The Transition from Community Care to Long-Term Care
by Kyle Whitfield, Research Assistant, MAREP

From the literature, we know that the most significant reason that caregivers place their family member who has dementia in a nursing home is the burden of providing 24-hour care (Chenoweth & Spencer, 1986, cited in Aneshel, Pearlin & Sculer, 1993; McCarty, 1996). We also know that caregivers feel so overwhelmed with caring for their relative that their own physical and mental health eventually deteriorates to the point where they can no longer cope. Caregivers say it is one of the most challenging decisions they have to make in their caregiving role (Wackerbarth, 1999).

These issues are being explored further in a MAREP study taking place in three long-term care facilities in southern Ontario: Linhaven Home for the Aged, the Village of Winston Park, and Meadow Park Nursing Home. Individual interviews are being held with family members directly following the placement of a relative into a long-term care facility:

• to investigate how family members experienced the overall transition
• to explore what they found to be most difficult and most comforting during the entire transition process, including the actual move
• to examine family members’ understanding of their relative’s experience of moving
• to ask family members for recommendations that might help ease the experience for other families, as well as people who face being moved to a long-term care facility

This research is being conducted with families of relatives with dementia as well as family members of relatives with a physical impairment. The study will examine whether the experience of moving a loved one to a facility for physical reasons differs from the experience of moving a relative affected by dementia and, if so, how.

This study is currently in progress with a final report expected early in 2003. However, very preliminary findings suggest that the transition for family members is often “very difficult” and often results in “tremendous guilt.” Of the twelve families already interviewed, many talk about the lack of choice they feel they have in the entire transition process. For example, when a bed becomes available, they have 24 to 48 hours to make a decision to accept or not accept. If they do not accept, they “go to the bottom of the list,” often having to wait several more years before a bed becomes available. Also, moving their relative to a long-term care facility is most often the “last resort”; the family feels they have no other alternative.

Further interviews with family members will help us understand the experience of moving a relative into a long-term care facility in more detail. This information will help long-term care facilities develop strategies to ease this experience for both families and residents.

References
Community Involvement: Meanings and Challenges for Individuals Living in Long-Term Care Facilities

by Elaine C. Wiersma, Research Assistant, MAREP

Two years ago, I studied how residents of long-term care facilities viewed community involvement by interviewing six residents living in a small long-term care facility within a hospital in southern Ontario. The questions focused on preferred community outreach programs (i.e., programs offered by the facility to bring the residents into the community), motivations for and benefits of participation, challenges to participation, previous community involvement, and valued leisure activities.

From these interviews, I found that residents valued continued involvement and described various meanings of this involvement. The themes that captured their experience included:

- change in nature of community involvement
- value attached to involvement
- challenges to present involvement

Participants described how their current involvement had changed from when they were living at home, primarily in terms of volunteering activities. They described present community involvement as programs offered by the recreation services department, outings with family and friends, and even simply visiting the main lobby of the hospital. Some residents chose to participate in informal community involvement opportunities, while others chose more structured avenues.

While little consistency or continuity appeared in the types of activities enjoyed, the values attached to community involvement appeared to be similar:

- connection with the past
- desire for change
- socialization
- personal rewards

First, participation allows the residents to experience the community they have been a part of for most of their lives and to see how it has changed over the years. Connection with the past is enhanced through activities such as visiting home or family and participating in activities consistent with past interests. Second, participants indicated that a desire for change, especially a change of scenery, is an important motivator. Third, maintaining family relationships and contact with others outside the facility connects residents with the outside world and provides opportunities for valued social interactions. Finally, community involvement provides opportunities for personal rewards such as stimulation and the demonstration of continued competence and independence.

Participants emphasized the following challenges that either impacted their ability to participate or affected the quality of their experience:

- concerns related to illness or disability
- policies of the facility
- issues related to support
- negative attitudes towards other residents

As one might expect, health issues and functional status posed significant challenges and (as some participants commented) also affected the quality of their experience. The policies of the facility often prevented participants from engaging in community leisure opportunities as much as they would like. Some examples cited were quarantines due to influenza outbreaks and the requirements for appropriate supervision. Issues related to support, particularly a shortage of volunteers and staff to assist and supervise residents when off the floor, also limited ability to continue to participate. Finally, negative attitudes towards other residents posed challenges. One of the participants stated she rarely took part in outings because “I can’t communicate with anybody…there’s no companionship…no one to talk to.” Participants also expressed frustration over the behaviors of others with cognitive impairments.

The findings of this study provide valuable insight, but a number of challenges remain. For example, individuals with dementia experience many more significant challenges than the participants in this study, who are not cognitively impaired. Creative and innovative ways are needed to ensure that all residents can stay connected to their communities.

Various methods and strategies can be used currently within long-term care facilities. First, staff and families need to be made aware that everyone needs a regular change of scenery. They need to realize that, for many residents, continued involvement in their communities is very much linked to self-esteem, a sense of competence, and the maintenance of independence. Staff can play a facilitator role; they need to think beyond the walls of the facility, and develop partnerships with seniors’ centres, schools, seniors’ clubs, churches, and other organizations that can help provide opportunities for residents to access their communities. Creative ways need to be found to develop support systems (e.g., volunteers and families helping residents develop friendships in community programs, pairing of residents). Residents also need education to sensitize them to the circumstances of illnesses and diseases associated with aging, particularly dementia, and to help them develop more positive attitudes towards fellow residents. Institutional policies should be reviewed to ensure that they are not inhibiting or prohibiting involvement.

