A blueprint for action developed by leaders in active aging

Strategies for bringing wellness to people with cognitive decline

Created by delegates to the ICAA Forum International Council on Active Aging
Introduction

As people grow older, changes in cognitive processes are a normal part of aging. When cognitive changes become sufficiently severe to interfere with the ability to perform activities of daily living, then individuals may be beginning the journey along the stages of cognitive decline and dementia.

Professionals who work in the active-aging industry, including age-qualified communities, community/seniors centers and social services, are very familiar with cognitive changes since they have daily contact with people 50 years and older—the age group that begins to experience changes associated with normal aging. These professionals are experienced in preparing programs and services for older adults who are cognitively healthy and wish to preserve their mental abilities, through people with mild cognitive impairments, to those with moderate-to-severe dementia. They have contact with the individual, as well as with family, friends and healthcare providers.

Many of the programs and services organized by active-aging wellness professionals aid people in maintaining their cognitive health. Programs that provide opportunities within the dimensions of wellness (emotional, environmental, cognitive/intellectual, physical, professional/vocational, social, spiritual) have been shown to influence cognitive health. In addition, active-aging organizations generally refer to or provide appropriate medical care. Because many organizations already organize opportunities for living a healthy life, the question became: How do active aging and wellness support people with cognitive decline and dementias?

The International Council on Active Aging® convened two meetings of professionals with the goal of developing strategies to bring quality-of-life wellness opportunities to older adults with cognitive decline. The delegates represented leadership in age-qualified communities providing independent living, assisted living and memory care services, as well as subject matter experts in cognition, Alzheimer’s disease and community services.

Operating principle:

The quality of life of people living with dementia can be enhanced with friendly, enriching environments that positively support the individual.

Goals:

• Identify barriers to developing wellness opportunities for older adults.

• Develop strategies that can be used to create positive wellness environments for people living with dementia.

• Consider the application of strategies to people at differing places along the path of cognitive decline.

To develop the strategies, delegates to both meetings worked from an abbreviated version of the Seven Stages of Alzheimer’s (Alzheimer’s Association).

“No matter how you define wellness or well-being, it all starts with a relationship... We have to understand the person and meet them where they are so we can create opportunities for them.”
Scope of the issue

Cognition is the ability to think, make decisions, remember and understand. Changes in cognition do occur as people age, but these are “normal” changes and do not affect the ability to engage in life. Examples of changes in cognition associated with normal aging are temporarily forgetting where the keys were placed or taking longer to make decisions.

Aging is not the same for everyone. Changes in cognitive health are very individual, and the experiences of one person are not the same as the experiences of another person.

Mild cognitive impairment (MCI) describes some lapses in thinking abilities, which can be managed by the individual using tactics such as writing notes or being advised by trusted family members. If a person progresses to dementia, further declines in thinking abilities occur. At mild-to-moderate stages of decline, a person may need help remembering and may need assistance with independent activities of daily living, such as managing money or making informed decisions. During latter stages, a person cannot live independently and requires assistance with basic functions.

There are multiple types of dementia; the most common form of dementia is Alzheimer’s disease. Worldwide, an estimated 47.5 million people have dementia, a number expected to increase along with the aging of global populations. In the United States, an estimated 5.1 people 65 years and older have dementia (2015). By 2025, the number of people ages 65 and older with Alzheimer’s disease is estimated to reach 7.1 million with an associated cost of US $1.1 trillion (2015 dollars). In Canada, an estimated 747,000 people were living with dementia (2011), or 14.9% of people 65 years and older.

There is no cure for dementia. As populations age, the number of people at a stage of cognitive decline will exert escalating pressure on families, caregivers, healthcare providers and social services as well as on the individuals themselves.

Promoting cognitive health

There are actions adults can take to promote their cognitive health. While some of the risks of experiencing dementia cannot be modified (such as age, genetic factors or low education in childhood), research studies indicate that lifestyle choices can help prevent or delay cognitive decline.

