

Alzheimer Society

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Introducing...2006-2007 Board of Directors, elected at the 2006 Annual General Meeting on May 30, 2006

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We are very grateful to these community-minded folks who volunteer their time and talents to the Chapter. We will be going through some interesting times as the Local Health Integration Networks come into being, as the Baby Boom generation ages and as demand for our services skyrockets.

Mark your calendars!



Monday, June 26, 10 am—noon. Eastminster United Church Parlour. We are delighted that Belleville lawyer, **Richard Wright**, will share his expertise with caregivers and families. Please call the office 962-0892 to reserve a seat.

In response to demand, we are offering a summer session of **The Alzheimer Journey**, a four-part series for families and caregivers. **Wednesdays in July (5,12,19,26)** from 10—noon at the Alzheimer Society office in the Bay View Mall, Belleville. Please call 962-0892 to register. There is no charge for this course, but we do encourage you to become a member of the Society.



Friday, August 18 is our 10th annual Golf Tournament at Oak Hills Golf Course. Registration forms are available now for this FUN event. \$55 will get you 9 holes of golf and a delicious dinner, along with lots of laughs for a great cause!

Thursday, September 21 is World Alzheimer Day. This coincides with the national fundraiser: Alzheimer Coffee Break™. See the attached flyer for more details.



Caregivers Column

When is it time for long-term care?

One of the most difficult steps in the Alzheimer journey is the decision to place a loved one in long term care.

Caregivers have to ask themselves a series of questions. Is the person with dementia having more difficulty with daily activities? Have there been increased episodes of aggression? Is incontinence becoming a problem? Is the person wandering more, or conversely, is the person becoming increasingly isolated?

The partner in care needs to take a long look at their own situation. Are you feeling overwhelmed? Are you getting enough sleep? Is your health being affected by the stresses of being a caregiver? Are you becoming increasingly isolated yourself?

As the disease progresses, the caregiver needs to look at their environment. Is the house safe for both of you? Is the person with dementia creating dangerous situations, such as leaving pots on the stove? Have stairs become a problem?

Families struggle with this decision, but there can be positives to the situation. One family visited a local Alzheimer Chapter looking for guidance, as they explained how they were dreading admission day. The son, who lived on the other side of the country, was sure that his mother would have to be dragged, literally kicking and screaming, into the home. Placement was his only option, as his father, the primary caregiver, had recently passed away. Imagine his delight when all went smoothly, and to top things off, he realized that his mother was blossoming in the home.

In hindsight, the son realized that his mother, who very much enjoyed the social scene, had been increasingly isolated at home as his father became more and more ill. In the long term care facility, she was once again in a social situation and eagerly participated in activities.

The routines of a long-term care home can provide benefits to people with dementia who often function better with regularly scheduled meals and activities. Many families leave in a distraught state, only to come back to find their loved one actively involved in one of the stimulation programs – baking when they've never shown any interest in baking before or playing bingo for the first time.

One method to help with the awkwardness of those first visits can be to coordinate a family visit with a scheduled activity that both will enjoy. The facility will have an activity calendar that will tell you, for example, when the next sing-song is. Arriving for the event and departing when it is over can help with the difficulties of actual leaving.

The adjustment period varies with every individual and family, keeping in mind that both parties are adjusting. One new resident will settle in almost immediately, another will take months to adjust to the new environment. By communicating and working with the facility staff, the process can be greatly eased for the benefit of all.

Ask the Expert...about Placement

Answers from Sharon Schleger, Case Manager-Placement and Phyllis Bement, Program Manager, Access Centre for Hastings and Prince Edward Counties

How do I get put on the waiting list for placement in a long-term care facility?

Call your local Access Centre (966-3530) where you will be assigned a case manager. The case manager will visit you to assess your eligibility, that is, your need for nursing home care. The case manager will suggest that you visit the homes in your area to become familiar with their services. By calling the homes first and making an appointment for a tour, you will be able to get a better idea of the range of options available. You can select up to 3 homes for placement, in order of preference.

