



## Living and Celebrating Life Through Leisure

Most approaches to leisure and recreation within the dementia context problematize everyday meaningful activities. That is, when someone is diagnosed with an illness causing dementia, leisure becomes “therapy.”

What would it mean to see leisure through an alternative, non-medicalized lens? Using a participatory action research approach, we brought together a group of stakeholders, including persons living with dementia, family partners in care, and professionals working in dementia care and recreation to explore this question. Members of the John Noble Home LEAD program — persons in early to mid-stages of dementia — served as our advisory committee.

Data have come from a number of sources including an online survey of persons living with early stage dementia, family members and professionals, and face-to-face interviews with persons living with dementia participating in a day program and living in a long-term care facility.

Our research showed seven core meanings given to leisure that focus on what it means to be fully alive. First, participants reported a preference for leisure experiences that were personally meaningful and connected with current and/or past interests. Leisure was viewed as a space for expressing the self, for **being me**: “*Playing the keyboard is something that I do strictly on my own. I use headphones so that no one hears but me and that way I can dream that I play like I used to. It still gives me the most pleasure. I LOVE MY MUSIC.*”

A second core component of the leisure experience was **being with**, feeling a sense of connection and communion with others. The third meaning focused on **seeking freedom**. Participants described leisure as a space where they could have a “break from the norm.” Some saw leisure as an “escape” from the stresses of daily tasks and responsibilities and the “pressure from others,” while others saw a chance to “get out” of socially and physically restrictive environments. Fourth, **making a difference** was important. Leisure experiences were most meaningful when participants felt valued and had “a sense of accomplishment” and purpose.

The fifth core meaning, **finding balance**, reflects the need to find the balance between “relaxation” and “keeping busy.” “[*Leisure*] can involve an activity as long as it is simple and relaxing while you enjoy the moment and time you are spending doing it. It can be spent alone or with someone that truly understands my journey. If I am happy and relaxed and not pressured, then I consider that to be leisure.” Sixth, leisure experiences provided opportunities for **growing and developing** by learning new things, including musical instruments, computer skills, and crafts. Finally, central to meanings of leisure was the experience of **having fun**. Participants attached feelings of pleasure, enjoyment, and happiness to the leisure experience.

These findings not only expand our understanding of the meaning of leisure for persons living with dementia but also have important implications for recreation professionals. Our research questions the continued practice of reducing leisure to status of therapeutic activities used to attain what is perceived to be some greater goal or objective. When we are faced with illness or disability, leisure provides a space not only for natural healing but also for being – for celebrating who we are. Leisure can only be meaningful to persons with dementia when they can reveal and engage the expressive sides of who they are as human beings: in the words of one participant, “*when the heart is at ease and happy, when the mind is calm, and when the soul feels like singing.*”

### Holiday Issue 2010: Volume 9, Issue 3

- 2 ... “A Changing Melody” Goes International!
- 3 ... Thank You to Our Donors
- 4 ... Lindsay Sprague: Changing the Culture in Long-Term Care

This edition of *Innovation* is dedicated in loving memory to our dear friend, Janet Mooney, who gave so much of herself to MAREP.

## A Changing Melody Goes International!

In conjunction with the 26<sup>th</sup> Annual Alzheimer's Disease International Conference, MAREP has partnered once again with the Alzheimer Society of Canada, the Alzheimer Society of Ontario, the Dementia Advocacy and Support Network International, and local Alzheimer Society chapters to host *A Changing Melody (ACM): A learning and sharing forum for persons with early-stage dementia and their partners in care*. For the first time, ACM will involve participants from around the world coming together to enhance dementia care. This international event will be held on March 26, 2011, at the Sheraton Centre Hotel in Toronto.

ACM will provide a safe space for persons with early-stage dementia, family members, friends, and a range of professionals to learn with and from each other about actively improving quality of life.

