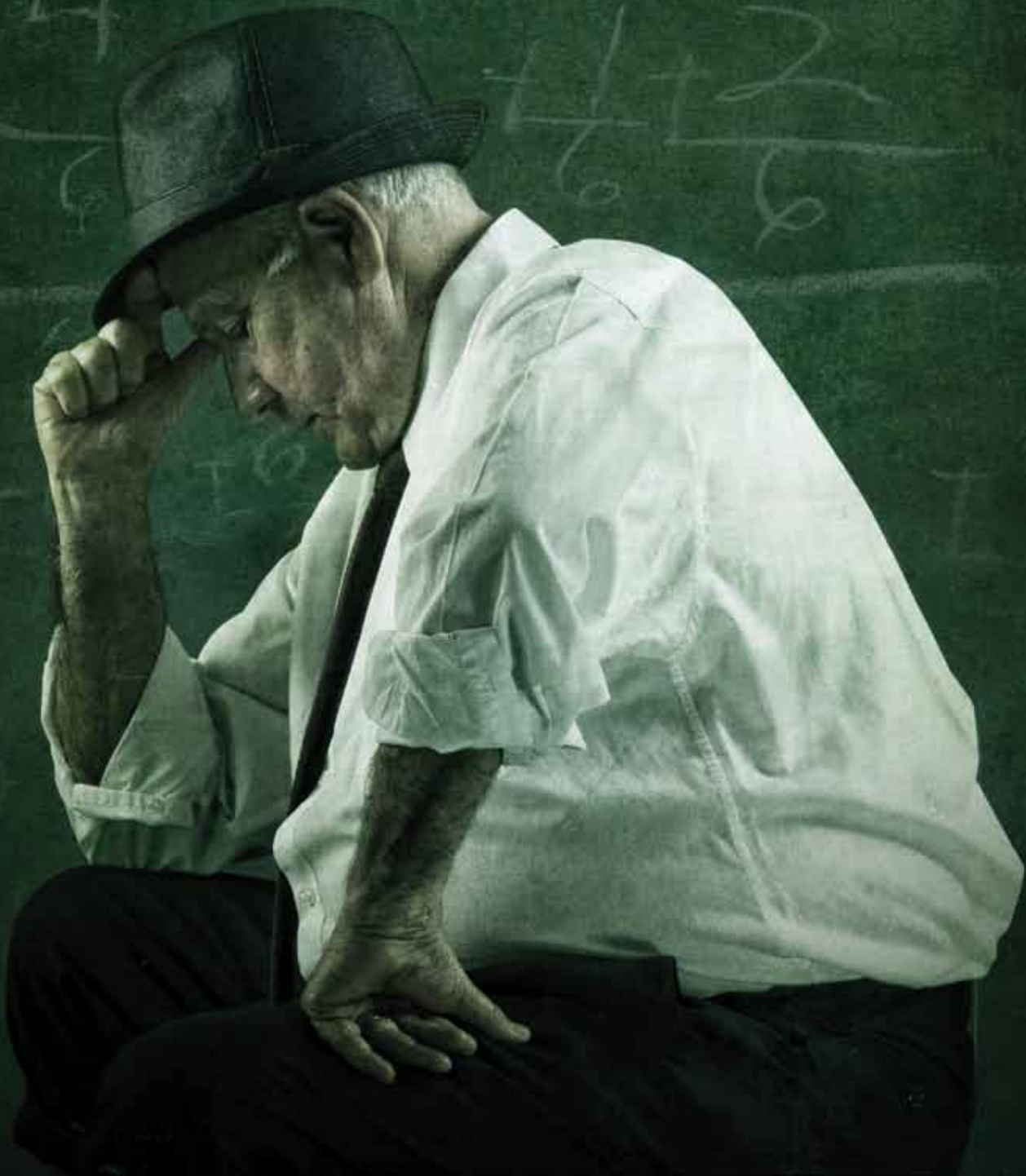


Living well with dementia: guidance for exercise instructors & wellness leaders



Read on to learn about key factors for wellness and exercise instructors in program planning and working with individuals with dementia