Once you are determined to be eligible, your name will go on the wait list, along with the date of being added to the list. This date will stay with your name, no matter what category you are eligible for.

What is a category? How are they determined? How do they change?

There are five categories: 3,2,1-Veteran, 1-Spousal, 1-Crisis.

Category 3: You are coping at home, perhaps with help from home services, family or friends. You are often living in a retirement residence, but don't need nursing care quite yet.

Category 2: You are in a hospital bed, but cannot return home, so will need a bed in a long-term care facility- or you are still living at home, but not coping quite so well, even with lots of help from community agencies. When the case manager asks "Are you prepared to go, if a bed is offered in 3 to 6 months?", your answer will be 'Yes!'

Category 1-Veteran. You served overseas with the Armed Forces and can be eligible for the beds designated in your area as 'Veteran Beds'.

Category 1-Spousal. Your spouse/partner/parent is already in a nursing home, and you are having difficulty coping at home. You need to join him or her in the home.

Category 1-Crisis. You have exhausted all community services and it's not safe for you to be living at home. Perhaps your spouse or caregiver has been hospitalized and there's no one to care for you at home.

As your circumstances change, and by staying in touch with your case manager, you can discuss if it's time to move

from one category to another. Your original wait list date will stay with your name as you change categories.

When a bed becomes available, what happens?

Your case manager will call you and you have twenty four hours to accept or decline the bed offer.

What happens if I say 'No'? Your file will be closed for six months. When it's re-opened, your name will be added to the wait list with a brand new date.

If I say 'Yes'? You have a 3-day period to prepare for the admission, including weekends. A bed offer made on a Friday means that you will need to move on Monday. This can be extended by two days, by paying a bed-holding fee.

What happens if the bed offer is from my third choice?

Am I stuck there forever? Your name will stay on the wait list in a category 2 and your placement will be considered an interim placement. When your first or second choice becomes available, you will be offered the chance to move.

What happens if I say 'No'? Your file will be closed and your current placement will be deemed your final placement. Many people, once settled, will decide to stay where they are because the disruption of moving is too difficult. Others will be anxious to move closer to family, for example.

How long will this interim placement last? Every circumstance is different. Some have been as short as two weeks; others last for years. It all depends on the facility choices you have made and how long their wait lists are.

I hear these places are expensive – what if I can't afford to go?

No eligible client will be denied a bed due to finances. Should your income not cover the fees, subsidies are available.

I have a lot more questions – who should I ask?

Call your local Access Centre (966-3530). They often have community education sessions on this very topic.

Research Notes

Understanding the Experience of Moving a Loved One to a Long-Term Care Facility: Family Members' Perspectives

Reuss, Dupuis and Whitfield *Journal of Gerontological Social Work*, 46,17-47.

Researchers at the Murray Alzheimer Research and Education Program (MAREP) conducted interviews with twenty-one families in Southern Ontario who had gone through the admission process at three different long-term care facilities. Not all the families were dealing with dementia, but the factors that contributed to either a positive or negative experience were the same.

Previous studies have revealed that the transition process is an emotional one, often with conflicting feelings: guilt, sadness, loneliness, anger, resentment, a sense of failure contrasted with feelings of relief and piece of mind. The purpose of this study was to expand on these findings by examining the process for family members during the transition and by identifying ways the transition can be eased for both families and new residents.

Findings

Each family's experience had its own complexities, but in all cases, the transition process left a profound mark on their lives. The stress of planning the actual move, combined with emotionally-charged tasks such as choosing personal belongings to accompany the new resident, took its toll on everyone.

The combination of long waiting periods, followed by the rush to move when a bed finally became available, were particularly stressful. Many family members just couldn't find the time to fit in all the tasks: visiting the facility ahead of time, filling out paperwork, hiring a

mover, preparing their loved one for the move. The study also showed that the emotional trauma of the transition process was greater if the family had poor regarding the quality of care their loved one would receive after the move or was currently receiving in the facility.