And, most importantly, staff and families need to listen to residents and respect their wishes.
New Initiatives...

“Living Metaphor” at Homewood
Described as a “living metaphor for our interior journeys,” a labyrinth is a circular walking path, based on a medieval design, that leads to and from a centre. Unlike mazes, which have many dead ends, a labyrinth offers a single, winding route to one point. For centuries, Christian pilgrims walked labyrinths in search of inner peace. In recent years, scientific studies have proven that the labyrinth offers tangible benefits as a healing and meditative tool.

This concept first came to Homewood Health Centre in Guelph as a portable canvas labyrinth presented by the Centre’s chaplain. The patients’ response was so overwhelmingly positive that the creation of a permanent structure was suggested. And so, with the time and support of many dedicated people, a permanent labyrinth now exists as one of the focal points in Homewood’s “healing garden.” It is composed of seven concentric circles divided into four quadrants. Pathways of limestone screenings are lined with more than 3000 thyme plants. MAREP staff were delighted to attend the opening and dedication of Homewood’s labyrinth on July 17, 2002.

“Saints Alive!” at Winston Park
Residents and staff at Winston Park spent many hours over the summer months performing their musical hit, “Saints Alive: Aging to Perfection!” The singers and actors included nursing home residents, retirement home residents and Winston Park staff. Not only did the group perform several times at Winston Park, they also took the musical on the road to display their talent at various facilities in Waterloo Region and the surrounding area. The opportunity of being “stars” for a day boosted the self-confidence of the participants and left them with a sense of empowerment. As the days turn cool, residents can still be heard chatting in the hallways about this wonderful program.

Alzheimer Resource Manual
Care providers frequently comment that there is a need to understand ...
- why residents with Alzheimer’s disease act the way they do
- what programs and interventions have been shown to be effective
- what can be done to enhance the quality of life for these individuals

The Alzheimer Resource Manual 2000 was created to respond to this need. This manual is a comprehensive collection of information about Alzheimer’s disease and other dementias, distilled from the research literature and from research activities. Representing the most up-to-date findings on diagnosis, treatment and care of persons affected by Alzheimer’s disease, the information is presented in point form and in simple language. The manual is intended for both formal and informal caregivers:

In long-term care facilities ...
- staff from all areas — nursing, dietary, housekeeping, activity departments, as well as management and administration — will find useful information. The manual will be of particular interest to individuals who work closely with residents with some form of cognitive impairment.

In the community ...
- the manual can help informal caregivers carry out their tasks with greater understanding of the course of the disease.

Contact Beverly Brookes to order your copy of the Alzheimer Resource Manual 2000. ($125)

Partnering with MAREP
This year MAREP has experienced successful partnerships with the following long-term care facilities:
- Homewood Health Centre Inc., Guelph
- Linhaven Home for the Aged, St. Catharines
- Marianhill, Pembroke
- Meadow Park Inc., London
- The Village of Winston Park, Kitchener

If you are interested in working with MAREP to improve the quality of life of persons with dementia, please call Cathy Conway.

Thanks to Maple Villa and Royal Terrace
A special thank you to the residents, their families, staff and volunteers of Maple Villa Long-Term Care Centre in Burlington and Royal Terrace in Palmerston who work so hard each year to raise money during Long-Term Care Facility Month. MAREP is very proud to have been chosen as a recipient for the past several years.

MAREP depends on donations from individuals, groups, and organizations to continue its efforts to improve the quality of life of persons with dementia and their families. (Donors receive charitable donation receipts.)
Lemon Balm — A Good Way to Manage Agitation?


Aggressiveness, restlessness, excitability — these symptoms, experienced by more than half of people with severe dementia, are distressing for patients and problematic for caregivers. The typical first-line treatment for what are conventionally referred to as “behavioural and psychological symptoms in dementia” is pharmacotherapy, specifically neuroleptic agents. But neuroleptics are often very poorly tolerated by people with dementia and are associated with increased social withdrawal. Also, the risk of adverse side effects — such as parkinsonism, drowsiness, falls, accelerated cognitive decline, or increased mortality — is high.

In light of promising preliminary evidence, Ballard et al. (2002) undertook the first double-blind, placebo-controlled study to assess the value of using aromatherapy with essential oil of Melissa officinalis (lemon balm) to treat agitation in people with severe dementia. Seventy-two people living in long-term care facilities in the UK were randomly assigned to aromatherapy or placebo (sunflower oil), combined with a base lotion. Caregiving staff applied the oils to patients’ faces and arms twice a day. Over four weeks of treatment, changes in clinically significant agitation and quality of life indices were compared.

No significant side effects were observed. Aromatherapy treatment resulted in a 35% improvement in agitation compared to 11% with placebo treatment. Scores on quality of life indices also improved significantly. Researchers concluded that aromatherapy with essential balm oil is safe, well-tolerated, and highly efficacious. Further controlled trials are recommended.

Innovations: Enhancing Ability in Dementia Care

is published quarterly by MAREP, an innovative program which integrates educational and research activities in an effort to improve dementia care practices in Canada. The goal of MAREP is to enhance the ability of care providers, both formal and informal, to respond to the needs of persons with Alzheimer’s disease and related dementias, and ultimately to improve the quality of life of persons with dementia and their families.

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Innovations is designed to provide accurate information. Although the information presented and the opinions expressed are gathered from sources thought to be reliable, their accuracy and correct interpretation cannot be guaranteed.

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