by Bob Laventure, MEd, and Claudine Aherne, MA

This article completes the authors' "Living well with dementia" series in the *Journal on Active Aging*[®]. In the September/October 2009 issue, the first "Living well" article proposed a framework for programs. The second article, published in the March/April 2010 issue, explored how wellness managers and instructors could translate principles of planning into practice. This final article examines the implications of the person-centered model for wellness professionals. Members of the International Council on Active Aging[®] (ICAA) can access these articles in the online "Articles archives" (Wellness), located in the members only section at www.icaa.cc.

Living well with dementia will challenge increasing numbers of people in the years to come, as the prevalence of Alzheimer's disease and other dementias continues to rise¹ (see the box on page 66). Wellness and exercise instructors and physical activity leaders have the opportunity to play a particularly valuable supporting role. Understandably, however, many find it difficult to know where to start or how to approach this area of practice.

To help, our "Living well with dementia" series introduces a framework for planning wellness activities for this population. This framework includes a set of key values and principles that underpin dementia care, and are equally relevant for wellness professionals working in this area. We also focus on the concept of "person-centeredness," an approach that places the person with dementia at the heart of any activity or wellness planning. The element of individuality—which is integral to this model—is particularly relevant for these clients. Dementia takes

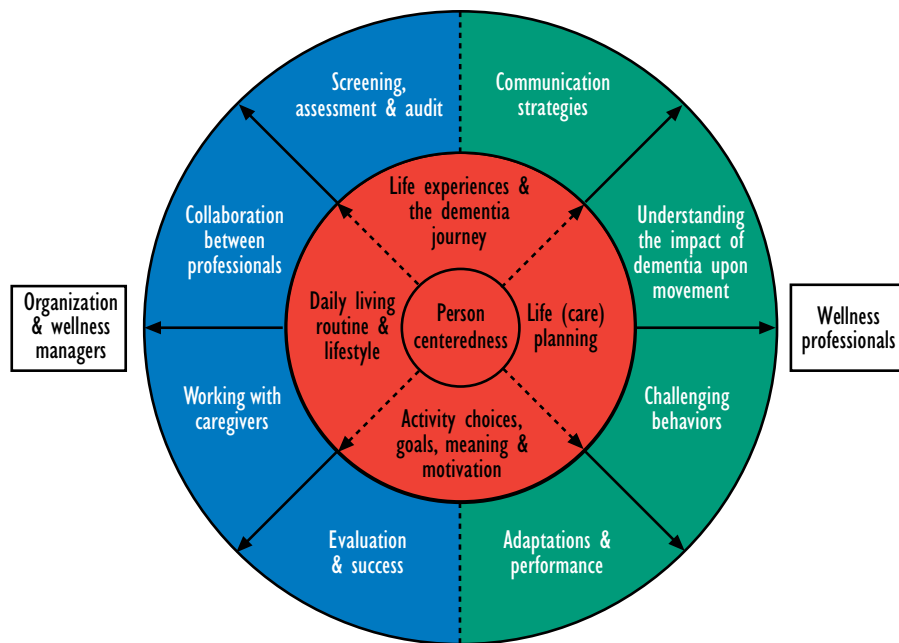


Figure 1. Person-centeredness: a planning framework

the form of a disease with a particularly individual progression, and all those who live with dementia will experience their own, unique "dementia journey."

In our framework, we identify topics to consider when planning a person-centered wellness program (see "Figure 1. Person-centeredness: a planning framework" above). Taking a person-centered approach ensures we will more successfully match needs, abilities and activities to the dementia journey. The framework also identifies some implications of this model for people who plan and deliver wellness programs for those with dementia, distinguishing between organization/wellness managers and wellness professionals (the latter operate in a more front-line, delivery capacity).

Our second "Living well" article, published earlier this year, explored the implications for managers. These include the need for screening, assessment and audit, and emphasize collaboration between professionals and working with caregivers. We also considered how to evaluate the success of programs.

