

Ontario's Dementia Strategy:

Response by: Activity Professionals of Ontario &
 Therapeutic Recreation Ontario

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"We don't stop playing because we grow old; we grow old because we stop playing".

George Bernard Shaw



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Ontario's Dementia Strategy: Activity Professionals of Ontario and Therapeutic Recreation Ontario

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Overview of Therapeutic Recreation and Recreationists

Therapeutic Recreation is a process that utilizes functional intervention, education, recreation participation, and meaningful activity to enable persons with physical, cognitive, emotional and/or social limitations to acquire and/or maintain the skills and knowledge that will allow them to enjoy their leisure optimally, function independently with the least amount of assistance and participate as fully as possible in society. Therapeutic Recreation supports individuals in living life to the fullest. Therapeutic Recreation is provided by trained professionals in clinical and/or community settings.

The **purpose** of TR is to enable all individuals to achieve quality of life and optimal health through meaningful participation in recreation and leisure. The profession recognizes the importance of the recreation experience and supports all individuals in having full access to and the freedom to choose recreation and leisure opportunities.

(Therapeutic Recreation Ontario, TRO)

Recreation professionals, a key component of the interdisciplinary team, provide to residents of all levels of physical and cognitive function, meaningful and stimulating programs and activities aimed at ensuring engagement in spiritual, physical, intellectual, and emotional areas. Maximising resident wellness and a life of meaning, the recreation professional liaises regularly with residents and family councils, community involvement, volunteer management, and continuous assessment and quality improvement.

(Activity Professionals of Ontario, APO)

In response to the Ontario Dementia Strategy Report we would like to discuss opportunities to enhance quality of life for persons with dementia and their care partners through the recognition and inclusion of professions currently underutilized. Recreation and leisure play an integral role in life quality for individuals and communities and are an important component of person-centred, relational, and holistic approaches to health care. At times misconstrued as a means of diversion, when facilitated by properly trained Recreation Therapists and Recreationists, recreation and leisure can be instrumental in, and in fact essential to ensuring quality of life.

1) Recreation as Part of the Health Care Sector and Healthy Communities

Research with Canadians across the country has identified leisure and culture as one of the eight domains of well-being important to Canadians (Canadian Index of Wellbeing (CIW), 2016). Despite this, data from the most recent CIW National Report "How are Canadians Really Doing? The 2016 CIW Report" demonstrates a 21 year downward trend in access to leisure and culture, threatening the well-being of Canadians. The CIW recommended universal access to leisure and culture, emphasising: "To help reverse the downward trend over the past 21 years, leisure should be regarded not just as a basic human right but should be considered a *public good*" (Canadian Index of Wellbeing, 2016). This is especially true for people living with dementia who often are denied access to social inclusion and community engagement.

Bamford and Bruce (2000) examined the desired outcomes of community care from the perspectives of persons with dementia and their partners in care. An important aspect of quality of life for the participants in the study was their continued need "to access normal activities and patterns of life in ways that maximize choice and control" (p. 553). The participants emphasised that valued activities do "not simply centre on personal care and domestic tasks but include opportunities to socialise, to engage in activities and to achieve a sense of social integration" (p. 553). The importance of continued companionship, social integration, and meaningful activity to quality of life and well-being for persons with dementia has been documented in other research with persons with dementia (see Chung, 2004; Dupuis et al., 2012; Lam & Beech, 1994; Mitchell et al., 2006; Murphy et al., 1996; Raynes, 1999; Sperlinger & McAuslane, 1993; Sutton & Fincham, 1990). In fact, continuity of valued activities and lifestyles may assume even greater significance after the diagnosis of an illness causing dementia (Menne, Kinney, & Morhardt, 2002). Any strategy focused on dementia must recognize that at all places along the dementia journey and no matter where one lives; persons

with dementia have the right to be fully engaged in meaningful activities and in their communities. This acknowledges the continued potential of all persons with dementia and that all persons with dementia have a future despite the fact that they are often “written off” after a diagnosis. It requires understanding the person’s hopes, goals and aspirations and assisting him or her to achieve them and to continue to grow and develop. It requires access to meaningful interactions and activities and ensuring that all persons with dementia continue engaging with his or her community through participation and involvement. It requires a service culture that is open to possibilities, willing to take risks, and creative in their abilities to think outside traditional models (Dowling et al., 2007). It requires active inclusion of therapeutic recreation and other recreation professionals. Engagement in recreation and leisure is critical for people with dementia and their families to continue to live their lives to the fullest.

