

# Living well with dementia: a framework for programs

**With the increasing prevalence of Alzheimer's disease and other dementias, wellness professionals must find ways to help people with dementia and their caregivers live 'well.' This article provides a framework for creating programs that will help**

*by Bob Laventure, MEd, and Claudine Aherne, MA*



The role of physical activity in the prevention of dementia has been previously outlined in the *Journal on Active Aging*<sup>®</sup>. In his 2005 article on strategies for keeping the brain healthy, neurologist William Rodman Shankle, MD, cited a study showing that regular exercise reduces the risk of Alzheimer's disease and other dementias by about 50%.<sup>1</sup> Our understanding is also increasing about the links between regular physical activity, the prevention of dementia and related risk factors.<sup>2,3</sup> However, less is known about the potential of physical activity and exercise to impact upon the lives of people with dementia.

Dementia takes the form of a progressive disease, involving physical and psychological decline and loss. Evidence from emerging studies indicates that physical activity can contribute towards the quality of life and wellness of people living with dementia. The question is: How can we, as wellness professionals, help people with dementia (and their caregivers) live well?

In this article (together with a follow-up article next year), we will look at how wellness professionals can begin to plan and make decisions about, and with, people with dementia and their caregivers. We will build upon previous *Journal on Active Aging* contributions and provide a framework for appropriate programs. Let's begin by turning our attention to dementia itself.

### **A brief overview of dementia**

Dementia has been defined as:

*"A word for a group of symptoms caused by disorders that affect the brain. It is not a specific disease. People with dementia may not be able to think well enough to do normal activities, such as getting dressed or eating. They may lose their ability to solve problems or control their emotions. Their per-*

*sonalities may change. They may become agitated or see things that are not there."*<sup>4</sup>

Alzheimer's Disease International estimates that there are 30 million people with dementia worldwide, with 4.6 million new cases annually. International studies make it clear that dementia occurs in every country of the world, affecting one in 20 people over age 65 and one in 5 over age 80. Further, the estimated number of people with dementia is expected to rise to over 100 million around the world by 2050.<sup>5</sup> [Ed. As we go to press, a new report from this London-based organization paints an even bleaker global picture. More than 35 million people now have dementia, and the projected prevalence by 2050 is more than 115 million people.<sup>6</sup>]

While these figures highlight the enormity of dementia as a global health concern, they can mask the personal impact of this potentially devastating condition upon individuals with dementia, and their caregivers, friends and family.

The most common dementia symptoms include loss of memory (short term, in particular), confusion, and changes in personality, mood and behavior. Alzheimer's usually presents with memory loss, especially for learning new information. Other higher cortical functions are affected as the disease progresses—for example, communication problems and language, executive function and motor performance ability. Behavioral and psychiatric disturbances are also seen.<sup>3,4</sup> In the later stages, the person affected will have difficulty carrying out activities of daily living (ADLs) and will become increasingly dependent on other people. Because dementia is progressive, symptoms will gradually get worse. Yet the speed of progression can vary between individuals.

The needs of people living with dementia may be complex, but they are likely to

### **Practical strategies for wellness programming**

In a future edition of the *Journal on Active Aging*<sup>®</sup>, Bob Laventure and Claudine Aherne will explore practical programming strategies for wellness professionals and organizations to include for people living with dementia. Laventure and Aherne will present on these practical strategies in the seminar "Work with me: wellness promotions for dementia" at the upcoming International Council on Active Aging Conference 2009 (see page 32).

include comorbidities and other chronic medical conditions. These include, among others, hypertension, diabetes, heart disease, respiratory disease, as well as possible visual or hearing impairments. Dementia also coexists with other conditions such as stroke and Parkinson's disease. People with dementia are at greater risk of falling, have higher levels of depression and anxiety, experience sleep disturbances, and are prone to wandering. Finally, loss of the ability to perform ADLs contributes towards loss of independence.

While research moves rapidly forward into the genetic and lifestyle factors that cause dementia, there is general consensus that a "magic bullet" or cure is some considerable distance away. So the issue that confronts us, as wellness professionals, is how to work effectively with the increasing numbers of people who are living with dementia.

