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Framing meanings of leisure

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Summary

An important aspect of living well for people living with dementia is continued engagement in life. This includes being able to make decisions about your own life. It also involves having access to meaningful activities and caring relationships and being able to continue valued life patterns and routines, such as daily walks around the neighbourhood. Leisure provides an important way for people living with dementia to remain engaged in the world. Yet for people living with dementia, leisure is often seen *only* as therapy. For example, enjoying music and singing becomes music therapy. Enjoying gardening becomes horticultural therapy. This approach is based on professionals' perspectives and denies people living with dementia the opportunity to experience leisure for its own sake. Very little attention has focused on how people living with dementia think about leisure in their own lives. In this chapter, we describe a Canadian project in which we partnered with people living with dementia, family members and professionals to research and understand the meanings of leisure from the point of view of people living with dementia. People living with dementia described how leisure is an important way to celebrate *living*. For example, leisure provides opportunities to be with others, make a difference in the world, grow and develop and have fun. These findings expand our understandings of the meanings of leisure for people living with dementia. They can also help families and professionals to better support people living with dementia in living life to the fullest through leisure.

Introduction

Despite the significance of leisure to the quality of life of people living with dementia in the community and in residential care settings, individuals often lack access to, and are excluded from, opportunities to experience personally valued and meaningful engagements. When available, many approaches to leisure and recreation within the dementia context continue to dismiss the natural

value of leisure. In care settings with an emphasis on biomedical models – approaches that make disease, symptom management and physical care the focus – there are increasing institutional pressures towards the ‘clinification’ of leisure and the arts. Activities and experiences that were once part of one’s very essence become therapy (e.g. music therapy, horticultural therapy, pet therapy) used as non-pharmacological interventions with the aim of addressing misunderstood ‘behaviours’, improving functioning and reducing the ‘burden’ of care (see for example, Kolanowski et al. 2011; Seitz et al. 2012). While various activity therapies do support specific clinical outcomes, they also objectify and stigmatize people living with dementia when used inappropriately, and they deny opportunities to experience leisure for its own sake.

With the focus on using leisure for medical and functional aims, little attention has been given to how people living with dementia think about leisure in their lives, with most efforts relying on the perspectives of professionals and family. Although including family and professional care partners was an important first step in a (far too long) journey to include the voices of people living with dementia in research and practice, their exclusion continues to be problematic; research demonstrates that staff and family perspectives about what is meaningful to people living with dementia can differ in significant ways from the perspectives of people living with dementia, with staff and family members prioritizing clinical and functional outcomes (Harmer and Orrell 2008). There is a crucial need for more conceptual development on the meanings that people living with dementia themselves attach to leisure to ensure leisure practitioners are better able to support what is most meaningful to them.

To contribute to this conceptual development, the authors of this chapter initiated a large participatory action research project. It was guided by authentic partnerships, an approach that recognizes the capacities of people living with dementia and seeks to work in partnership with diverse stakeholders, including people living with dementia, to challenge stigma and promote inclusion and social justice for all people with dementia (Dupuis et al. 2012a). We brought together a team of people living with dementia, family members, professionals and researchers with the collective aims of:

- opening up possibilities for leisure in the dementia context by prioritizing a conceptualization of leisure grounded firmly in the meanings and experiences of people living with dementia
- supporting the social citizenship of people living with dementia by demonstrating the participatory roles they can play in challenging the status quo.

Our process resulted in the co-creation of the Living and Celebrating Life through Leisure Framework. A detailed description of our participatory process, which included open-ended questionnaires, individual and small group research conversations (some using the arts) with people living with dementia in diverse settings, and photovoice methods, has been published elsewhere (Dupuis et al. 2012b). Integrating our own data and findings with insights from the literature, the primary purpose of this chapter is to present the Framework

and to provide examples of how it is being used to better support the leisure lifestyles and well-being of people living with dementia and care partners alike.