In this article—the third, and final, installment in our series—we examine the implications of the person-centered model for wellness professionals. This group

includes any exercise instructors, physical activity leaders, activity coordinators or other professionals who want to enable clients to experience the many benefits of physical activity and exercise. We'll start with the question, "Is there a perfect or model exercise program for people living with dementia?"

Determining the ideal program

Growing evidence supports the benefits of exercise in dementia prevention, care and treatment,² and shows that a range of physical activities can be employed for people living with dementia. The person-centered model of wellness permits individuals to choose activities with which they are comfortable and successful, and which lead to achievement. In determining a model or ideal program, our starting point is no different to working with other older participants: We match individual needs to key components of fitness and exercise identified by the American College of Sports Medicine³ and others⁴ for this specific group. Thus, program design for people with dementia should focus on improvements in cardiovascular health, strength, balance, flexibility and coordination, which can help clients maintain their independence, activities of daily living, mobility and well-being.

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Additional evidence from studies of this population^{5,2} tells us that aerobic activities (e.g., walking, dancing, swimming) are known to enhance brain functioning and improve mood, as are strength-training programs. Other studies⁶ indicate that strength, balance and walking are the keys to independent living.

As dementia progresses in individuals, fine and gross motor skills may deteriorate, and additional declines may take place in strength, power, balance

and coordination. The result is a loss of many functional activities. Programming should therefore focus on maintaining the highest possible level of independence and activities of daily living.

Programs that contain aerobic activity, strength, balance and walking are the basis of a model program for those living with dementia. The challenge for wellness instructors and physical activity leaders is to ensure that such individuals can access a program with these components.

Person-centered challenges for wellness instructors

No journal article will provide a single, complete guide to exercise for people living with dementia. But there are critical key factors to program planning and the work of wellness instructors that our framework identifies. They are:

- understanding the impact of dementia upon movement;
- communication strategies;
- challenging behaviors; and
- adaptations and performance.

Although these four factors will serve as a guide to instructors and leaders, learning really starts with knowledge of the individual participant and gleaning from the skills of caregivers (including family members) who work with this population. The sections below explain these key factors for readers.

I. Understanding the impact of dementia upon movement

Individual differences and changes in cognition and memory will affect movement and physical activity performance in many ways.

Memorizing tasks. With the loss of short-term memory, there is no guarantee that an individual will remember tasks and actions from week to week or during a single session—even when repeated rhythmically. Each time a participant performs an action may feel like the first time. Bringing up childhood activities, thereby accessing long-term memory, may provide better recall.

Concentration span. An individual with dementia may have a variable concentration span. A change of action or task may refocus attention if the participant becomes distracted or engages in overly repetitive activity.

Understanding of tasks. Compared to a request to go through a warm-up, a simple instruction and demonstration of “Let’s

march” will provide a client with a more meaningful (and visual) image of the task required.

Changes in awareness of the body and spatial orientation. These changes may limit a person’s ability to perform whole-body movements and move the body into certain positions.

Dementia also affects people’s abilities to remember how to do something—walking and swimming, for example.

2. Communication strategies

Marge Coalman, EdD, summarizes a range of communication strategies for wellness and exercise instructors working with clients with dementia—“the invisible population”—in an article published previously in the *Journal on Active Aging*.⁷ [Ed. Coalman’s article is posted in the members only “Articles archives” (Mental health) at www.icaa.cc.] In the early stages of practice, however, there may be no substitute for working with an experienced dementia professional to observe and understand the unique interaction between professional and participant, as well as appropriate communication styles and strategies.

It is important to consider the distinction between communication and conversation in people with dementia. Most descriptions of communication refer to:

- remembering words or meanings of words;
- understanding abstract concepts;
- finishing sentences or expressing ideas;
- mixing up words or producing the right sounds;
- confusing past and present; and
- talking to someone who is known, rather than a stranger.

Given that over 80% of communication among healthy people is nonverbal, wellness instructors should explore many more avenues of communication with clients living with dementia. Examples

include body language, poses and stances adopted, speed of body or limb movement, facial expressions, eye-to-eye contact, and touch as a means of communicating/indicating desired actions and activities.