Suggestions for easing this process included:

- Visits to the facility with the resident and family before the actual move
- Preparation of the room ahead of time for the new resident, decorated with familiar objects
- Availability of information packages on what to expect in the admission process and procedures
- Increased flexibility in the facility's admission process to allow more time to adjust and cope
- More open communication between staff and families
- More support from facilities and community agencies to help families handle the emotional trauma of the move, such as support groups and volunteer visiting

A successful application for a postdoctoral fellowship from the Alzheimer Society of Canada means that MAREP will be continuing their work in this area beginning this fall. The expanded study will include a greater diversity of families as well as community health care professionals, facility staff members and other key stakeholders involved in the transition process..

The following is a summary of principles to use as a basis for formulating policies and transition models...whether a person is moving from home to a long term care facility, from one facility to another, or even from one unit to another within a facility.

From research conducted by *Sherry L. Dupuis*, Ph.D. Director, Research, MAREP

For the full report: <http://www.marep.uwaterloo.ca/research/>

Principle One: The fewer moves, the better

Principle Two: Prepare families and residents for the move

Families need timely and accurate information on all details of the moving process.

Provide more time to make the decision, arrange for the move, and prepare the new setting for the resident – the more familiar the new room the easier the transition for the resident

Introduce family and the new resident to the new environment and staff in that new setting *before* the move

Principle Three: Be aware of the experience for family members and new residents

Different families will experience the transition and adjust to the move in different ways.

Principle Four: Help families feel more in control of the process

Listen to their concerns and wishes, respect and support their choices and work together to find the best solution
Be as flexible as possible throughout the process

Principle Five: Ensure the actual move is as easy and welcoming as possible for family members and the resident

Involve the new resident in a facility/unit activity so that the family can prepare room

Principle Six: Get to know the new resident and family

Show the family and resident that you value person-centered and/or family models of care by gaining knowledge of the new resident and her/his family

Principle Seven: Enhance communication between families and staff

Develop open, honest communication lines between staff, residents, and family members.

Introduce family members and the new resident to staff members who will be caring for the relative

Principle Eight: Help family members and residents build their resource base

Make families aware of supports and services available to them in the community and in the long-term care setting
Help in the development of new friendships for the resident in the new environment

Link family members up with others who have been through the process/family member mentors

Principle Nine: Strive for the highest quality of care

Homey environments that provide quality care by caring staff will help breakdown the stigma attached to long-term care settings

Principle Ten: Maintain continuity in the resident's life

Facilitate participation in valued activities and friendships in previous setting

Allow the family to set up the room prior to the move and in a similar way to the former setting

Your Voice

Placement: a personal story

“It was the hardest thing I’ve ever had to do in my life.” Bea Trites

Bea and Arthur Trites, after 22 years of marriage, are still very much in love. Many readers may recognize Arthur from the Belleville Chapter’s DVD “I have Alzheimer Disease” as the gentleman who recites the poem on love.

Following advice from the Alzheimer Society support group and the local Access Centre, Bea and Arthur toured the long term care homes in their community to check out their facilities and services. Their first choice boasted a beautiful enclosed garden where it would be safe and soothing for someone living with dementia to stroll. When Bea needed knee surgery, she placed Arthur there while recovering for several weeks. Arthur was very content with the arrangements, as he was eager to help Bea regain her health. This helped Bea feel sure that Arthur would be happy there, when the time came.

A few months later, the time did come. Bea received a phone call that a bed was available at their second choice of location. With a heavy heart, but with support and encouragement from her daughter, Bea called back the next day to say she would accept the spot. “Oh, sorry, we made a mistake – this bed is on a ward, and you indicated semi-private or private.” Bea’s heart flip-flopped and her spirits flew! “I won’t lose him today!” she thought joyfully.

A few weeks, later the time really did come. A semi-private room was available in their first choice facility. Bea had 24 hours to decide whether to accept the bed. Arthur’s condition was such that Bea’s health was suffering and Bea really had no choice. Once again, her doctor and her daughters encouraged her to go ahead.