The Living and Celebrating Life through Leisure Framework

People living with dementia consistently emphasize how, despite the current focus on servicing the illness, what they really want is to be able to continue to flourish despite dementia. When first diagnosed, 'life is spinning seemingly out of control', like living in the eye of the storm. However, over time 'a rich tapestry of meaningful experiences and understandings [emerge], often facilitated through leisure' (Dupuis et al. 2012b: 246).

From our research, we were able to identify seven common leisure experiences that reflect what people living with dementia need to nurture *living* (see Figure 2.1 below).

Although the leisure experiences are presented separately here, they are highly interconnected, each supporting the others. Different people living with dementia will place more or less importance on each of the experiences at any given moment in time, with some having more or less value or significance at certain times. People with dementia flourish when they have opportunities to engage in all the experiences that are most meaningful to them.

Figure 2.1 The Living and Celebrating Life through Leisure Framework



Image created by Dr Lisa Meschino and the members of the John Noble Home LEAD (Leadership, Empowerment, Achievement and Dignity) Program

Being Me

And the gentleman with the garden, starting with seeds and nurturing it to be something to be enjoyed ... and with the carpenters, there again, starting from scratch and being creative ... *bringing out your soul*. (Discussion with people living with dementia on meanings of photos connected to *Being Me*)

People living with dementia experience continual threats to their personhood and sense of identity. So it is not surprising that our partners living with dementia describe leisure as a crucial space for *Being Me*, especially when work roles are no longer available to them. *Being Me* recognizes that identity is sustained for people living with dementia and can be expressed in many embodied ways. Consistent with a social citizenship lens, *Being Me* recognizes that our sense of self is not fixed and static, but fluid, evolving over time. It acknowledges the multiple identities and social positions a person living with dementia may occupy, and that they may reveal or conceal different aspects of the self in different contexts depending on the nature of those contexts.

Being Me happens when leisure supports and reaffirms expressions of self and provides opportunities for transformation of self. Other researchers have emphasized the importance of meaningful engagements for maintenance of identity and discovering new aspects of the self (e.g. Han et al. 2016; Górska et al. 2018). In fact, engagements misaligned with valued interests can be detrimental, threatening autonomy and one's sense of self with negative mental health consequences. *Being Me* is supported by past and new activities and often includes experiences that help develop gifts, talents, skills, hobbies and interests.

There are examples of the importance of leisure for *Being Me* in the research literature. Kielsgaard et al. (2021), for instance, described how a walk in the park supported a former postal worker in reconnecting with himself and how a village, specifically designed with people with dementia in mind, supported a woman's valued identity as a shopper. Others have drawn attention to the importance of family rituals and celebrations in supporting the gendered identities and social positions of people living with dementia, and of cultural and spiritual events for nurturing cultural and spiritual identities (Phinney et al. 2013; Han et al. 2016). A dementia-inclusive golf programme supported the construction of a continuous life story for some people living with dementia, while others new to golf described it as an opportunity to create an alternative sense of self (Dupuis et al. 2019).

Arts-based activities (e.g. music, movement, dancing, visual arts) can provide an especially significant means of self-expression for people living with dementia, particularly when they are no longer communicating through words (Han et al. 2016; Wright 2018). Leisure and the arts are also used by people living with dementia to resist stigmatizing identities and to reinforce desired identities (Genoe and Dupuis 2011). While people living with dementia may have to adapt their approaches and expectations about leisure, the meaning attached is not necessarily altered with a diagnosis. For example, one of our partners with dementia describes what *Being Me* means to her:

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. I now have to play using sheet music, but every once in a while some tune will come to me, and I feel like it is 20 years ago. It still gives me the most pleasure. I LOVE MY MUSIC.

Through their leisure experiences, people living with dementia demonstrate to themselves and others that they are 'still me' and that they still have worth.