3. Challenging behaviors

As individuals each make their dementia journey, they may exhibit unique and challenging behavioral symptoms. These might include pacing, wandering, aggression, anger and depression, and in some cases, hallucinations and delusions.⁸ Wellness instructors need to understand the reasons behind such behaviors (e.g., unmet needs, pain, anxiety), plus become proficient in resolving potentially difficult situations that may become distressing to the individual, other participants or the instructor. A participant’s care/living plan will indicate patterns of challenging behaviors. Some behaviors may arise, however, as a result of physical activity participation—for example, increased agitation due to overstimulation or a desire to be somewhere else, or anxiety brought about by a new face, unfamiliar activity or environment. Professional caregivers employ a range of strategies in such situations. Key to these strategies is avoidance of a confrontation and an escalation of anxiety, which would cause further distress.

The use of appropriate communication skills helps with building a trusting relationship between instructor and participant. Some behaviors may simply reveal a participant’s feelings at a particular moment or indicate longer-term anxiety and/or depression, which is common in people living with dementia. People’s likes, dislikes and interest levels may change, and what worked well last week may not be so successful today. There is also a danger that by highlighting and anticipating challenging behaviors, we may stereotype people living with dementia as

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Resources

Additional learning

For wellness professionals who want to learn more about working with people with dementia, training providers have now moved towards a range of online and distance learning packages. Examples include:

- **Inside the Brain: An Interactive Tour**
www.alz.org/alzheimers_disease_4719.asp
- **California Distance Learning Project**
www.cdplonline.org
- **Social Care TV Dementia Care Training**
www.scie.org.uk/socialcaretv/default.asp

Key resource article

The Seattle Protocols

Based on social learning and gerontology theories, The Seattle Protocols are grounded in an understanding of the neuropsychological and behavioral changes that occur in people living with dementia. They have been used to develop a standardized approach to care that focuses on:

1. identifying, initiating and maintaining participation in enjoyable physical activity;
2. teaching behavioral strategies and problem-solving skills for overcoming such obstacles to such activities;
3. engaging interpersonal support to maintain exercise programs; and
4. encouraging walking and other easy-to-achieve accessible and available physical activities in the community.

Publication source: Teri, L., Logsdon, R. G., & McCurry, S. M. (2008). Exercise interventions for Dementia and Cognitive Impairment: The Seattle Protocols. *Journal of Nutrition, Health and Aging*, 12(6), 391–394

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being difficult. Person-centered planning tells us that knowledge of the individual is the starting point for both communication skills and understanding different behaviors, but there are few specific rules.

4. Adaptations and performance

As suggested previously, the development of aerobic, strength and balance activities is integral to programming for people living with dementia. To ensure these clients have access to physical activity and exercise programming, exercise instructors will need to enhance their ability to adapt activities to the individual level of ability and interest.

Large whole-body movements with simple movement patterns and lots of repetition will greatly assist with achieving aerobic activity. The person-centered choice, however, indicates that this kind of activity can be achieved through the use of exercise machines (e.g., cross trainer, rower, treadmill), regular walking (indoors or outdoors), dancing and swimming.

Similarly, strength and balance training can be achieved in numerous ways. Examples include a regular (two to three times per week) strength and balance program in a gym; use of resistance bands; regular engagement in strength and balance activities (e.g., climbing stairs, gardening) or functional activities (e.g., Sit to Stand, directional stepping); or activities such as tai chi, qigong or dance.

Themed activity sessions may more easily motivate individuals. These themed sessions may involve mime or copying (playing musical instruments or conducting an orchestra, for example), completing a home and housework routine, or recalling an activity from previous times.

Additional dimensions to programming

In addition to the key factors described above, wellness instructors can further

develop their skills and programs by examining, and including, other areas of program development. The following elements—which “sit outside” the individual with dementia—are part of strategies to enhance an activity friendly and supportive environment, designed to ensure appropriate and purposeful participation.