The day will be a truly international affair, featuring speakers from Canada (Mary McKinley, Cathie Borrie, Teferi Adem, Patricia Bower), Australia (Christine Bryden), Scotland (members of the Scottish Dementia Working Group), and the USA (Russ Belleville and Dr. Mitchell Sutzky). In addition to our guest speakers, the

forum will also include a blend of musical reflections, group sharing and dialogue, and opportunities for networking. Sessions will highlight each of the topics in this year's theme, **Coping, Adapting, Enabling, Creating: Striking a Balance:**

**Coping** with stigma and fear

**Adapting** to change so as to enhance well-being

**Enabling** persons with dementia

**Creating** strong partnerships in dementia care

The cost to attend is \$50 for persons with dementia, family partners in care, and students; \$75 for professionals accompanying persons with dementia; and \$155 for health or other professionals. A travel subsidy is available for individuals with dementia and their family partners in care. We will also be offering a live U-stream video feed option for our national and international partners.

Look for a brochure soon — registration begins in January 2011. For more information and updates, please visit [www.marep.uwaterloo.ca](http://www.marep.uwaterloo.ca).

### FORUM SCHEDULE

09:00 – 10:00	Registration and Continental Breakfast
10:00 – 10:15	Welcome: This Little Light of Mine
10:15 – 11:00	<b><u>Session 1: Coping with Stigma and Fear</u></b>
11:00 – 11:20	Refreshment and Networking Break
11:20 – 12:15	<b><u>Session 2: Adapting to Change</u></b>
12:15 – 01:15	Lunch and Networking Break
01:15 – 02:00	<b><u>Session 3: Enabling Persons with Dementia</u></b>
02:00 – 02:20	Refreshment and Networking Break
02:20 – 02:50	<b><u>Session 4: Creating Strong Partnerships</u></b>
02:50 – 03:00	Closing: We Are a Changing Melody

## Alzheimer's Disease International Annual Conference, March 26, 2011

Alzheimer's Disease International (ADI) is the umbrella organization of more than 70 Alzheimer associations worldwide. From its beginnings as a venue for members and those with an interest in dementia to network and obtain updates in science and care, this conference is now recognized for its depth of content and education.

This unique multidisciplinary event brings together people with dementia, family partners in care, staff and volunteers of Alzheimer associations, care professionals, clinicians, and scientists to share achievements in the medical field, new and innovative research, and best practices in dementia care, and to challenge perceptions of dementia. The 26<sup>th</sup> ADI 2011 conference will be held immediately following the ACM forum (see above). As the theme **The Changing Face of Dementia** suggests, it is time to rethink our understanding — and thus our care and

treatment — of dementia and to define which directions research should take to determine how best to slow the progress of the disease and even prevent its onset.

The scientific programme will include a plenary lecture by Christine Bryden, who was the first person living with dementia to speak at an ADI conference ten years ago in New Zealand. Other plenary lectures on new treatments and developments in dementia, psychosocial interventions, lifestyle factors and prevention, and dementia in indigenous communities will lead the conference. A wide variety of parallel sessions and workshops will complete the programme with active involvement from people living with dementia from around the world.

For details, please visit the conference website, [www.adi2011.org](http://www.adi2011.org), and the ADI website, [www.alz.co.uk](http://www.alz.co.uk).

# Sincere Thank You to Our Volunteers and Donors

Your gifts of time and financial support are making a difference!

MAREP relies extensively on the generosity of many individuals and organizations who support us with time and money.

Many selfless individuals, including persons living with dementia, family members of those diagnosed with an illness causing dementia, and professionals, provide thousands of hours of their time each year to help us with our work. Without their willingness to actively engage with us in our projects, we would not be able to do the important work we do that is making a significant impact around the world.

