



Living with Hope in the Midst of Change Understanding Leisure Within the Context of Memory Loss

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Although great strides have been made, the experience of memory loss from the perspective of those living with it is not entirely understood. We do know that despite the challenges people face when diagnosed with dementia, they find ways to continue living meaningful lives.

Part of the experience of dementia includes threats to one's identity that arise from both the changes that result from dementia and the stigma society has placed on memory loss. However, little is known about the role of leisure in the lives of persons living with memory loss.

In this study, I asked people with memory loss about their experiences with leisure. I wanted to find out what role leisure plays in maintaining identity when one experiences such threats to one's identity.

To gather data for this study, I had the privilege of working with four persons living with early-stage memory loss. The participants and I discussed their experiences with leisure and dementia over about ten months. On four separate occasions, we sat down together and the participants willingly shared their stories, opinions, and thoughts about leisure within the experience of memory loss. As well, we engaged in one or two of their favourite leisure activities together. We played games, socialized, went for walks, practiced putting, and did crafts.

I also asked the participants to take photos of people, places, and things that are meaningful for their leisure. Using these photos, we discussed what their leisure meant to them, some of the challenges they faced with respect to leisure, and how challenges can be overcome.

Living in a Paradox of Challenge and Hope

Through our conversations, our discussions of the photos taken by the participants, and our engagement in leisure activities, I found that the participants experienced their memory loss journeys within a paradox of challenge and hope.

The participants have faced many changes in their lives since being diagnosed with dementia, changes that often have an impact on their leisure. For example, they forget rules to games they've always played, or steps to a dance they learned long ago. They feel more tired than they used to and may not be able to engage in their favourite leisure activities for long periods of time.

Despite these changes, the participants feel hopeful about their lives. They remain actively engaged in the world around them. They continue to be involved in relationships with family and friends, and to be a part of their communities. Through participation in a variety of leisure activities that allow them to show others that they continue to be capable people, they maintain their identities.

Overcoming Leisure Challenges

The challenges to leisure experienced by participants as a result of memory loss prompted them to find creative ways to continue to engage in valued activities.

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They alter their expectations of themselves when performing a leisure activity. For example, instead of being competitive while playing a game, they focus on practicing the skills that the game requires. They set achievable goals and celebrate their success.

They also change the activity to suit their current level of ability. One participant, for example, attempted a 500-piece puzzle when the 750-piece puzzle became more challenging, hoping to work her way back up.

Relationships with others are important for maintaining leisure engagement, as the participants are supported and encouraged to engage in their favourite activities.



Mentally stimulating activities, such as jigsaw puzzles, help exercise one's mind.

Leisure helps maintain valued roles, such as caring for others.



Meanings of Leisure in Living with Memory Loss

Mentally stimulating leisure activities are valued for exercising one's mind

Participants use leisure activities, such as puzzles and games, to stretch their minds. Physical activity is also important for keeping one's mind active, and participants walk, play golf, and generally try to remain active to help maintain cognition.

Leisure is an opportunity to spend time with family and friends

Participants enjoy their leisure time with their care partners, their family, and their friends. Leisure is a chance to be social and engage with others.

Leisure is a way to relax and have fun

Participants define their leisure in terms of having fun. They choose enjoyable activities that help them to relax. Time passes quickly when engaging in leisure.

Leisure activities can substitute for lost work roles or other valued roles

When valued roles are lost because of memory loss, participants use leisure to replace these roles. In this way, leisure helps them to sustain their identities and increases self worth. For example, some participants replaced their lost work roles with leisure. Others use leisure to show their family and friends that they can solve their problems and lead a meaningful life.

Leisure is a way to create enduring memories

Participants engage in leisure so that their loved ones will remember them in positive ways. They help other people who are living with dementia by sharing their experiences and advocating. They want to be remembered for being good friends, and for working hard to fight dementia.

What Do These Findings Mean?

To summarize, the findings of this study reveal that meaningful leisure is:

- a space for persons living with memory loss to sustain their identities
- a space for persons living with dementia to resist negative stereotypes, emphasize continued abilities, and experience a sense of hope despite a great deal of loss
- vital for growth and development when living with memory loss

These findings have important implications for persons living with memory loss, their partners in care, and formal service providers. We've learned that persons living with memory loss value their leisure and that it plays a vital role in their lives. Clearly, leisure involvement should be supported and encouraged, since it helps to counteract the threats to identity faced by people with memory loss.

Although further research is needed, this study reveals that leisure continues to be important and provides a sense of hope in the face of a great deal of change.

Hot Off the Press!

MAREP proudly announces the release of two new guides in the *By Us For Us* (BUFU) series. *Enhancing Wellness* and *Tips and Strategies* were officially launched at the November 2008 *A Changing Melody* forum and are now available to the general public.

Completely researched and designed by persons with dementia, *Enhancing Wellness* focuses on maximizing physical, psychological and emotional, social, and spiritual well-being in order to live life to the fullest, even after a diagnosis of dementia. This guide provides tips for eating well, taking care of your body, being physically active, staying centred with yourself, staying connected with others, and living in peace — all of which are important in enhancing wellness.