### **Framework for living well with dementia**

In our view, there are some key components that should guide and underpin our wellness programming for people with dementia. These are:

- understanding our key values and principles

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## Alzheimer's disease in the United States

Alzheimer's disease (AD), the most common form of dementia, currently affects up to 5.3 million Americans. In fact, someone in the United States develops AD every 70 seconds. Direct and indirect costs for individuals with AD alone are estimated to be \$148 billion per year. **Source:** Alzheimer's Association. 2009 Alzheimer's Disease Facts and Figures

- maintaining the concept of "person centeredness"
- matching needs, abilities and activities to the "dementia journey"

We have developed this framework to highlight the uniqueness of the individual, with each component explained below.

### 1. Understanding our key values and principles

The development of dementia care worldwide is underpinned by the following key values and principles, adapted from Geboy (2009):<sup>7</sup>

- recognize individuality, uniqueness and person centeredness
- provide opportunities for activities with integrity, dignity, purpose and meaning
- develop appropriate teaching styles and strategies
- match individual needs, interests and abilities
- promote "social confidence"—the expectation that each person can interact positively with others
- recognize "self-worth"—providing roles, opportunities and activities that compliment a person's self-worth
- inspire "hope" that there are things to look forward to every day
- offer opportunities for every person to interact with the environment and

- others in meaningful ways—engagement is a sign of well-being
- support independence

As wellness professionals, we need to reflect on how we can incorporate these principles into our planning and programming.

### 2. Maintaining the concept of 'person centeredness'

Over the last 20 years, dementia care philosophy and practice has been driven by person centeredness or person-centered care,<sup>8</sup> which places the person with dementia at the heart of planning. Person-centered activity has been interpreted as:

*"A meaningful activity that has purpose, it is done voluntarily, it feels good to the participant, it is socially appropriate and imparts a sense of success."*<sup>8</sup>

Using the concepts of individuality and uniqueness contained within person-centered care, we can begin to identify needs related to wellness and physical activity.

The overriding challenge in working with people with dementia, however, is to recognize individual differences. We start with people who are very different individuals, then add a disease that has a very individual progression and fundamentally affects the individual's personality in ways that cannot be predicted. There is no strict protocol or guidance with dementia, unlike many chronic conditions.

### 3. Matching needs, abilities and activities to the 'dementia journey'

Key to our understanding of wellness promotion, dementia and person-centered care is our ability to identify and match the needs of individual participants with their abilities and their stage of dementia. Figure 1 on page 28 sets out a possible means by which we can match

the needs and abilities of individuals to opportunities for wellness activities through the dementia journey.

We can use this model to consider which key questions we should ask ourselves when planning our programs. Some examples include:

- What is the **purpose** of our wellness activities?

Examples of answers:

- reversing or slowing progression in early stages
- maintaining quality of life and function in later stages
- adding to "personhood," dignity and care
- What are the relative **merits** of different activities illustrated here and their contribution to the various dimensions of wellness<sup>10</sup> throughout the dementia journey?
- Can we plan activities that are known to offer optimum physiological responses and maintain functioning (e.g., aerobic, strength and balance activities)?
- Are we able to provide a **range of experiences?** For example, connecting with nature (being in the outdoors and natural environments) or water-based activities?
- Can we ensure that wellness activities are **continuous and sustained** throughout the dementia journey (e.g., walking with purpose, shopping, visiting parks and gardens)?

Next, let's look at how the concept of person-centeredness may be incorporated into the heart of our practical program planning.

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## Matching needs, abilities and activities to the dementia journey