Many others provide financial support. Every contribution — regardless of size — supports both the operations of MAREP and the many educational and knowledge translation projects we work on each year. Currently, these contributions are helping us with the following projects:

- the development of a new By Us For Us Guide for persons living with dementia and a new By Us For Us series targeted at family care partners
- the creation of a web-based tool to support persons with dementia and their family members at diagnosis
- an “age friendly communities” initiative that is helping to make communities more enabling and supportive for all citizens
- the planning and implementation of an *International “A Changing Melody”* forum – a learning and sharing forum that will bring together persons with dementia, family members, and professionals from around the world to learn with and from each other; this forum is to be held in conjunction with the Alzheimer’s Disease International conference in March 2011 (see page 2)
- the development of a new recreation resource guide for professionals working in dementia care
- an evaluation of the First Link® Learning Series
- the education of front-line staff members in long-term care homes
- the provision and mentorship of undergraduate and graduate students interested in the dementia cause
- a major culture change project focused on developing strong partnerships in dementia care that incorporate the voices of all involved, including those living with dementia



On behalf of the MAREP team, I would like to thank everyone who gives so generously of time and financial contributions. Your support is truly a gift and we are grateful!

Wishing you peace, joy and health over the holiday season and in the coming year.

Sherry Dupuis, Director, MAREP

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## Lindsay Sprague: Changing the Culture in Long-Term Care



With much excitement we are pleased to announce that Lindsay Sprague has joined the MAREP team. As knowledge translation specialist, Lindsay's primary role is to develop tools and resources for the Partnerships in Dementia Care Alliance project, funded through the CURA (Community University Research Alliance). This project focuses on changing the culture in long-term care to improve quality of care for persons with Alzheimer's disease or a related dementia.

Lindsay's background in Alzheimer's disease and dementia began in secondary school when she worked part-time as a nurse's aide in a rural long-term care facility. It was there that she was introduced to the impact of Alzheimer's disease on individuals, families, and long-term care staff. Lindsay first became aware of the MAREP team in 2008 when her grandparents participated in the "Eating Together" project. So began an exploration of the exciting and meaningful work MAREP conducts with community partners, health practitioners, and persons with dementia.

Since beginning her position in November 2010, Lindsay has attended a training program on compassion fatigue with the aim of developing workshop materials and resources for care partners who are supporting individuals living with dementia. Also, along with the other members of the MAREP team, she recently participated in a workshop on the Appreciative Inquiry approach to facilitating culture change, which assesses the strengths of an organization or group in order to build capacity, facilitate change, and/or improve services and care. Lindsay's role involves developing some practical training modules, tools, and resources for the Dementia Care Alliance partners using an Appreciative Inquiry approach. It is hoped that employing this strengths-based approach will work towards creating sustainable relationships and culture change in long-term care to better support persons with dementia, staff working in long-term care, and families.

Lindsay completed her BA in Anthropology at the University of Waterloo in 2005 and then pursued graduate studies in medical anthropology at Queen's University in Belfast, Northern Ireland. Her PhD research looked at the socio-cultural experience of living with HIV/AIDS in the United Kingdom, using a narrative approach. The focus of her thesis included the bodily effects of living with a stigmatized illness, the strategic use of disclosure, and how people living with HIV resist medicalization of their illnesses. Upon completing her doctoral studies in December of 2009, Lindsay returned to the Kitchener-Waterloo area where she worked as a social program evaluator at a local non-profit research agency prior to joining the MAREP team.

Welcome to the MAREP family, Lindsay!

9(3): Holiday Issue 2010 ~ page 4

Kenneth G. Murray Alzheimer  
Research and Education Program

# MAREP

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*Innovations: Enhancing Ability in Dementia Care* is published quarterly by MAREP, an innovative program that adopts a partnership approach and integrates research and educational activities in an effort to improve dementia care practices in Canada and beyond. The goal of MAREP is to enhance the ability of all involved in dementia care, including persons with dementia, their family partners in care, and professional care partners, to respond to the needs of persons with Alzheimer's disease and related dementias and ultimately improve the quality of life of all those experiencing dementia.

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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.

#### Editing/Layout

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