The same actions that aid overall health, and particularly cardiovascular health, may improve cognitive reserve (the brain’s ability to protect itself against decline). While lifestyle choices are important at all ages, emerging evidence indicates that the following actions may reduce the risk of dementia in late life.

- Maintain healthy blood pressure; manage diagnosed hypertension
- Stop smoking
- Reduce risk of type 2 diabetes; effectively manage diabetes
- Make lifestyle choices to prevent obesity, or lose excess weight
- Be physically active
- Engage in mentally stimulating activities
- Be engaged socially
One risk factor for cognitive decline is a head injury. Among older adults, falling is the most common cause of traumatic brain injury, which can lead to changes in thinking, language, emotion and sensation. There are multiple actions that can be taken to prevent falls, such as exercise to improve lower-body strength and balance, eliminating fall hazards by removing throw rugs and avoiding icy stairs, and adjusting medications.

These actions, and their goals, are components of the dimensions of wellness.

### Wellness dimensions frame actions for cognitive health and dementia-friendly environments

<table>
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<tr>
<th>Dimension</th>
<th>Descriptions</th>
<th>Examples</th>
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<tr>
<td><strong>Emotional</strong></td>
<td>managing and directing feelings; coping with challenges and behaving in trustworthy and respectful ways</td>
<td>peer counseling, stress management, humor/laughter, personal histories</td>
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<tr>
<td><strong>Environmental</strong></td>
<td>appreciating the physical world and nature; respecting resources; utilizing eco-friendly products, services, processes and designs</td>
<td>meditation gardens, food and flower gardens, walking paths, city and community design, outdoor activities, “green” building and operations</td>
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<tr>
<td><strong>Cognitive, intellectual</strong></td>
<td>engaging in creative pursuits and intellectually stimulating activities; problem solving and reasoning</td>
<td>classes with a cognitive component, cultural activities, arts and crafts, journaling, games/puzzles, reading, lifelong learning</td>
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<tr>
<td><strong>Physical</strong></td>
<td>choosing lifestyle habits that maintain or improve health and functional ability</td>
<td>exercise, nutrition, sleep, self-care, tobacco cessation, chronic disease management, health care</td>
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<tr>
<td><strong>Professional, vocational</strong></td>
<td>maintaining or improving skills, abilities and attitudes that help self or others</td>
<td>paid work, volunteer work, mentoring, tutoring, hobbies, making arts and music, caregiving</td>
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<tr>
<td><strong>Social</strong></td>
<td>interacting with others for mutual benefit, awareness of the larger community and participation within it</td>
<td>clubs, volunteering, dancing, connections with friends and family, group and intergenerational activities, travel</td>
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<tr>
<td><strong>Spiritual</strong></td>
<td>living with a meaning/purpose in life; exploring beliefs and values that create personal peace and understanding</td>
<td>group and/or individual faith-based activities, personal meditation, reflection, mindfulness, experiencing nature</td>
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Themes to guide the future

Several themes emerged as the delegates solidified the concepts and strategies for connecting wellness to people living with dementia.

- Individuals with dementia live in a world that is different from the world inhabited by family members, staff, healthcare providers and others who influence their lives. Key to dementia-friendly wellness is engaging people in their worlds rather than trying to force them into a non-dementia reality. Enjoy being in a place that doesn’t make sense.

- Cognition is very individual. A person may be functioning in two or more levels of cognitive decline at the same time. The boundaries between definitions of decline must be porous and flexible.

- Dementia-friendly wellness approaches partner with medical treatments to improve dementia-generated feelings and behaviors.

- For lifestyle/wellness, “care” might not be the right word to use since it more reflects the medical model and historical thinking. While people with impaired thinking and decision-making skills do need care, a wellness approach looks at the individual beyond care needs and emphasizes comfort in daily life and engagement in meaningful programs.

Blueprint for action

Some of the following strategies are more pertinent to people living with moderate-to-severe dementia, while others are more relevant to people who are mildly impacted and live independently. Often, the concepts in each can be applied to multiple stages of cognition.