Despite the importance of recreation and leisure in people’s lives, recreation professionals are still not considered an essential part of the health care sector. This was evidenced on page 31 of the report where therapeutic recreationists/recreation therapists were excluded from the list of health care service providers involved in “delivering high quality care”. It is also evidenced in the long-term care sector where the vast majority of funding is focused on the two to three hours of body care needed and yet there are 24 hours in day. People in these settings are much more likely to express feeling bored, helpless, isolated, and lonely than their peers without dementia. As one person with dementia involved in a research project by Dr. Sherry Dupuis stated: “Many think it is the disease that causes us to withdraw, and to some extent I believe this is true. But, for many of us, we withdraw because we are not provided with meaningful opportunities that allow us to continue to experience joy, purpose, and engagement in life.”

Recreation and Leisure may also play an important role in maintaining cognitive health. In samples of older adults without dementia, more frequent participation in stimulating activities has been associated with higher levels of cognitive function (e.g., Pignatti et al., 2002; Schooler & Mulatu, 2001; Seeman et al., 2001; Wilson et al., 1999, 2003a), reduced rates of cognitive decline (e.g., Hultsch et al., 1999; Wilson et al., 2002, 2003), and a reduced risk of Alzheimer Disease (e.g., Balfour et al., 2001; Laurin et al., 2001; Scarmeas et al., 2001; Verghese et al., 2003; Wang et al., 2002; Wilson et al., 2002). Results from studies using functional imaging also suggest that older adults who are actively engaged in stimulating activities and environments may be able to tolerate more dementia pathology, providing some support for the cognitive reserve hypothesis (see Scarmeas & Stern, 2003).

Not valuing and including recreation professionals as an integral component of quality health care and to quality of life is an enormous oversight and fails to recognise that therapeutic recreationists/recreation therapists currently work in hospital settings, rehabilitation, mental health facilities, adult day programs, home-based care, and long-term care homes. Until

therapeutic recreationists/recreation therapists are included as a valued component of the health care sector and healthy communities we will never be able to truly support people with dementia in LIVING their lives.

Our recommendations:

- Recreation Professionals must be included as a recognized and valued component of quality dementia care and in all dementia care settings. Therapeutic Recreation and Recreation Therapy encourages engagement in experiences that are meaningful to the person. It is participation in these pursuits that support individuals to thrive, to see a life worth living when suicides among people with dementia are on the rise, and can decrease the likelihood of responsive behaviours and hospital admittance or re-admittance.
- The Dementia Strategy recognizes the importance of maintaining hobbies, interests and skills to health and well-being. People with dementia also need opportunities to be able to continue to contribute to their communities and for growth and learning, not only in community-based settings but also in residential care settings.
- Recreation and leisure must be an important aspect of all dementia friendly community initiatives. Meaningful community recreation and leisure programs that are inclusive and accessible to everyone in the community would support the inclusion of persons with dementia and/or their care partners in ways that support the full citizenship of people with dementia rather than only treating them as medical 'patients'. We need innovative programs in community that view people with dementia as citizens first and to ensure that people with dementia have access to a broad range of community opportunities for meaningful and relevant activity beyond just adult day programs. For example, many adult day programs are not appropriate for people with young onset dementia. The Bitove Wellness Academy in Toronto is an example of a program that has abandoned the medical model completely by focusing instead on developing the talents, gifts, and self-expression of people with dementia across the dementia journey using the arts and intergenerational programming.

2) Enabling Persons with Dementia in Self-Directed Care and in Navigating the Healthcare and Community Support Service Systems

An issue that comes up over and over again in research on dementia is how, once diagnosed, people with dementia and their family members do not know where to turn for assistance and

support. When they try to seek out help, navigating the system often becomes so challenging that families give up and try to manage on their own (Dupuis & Smale, 2004). People with dementia and their families need options for care that also include directing their own care and supporting them with self-management.