Stage	Early dementia (Mild Cognitive Impairment)	Early to middle dementia (Mild Alzheimer's Disease)	Middle to late dementia (Moderate Alzheimer's Disease)	Late dementia (Severe Alzheimer's Disease)
<b>Characteristics</b>	First signs of the condition are appearing.	Powers of deductive reasoning are diminishing, increasingly reliant upon symbol in mental processing.	Thought is becoming progressively more concrete and impoverished. Only a most primal level of function remains.	Sometimes described as vegetative, where actions, rather than activities, are possible.
<b>Needs</b>	Reflective	Symbolic	Sensorimotor	Reflexive
<b>Wellness experiences</b>	STRUCTURED, FORMAL, TASK-FOCUSED (can be individual or in a mixed group—including people not living with dementia)		LESS STRUCTURE, MORE FLEXIBILITY (less task-centered, fewer rules to learn and remember, more assistance/support required)	
	Structured with specific outcomes (e.g., strength & balance)		Falls prevention & functional ADL training	Movement & circulation
	Dance, playing music, singing (groups)		Music & movement (release), making sounds & rhythms	Singing, listening
	Shopping, cooking, housework		Light housework, tidying, sorting, washing up, preparing cold food	Enjoyment of food & drink—taste & smell
	Individual & group walks, to the shops, parks & gardens		Accompanied & assisted walks, dog walks	Safe environment (indoors & outdoors)
	Games & sports		Modified & adapted versions of activities with assistance	Engaging the self through playful moments
	Outdoor adventure, climbing, rambling, gardening		Assisted walking, gardening, watering & picking flowers	Looking at birds/flowers, bring outside in (pots & fresh flowers)
	Aqua-cise, swimming, canoeing, sailing, spa experiences		Engaging the senses—bathing, spas, paddling & wading	

After Perrin, T., & May, H. (2002). *Well-being in Dementia*. London UK: Harcourt.(9)

Figure 1. Matching needs, abilities and activities to the dementia journey

### Person centeredness— a planning framework

Three sets of issues should be considered by wellness organizations and professionals (including exercise instructors and caregivers) wishing to ensure person centeredness in programming. These issues include:

- planning for person centeredness
- planning for wellness and organization managers
- planning for wellness professionals

Figure 2 on page 30 shows the elements of this planning framework, which are described more fully below.

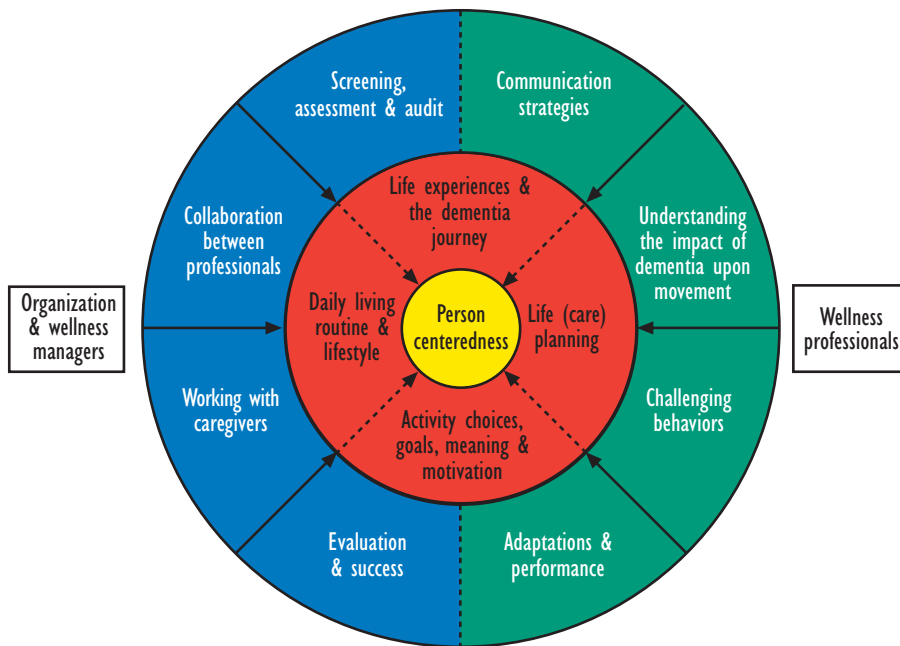
### Planning for person centeredness

A person-centered wellness program must take into account an individual's personal history, likes and dislikes when planning activities. For us as wellness professionals, understanding this information is no different than working with

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**Figure 2.** Person centeredness: a planning framework

other older individuals; however, the information may be harder to clarify and of much greater importance.

When using the framework and planning wellness programs for people living with dementia, it is important to take their enjoyment and feelings of comfort and security into account. These things will relate in particular to the activities themselves, the timing and location, and the individuals with whom these are performed (e.g., staff, caregivers and other participants).

Some other things to consider include:

*Life experiences and the dementia journey.*

People living with dementia all have a unique set of life skills and experiences, including physical activity experiences. For each person, the dementia journey will be different and needs will change along the way. In addition, each individual will experience a different rate of change.