In keeping with the themes identified by the development groups, people living with dementia are referred to as “individuals” or “people,” but not as “patients.” The term “memory care” refers to residential living for people with dementia.

PROGRAM AND SERVICES

1. Consider the individual, family and staff in all aspects of programming and services.

- Build programs that incorporate all the dimensions of wellness (cognitive/intellectual, emotional, environmental, physical, social, spiritual, professional/vocational) for people who need assistance because of dementia as well as those who live independently and are cognitively healthy.

- Develop lifestyle plans in partnership with the person who will be affected by it. Include the adult in all aspects of planning that will affect his or her life.

- Involve individuals, family and staff in the creation of a menu of services and programs based on their needs and interests. Determine how the person, family members and staff will be involved. At what level of involvement?

- Evaluate the resources available to staff members and determine how the resources can be used for implementation.

- Negotiate risk versus opportunity by educating everyone involved. For example, it may seem risky for a person with dementia to go outdoors, but time in nature can have many benefits. Appropriate companionship and enclosed outdoor spaces can mitigate the risk.

2. When a person needs assistance, implement policies and encourage attitudes that result in ongoing communication among everyone connected to the individual.

- Establish relationships with everyone who will touch the individual: care staff, therapist, dentist, physician, dietitian, activity leaders, family members and others so everyone is aware of the current status of the individual as well as the person’s needs and interests.

- Collaborate with members of the interdisciplinary team to learn from one another and share observations.

- Schedule daily meetings with all staff so that everyone is aware of the individual’s current mood and scheduled activities.

“Everyone has needs, whether or not they are living with dementia. Programs and environment should reflect all the dimensions of wellness, while making sure that a program is individualized for each person.”
• Educate all staff members, including those who are not care staff, about the stages of cognitive decline and key behaviors so that they can share an observed behavior with the appropriate colleague, even if they do not know what caused the behavior. For example, family members or housekeepers may observe behaviors that can aid care staff.

3. Learn each individual’s interests and preferences to discover what will keep the person engaged; use ongoing assessment to plan appropriate programs.

• Establish a consistent process to determine the primary needs of each person, across all stages of decline, and regularly update programs to meet those needs.

• Move beyond a nursing assessment to record a life history of the person, for example, whether he prefers macaroni and cheese or spent his life outdoors as a farmer.

• To individualize services, use assessments such as the Senior Fitness Test, Mini-Mental State Examination and fall prevention awareness questions. Based on the assessment results, determine what type of services are needed, such as physical therapy or a cooking class. The individual’s program does not need to include a clinical piece, although it could.

4. Provide support for family members.

• Provide compassionate explanations of the progress of dementia and help build accurate expectations of cognitive changes.

• Educate family members on signs of changing needs, and where to go for assistance.

• Refer family members to peers and support groups that can aid them as their loved one progresses.

• Explain elements of risk to family members so they better understand what is safe for a person with dementia, and what changes can be made to make environments more safe.

5. Become a resource on cognitive aging and dementia.

• Educate individuals and community members about the aging process so they recognize cognitive changes and know how to respond, and where to go for assistance. Provide listings of available resources and providers who can supply additional information or expertise.

• Assist individuals in identifying their own signs of change, so they can reach out and ask for help.

• Share best practices and expand skills by collaborating with all the organizations (e.g., seniors/community centers, memory care residences, university research centers) to enlarge the availability of community resources.

6. Involve upper management in staffing levels, recruitment, training and retention efforts.

• Provide evidence of staffing ratios that result in more positive outcomes.

• Allow time for wellness activities beyond what is required by law.

• Create a dashboard of outcomes to help upper management understand the value of a multidimensional program guided by a multidisciplinary team.

“Cultural diversity is huge. We want to be respectful, we want staff to understand the needs of different cultures. It’s like throwing a melting pot of people into one room and saying, ’now get along, we all want the same thing.’ They’re not going to [unless we help them].”
7. Hire people who have the right qualifications and education to work with people at different stages of dementia as well as the desire to work with them.

- Establish a hiring strategy that supports a “hire the desire” thought process: candidates who want to work with the team, want to succeed and want to grow.

