I once met a woman with Alzheimer’s disease (AD) who remarked, “I am not dying from this disease, I am living with it. I still have a whole lot of living to do. I need the help of others to make my life as meaningful as possible.” Her remark echoed a statement by Robert Davis in his personal account of living with AD: “I want to participate in life to my utmost limit.”1(p100) Such statements have become familiar in recent years as people with AD have emerged from the shadows and are speaking out about their wants and needs. They are interested in adding life to their remaining years, not years to life. However, people with AD face a dilemma: how to preserve their independence yet accept the help of others to live as fully as possible. Enabling them to achieve this delicate balance is no easy task for family members, friends, and professionals who provide care. How do we know that our caregiving efforts are effective? How do we measure success in terms that are truly meaningful for someone with AD? What does it mean to live a good quality of life with this disease?

This issue of *Alzheimer’s Care Today* is focused on quality of life (QOL). This topic is not as abstract as it may appear at first glance. QOL is a matter of vital importance to people with AD, their families, and the professionals who provide care. How do we know that our caregiving efforts are effective? How do we measure success in terms that are truly meaningful for someone with AD? What does it mean to live a good quality of life with this disease?

Assessing QOL in AD is challenging for several reasons. First, individuals with the disease eventually lose the ability to comprehend questions or communicate their own subjective states. Persons in the early to middle stages can typically respond to structured interviews. For individuals in the late and final stages of the disease, it is often necessary to have others report in their behalf or make behavioral observations, which introduces the risk of bias. In fact, studies consistently show that QOL is self-rated higher by persons with AD than proxy reports by their caregivers.4–8 Substituted judgments often fail to capture the subjective experience of persons with the disease. Although impaired insight may account for such differences in perspectives, the subjective experience of QOL may well trump how others perceive their experience.

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from home to assisted living, and finally, to a nursing home. Different living situations offer different environments, with different opportunities for physical, social, psychological, and spiritual well-being. Private and public funds support these living arrangements. Payors want accountability for maintaining standards of care. Untold sums of money are spent annually on compliance with federal and state regulations. How do standards of care and regulations affect QOL of those being cared for?

QOL must be assessed from multiple perspectives—the person with AD, family members, professional care providers, and society as a whole. Over the past decade, numerous researchers have focused on ways to measure QOL in AD from these different perspectives. A consensus has arisen that QOL must include an assessment by the person with AD whenever possible and a key informant such as a family member. Which questions are most pertinent and how to best collect such information is still subject to debate. This issue of *Alzheimer’s Care Today* highlights many standardized tools that have been developed to assess both objective and subjective factors in QOL.

Reasons for measuring QOL in people with AD are now quite clear. First, drug treatments for AD have become increasingly available. Do these drugs impact QOL? Do services and psychosocial interventions “work” from the perspective of “consumers”? Assessing QOL can help identify ways of improving treatments and services that are not assessed by tests of memory and other cognitive skills (eg, MMSE, ADAS-COG). Assessing QOL requires scrutiny of our motivations and the means for delivering care. Why do we do what we do in behalf of people with AD? How are our care practices experienced by them? According to Albert and Logsdon, QOL in AD “is achieved through the care received, the accomplishment of desired goals, and the ability to exercise a satisfactory degree of control over one’s life.”

If we keep our eyes closely fixed on the person with AD, then QOL will become a central focus of caregiving.

In this issue, Richard Taylor leads off with his perspective on living with AD. He remains a prolific writer in spite of his AD, and he again challenges individuals and organizations that do not take seriously his need for living life with quality. In his article, he emphasizes the need to always put the individual ahead of the disease and highlight personal strengths instead of symptoms. Writing from the perspective of a family caregiver, Ann Davidson tells her family’s story and describes how she and her husband with AD struggled to enjoy life, yet managed to make lemonade out of lemons. Her insights and experiences provide a roadmap to others on this journey. In the *Partners in Care* column, Phyllis Dyck shares the key ingredients of a good quality of life as described by members of her early stage support group.

In the *Best Practices* column, Julie Lambert, Perry Edelman, and Brad Fulton describe how collecting QOL information in a dementia-specific adult day center has led to programmatic changes and increased awareness by staff into the personal experience of AD. Rebecca Logsdon, Susan McCurry, and Linda Teri from the University of Washington offer an excellent review of evidence-based interventions to improve QOL for individuals with dementia living in the community. Care practices that have proven success in terms of measurable outcomes must become as widely available as any antidementia drug.

Simon Duff and Daniel Nightingale of the United Kingdom describe their exploratory study of a novel approach to maintain or improve QOL: hypnosis. This intervention challenges customary notions about the capacity of people to participate in an activity requiring concentration. Perry Edelman and colleagues describe collaboration by researchers and practitioners to develop 2 observational tools for assessing QOL in congregate care settings; one of these tools will be of special importance to those who care for people in the late and final stages of AD.

Karminder Gill and colleagues from the University of North Carolina describe quality of care as reported by residents with dementia living in 45 long-term care facilities in 4 US states. This study demonstrates that even residents with advanced dementia can reliably and validly report on their own care if only we ask them the right questions. A tool for accessing information that is relevant to them is introduced.

The last article in this issue by medical anthropologist Athena McLean also concerns nursing home care in the United States. Her essay stems from an in-depth study of nursing homes and her conclusion that dementia care is a moral enterprise that is severely hampered by capitalistic notions about time and money. She raises important questions that are also raised in a new book, *Dancing With Rose*, in which a journalist immerses herself in a dementia-specific facility as a resident assistant and asks, “The important question is whether I—whether any of us—have the gumption, foresight, creativity, fearlessness, imagination, whatever it would take, to do something about eldercare before it’s our turn.”

Finally, I wish to draw attention to the new pull-out section of *Alzheimer’s Care Today* that is intended to offer practical tips; included is a table describing a number of QOL assessment tools to consider using in your work.
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