The second guide, *Tips & Strategies*, is a resource for living with an illness causing dementia. In addition to general ideas and suggestions for daily living, the guide provides more memory “workout” ideas and tips for those in the workforce.

In a letter written to the over 40 contributors to these guides, Brenda Hounam, the founder and driving force for the series, states: “The *By Us For Us* series has become an invaluable resource for people newly diagnosed as well as those who are looking to make changes. These guides have also been so helpful for our personal care partners, including family members, friends, and professionals in the field of dementia care. Not only are these guides widely used locally but they have been requested by individuals and organizations nationally and internationally. The *BUFU* guides have demonstrated how much people with memory



loss can still accomplish and contribute when joining forces.”

These two new resources are the fourth and fifth in a series written by a dedicated and passionate group of persons with early-stage dementia for persons with early-stage dementia. Information about the first three guides — *Memory Workout*, *Managing Triggers*, and *Enhancing Communication* — can be found on the MAREP website.

Later this year, the *BUFU* team will be releasing a crossover guide written by persons with dementia and family partners in care for persons with early-stage dementia and family members. This sixth guide in the series will deal with the process of transforming and living with grief and loss.

MAREP has also been fortunate to receive funding from the Homewood Foundation to produce a five-part series of *BUFU* guides for family partners in care. These guides will be produced and launched over the next two years.

The series has become increasingly popular since the release of the first guide in 2006. Although encouraged by this, the *BUFU* group needed to ensure that the project would remain sustainable and that the guides would continue to be accessible to those for whom they are most helpful. To address this issue, the group decided to apply a nominal fee of CDN \$1.00 per guide.

If you are interested in becoming involved in the production of the *BUFU* guides, please contact Lisa Loiselle at 519-888-4567, ext. 35040, or loiselle@uwaterloo.ca.

For more information on the *By Us For Us* guides and/or to place an order, please visit the MAREP website at <http://www.marep.uwaterloo.ca/products/bufu.html>.

what users are saying ...

The *BUFU* guides have helped to open up a conversation with my support group members. I've learned the importance of keeping my sense of humour and planning ahead.

~ Richard Fagan, member of the Royals Early-Stage Support Group

I'm thrilled to have access to such high-quality resources to share with individuals who have recently been diagnosed with early stage memory loss. These booklets have made a real difference to many of our members.

~Julie Mitchell, Alzheimer Society of Guelph-Wellington

Lynn Jackson: Portrait of a Partner



In 1999, at age 44, Lynn Jackson was diagnosed with the early stages of frontotemporal dementia. Since her diagnosis, Lynn has been a dedicated advocate for people living with early-stage dementia. In 2000 she helped found “DASNI” – the Dementia Advocacy and Support Network International – an Internet-based organization whose mandate is to:

- promote respect and dignity for persons with dementia
- provide a forum for information exchange
- encourage support mechanisms such as local groups, counselling groups, and Internet linkages
- advocate for services for people with dementia
- help people connect with their local Alzheimer’s Society

DASNI believes that people in the early stages of dementia can be autonomous and competent, that shared knowledge fosters empowerment, and that its members’ strengths provide a supportive network.

Lynn’s involvement with MAREP began when Sherry Dupuis, MAREP’s director, wrote to DASNI broaching the idea of developing some sort of “conference” for people with early-stage dementia and their partners in care. That conference became a forum called *A Changing Melody*. DASNI was asked to be a “partner” in the planning and implementation of this forum, and Lynn, on behalf of DASNI, has been actively involved since its inception. Over the past seven years, Lynn has served as a member of the organizational committees for *A Changing Melody*, relying on DASNI members in its e-mail community for input and advice when making pivotal decisions.

Lynn has spoken locally, nationally, and internationally in an effort to promote better diagnosis, enhanced access to treatment, and inclusiveness. She has taken a particular interest in breaking the stigma surrounding a diagnosis of dementia, participating in Alzheimer’s Disease International working groups to help member countries become more inclusive of people with dementia.

Currently, Lynn co-facilitates the Alzheimer Society of BC’s Vancouver Early-Stage Support Group, which she was instrumental in starting in 2001. She also serves on the Advisory Committee for the Centre for Research on Personhood in Dementia at the University of British Columbia, and on the Ethics Committee of Delta View Campus of Care.

MAREP has been very fortunate to partner with Lynn for so many years. Her contributions have been immeasurable. She has been an inspiration to many of her peers and to everyone with whom she has worked at MAREP. We are grateful to Lynn for her tireless advocacy and her dedication to helping others, and we look forward to continuing our partnership.



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 all involved in dementia care, including persons with dementia, their partners in care, and formal care providers, to respond to the needs of persons with Alzheimer Disease and related dementias and ultimately improve the quality of life of persons with dementia and their families.

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This newsletter 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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