Being With

If there were a different group of women involved on my dart team, this activity would have gone by the wayside a few years ago. They have done everything possible to keep me involved, even though I don't play nearly as many games as before and I do slow things down. It is the one night out that I have desperately been hanging on to. I actually feel as if I am still part of a team. (Questionnaire response from person living with dementia in the community)

Relational theories place compassionate relationships at the core of human wellness, highlighting that human beings learn, evolve and thrive best in mutual and reciprocal relationships (Jonas-Simpson et al. 2021). People living with dementia often emphasize that they are social beings who still have relational needs and capacity for connection. Despite the importance of relationships to people living with dementia, they are at much higher risks of social isolation and loneliness (Fortune et al. 2021). In fact, a common experience for many people living with dementia is the withdrawal of friends and family who may not know how to communicate and act with them after diagnosis. Couples also report a lack of opportunities to engage in meaningful shared leisure experiences in their communities (Fortune and McKeown 2016). Yet relational efforts of friends and family play a critical role in the continued leisure engagement of people living with dementia (Fortune et al. 2021).

Leisure provides an important space for *Being With*, being with others, where people living with dementia can build and nurture reciprocal, compassionate relationships – feel a part of the world. Thus, leisure experiences that foster a sense of connection and community are highly valued by our partners living with dementia, as this contribution from a person living with dementia shows: '*Being With* means you feel like you belong. You have friends around you, and you belong to something. You're not isolated.'

Researchers have demonstrated how people living with dementia use leisure to make connections with others and how these experiences can nurture relational engagements and communities, particularly when intentionally designed to do so (e.g. Jonas-Simpson et al. 2021; Kielsgaard et al. 2021). For example, music-making spaces can support increased cooperation, interaction and conversation among diverse performers, building cohesion within the group, and

providing important opportunities for meaningful engagement *in* community (Dowlen et al. 2018; Tischler et al. 2019; Smith et al. 2022). For others, physical activities such as exercise, golf and dancing provide spaces for social interaction and connection. Wright (2018), for instance, shares the story of Megan who did not communicate with words, but through dance was able to connect in meaningful ways with others. Shared family activities are important for maintaining family relationships and family identity (Phinney et al. 2013). Social clubs such as Memory Boosters, a peer-led social leisure programme for people living with dementia and their care partners (Fortune and McKeown 2016), Leisure Connections, a social recreation group for people with early dementia (Phinney and Moody 2011), and Paul's Club, a social group for people with young-onset dementia (Phinney et al. 2016), create safe spaces for people living with dementia (and care partners) to feel accepted, meet new people, build new friendships and reclaim a place in the community. People with dementia do not just desire connections with people, but also with other meaningful living and non-living things, such as pets, plants and nature (as we discuss under *Seeking Freedom*), valued possessions and higher beings.

Technology, especially during the Covid-19 pandemic, has opened avenues for staying connected, as evidenced by this quote from a project partner living with dementia: 'I have online friends from around the world ... Staying in those virtual communities and expanding them has helped me a lot now that I have been forced to retire and move across country to be close to my son.' The intentional creation of social spaces in day programmes (e.g. community support services that provide, for example, an organized programme of activities for people living with dementia and respite for care partners) and residential care settings can support natural and spontaneous connections between residents taking part, family members and professionals, and thus enrich the social environment (Whyte and Fortune 2017).

Being With is also an important space to combat the stigma associated with dementia. Engagement in leisure activities in public spaces, such as art galleries (Camic et al. 2016), or sports grounds through football games (Carone et al. 2016), and dementia-inclusive golf programmes (Dupuis et al. 2019), has potential to create more compassionate communities through raising awareness about dementia and challenging assumptions associated with it. Similarly, Dupuis et al. (2016: 372) demonstrated the possibilities of collaborative arts for personal change and social justice:

In the community that was created, we all were opened up to the roles and power we have in supporting the citizenship of each other; we all saw new possibilities for actualizing relational citizenship and came to understand how we could do citizenship differently – be better citizens.

The possibilities for challenging the negative stereotypes and misunderstandings of dementia are even more powerful when designed and led by people living with dementia (Dupuis and Gillies 2014).

