Support:** Don't underestimate the power of friends, family, and neighbours. Something as simple as a phone call, a chat over coffee, or a nice e-mail or letter can brighten your mood.
- 9. Catch Some Zzzz's:** People naturally want to sleep a little bit more in the winter. However, with all that's going on, sometimes sleep is the first thing to go. Aim for 8 hours a night, and try to keep your bedtime and waking time consistent. Try not to oversleep—those 12 hour snoozes can actually make you more tired.
- 10. Watch What You Drink:** Limit your intake of alcohol, caffeinated coffee and tea, and fizzy drinks. Caffeine can make you more alert for an hour or so, but later you get the opposite reaction.

The full article on how to meet the winter blues can be located at:
<http://www.divinecaroline.com/22189/63887-ten-cool-ways-beat-winter>

Alzheimer Society of Niagara Region's News and Events

For more information
please call: (905) 687-3914

Best Friends Coffee Club
on the second and fourth
Thursday of each month.
We invite you to join us
for the Best Friends
Coffee Club

A Changing Melody is
a conference for persons
with early-stage dementia
and their care partners.
For the first time, A
Changing Melody will be
coming to Niagara in the
Spring of 2010. The
conference will be taking
place on April 10th, 2010.
If you would like more
information about the
conference, please
contact Gina Bendo at:
(905) 687-3914.

**The Curl for Memories
Bonspiel**
in support of the Alzheimer
Society of Niagara Region
is taking place on Saturday,
March 20, 2010, at the
Welland Curling Club.
For more information about
this event please call:
(905) 687-3914.

From the Editor...

Welcome to our February 2010 edition of Connections, our newsletter for you, persons with early-stage dementia. On behalf of the Connections team, I want to wish you and yours a very Happy New Year! We also want to sincerely thank the Alzheimer Society of Ontario for the Innovation and Leadership grant which provided the financial support for the development and production of our newsletter.

Please take a few moments to read our feature article about *“A Changing Melody”* forum which will take place in St. Catharines on Saturday, April 10th, 2010. This unique conference is for persons with dementia and their care partners. Please consider attending this wonderful event with a friend or family member. You will have an opportunity to meet so many other people who share the experience of living with dementia.

February is also the month of the groundhog. Will we have 6 more weeks of winter or is spring just around the corner? Have fun reading about the history of Groundhog Day and completing the word search.

As always, we welcome your thoughts and ideas about the newsletter. Please contact me at (905) 687-3914. Many thanks to our Connections team, Cynthia Krawczuk, creative genius and Graphic Designer, Carolyn Dowd and Sarah Putman, assistant editors.

Warmest regards,
Gina Bendo RegN

Current Research

Ebixa (also known as Memantine Hydrochloride)

Neurotransmitters send messages across the space between nerve cells. As Alzheimer's disease progresses, the neurotransmitter glutamate leaks out of nerve cells and is re-absorbed at levels that are toxic to the cell. Ebixa works by blocking the re-absorption of glutamate into nerve cells. It is the first drug therapy approved for individuals whose symptoms are moderate to severe. Ebixa may be used on its own or in combination with cholinesterase inhibitors (i.e. Aricept, Exelon, or Reminyl ER). Ongoing research suggests that there may be greater benefit to using cholinesterase inhibitors and Ebixa together, however, more and larger trials are needed to confirm these results.

Please check with your doctor for further information and guidance. You may also contact the Alzheimer Society of Canada for fact sheets and brochures.

FEBRUARY QUOTE

Thirty days hath September, April, June, and November;
All the rest have thirty-one, Excepting February alone
Which hath but twenty-eight, in fine, Till leap year gives it twenty-nine.

Did You Know...



