

The By Us For Us Guides: Resources Created By and For Persons with Alzheimer's Disease and Other Related Dementias

When Brenda Hounam was diagnosed with Alzheimer's disease nine years ago, she realized how very little information was available for persons living with early stage memory loss. This omission inspired her with an idea - to develop a series of resources specifically designed **by** and **for** persons with dementia. Through Brenda's contacts at the Alzheimer Society of Brant, the Alzheimer Society of St. Thomas and the Murray Alzheimer Research and Education Program at the University of Waterloo, Brenda connected with various persons living with dementia from all around Ontario to work on what is now aptly called, the By Us For Us guides. With the support of MAREP and the Alzheimer Society of Brant, five *By Us For Us* (BUFU) guides have been developed and include information gathered from persons living with early stage memory loss through early stage support group meetings, individual contact, and open-ended, mail-out questionnaires. All five guides have been well received in Canada and are being requested by individuals and organizations around the world.

The first guide, *Memory Workout*, encourages people with dementia to develop and maintain regular "workouts" for the brain so as to enhance functioning while engaging in enjoyable activities. The second guide, *Managing Triggers*, outlines the main triggers experienced by persons with memory loss, and offers solutions for how persons with dementia and their partners in care can manage and alleviate them. The third guide, *Enhancing Communication*, outlines the challenges experienced when communicating with family, friends, and health care professionals. It provides tips on how to enhance communication with those living with memory loss, and it emphasizes the importance of using a wide range of communication strategies. The fourth guide, *Enhancing Wellness*, provides tips and focuses on how enhancing physical, psychological and emotional, social and spiritual well-being can help us live our lives to the fullest extent, even after a diagnosis of dementia. Finally, the fifth guide, *Tips & Strategies*, is a

helpful resource that contains ideas and suggestions for living daily with an illness causing dementia.

The BUFU team developed a new cross-over guide which was released on October 26, 2009. This cross-over guide focuses on living with and transforming loss and grief, and will incorporate not only the needs of persons with dementia, but the needs of their partners in care.

As BUFU team member Gail Robinet states in the *Enhancing Communication* guide, "We hope that, through this guide, you can gain a better understanding of our experience and gain tips on how we can all work together to enhance our lives together".

The guides are available at a minimal cost of \$1.00 per booklet and can be ordered through the MAREP website <http://marep.uwaterloo.ca/products/bufu.html> or by calling 519-888-4567, ext. 32920.

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EXCERPT FROM THE ENHANCING COMMUNICATION GUIDE

Things we have always wanted to say

We are so close to our family partners in care, and we realize how much we rely on them at times, so we do not want to hurt them with our feelings. This is why it is often hard to say what we really want to say, which is...

- I need to be open about my experiences and not protect you.
- I get frustrated, too.
- Treat me like an adult.
- Please don't make assumptions or speak for me. Listen to me.

PSW Corner

There is something new on the Alzheimer Society of Toronto website - www.alzheimertoronto.org. If you click on the button marked PSW Corner on the top right-hand corner of the home page, you will enter a space created especially for front line professional caregivers for persons with dementia, or Personal Support Workers (PSWs). Much of the training done by our Public Education Coordinators is for these formal caregivers. Unfortunately, many PSWs cannot come to training sessions at our offices. Many work shift work or second jobs, and many are not working for organizations that invite the Society educators to come to their agencies or facilities, or have in-service education.

The role of the PSW Corner is to provide access to education and support to all front line workers who care for persons with dementia in long term care homes, community agencies, supportive housing, adult day programs, or private homes.

The mission of the PSW Corner is to inspire front line workers who care for persons with dementia. Being a PSW can be rewarding and challenging, and it is also a vitally important job. Sometimes these individuals are undervalued, underpaid, and unrecognized for the important work they do. The PSW Corner is a place where they can learn more about caring for people with dementia, where they can ask questions, and where their value is recognized. The PSW corner includes items such as:

- Learning sheets specific to different aspects of care, including “The Progression of Alzheimer’s Disease” and “Safety for Persons with Dementia”
- A study module and quiz on “Communication”
- Useful links to other websites of interest to PSWs
- Reviews of resources available on our Resource Centre

In preparation for the launching of the PSW Corner, we held focus groups to determine the needs and concerns of PSWs. Thanks to their input we have included a section on the site entitled, ‘The Joys of Being a PSW’, where PSWs can showcase their positive stories about caring for persons with dementia.

The site will be updated quarterly, building on the information already in place. Excerpts from our annual PSW Forums will be included as well as excerpts from DVDs and videos relevant to the work that PSWs do. We hope the PSW Corner will become an indispensable resource for PSWs across Toronto and beyond.