Self-management options have been slow to be recognized in the area of dementia care for a number of reasons, but most importantly because images of dementia tend to be of later stages and, therefore, it is assumed that persons with dementia cannot learn new skills or participate in their own care and in decisions affecting their lives (Mountain, 2006). These ideas have begun to be challenged with research demonstrating how people with dementia, particularly in earlier stages of the disease, can learn and adjust to their illness and participate in their own care, given appropriate support (Barnett, 2000; Kitwood, 1995; Sixsmith, Stilwell, & Copeland, 1993). Thus, models of self-care involving persons with dementia working alongside their partners in care are beginning to emerge outside of Canada (Moniz-Cook, DeLepleire, & Vernooij-Dassen, 2004; Romero & Wenz, 2001; Vernooij-Dassen & Olde-Rikkert, 2004). However, in order for self-care options to work, a number of factors need to be in place, including: "early disclosure of the diagnosis; support with the consequences of disclosure; a focus upon the needs of persons with dementia; identification of specific interventions that might facilitate self-management; meeting needs for professional education and support; and a whole systems approach towards treatment and care" (Mountain, 2006, p. 435). Such a system must ensure that a wide-range of health and community support services are available to respond to the needs of persons with dementia and their family partners in care from early in the disease until end of life.

Further, it is recognized in the Report that "Keeping people with dementia in mind while designing transportation, housing, health, social and other services can go a long way in supporting individuals to live meaningfully and independently" (p. 20). We would argue that people with dementia should not just be kept in mind but be actively involved as authentic partners in the planning, designing, implementation, and evaluation of services and programs designed to meet their needs (Dupuis et al, 2012).

Our recommendations:

- People with dementia need opportunities to learn about and be supported with self-management. Dr. Elaine Wiersma and her team that included people with dementia worked with the Alzheimer Society of Ontario to create a self-management program designed specifically for people with dementia. All people newly diagnosed with dementia need access to this program. Recreation and leisure professionals can play an important role by including leisure education in this process.
- People with dementia need opportunities to learn with and from peers about how to live well with dementia. Programs like the Murray Alzheimer Research and Education Program's *A Changing Melody* is now being implemented in communities across Ontario. It is a learning and sharing forum that brings people with dementia together with other people with dementia to learn tips and strategies to live with memory loss.

- People with dementia also need opportunities to support them in being strong mentors for others living with dementia. Recreation provides a forum conducive to this occurring and recreation professionals can facilitate such processes.
- In order to assist people and families in directing their own care, alternative options used with other populations need to be explored in the dementia context. We see much possibility of translating the independent facilitation model, used to support people with disabilities in directing their own lives, in the dementia context. Independent facilitation addresses social exclusion and isolation experienced by so many individuals and families experiencing dementia by:
 - ✓ viewing and treating people as valued citizens
 - ✓ assisting them in imagining and creating a desirable future
 - ✓ supporting choice and self-directed Living
 - ✓ developing and nurturing the caring networks necessary to live the desired future
 - ✓ building inclusive communities where all feel included and a sense of belonging.

Research should be conducted that explores the feasibility of independent facilitation in the context of dementia care.

- Persons with dementia, family members and professionals have different information needs. Any resource that provides information needs to be accessible and relevant to these very diverse groups and should build on important work already done in the Province. For example, the Murray Alzheimer Research and Education Program at the University of Waterloo has worked with people with dementia, family members and professionals to develop web-based resources called *Living with Dementia* and a series of *By Us For Us Guides* – new resources need to build on these important resources rather than re-inventing the wheel. Further, it is often challenging for people with dementia and their family members to find and access reliable resources. All quality resources need to be available at one place for people living with dementia to access.