- Recruit a multidisciplinary staff that can offer a variety of approaches.

- Recruit people with excellent verbal and written communication skills as well as the physical ability to perform the work.

- Recruit people who are kind, loving, resilient, flexible and creative.

- Hire for culture fit, using interviewing techniques that uncover a candidate’s beliefs about aging (positive and negative), communication abilities, learning styles and core competencies.

- Choose team members who will work with and for residents with a lifestyle “hospitality” approach rather than a strictly clinical approach.

- Avoid hiring simply to fill a position.

8. Empower staff members for independent decision making.

- Provide the resources that make staff members capable of providing concierge-style services.

9. Establish a person-centered curriculum for dementia care that is provided on an ongoing basis.

- Include education on the aging process, cognition, brain health, behavior triggers, communication skills and redirecting behaviors.

- Include training on collaborating with other professionals as well as with residents and family members.

- Timeline training to match the time periods of performance reviews.

10. Establish a well-being plan for staff.

- Incentivize staff to participate in the employee wellness program as well as making time available to engage in program options.

- Provide an onsite day care program for staff’s children. This is a service for staff members as well as an opportunity to provide intergenerational programs and contact for the people with dementia.

11. Use an interdisciplinary approach to provide aesthetically pleasing environments for a safe and secure home that reflects meaning and purpose.

- Include wellness, activities, fitness and caregiving staff in all stages of planning remodeled or new buildings.

- Include external features such as a garden and courtyard with benches, shade and places for active engagement. Conduct programs outdoors as well as indoors.

- Internal needs include common spaces, living rooms, dining options and offices. Address sensory needs for lighting, hearing and vision. Choose colors appropriate for people with cognitive decline. Provide windows.

- Acknowledge that perceptions of the physical environment will change as people journey through stages of dementia, and accommodate their changing needs.

12. Remodeled and new construction should be planned with accessible design and universal design features.

- Plan every program and service to be easily accessed by people at varying stages of dementia. Accessible design makes areas navigable by people with disabilities, universal design accommodates people of all abilities.11

“Memory care is not only a place to live, it is a place where you can still live. It’s home, not ‘homelike.’”

“The resident is giving to staff, staff are giving to the resident, both are giving to the community, and the community is giving back to the resident and staff.”
• Create an enclosed, safe space where people can go outdoors by themselves, independently.

• Incorporate wayfinding features inside and outdoors so people with dementia can travel easily. Aim for circular routes so individuals arrive where they started and avoid dead ends.

13. Leverage technologies that help adults at multiple stage of cognitive decline.

• For daily living, use simple devices such as recorded reminder messages, dementia-friendly clocks, and pill boxes or automated medication dispensers.

• Activity trackers and motion sensors can help locate a person with dementia who wanders, or alert staff to a change in daily behaviors.

• Smart home systems, that are available for everyone, are useful for seeing the status of appliances and utilities for people who live in private homes.

14. Expand the definition of “physical environment” to include places in the larger community as well as in a residence.

• Provide transportation and companionship so people with dementia can travel to and be part of the larger community.

• Invite volunteers from the community to lead or participate in programs for people in memory care residences.

Moving from strategies to action

A positive quality of life is a goal for most people, regardless of their level of cognition. Embracing a wellness culture, along with the clinical perspectives of the medical model, can aid individuals by creating a positive, meaningful atmosphere. The professionals who touch the lives of older adults are well-positioned to understand the process of cognitive aging and prepare their organizations for the inclusion of people who are cognitively healthy and those who are traveling through the stages of cognitive decline.

Development of the blueprint for bringing wellness to people with cognitive decline

Key issues of culture, staffing and physical environment that enable wellness services and programs for people living with dementia were identified during an International Council on Active Aging (ICAA) Forum brainstorming session in November 2014. These areas were developed during the Spring 2015 ICAA Forum ideation session that brought together the expertise of industry professionals (wellness programming, administration, person-centered care and products/services).