Seeking Freedom

It all comes down to being free. (Research conversation with people living with dementia)

Leisure scholar and philosopher, Charles Sylvester (1987: 58) emphasized: 'Leisure ... is the celebration of freedom at its crowning point.' This sentiment resonated in our exploration of meanings of leisure for people living with dementia. Living and celebrating life means having opportunities to have a 'break from the norm'. *Seeking Freedom* through leisure provides for this much-needed break, although people living with dementia describe diverse understandings and approaches to *Seeking Freedom*. Some people living with dementia value the spontaneity in life that leisure affords. Others view it as an opportunity to 'escape' the stresses of life and the monotony of day-to-day routines and responsibilities; this can be an important motivation for participation in social leisure programmes (Phinney and Moody 2011; Fortune and McKeown 2016). For some people living with dementia, meaningful leisure experiences provide a necessary escape from their dementia – a way to transcend the disease (Carone et al. 2016). Others describe *Seeking Freedom* as an opportunity to 'get out' of environments that are socially and physically restrictive, such as segregated and locked memory/dementia care units in residential care homes (a description we use with intention); having access to outdoor spaces is important for supporting *Seeking Freedom*. When discussing photographs they had produced reflective of *Seeking Freedom*, one of our partners living with dementia said: 'Obviously nature plays a big part for us, freedom has to do with enjoying nature, whether it be the birds, bees, and blue sky.' In fact, many of the photos shared with us pictured people living with dementia in the outdoors (see Figure 2.2).

Figure 2.2 Examples of photos reflecting Seeking Freedom



Having access to outdoor spaces was particularly important for our partners living in residential care settings who found life in these settings monotonous and restrictive. One of them describes it in this way: ‘It’s just the confined ... being inside so much. Like you go home, you’re inside, you go outside but you’re not, again it’s freedom. It comes all down to being free.’

Other researchers have noted the importance of access to and use of outdoor spaces as a means of *Seeking Freedom* to re-energize (Olsson et al. 2013) and promote well-being for people living with dementia (Han et al. 2016; Phinney et al. 2016; Górska et al. 2018). In fact, lack of access to outdoor spaces and inadequate support to ensure safe outdoor experiences are associated with loss of freedom, lower levels of self-esteem and psychological well-being and decreased quality of life (Olsson et al. 2013). Given the growing recognition of the importance of *Seeking Freedom* for people living with dementia, Dementia Adventure, a dementia-specific travel programme, was developed in England as a means of providing opportunities for people living with dementia and their families to experience outdoor spaces and a sense of adventure in life (Mapes and Hine 2011).

Seeking Freedom also means having the freedom to make choices and have those choices respected. The intentional construction of freedom in both arts and outdoor spaces can nurture emergent and spontaneous engagement, allow for freedom of movement and support the freedom of choice of people living with dementia (Phinney et al. 2016; Jonas-Simpson et al. 2021). When people living with dementia are excluded from decision-making, including about their leisure lifestyles, and denied access to valued spaces, their social citizenship and quality of life are severely threatened (Bartlett and O’Connor 2010; Birt et al. 2017).

Finding Balance

I have given up being all things to everyone. I need to pace myself and do what is good for me. (Research conversation with people living with dementia)

Living with dementia has been described as a balancing act, as people living with dementia work to navigate the losses they face with feelings of hope (Genoe and Dupuis 2014). Leisure is essential for *Finding Balance* and, for our partners with dementia, means ensuring balance between relaxation and keeping busy – too much of either is not a good thing.

For people living with dementia who like to be active, *Finding Balance* means finding ways to stay engaged – for instance, through productive or work-related activities or physical activities such as exercise, dancing, going for walks or participating in social programmes. Given the lack of access to meaningful activities, and the barriers and exclusion faced by people living with dementia, it is easy to become bored and withdraw from the world, as one partner with dementia highlights: ‘Leisure means to me that I [am] with people to stimulate me and my desire to do challenging things. I have too much time by myself, and I can sometimes become a hermit. I need to be with people, then I feel that I ... can still be a productive member of society.’ Leisure also provides

opportunities to work off accumulated energy built up over days of inactivity, providing a sense of relief and comfort (Wright 2018).