3) Supporting Care Partners through Leisure

Many care partners also have difficulty around the changing relationship they have with their loved one. In these changing roles many care partners neglect their own health and care needs as they struggle to address the increasing needs of their relatives, neighbours or friends for whom they are caring. Caring for a family member or friend substantially reduces participation in recreation and leisure activities and significantly diminishes the opportunities for social

interaction. Along with the loss of valued leisure activities or the reduction of time available to participate in these activities, carers experience a loss of freedom, independence, and spontaneity in leisure upon assuming the care role. Further, the leisure experience itself often changes after an individual assumes caring responsibilities. In a study of community-based, spousal carers, Weinblatt and Navon (1995) noted:

[T]he few leisure activities that they managed to maintain failed to provide the caregivers with the feeling of joy, the escape from routine, and the sense of self-actualisation that had characterized these activities in the past. Most of them reported that even when crocheting or watching television, for instance, they constantly felt like prisoners, and that their minds were still preoccupied with caregiving-related concerns. (p. 314)

Carers have identified the difficulty of accessing free time for themselves and limitations in social life as major problems associated with the care role (Dupuis, Epp & Smale, 2004). Concomitantly, reduced opportunities for social and personal recreational and leisure activities are associated with lower self-reported and greater levels of global stress (Dupuis, Epp, & Smale, 2004). In fact, the lack of free time is significantly related to higher levels of carer stress and burnout (Dupuis, Epp, & Smale, 2004).

Despite the reduced access to personal leisure, much research supports the notion that participation in leisure activities and exercise can contribute to life satisfaction and psychological well-being, to physical well-being, and to the development and maintenance of friendships and other social support networks so important as coping resources. Within the care context, leisure may serve as a means of coping by providing relief and escape from the responsibilities of care and may serve to help carers become recharged for the role (Dupuis, Epp, & Smale, 2004). This, in turn, helps to reduce tension and stress associated with the care role and helps them handle the stresses of care more effectively (Dupuis, Epp, & Smale, 2004).

Supports for care partners to ensure they continue living meaningful and active lives should to be available in their home and in the community. It will be important to leverage existing research programs, initiatives and networks across Canada in order to develop innovative solutions that support the health and quality of life of care partners and help them in maintaining strong relationships with their relatives with dementia. Recreation and leisure professionals play a key role in assisting care partners in maintaining their leisure lifestyles and also in helping them to learn new skills and activities for supporting the leisure lifestyles of their loved ones.

Our recommendations:

- Family carers need opportunities to define what respite means for them and be supported in maintaining their leisure lifestyles. Recreation professionals should be an integral part of the community-health care teams both in supporting family carers in

maintaining meaningful activities outside of their carer roles but also in providing quality leisure and recreation programs in the home for people with dementia and education for family members about how to support the leisure lifestyles of their relatives with dementia.

- Families need opportunities to continue to participate in meaningful leisure and social activities and experiences together. One group of couples experiencing dementia in Southern Ontario did not find opportunities available in the community where they felt both the person with dementia and their care partner were welcomed and included. They developed their own social group for families experiencing dementia. Many more of these opportunities are needed in communities.
- Research is needed to explore how independent facilitators could work closely with persons living with dementia and their care partners to identify services and supports that would help them live well with dementia, make the connections to services and supports by helping to navigate the system, assist with the development of circles of care around the family to better support the person/family, and ensure that people with dementia and their care partners continue to be engaged in meaningful ways in their communities. Once a person has to transition to residential care, the independent facilitator serves to pave the way for a positive transition and helps the person and family adjust to their new lives. Transitions are the most challenging points in the dementia journey and independent facilitators can play a key role in supporting individuals and families through these transitions.
- Communities need to ensure there are consistent, high quality supports and services in all communities that care coordinators/independent facilitators can connect people to. Programs and services are not accessible in all communities and reaching people in rural communities is extremely challenging. So, much thought needs to be given to how supports are made accessible to all people with dementia and their care partners.
- The care roles that family care partners take on needs to be recognised and valued. It was interesting that providing financial compensation to family carers, especially to carers who have to leave the work force to care, was not identified as an option in the report. Many family members cannot maintain their leisure lifestyles because they lack the financial resources to afford regular respite and other support services. This has detrimental consequences on their health and well-being. Families need to be able to have self-directed care options (such as in the disability world) where they get financial support for the care work they do and, with the person with dementia, determine what supports to use and how to receive the care and supports they need.