This project was generously funded by the *Griggs Family Foundation, Toronto Fund at the Toronto Community Foundation, and Great-West Life, London Life, and Canada Life.*

**PSW
CORNER**



Book Review: Still Alice by Lisa Genova



The descent of Dr. Alice Howland, a celebrated Harvard professor, into the world of early onset Alzheimer’s disease starts with a forgotten word during a presentation: lexicon. As a loving wife and mother of three, Alice struggles to maintain control over the life that she has worked so hard to build, but the effects of the disease slowly manifest itself in her work, her relationships, and finally her sense of self. As Alice’s disease progresses, the reader follows her through this difficult journey. With a writing style that

mimics her awareness of the world around her, we follow Alice as her voice changes from that of a world expert in linguistics, to that of someone struggling with the confusion and loneliness this disease can bring. But all is not lost. Alice’s illness, devastating as it may be, draws her family together through those unbreakable bonds, and reveals a journey that is both hopeful and heartbreaking. Through the beautiful writing of Lisa Genova, we are invited to observe the world of early onset Alzheimer’s through the lens of Dr. Alice Howland, and we are reminded to look beyond the disease and for the person who remains.

2010 Manulife Walk for Memories

Join us on the morning of **Saturday, January 30 in the Allen Lambert Galleria, Brookfield Place** for a warm indoor walk through the PATH system, and help us raise \$400,000 for Alzheimer's.

Come and tie a yellow shoelace around your finger to honour and remember those you love with Alzheimer's. We'll have great entertainment, goodies and prizes BUT best of all you can dress up in a costume of your choice.

Get friends, family and colleagues together and form a Team, and we promise you... you'll all have a very special time with us.

Register now at www.alzheimertoronto.org or call us at 416-322-6560... and we'll get you started.



Scotiabank Waterfront Marathon

On Sunday, September 27, eighty one runners and walkers put on an Alzheimer Toronto Team t-shirt, to run or walk for Alzheimer's. We are so grateful to each and every one of you for having reached out to family and friends to raise money for us. Over \$55,000 was raised – which is amazing.

We do hope to see you again in 2010, and thank you for all of your hard work.

Cheers to all our Coffee Breakers

Thank you all so much for bringing so many people together to make Coffee Break such a fabulous success.

You are all wonderful... but here are a few special mentions. A big thank you to Megan Hodges, who raised \$3,400 online with her virtual Coffee Break, and our great friend, Barry Lew from Timothy's who donated, and even served coffee at our own little break.

Special Thanks to our Wonderful Friends

Over the past few months, so many of you have planned events, and raised money for the Alzheimer Society. Here are just a few who we'd love to thank...

- **Norman Hardie**, who climbed to the very top of Mount Kilimanjaro and raised over \$32,000
- **The Executive Women's Golf Association** who brought in \$9,000 thanks to their Annual Charity Golf Tournament
- **Danielle Siciliano**, who hosted an afternoon tea at the Old Mill with 60 of her very best friends and raised over \$2,000
- **Jennifer & Adam, Jennifer & Todd, Salomeh & Mehran** and **Shannon & Aaron** who all chose to honour someone special in their lives at their wedding

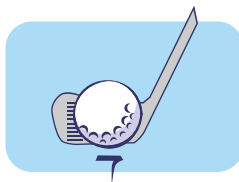
So Many Ways to Help

Celebrate and Give



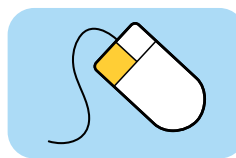
For weddings, birthdays, anniversaries, bat-mitzvahs ... call Kendel at 416-322-6560.

Plan Your Own Event



Wine tastings, tea parties, sports tournaments...call Jane at 416-322-6560 to chat.

Donate Online



Donate in Memory



www.alzheimertoronto.org

The Challenge of Caregiving in Frontotemporal Dementia

People with frontotemporal dementia offer special challenges in caregiving. Frontotemporal dementias (FTD) make up a group of disorders, which, in contrast to Alzheimer's disease, commonly show important behavioral disturbances as their first manifestations. In Alzheimer's disease, behavioral disturbances such as disinhibition typically occur only later in the course of the dementia. The disturbances that occur early in Alzheimer's disease, such as decreased initiative, and irritability, while troubling, are on a different scale from those seen in FTD. In FTD the course is often marked by early disinhibition. For example, impaired judgment may manifest itself in behaviours such as commenting on the appearances of strangers (*"my, she's fat!"*).

To facilitate discussion around the challenge of care, a group of caregivers met at Baycrest in early October, and I was privileged to meet with them. Caregivers of patients at Baycrest answered an online questionnaire through the website www.dementiaguide.com, and the 39 people who replied described their more difficult problems. The caregivers of persons with FTD cited impaired judgement and insensitivity as being difficult problems, whereas a similar survey on Alzheimer's disease has shown that caregivers most often identify problems with recent memory, repetitive questioning, misplacing objects and decreased initiative as common and troubling.

Something that I found very striking is the burden that caregivers felt from having to be responsible for all the decisions that were being made. It seems that often in dementia, either when it occurs with some insight (more

commonly Alzheimer's disease) or without insight (most common in FTD) patients give over decision making on a great many day-to-day items. Caregivers described how burdensome this was, particularly if this was not their usual role. Behavioral problems were also identified, and issues such as being irritable and rude with strangers, or petty thievery, can also impose a great stress. In addition to these issues with behavior and judgement, another great source of strain for a caregiver of someone with FTD is the early loss of personality – *"he's not himself"*, *"she's just not there anymore"*, etc. While at first personality can coarsen and prior characteristics can be enhanced, many patients develop either extreme passivity or continuous irritability and disinhibition. Despite these many challenges, caregivers at the Baycrest conference found humor and positive aspects to their experiences.