While not having enough meaningful engagements leads to boredom, our partners also emphasize that having too many activities or pressures leads to feeling overwhelmed and stressed. Thus, distractions from the busyness of life, being able to slow down and opportunities for relaxation, solitude and to feel contentment and at peace are also valued. One of our partners describes the connection between *Finding Balance* and leisure like this: '[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.' Another shares how leisure is an important way to regain balance in life when feeling overwhelmed: 'So I can go in and even lay down on the bed and ... turn the radio on and listen to music or the stereo or whatever ... it calms you down that way.' Our partners with dementia use different ways to support this aspect of *Finding Balance*, such as spiritual activities, meditation/reflection, reading, sleeping, sitting in a hot tub, listening to music or watching the television.

The stresses experienced by people living with dementia may increase as the day progresses, causing unnecessary distress, making it particularly important to attend to *Finding Balance* by providing private space and restful and solitary experiences (Han et al. 2016). Also, when people living with dementia take the time to slow down, they are able to 'stop and smell the roses' (Mitchell et al. 2006: 69), see things they haven't noticed before and appreciate the awe and wonder of life around them. When discussing the photos reflecting *Finding Balance*, one of our partners described it like this:

[It's like] developing yourself in an inner spiritual soul-like way that you didn't take time to do before when you were busy ... Like when you're busy with everyday life, you don't even see the beauty of the weeds and nature ... but when you really look at them, they're beautiful.

Growing and Developing

Learning that I could learn even with my dementia was so important. (Mitchell et al. 2006: 57)

Because of the stigma associated with dementia it is often assumed that people living with dementia are not able to grow and develop new skills. Yet people living with dementia continue to challenge these misunderstandings. In fact, despite the common push toward so-called 'failure-free activities', not only is maintaining engagement in previously valued pursuits important, people living with dementia also value having opportunities to seek out new challenges and develop new aspects of the self. Leisure provides an important space for *Growing and Developing*.

For some of our partners living with dementia, *Growing and Developing* meant continuing to challenge the mind and body. People living with dementia

seek out intellectually and physically stimulating activities – e.g. doing puzzles or exercising – because they perceive these activities as helping them to enhance cognitive and physical abilities and valued skills, improve the ability to perform daily tasks and slow down the progression of the disease (Genoe and Dupuis 2014; Han et al. 2016; Wright 2018).

People living with dementia find meaning in being able to try new activities, take on new roles and learn new knowledge and skills. As examples, our partners with dementia emphasize the importance of their new advocacy roles and supporting research initiatives as co-researchers. Some people living with dementia return to education to finish degrees or learn about new subjects. Participating in cultural and relational arts-based activities, such as through the Culture Bus in the United States and at the Dotsa Bitove Wellness Academy (now The Bitove Method) in Canada, assists all involved in expanding their knowledge about themselves, others and the world (Partners for Livable Communities 2012; Jonas-Simpson et al. 2021). People living with dementia also discover and develop new talents. For instance, one of our partners turned to poetry writing after her diagnosis. Another was enjoying learning a new musical instrument: ‘you met Chris today ... he’s teaching me to play the xylophone ... if Chris is here and has free time then we jazz it. Many people living with dementia learn computer skills so they can feel connected to family, friends and the world, and maintain valued activities in new ways (Cutler et al. 2016).

Growing and Developing through leisure is important for maintaining a sense of hope after diagnosis and promoting meaning in life. In fact, growth may be the strongest predictor of presence of meaning in life for people living with dementia (DeWitte et al. 2021). *Growing and Developing* is also essential for social citizenship as Bartlett and O’Connor (2010: 40) emphasize:

when talking about the well-being of persons with dementia, it does not make sense to restrict the focus to comfort and a sense of psychological security; it places boundaries on and narrows our understanding of the situation and practices of people with dementia. Moreover, it leaves the field without a structure or language for theorizing the ways in which people with dementia seek to develop, experiment, and grow as citizens.

Further, recognizing and providing opportunities for personal development and to learn new skills challenges the dominant tragedy discourse associated with dementia, enabling positive narratives that defy deficit-focused understandings (Birt et al. 2017).