“It was the hardest thing I’ve ever had to do in my life,” recalls Bea. “Just thinking about it brings back the pain. I felt like I was giving a death sentence to my dear Arthur. My head knew it was the right thing to do, that he would get excellent care, that I would see him the very next day...but my heart was breaking.”

Admission day is still a blur for Bea. Clothes had to be left for marking. Paperwork had to be filled out - all while Bea was riding an emotional roller coaster. Using her sore knee as an excuse, Bea asked her daughter to take Arthur to his room. “I could never have survived the process without my daughters,” Bea explained. “The house wasn’t empty when we got home and that helped me get through the day.”

Arthur has been in the facility for two months. Bea has placed two large pictures of Air Force planes on the walls, brought in his favourite comforter, and decorated with a few select items that Arthur always enjoyed, such as a carved wooden duck.

Your Voice, cont'd

Adjustment has been difficult for both Bea and Arthur. Arthur is showing signs of anger and is challenging staff and other residents. Bea is worried about him losing weight. His restlessness makes mealtimes challenging, but Bea's presence can be very helpful in keeping him focused on the food.

Is life easier? "I don't think so," replied Bea, "Although he's not the gentle Arthur I have always known, it's still hard to be separated from him. I used to visit twice a day, but he might be more manageable if I only visit once a day or even every other day. My heart is still breaking every time we say good-bye."

Despite Bea's sadness about placing Arthur, she has made good use of the services that the facility offers. They regularly take walks in the enclosed garden. She and her daughters have reserved the unit's family dining room for special occasions. She's made friends with other residents and their families, inviting them to join in card games. Bea has encouraged others in her support group to

take advantage of the facility's respite beds. "Knowing a bit about the routines and procedures from our respite use did help me get through the actual admission day," explained Bea, "But I don't think you can ever be fully prepared for what it will feel like. I know I thought I was prepared, but I wasn't!"

Words of advice for others? "Check out your local facilities well ahead of time. Ask lots of questions. Ask for help from family, friends and the Alzheimer Society. And be prepared for heartache. It was the hardest thing I ever did."



Alzheimer Society Belleville-Hastings-Quinte Directory

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This Just In...

Community Respite through *Neighbours Helping Neighbours*, a VON initiative that received a National Award for Innovation, is ready to be rolled out!

Did you know that small acts of kindness could make a huge difference to a caregiver, and help keep someone at home where they want to be? You don't have to be a professional to provide respite!

VON Hastings, Northumberland Prince Edward understands the needs of caregivers, and developed an educational tool kit to build community respite. The program is offered free to community groups, churches, service clubs who would like to build that informal capacity within their group or community. It is a six-hour training program that can be divided into several modules. It is meant to provide an understanding and a comfort level to those individuals wishing to help out in the community, who don't know how to start, or go about it. The training is written in simple terms, anyone can do it, from youth to seniors. The kit is all-inclusive, with handouts, overheads, exercises, and full instructions to facilitate the training from beginning to end. It's easy, and it's free.

Make a difference; bring *Neighbours Helping Neighbours* to your community. It is an investment that will develop great returns! For more information contact Carole Dove Manager of Community Development at VON HNPE 1-888-279-4866, email carole.dove@von.ca

**Canadian Caregiver Coalition
First issue of newsletter available**

In November 2005, representatives from the Care Renewal projects shared learnings from their experiences at a one-day national symposium in Ottawa hosted by the Coalition. The *Becoming Partners: Tools for Transition* symposium enabled national health organizations, caregiving associations and service providers (e.g., family physicians, nurses, social workers, etc.) to explore how caregivers can be included as members of the interdisciplinary care team in both policy and practice.

The Canadian Caregiver Coalition hosted a national consultation on its draft *Caregiving Framework* as part of the National Conference on Caregiving. The revised framework will be available shortly via the CCC Web site and electronic newsletter.

The Coalition has recently been contracted by Social Development Canada to conduct an environmental scan of supports available to caregivers by community-based organizations and caregiving associations. A final report will be submitted to Social Development Canada in March 2006.

If you would like to learn more about the work of the Coalition and how to become a member, please visit their website at www.ccc-ccan.ca