- Social support services help maintain the well-being of care partners, including support groups, counselling services, workplace supports and recreational opportunities where both a person with dementia and their care partner can participate in activities together. Communities need to be creative and expand what can be supportive to people with dementia and their care partners (e.g., Neighbourhood associations include events for older adults to get-together, not just events for young families; repair trails and improve accessibility within parks and neighbourhoods for people of all ages to gather, walk, exercise).

4) *Creating Informed Societies*

Proper education and training is essential to ensure that persons with dementia receive quality care and services. Whether in a long-term care or retirement home, hospital or community setting, misunderstanding, misconceptions and stigma about dementia and persons living with it persist and need to be addressed. An informed society is an important step in eliminating the stigma associated with dementia, and in assuring quality of life (Dupuis, 2010). When a society is informed, the individual citizen is knowledgeable about how to improve his or her health as well as about situations that affect others in the community. An informed society requires ready access to the resources that support such a degree of awareness. An informed society in the context of dementia would be one in which all members of society have an informed understanding of Alzheimer's disease and other related dementias, an understanding based on the experiences of persons living with dementia. An informed society would also ensure that all professionals working with people with dementia have specific knowledge and training in dementia and in alternative care models including person-centred and relational care approaches. When dementia-related information is effectively distributed at the individual, school, service, and broader community levels, then the preconditions for an informed society about dementia are assured (Dupuis, 2010).

- Public service campaigns could help start the discussion and move us in the right direction. Brain health is important component in general health and healthy aging. Encouraging all Ontarians especially seniors to stay healthy is a preventative action to stave off the onset of dementia.
- Innovative approaches to addressing stigma should be explored more seriously. Collective Disruption has used theatre as a way to expose the consequences of stigma and inhumane practices and policies in dementia care. Audience members have indicated that more people who care for someone with dementia should see *Cracked*:

New Light on Dementia: "Very emotional. Everyone who cares for someone should watch this. Very impressed that the depiction is so accurate. Makes us look at our practices and review them." Initiatives like these need to be more widely supported so that they are accessible in healthcare settings, communities, and schools.

- All persons working with people with dementia should have a strong understanding of person-centered and relational caring philosophy and these care approaches should be core competencies for all healthcare professionals. Building on person-centred care, relational caring recognizes that relationships are at the core of human development, growth, and wellness. It also recognizes that quality care and quality of life cannot be achieved unless everyone in the caring context (persons with dementia, family members, staff) have their needs met. Therapeutic Recreation plays an important role in building and nurturing relationships and to enhancing holistic wellness for all in the care context.

On behalf of Activity Professionals Ontario (APO) and Therapeutic Recreation Ontario (TRO), I would like to thank you for the continued opportunity to engage with the ministry by providing written comments. Please do not hesitate to contact us in the future should you require clarification on any of our responses.

Sincerely,



Leanne Hughes
President-Elect Therapeutic Recreation Ontario

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Words to Know

Leisure:	<p>Leisure is defined by the main variables of perceived autonomy or freedom that reflects behaviours that are enjoyable</p> <p>(Stumbo&Peterson, 2009)</p>
Quality of Life:	<p>The degree to which a person enjoys the important possibilities of his or her life”</p> <p>(Quality of Life Research Unit, 2005, para. 4)</p>
Recreationist:	<p>Recreation professionals, a key component of the interdisciplinary team, provide to residents of all levels of physical and cognitive function, meaningful and stimulating programs and activities aimed at ensuring engagement in spiritual, physical, intellectual, and emotional areas. Maximising resident wellness and life of meaning, the recreation professional liaises regularly with residents and family councils, community involvement, volunteer management, and continuous assessment and quality improvement.</p> <p>(Activity Professionals of Ontario, APO)</p>
Recreation Therapist:	<p>A Recreation Therapist is a skilled professional that utilizes a process of functional intervention, education and recreation participation to enable persons with physical, cognitive, emotional and/or social limitations to acquire and/or maintain the skills, knowledge and behaviours that will allow them to enjoy their leisure optimally, function</p>

independently with the least amount of assistance and participate as fully as possible in society. Therapeutic Recreation intervention is provided by trained professionals in clinical and/or community settings.

(Therapeutic Recreation Ontario, TRO)

Well-being:

Well-being is defined as a state of successful, satisfying and productive engagement with one's life and the realization of one's full potential