Home-based and independent activity

Wellness instructors are committed to running safe, enjoyable programs for participants, and to ensuring participants (when able) take part independently in their own time and in their own home,^{6,9} thus increasing both activity frequency and potential for greater returns. In many cases, people living with dementia may require support strategies to achieve home-based and independent activity. A couple of examples include a home activity buddy/partner and laminated exercise or cue cards.⁹ For individuals with more significant cognitive impairment, training can include a family member, friend or professional who can assist them with regular and additional participation.

The role of the family caregiver

For wellness instructors, another important consideration is the role of the family caregiver, as well as the caregiver's physical activity and health needs. Family caregivers have a critical part to play in increasing client motivation and participation by offering prompts and reminders, more active support such as buddying and, where appropriate, sharing participation. Their knowledge of, and motivation towards, regular physical activity will be influential. This influence can be potentially negative as well as positive, however—and rather than sharing participation by accompanying someone to class, a caregiver may see it as an opportunity to do something different, recharge batteries and rest. Caregivers can also help if they understand the programming needs of the person with dementia and know the specifics of any program devised for the individual.

Worldwide costs of dementia set to soar

The total estimated worldwide costs of dementia in 2010 are \$604 billion (US), according to the World Alzheimer Report 2010: The Global Economic Impact of Dementia,¹ released in September by Alzheimer's Disease International (ADI). Based on the predicted rise in the number of people with dementia, worldwide societal costs will increase 85% by 2030, the report states—a very conservative estimate considering only increases in the number of people with dementia. Last year's report estimated that 35.6 million people worldwide are currently living with dementia, with that number projected to rise to 65.7 million by 2030.

It is well known that family caregivers can experience significant distress, anxiety and depression as a result of their commitment to caregiving. In many cases, the caregiver's own health may deteriorate. Consequently, wellness instructors should seek ways to work with caregivers to look at how they, too, can participate in physical activity, with or without the person for whom they care.

Program scheduling

One indicator of the importance of physical activity programming may be the extent to which the schedule is fixed in the minds of all concerned and seen as a nonmovable activity, integral to the life of an organization or individuals. This would entail the following:

- Preparation of the physical activity area is routinely completed.

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- Participants are prepared (e.g., clothed appropriately).
- Equipment is readily available.
- Other staff and/or buddies are actively engaged to support activities.
- Time is built into programming for evaluation and sharing successes/achievements, as well as additional social and group activities.

The physical activity environment

As our knowledge of dementia care increases, so too does our understanding of the importance of an appropriate environment for physical activity participation. In addition to a safe environment, it is essential to provide a calm, quiet space that limits distractions—other people, noise, and interruptions, for example. A space should also have good and, where possible, natural lighting that eliminates shadows and glare and helps compensate for poor vision.

Motivation

Most motivation is achieved through success and achievement. This motivation is enhanced when participants have opportunities to recognize and, where appropriate, record and celebrate positive, pleasant feelings and experiences, no matter how fleeting or short lived. A participant's mood, however, may change in an instant, from day to day or week to week. Apathy and a loss of interest (in life in general) may also contribute to low expectations and motivation. Wellness instructors can improve client motivation by ensuring that activities provide a sense of purpose (relevance to the here and now, interaction and social contact with others) and meaning (related to life history and identity) for participants. Significant others—such as caregivers, peers and family—also have a role to play in creating supportive environments.

Wellness instructors should not forget the value of opportunities for fun, enjoyment, self-expression and play, which are predominantly in the “here and now”

and the “moment of being.” These opportunities offer time out, relaxation and a diversion from other concerns.

Making a start

Working with people living with dementia is one of the greatest challenges for wellness and exercise instructors. Although research and evidence are always valuable, it is the individual experiences and knowledge of people who work with those with dementia that often provide the best insights and learning for others. In this vein, while instructors will find further reading and training courses of great value (see “Resources” on page 65), there is no substitute for making a start, learning on the job with experienced professionals and “just doing it.”

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