Clearly, however, struggling with these fundamental issues of who we are, how our brains control our actions and who is responsible for what we do are amongst the most challenging of life's mysteries. That caregivers can cope, that they can find meaning in their experience and that they can share it with others is something that I and many other physicians who care for patient's with dementia find inspiring. As one of my patients told me *"it may be tough, but it's life itself"*.

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The mission of the Alzheimer Society is to alleviate the personal and social consequences of Alzheimer's and related dementias and to promote research.

The role of the Alzheimer Society of Toronto is to offer support, information and education to people with dementia, their families and their caregivers, to increase public awareness of dementia, to promote research and to advocate for services that respect the dignity of the individual.

COUNSELLING PROGRAM

The Counselling Program offers counselling, information, referral as well as educational workshops and support groups to individuals and families coping with Alzheimer's disease and related dementias.

Counselling

Counselling is available on a variety of issues such as getting a diagnosis, understanding dementia, immediate and future care of the person with dementia, family concerns, stress and coping. This personal, confidential service is available either over the phone or in person.

Information and Referral

Information and referral are provided to help persons with dementia and their families consider different options. Information can be provided on current issues such as research, treatment and medications. Counsellors are also able to refer persons with dementia and their families to appropriate services and programs available to them in the community such as Adult Day Programs, support groups and respite options.

Counselling and Information and Referral Services are available:

- **by phone:** 416-322-6560 Monday to Friday, 9:00 a.m. to 5:00 p.m.
- **at our office:** 20 Eglinton Ave West, 16th floor Monday to Friday, 9:00 a.m. to 5:00 p.m.
(*new address*) (appointment recommended)
- **at your home:** Call us to book an appointment Monday to Friday (limited service)

EDUCATIONAL WORKSHOPS FOR FAMILIES

To register please call 416-322-6560, or send us an email at contact@alzheimerontario.org

Where to Begin: An Introduction to Alzheimer's Disease

This workshop for family caregivers will explore ways to improve the quality of life for persons with dementia, and their caregivers in the **early stages**. Topics include: the nature of Alzheimer's disease, progression and supports available.

Thursday, November 12, 2009	2:00 to 4:30 p.m.
Thursday, December 10, 2009	5:30 to 8:00 p.m.
Wednesday, January 27, 2010	1:30 to 4:00 p.m.

The Journey Continues

This workshop for family caregivers will focus on communication guidelines as well as understanding and managing behaviours such as agitation and wandering. (Previously known as The Middle of the Journey).

Monday, January 11, 2010	5:30 to 8:00 p.m.
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Caregiver Stress

This educational workshop is to help family caregivers learn to cope with the stresses of caregiving.

Monday, November 23, 2009	5:30 to 8:00 p.m.
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Placement Series: Decisions and Choices

This set of three educational workshops aims to give family caregivers an overview of issues related to Long-Term Care Placement. A guest speaker from the Community Care Access Centre will also be facilitating. Family members may choose to attend one session or all three sessions.

Session 1: Decisions and Choices Wednesday, November 4, 2009	5:30 to 8:00 p.m.
Session 2: Procedure and Adjustment Wednesday, November 11, 2009	5:30 to 8:00 p.m.
Session 3: Day to Day Life in Long-Term Care Wednesday, November 18, 2009	5:30 to 8:00 p.m.

WORKSHOPS FOR PERSONS WITH DEMENTIA

Early Stage Workshop

Have you or someone in your family recently been diagnosed with a dementia? This educational workshop for **persons in the early stages of dementia** and their family members will focus on gaining an understanding of Alzheimer's disease or related dementias and ways of coping.

Thursday, November 5, 2009	3:00 to 4:00 p.m.
Tuesday, January 26, 2010	4:00 to 5:30 p.m.

Expressive Arts Workshop

This two-part workshop for persons with dementia will be an opportunity to use various art modalities for therapeutic self-expression. Guest: Cher Curshen, Expressive Arts Therapist, The Dorothy Ley Hospice and Palliative Care Centre. If you are interested in attending this two-part art therapy workshop, please call Caitlin Agla at 416-322-6560. ** Note: All potential participants will be interviewed.

Thursday, November 26, 2009	2:00 to 3:30 p.m.
Friday, December 4, 2009	2:00 to 3:30 p.m.

ON-GOING FAMILY SUPPORT GROUPS

Please call our counsellors at 416- 322-6560 to discuss participating in one of our groups. *Registration is required:*

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| ▪ Vascular Dementia:
Tuesday evenings, 5:00 to 6:30 p.m. | ▪ Early Onset Dementia (under 65):
Tuesday evenings, 6:00 to 7:30 p.m. |
| ▪ Lewy Body Dementia:
Wednesday afternoons, 4:30 to 6:00 p.m. | ▪ Frontotemporal Dementia:
Tuesday evenings, 5:30 to 7:00 p.m. |