Making a Difference

[I would like to] get out and help other people if they’d let me. (Research conversation with people living with dementia)

Leisure provides experiences that fulfil a sense of purpose. For many people living with dementia, this is strongly connected to *Making a Difference* in the

world. Our partners with dementia living in the community and in residential care homes desire opportunities to continue to contribute to their own lives, the lives of others, their communities and to the common good. Activities are more meaningful when they provide a sense of feeling valued and offer opportunities to give back. *Making a Difference* through leisure is also an important space to resist dominant assumptions of dementia.

There are many ways that leisure supports experiences of *Making a Difference*. In the following quote, a partner describes how quilting for a new grandchild gave her a new purpose: 'Quilting is always in my hand ... now is another baby coming again so when I make another quilt already for the baby crib.' Others share the pleasure they receive through their dementia advocacy work: 'I am so driven by my newfound purpose to speak up and speak out. I find so much satisfaction from my purposeful activities that I have little time for gardening.' Other researchers have described the active engagement of people living with dementia in raising awareness and campaigning for the rights of people living with dementia (Bartlett 2014). People living with dementia feel a great sense of pride when able to support others and contribute to their communities, as one of our partners explains after being able to help raise money for a new bus: '[The doll house raffle] made a difference in buying a new bus. We raised \$400, we did it all by ourselves, and then we presented it to [programme leader].'

Even though *Making a Difference* is extremely meaningful for people living with dementia, they are often not provided with opportunities to do so, perhaps because professionals frequently do not identify this as important for people living with dementia. Yet research highlights the significance *Making a Difference* can have on people living with dementia. For instance, Fortune and McKeown (2016) described how the development of a peer-led social programme addressed the social inequities and exclusion of people living with dementia and their partners in one community by creating a safe space for them to remain engaged in community. Moving from a focus on occupation to prioritizing purpose – *Making a Difference* – further supports the social citizenship of people living with dementia.

Having Fun

[During leisure] my heart is at ease and happy when my mind is calm, when my soul feels like singing. (Questionnaire response from person living with dementia in the community)

Central to meanings of leisure for people living with dementia is the experience of *Having Fun*. People with dementia desire opportunities to experience joy, pleasure, enjoyment, happiness, playfulness, mischievousness, and to demonstrate their sense of humour. One partner describes the enjoyment of being able to dance in the middle of the afternoon: 'The [day programme staff] treat you good and of course you dance, people try to anyway ... but at two o'clock in the afternoon! My doctor said heck with this, I'm going there. He says, where else can you go at two in the afternoon and dance?'

Having Fun can happen in diverse ways for people living with dementia. As in other research on experiences of dementia, our partners with dementia emphasize the importance of humour and laughter to *Having Fun* and life quality; humour is an important coping strategy for people living with dementia (Wolverson et al. 2016). One of the dominant experiences of social programmes described by people living with dementia is having fun (Phinney and Moody 2011). In Paul's Club in Canada, for example, walking with others provides an important space for fun (Phinney et al. 2016). Other group activities, such as exercise and dance programmes, collaborative music-making, theatre and relational arts provide opportunities to be humorous, playful and silly and are highly valued by some people living with dementia because of the sense of enjoyment they bring (Wright 2018; Tischler et al. 2019; Jonas-Simpson et al. 2021). Yet because of the focus on clinical and functional outcomes, *Having Fun* is rarely prioritized, as Phinney and Moody (2011: 126) point out:

Having fun as a feature of group interventions is something that is rarely mentioned in the literature ... While improving function, mood, and behaviour may be important program objectives for persons with dementia, living a good life may be a more significant goal, and having the opportunity to laugh and have fun together with other people is vital.

Putting the Framework into practice

Our partners living with dementia felt strongly that the Framework should be shared widely and be accessible to others so it could be used to support people with dementia in living well. One of the ways this was done was through the creation and sharing of a *By Us For Us Guide* focused on the Framework, facilitated by Brenda Hounam and our partners living with dementia (Murray Alzheimer Research and Education Program 2020). We also worked together to create a *Photographic Discussion Guide* using the photos shared by people living with dementia (some of which are included in this chapter) and a set of prompts to be used by professionals as an alternative to traditional assessment approaches and a way of getting to know what is most meaningful to the people living with dementia with whom they work.