It is believed that the origin of Valentine's Day dates back to the time of the Roman Empire during the reign of Claudius II, 270 AD. Claudius didn't want men to marry during wartime because he believed single men made better soldiers. Bishop Valentine went against his wishes and performed secret wedding ceremonies. For this, Valentine was jailed and then executed by order of the Emperor on February 14. While in jail, he wrote a love note to the jailor's daughter signing it, "From your Valentine." 'Sound familiar?

Groundhog Day is an annual holiday celebrated on February 2 in the United States and Canada. According to folklore, if a groundhog emerging from its burrow on this day fails to see its shadow, it will leave the burrow, signifying that winter will soon end. If on the other hand, the groundhog sees its shadow, the groundhog will supposedly retreat into its burrow, and winter will continue for six more weeks.

The holiday, which began as a Pennsylvania German custom in southeastern and central Pennsylvania in the 18th and 19th centuries, has its origins in ancient European weather lore, wherein a badger or sacred bear is the prognosticator as opposed to a groundhog. Groundhog Day proponents state that the rodents' forecasts are accurate 75% to 90%. A Canadian study for 13 cities in the past 30 to 40 years puts success rate level at 37%. Also, the National Climatic Data Center reportedly has stated that the overall predictions accuracy rate is around 39%.

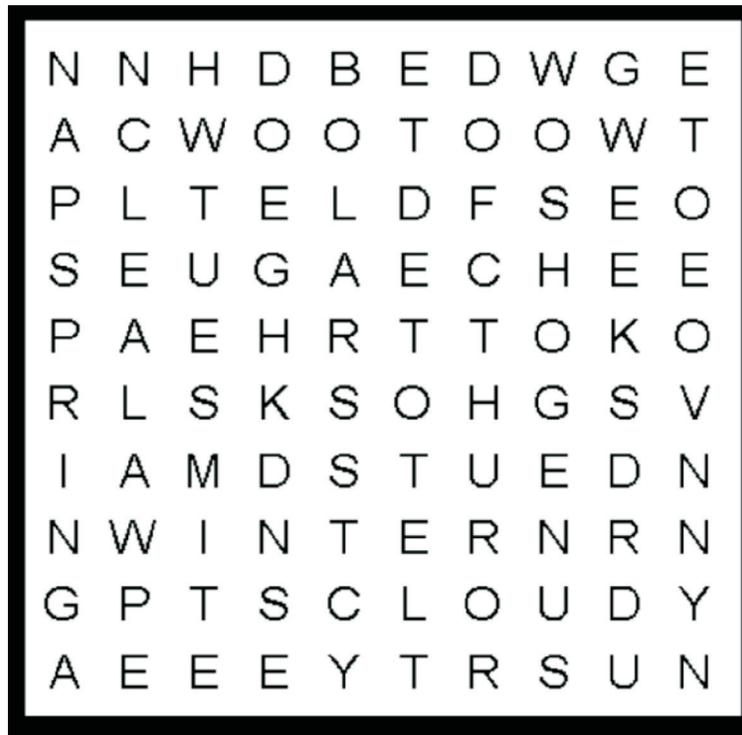


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Cohen, H.; Coffin, T.P. (1987). *The Folklore of American Holidays*. Detroit, Michigan: Gale Research.
Yoder, Don (2003). *Groundhog Day*. Mechanicsburg, Pennsylvania: Stackpole Books. ISBN 0811700291.

Surprise!

Take a break from reading and challenge your brain in a fun way! Activities like word searches, crosswords, puzzles and Sudoku are great ways to exercise your brain.



Words to Find

WEATHER
SHADOW
GROUND

WINTER
SPRING
CLOUDY

HOG
SUN
FOG

WEEKS
HOLE
PEEKS

Contact & Feedback

What I liked: _____

What I didn't like: _____

Things I would like to see in the next issue: _____

How I would like to contribute: _____

My question for Dr. Phill: _____

Other comments: _____

How to reach us

By mail:

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St. Catharines, ON L2N 1L5

By phone (Gina):

905-687-3914 extension 543

By email:

gbedo@alzheimerniagara.ca