*Daily living routine and lifestyle.* Most people with dementia live at home,

supported by their families and local services. It will help to consider to what extent their needs, daily living routine and lifestyle differ from those living in retirement communities or care settings.

*Activity choices, goals, meaning and motivation.*

Goal-setting is an important motivational tool with people who have dementia, as it is with participants in other wellness programming. Goals need to relate to individual needs (see Figure 2 above), offer purpose and meaning to the individual, and set the boundaries and framework for program evaluation. Activity choices are the means by which these goals can be achieved.

*A living (instead of a care) plan.*

Consistent with the concept of living well with dementia is the “living plan.” People with dementia will usually have some form of care plan, where individual needs have been identified. A living plan, however, offers a less passive and more optimistic view of living with dementia, and should include steps to achieve living well.

**Planning for wellness and organization managers**

Wellness and organization managers are uniquely positioned to ensure that wellness programs for people with dementia become a reality. Policies, procedures, and recruitment/retention of staff with appropriate experience and skills all contribute towards successful implementation. The following are also part of that process.

*Screening, assessment and audit.* Screening and assessment of individuals for conditions and contraindications should be commonplace. Such assessment should also include caregivers and an audit of organizational skills, capacities and facilities, as well as comprehensive risk assessments. But we need to consider how we can manage risk assessment and the tension between ensuring the safety of individuals and letting them make their own decisions about how they want to live their lives.

*Collaboration between professionals.*

Planning and programming across an organization will require the contributions of a range of wellness professionals, including physicians, caregivers, facility managers, nursing staff and exercise instructors. Collaboration will ensure that person-centered planning applies to all potential participants, and appropriate policies, systems and procedures are in place and fully understood.

*Working with caregivers.* Caregiver engagement (especially family and friends) is vital. Opportunities exist to explain the benefits of wellness programs for both individuals with dementia and their caregivers, as well as to ensure that caregivers can play an active role in all aspects of living well.

*Evaluation and success.* A wide range of measures and outcomes can be recorded to demonstrate the effectiveness of a wellness program. However, these will

depend on the resources available. As wellness professionals, we may have to think beyond formal and structured fitness or functional assessments and make program evaluation more personal and relevant to the individual. Evaluation should also include feedback from caregivers and family members, as well as the impact on the caregiver (e.g., quality of life and well-being). Fundamental to program evaluation is the setting of realistic and appropriate goals for participants and being clear about a program's purpose in partnership with participants.

### Planning for wellness professionals

For those of us who work directly to design and implement programs for people with dementia, the key factors below stand out as critical to success.

*Understanding the impact of dementia upon movement.* Changes in cognition and memory will affect movement capacity in several ways. These include the memorizing and understanding of tasks, concentration span, awareness of the body and spatial orientation, and a changing relationship between individual and environment. These impacts will vary according to the individual.

*Communication strategies.* The *Journal on Active Aging*<sup>1</sup> has previously highlighted the importance of developing appropriate communication skills when working with individuals with dementia. These skills include, for example, the phrasing of verbal instructions, use of manual guidance, demonstration and cueing of activities, and successful presentation of an activity. When working with those with demen-

tia, we will need to develop our kit of communication strategies.

*Challenging behaviors.* In addition to memory loss, language difficulties and confusion, people with dementia may exhibit a number of challenging behavioral symptoms, including wandering, pacing, aggression, agitation, anger, depression, hallucinations and delusions. It is important to understand the possible reasons behind such behaviors (e.g., unexpressed or unmet needs) and develop strategies to resolve potentially distressing or difficult situations.