In addition, as professionals working in dementia care take up the urgent calls for culture change in dementia and residential care, they are adopting the Framework to shift how they think about and approach leisure and wellness in those settings. As an example, in 2018, Carol Woods Retirement Community in the United States partnered with Jennifer Carson on an initiative called *The Quest Upstream*, with the aim of exploring and documenting the organizational requirements of inclusive living for residents living with dementia, while proactively supporting the well-being of all community members. Central to the project was the belief that the distress people living with dementia might express is not an inherent result of dementia (i.e. so-called 'behaviours') but a sign that aspects of well-being are not being addressed or met. Given its focus on the

perspectives of people living with dementia, the team grounded their conceptualization of well-being in the Living and Celebrating Life through Leisure Framework.

Guided by participatory action research, representatives of all members of the Carol Woods community (residents, family care partners and team members) met first in neighbourhood retreats and then regularly in weekly neighbourhood huddles to explore and collaboratively develop an action plan for enabling chosen well-being goals in leisure experiences and activities shaped by our Framework.¹ The process was further supported through daily shift huddles to improve communication, strengthen teamwork and develop and support individual resident well-being plans. The huddles and resident well-being plans are now part of life at Carol Woods. Members of the Carol Woods community believe that the proactive support of well-being guided by the Framework is essential to maintaining their dementia-inclusive approach to care and support.

In another example, the artists at the Dotsa Bitove Wellness Academy (now The Bitove Method), a community arts-based academy grounded in relational caring (Jonas-Simpson et al. 2021) in Canada, used the Framework to guide the focus of relational arts-based engagements with people living with dementia. Using the arts (poetry, visual arts, improvisation, dance, music), people living with dementia, care partners, staff, volunteers and the artists were supported in exploring what the Framework experiences meant for them personally. Every engagement with the Framework provided opportunities for self-discovery and relationship-building for all involved and identified new possibilities for supporting strengths and interests in future programming of activities.

So what does this mean in practice? A call to action

Sylvester (2015: 185) called for ‘a critical theory of therapeutic recreation that sustains a posture of re-imagination and change’. The perspectives of people living with dementia, reflected in the Living and Celebrating Life through Leisure Framework, support this call and highlight the need for the liberation of leisure from the therapy culture. We suggest that seeing leisure anew facilitates and nourishes diverse ways of being, being in and relating to the world by both people with dementia and those who support them.

For those supporting or enabling the involvement in leisure of people living with dementia

- Remember that a focus solely on symptom management and clinical and functional outcomes can stigmatize people living with dementia and deny them access to opportunities to have meaningful experiences and flourish.
- Using the Living and Celebrating Life through Leisure Framework ensures that the leisure experiences most meaningful to people living with dementia – *Being Me, Being With, Seeking Freedom, Finding Balance, Growing and*

Developing, Making a Difference and *Having Fun* – are identified, supported and documented.

- Living and Celebrating Life through Leisure must actively include people living with dementia in decision-making about what is most meaningful to them, recognizing that people living with dementia use a range of ways to communicate their experiences and perspectives.
- It is important to regularly revisit the Framework and re-evaluate how perspectives and personal goals might be shifting as people living with dementia continue to change and develop.

For people living with dementia or their informal or family carers

- Think about which of the Living and Celebrating Life through Leisure experiences are most important to the individual concerned – *Being Me, Being With, Seeking Freedom, Finding Balance, Growing and Developing, Making a Difference* and *Having Fun*. Share this information with others and work together to identify ways to support the experiences that are most meaningful.
- Informal or family carers should not assume that they know what is most meaningful to the person living with dementia; they should ask and listen.
- Advocate for the inclusion of people living with dementia in decision-making in research and practice.

Endnote

- 1 A 'neighbourhood retreat' is a half- to full-day meeting or get-together to which all those living on, working on or visiting a specific floor or unit are invited. In some residential care settings that have embarked on culture change, these floors or units are called 'neighbourhoods'. 'Huddles' are brief meetings held on the floors or other community areas in residential care settings.

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