

Implications

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Living with Alzheimer's

Editor's note: Literature on designing the physical environment for aging populations, especially those who suffer dementia, has increased steadily in recent years. This issue of *Implications* aims to give readers insight into the human side of the disease as they design spaces for this population and their caregivers.

The Human Side of the Disease

A minister, married 52 years, wakes one morning to find his wife no longer recognizes him. A university scientist in his mid-50s is no longer able to perform his duties because he can no longer remember details about his research. A business executive faithfully visits his father in a nursing home, gently guiding him in how to eat with a fork and knife. The faces of Alzheimer's are varied, but all share the pathos of the lost—those for whom the world has turned from familiar and secure to alien and uncertain.

We have felt helpless in the face of Alzheimer's. We hope for a cure but expect suffering and decline. We expect those afflicted to fade away into disorientation and confusion, but the human spirit is resilient. Persons with dementia and their families find ways to cope. They do this by adapting their lives to meet the demands of the illness.

The person with dementia is an active responder, not a passive victim to their impairments. Persons with dementia struggle to understand an increasingly confusing world. By understanding the inner experience of dementia, we can better understand how to help support elders in this struggle.

Person-Environment Fit

Persons with Alzheimer's suffer multiple impairments in mental functioning. They become forgetful, have difficulty concentrating, struggle to form words and sentences, may not understand what others are saying, lose track of time and place, and lose the ability to complete tasks from beginning to end. In short, everyday life becomes taxing and stressful. This stress can then lead to worsening symptoms—delusions, agitation, and even aggression.

Lessening the load of cognitive demands by simplifying the environment has substantial benefits. Persons with dementia can be offered fewer and simpler choices. They can be given more cues about what to do. Distracting noise, colors, and shapes can be eliminated from their surroundings. The physical world in which they live can be made friendlier to their impaired faculties.



IN THIS ISSUE

Living With Alzheimer's
Related Research
Summaries



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Family Centered Care

But we are learning that adapting the physical environment is not enough. The social and emotional environment is of vital importance. Relationships must also adapt. People with dementia need more attention, support, and love. Thomas Kitwood (1993) observed that persons with dementia are too often subjected to ‘malignant social psychology’—that is, a social environment that depersonalizes and disables. Persons with dementia lose more than cognitive abilities. They lose self-confidence. And unless emotional support and recognition are given, they can lose their sense of self, feeling unwanted and invisible in an increasingly alien world.

The family provides the emotional support for persons with dementia, and this is a challenging task. Family members must adapt to the emotional needs of the person with dementia, and at the same time manage their own loss and grief. All too often, families get caught in a vicious cycle of ambiguous loss (Boss, 2000). Ambiguous loss is chronic and defies resolution because the person grieved as lost is still present. Research has shown ambiguous loss is a major factor in the distress of both persons with dementia and their caregivers (Caron, Boss, & Mortimer, 2000).

It is crucial to learn more about supporting family centered care of dementia. By family centered care, we mean care centered in the culture of family life. We can contrast this with medical or institutional care, where the culture of professionals dominates. The culture of medical or institutional care emphasizes pathology, technical knowledge, and interventions to cure or control. The culture of family life emphasizes the person more than their symptoms, intimate knowledge that comes from shared life history and emotional support. Medical professionals treat diseases. Families care for persons.

The Seven Phases of Family Care for Dementia

The family adapts to the changing landscape of Alzheimer’s by facing a series of challenges over the course of the illness. These challenges arise as dilemmas—problems seemingly without solution. The family faces conflicting demands. Addressing one issue creates other problems. We’ve identified seven phases common to the dementia care experience (Caron, Pattee, & Otteson, 2000). These phases represent periods when the family faces multiple dilemmas. Coping requires more than simple changes or adjustments; family life must transform.

The illness journey begins with the **Pre-diagnosis Phase**—the period beginning with the first sign of problems and ending with the final diagnosis. This is a time of uncertainty and ambivalence for families. There is uncertainty because the initial symptoms of Alzheimer’s are subtle and the onset insidious. Ambivalence arises out of denial (“this can’t be happening”) mixed with alarm (“something serious is happening”). Families must learn how to talk about the symptoms of memory loss and mental confusion in spite of not knowing whether these are signs of a disease or simply part of normal aging.



Each phase of family care presents new challenges for dementia sufferers, caregivers, and families.

When symptoms progress, alarm overcomes denial and a diagnosis is sought. We call this the **Diagnosis Phase**. Because no definitive test for Alzheimer’s exists, a clinical diagnosis must be made. In other words, the medical provider must establish the level of cognitive impairment and that there is a history of

progression. This can take time and increase family uncertainty. With the delivery of the diagnosis, family life forever changes. The future with the elder is set in place and it is grim. The news is traumatic, and families must find the strength to recover emotional balance.

The newly diagnosed person is now officially impaired and disabled. In day-to-day life, this means they must give up prized activities such as driving, managing their bills, and a host of others. The family enters the **Role Changes Phase**. Family members must now step in and take these tasks over—transporting the elder, making decisions about their finances, monitoring their medications, etc. The elder is challenged to surrender independence gracefully and family members are challenged to decide who will take on the caregiving roles.