*Adaptations and performance.* For people with dementia to participate successfully and enjoyably in wellness activities, we may need to adapt activities and tasks to meet their individual needs. Adaptations

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## Resources for wellness professionals

### INTERNET

#### Alzheimer's Association

www.alz.org

#### Alzheimer's Disease International

www.alz.co.uk

#### Alzheimer Society of Canada

www.alzheimer.ca

#### Alzheimer's Society UK

www.alzheimers.org.uk

#### National Institute on Aging: Alzheimer's Disease Education and Referral Center (ADEAR)

www.nia.nih.gov/alzheimers

### PRINT

#### Books

#### *Dementia*

Hurtley, R., & Wenborn, J. (2005). *The Successful Activity Co-ordinator*. Age Concern Books

Perrin, T., & May, H. (2000). *Well-being in Dementia*. London: Churchill Livingstone

Oddy, R. (2003). *Promoting Mobility for People with Dementia—A Problem Solving Approach*. Age Concern Books

Larsen, B. (2005). *Movement with Meaning: A Multi-sensory Program for Individuals with Early-stage Alzheimer's Disease*. Health Professions Press

Zgola, J. M. (1999). *Care That Works: A Relationship Approach to Persons with Dementia*. John Hopkins University Press

#### *Cognitive function and prevention*

Chodzko-Zajko, W., et al. (2008). *Enhancing Cognitive Functioning and Brain Plasticity*. Champaign IL: Human Kinetics

Poon, L. W., et al. (2006). *Active Living, Cognitive Functioning and Aging*. Champaign IL: Human Kinetics

Spiriduso, W. (2005). *Health, Exercise and Cognitive Function in Physical Dimensions of Aging*. Chapter 6. Champaign IL: Human Kinetics

Spiriduso, W., et al. (2008). *Exercise and Its Mediating Effects on Cognition*. Champaign IL: Human Kinetics

Shankle, W., & Amen, D. (2005). *Preventing Alzheimer's*. Penguin Books

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may also be required to ensure that activities are performed safely and effectively. Successful performance and achievement will also act as motivators.

## Challenges for wellness

As wellness professionals, we may encounter challenges as we move forward in developing wellness promotion for people living with dementia. Outlined below are some possible issues.

*Entitlement.* We have sufficient evidence that wellness should be an entitlement throughout the dementia journey, including for caregivers. The challenge is: How can we ensure that wellness and activity opportunities are continued, adapted and sustained throughout the journey?

*Individuality and tailoring.* As wellness professionals, we have a tradition of class

and group activities. Person-centered care may encourage us to look again at the structures and format for wellness provision.

*Experiences of the wellness professional.* People at different stages of the dementia journey may require professionals with different skills and experiences. Be aware of where your skills (or those of your staff) begin and end, to ensure the most appropriate activities and professionals are involved at every stage.

*Support of others.* Wellness programming will also challenge the values and beliefs of caregivers—whether family, volunteer or professional. Successful programs include caregiver wellness as well.

*Expectations.* Although there is no cure on the immediate horizon, people with dementia still have a life to live. We can

play our part in raising expectations of what people with dementia can experience and achieve. The challenge for us is to assist them in living well with dementia.

## Putting wellness into practice

In promoting wellness we challenge ourselves to offer an optimistic view of aging, health and life to the older population. Dementia is a disease that perhaps offers us one of the greatest challenges—and one that will last for some considerable time. We have increasingly supportive evidence from research that people living with dementia can benefit significantly from wellness programs. The question is, Can we make this a reality and put this into practice? ☺

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*Claudine Aberne, MA, is the founder and managing director of Vida Wellness Ltd. (www.vidawellness.co.uk), which runs active-aging programs in the UK. Aberne is an exercise specialist with many years experience working with older adults. Her background includes roles in consumer marketing and local government. Vida Wellness offers an innovative range of well-being and exercise programs, including functional training, fall prevention and brain fitness courses.*

## Mark your calendar



Bob Laventure



Claudine Aberne

Interested in delving deeper into a framework and practical strategies for working with individuals with dementia? Join Bob Laventure and Claudine Aberne at the Seventh Annual International Council on Active Aging Conference in Orlando, Florida, where they will present the following educational sessions:

**Friday, December 4, 2009**  
8:30 a.m.–10:00 a.m.

Work with me: wellness promotions for dementia

**Saturday, December 5, 2009**  
8:30 a.m.–10:00 a.m.

Motivate me: engaging and motivating older adults towards physical activity

For details, visit the “Conference” section at [www.icaa.cc](http://www.icaa.cc), or call ICAA toll-free at 866-335-9777.

The authors welcome the views of wellness professionals on this contribution and invite others to share their experiences of promoting wellness with people living with dementia. Emails can be sent to [bob.laventure@ntlworld.com](mailto:bob.laventure@ntlworld.com).

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