In facilitated sessions, delegates from diverse disciplines and work environments joined to write strategies that could be applied in many types of organizations, and were pertinent to individuals who live in private homes as well as in age-qualified residences.
References

1. NYU School of Medicine. Global Deterioration Scale; Profile of a Person with Memory Impairment. Alzheimer’s Disease Center, Center for Cognitive Neurology, Silberstein Aging and Dementia Research Center. Available at http://www.med.nyu.edu/adc/resources/clinical-tools

Resources

Cognitive aging: Progress in understanding and opportunities for action
Institute of Medicine

Discovering the connections between brain health and wellness
Report from ICAA Forum at Active-Aging, 2014

Strategies that create an environment for wellness
Report from ICAA Forum, Spring 2014

Alzheimer’s and Dementia Resources for Professionals
National Institute on Aging
https://www.nia.nih.gov/alzheimers/alzheimers-and-dementia-resources-professionals#disease

Key elements for developing a wellness program for older adults
White paper, International Council on Active Aging
http://www.icaa.cc/business/whitepapers.htm

Programs and environments for people with cognitive decline
ICAA Archives Articles: categories “cognitive health” and “environmental wellness”
ICAA Archives Videos and Webinars: category “cognitive health”
ICAA member access
http://www.icaa.cc

Thank you Forum sponsors
The sponsors of the ICAA Forum, Fall 2014, and the ICAA Forum, Spring 2015, enabled us to bring together the individuals and groups to develop this blueprint.
Helping people living with dementia experience the best possible quality of life can be challenging, and the number of barriers may seem difficult to overcome. However, there are actions that can be used and models that have been effective.

**Barrier:** Negative perceptions and stereotypes of dementia express themselves in an unwillingness to be near a person with cognitive decline. Some cognitively healthy older adults do not want to join activities also available to people with dementia, or share facilities.

**Options:**
- Introduce people with dementia to others through volunteer programs, intergenerational activity and family-focused events to counteract stereotypes.
- Enable individuals to share their feelings about loss of cognitive skills to build understanding.
- Constantly educate peers about cognitive aging and ways to interact positively with people with dementia.

**Barrier:** Regulations and reporting requirements for memory care and assisted living can be burdensome, resulting in time spent fulfilling requirements rather than engaging with residents. Staff training is directed to meeting regulations; funding for additional training is often not available.

**Options:**
- Explore software technologies that reduce paperwork and make it easier to meet reporting requirements.
- Educate upper management on the value of non-medical wellness programs for improved resident outcomes and potential cost savings.

**Barrier:** Staffing is an ongoing challenge in memory care, where there can be high turnover. Insufficient staff levels allow no time for extra engagement with residents or collaboration on wellness activities.

**Options:**
- Interdisciplinary training for all staff, not only care staff, on effective engagement with people with dementia.
- Schedule group classes led by professionals who can accommodate people at different stages of cognition.
- Reorganize departments and job descriptions to expand what each staff person can do.
- Show staff they are valued through recognition and rewards, encouragement to join the wellness program, and integrating each person in planning.

**Barrier:** Lack of knowledge about what programming is appropriate for people at which stage of decline, which makes it challenging to adapt current programs and develop new programs.

**Options:**
- Plan multidimensional programs that appeal to people at all levels of cognitive ability, such as music or art programs. Investigate evidence-based programs.
- Partner with organizations that already have successful programs in place.
International Council on Active Aging has been leading, connecting and defining the active-aging industry since 2001. Active aging promotes the vision of all individuals—regardless of age, socioeconomic status or health—fully engaging in life within all seven dimensions of wellness: emotional, environmental, intellectual/cognitive, physical, professional/vocational, social and spiritual.

Founded in the belief that unifying the efforts of the organizations focused on older adults benefits both the people they reach and the organizations themselves, ICAA’s vision is shared by over 10,000 organizations. ICAA’s support of the active-aging industry includes the ICAA/ProMatura Wellness Benchmarks and Industry Research Reports, bricks-and-mortar and program development, market development, education on successful aging and whole-person wellness, networking, best practice sharing, public relations campaigns and recognition programs.