With the progression of impairments, the elder requires increasing help and attention. There comes a time when they cannot be safely left alone, and care becomes constant. This is the **Chronic Care Phase**. Exhaustion (physical, mental, and emotional) is a main concern. Managing the illness can crowd out other parts of family life, resulting in the loss of normal family activities such as holidays and celebrations. To successfully navigate this phase, family members must protect normal family activities and resist pressures to focus on the ill member as defining family life. Family life must not become engulfed by caregiving, but must transcend the illness.

Ever-increasing caregiving demands mean that many families reach out for professional help. When these professional services involve providing direct care for the elder (e.g., an adult day service or companion program), the family has entered into the **Shared Care Phase**. Families must decide to use services and then find the right program or person to help. A key to this phase is developing a collaborative relationship with providers. When the provider and family can de-

velop a partnership, then services help. Without this partnership, a more distant provider-and-customer relationship results. Family centered care becomes supplanted with the culture of professional or institutional care, where the emotional needs of the person with dementia and their family may be ignored.



The person in the illness and the caregiving family both need support to adapt to ever changing circumstances.

For many families, the increasing care demands coupled with caregiver exhaustion lead to long-term care placement—either in a nursing home or in an Alzheimer’s unit in an assisted living facility. We call this the **Long-Term Care Phase**. As with the Shared Care Phase, the challenge for families is to establish collaboration with the staff caring for the elder. The task is to ensure that institutional care also includes personal care—in other words, care that treats the person with dementia as a valuable and unique individual. It is tempting for families to surrender care to the staff and difficult at times to develop a close working relationship with them. Institutional care can be unfriendly to families (Caron, 1996). But efforts to teach the staff to understand and honor the unique person can have great benefits (Caron, Hepburn, Luptak, Grant, Ostwald, & Keenan, 1999).

The illness journey closes with the **End of Life Phase**. As the disease progresses, the elder weakens and

withdraws into themselves. They become wheelchair- or bed-bound. Consciousness fades until a coma sets in. The family is called upon to make end of life care decisions. These final decisions are difficult and emotional. At the point when the elder passes on, the family has faced the final challenge in a series of daunting challenges.

Collaborative Learning Communities

This long and eventful journey is transformative. Family life undergoes change after change. To weather these changes, the family must become an adaptive learning system. In other words, family members must develop the skills to learn how to learn—adapt to ever changing circumstances.

Most caregiving educational programs aim to teach limited content either about the disease process or about specific caregiving skills. But how do you learn



Collaborative learning communities create opportunities to learn and share about dementia care.

how to learn? And how does an entire family accomplish this?

For the last six years, we have sponsored a collaborative learning community at the University of Minnesota called the Family Caregiving Center (<http://fsos.che.umn.edu/projects/fcc.html>). In a collaborative learning community, people come together both as teachers and students. In other words, everyone has

something to teach and everyone has something to learn. Our community is unique in that we include persons with dementia in all teaching and learning activities. They join in lectures and discussions. They offer unique perspectives and teach us important lessons about facing daunting life challenges. Family members support each other in learning how to manage daily challenges of care. The community also includes service providers and other professionals. They join persons with dementia and their family members to explore how to improve services and support.

This community has become vibrant and self-sustaining. Meeting every Saturday, those who live with dementia and those who work with dementia walk the journey together. We believe communities of this sort are essential to the future of dementia care. The minister who becomes a stranger to his wife, the scientist who cannot recall details of his research, and the son visiting a father who only dimly perceives his presence—each individual story reminds us that Alzheimer's has a human face. Supporting those with dementia begins and ends with nurturing the person in the illness and giving support to the caring family.

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Recommended Sources:

—Administration on Aging at www.aoa.gov
—Minnesota Board on Aging at www.mnaging.org
—Alzheimer Disease Research Center of St. Louis University at www.alzheimer.wustl.edu/adrc2
—Alzheimer's Association at www.alz.org
—North Ridge Press
www.northridgepress.com/default.html

About the Author

Wayne Caron, Ph.D., LMFT, is a senior lecturer and assistant teaching professor in the Department of Family Social Science at the University of Minnesota. He also directs the University's Family Caregiving Center. Caron has extensive experience as a family researcher, therapist, and educator in Alzheimer's disease. He has directed or participated in longitudinal studies of families and Alzheimer's disease, evaluations of family group therapy and psycho-educational programs, and nursing home care for dementia. As a therapist, he formed the first support group for persons with dementia in the Twin Cities in 1993, facilitating multiple group programs for persons with dementia and their family members. Caron, with James Pattee and Orlo Otte-



son, has authored *Alzheimer's Disease: The Family Journey*.

Related Research Summaries

InformeDesign has many Research Summaries about design for dementia, Alzheimer's and other, pertinent, age-related topics. This knowledge will be valuable to you as you consider your next design solution and is worth sharing with your clients and collaborators.

“Assisted Living Facilities as “Home””

—*Journal of Housing for the Elderly*

“Preventing Falls Among Adults with Alzheimer's”

—*Journal of Gerontology: Medical Sciences, Series A*

“Kitchens for Older People”— *Housing and Society*

“Increasing Place Attachment for Older Adults”

—*Journal of Interior Design*

“Signage Design for Older Adults with Dementia”

—*Environment and Behavior*

“Difficulties of Aging in Place for the Elderly”

—*Family and Consumer Sciences Research Journal*

“Private Rooms Improve Outcomes for Dementia Patients”

—*Environment and Behavior*

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