

AN ALZHEIMER'S DISEASE BILL OF RIGHTS

The Best Friends Approach to Alzheimer's Care
By Virginia Bell and David Troxel. (1997) [pages 39-42]

Every *person* diagnosed with Alzheimer's disease or a related disorder deserves the following rights:

To be informed of one's diagnosis

To have appropriate, ongoing medical care

To be productive in work and play for as long as possible

To be treated like an adult, not like a child

To have expressed feelings taken seriously

To be free from psychotropic medications, if possible

To live in a safe, structured, and predictable environment

To enjoy meaningful activities that fill each day

To be outdoors on a regular basis

To have physical contact,
including hugging, caressing, and hand-holding

To be with individuals who know one's life story,
including cultural and religious traditions

To be cared for by individuals who are well trained
in dementia care

THE RIGHTS OF THE *PERSON* WITH ALZHEIMER'S DISEASE

Every *person* diagnosed with Alzheimer's disease or related disorders deserves the following rights.

To be informed of one's diagnosis

Typically, a patient is informed of a serious medical diagnosis, even against his or her family's wishes. For example, it is highly unusual for a physician not to inform a patient of a diagnosis of terminal cancer. When the *person* inquires, "What is wrong with me?," he or she should be told that he or she has a medical problem affecting the thinking process, memory, and judgment. If the *person* asks, "Is it Alzheimer's disease?," he or she should be told the truth. Withholding the truth and the reasons for a *person's* medical and psychological condition can be crueler than the effects of this disease.

To have appropriate, ongoing medical care

Great strides have been made in educating the public about the importance of receiving a thorough medical evaluation when symptoms of dementia appear. Some dementias are treatable. Yet, after an Alzheimer's disease diagnosis, families struggle to find appropriate, ongoing care from physicians with geriatric experience. Just as women have successfully fought for medical care that is sensitive to their special concerns and needs, we must now fight for improved geriatric care.

To be productive in work and play for as long as possible

All of us have a need to contribute to, and be a part of, the world around us—whether through work, recreation, or even helping with a simple chore. *Persons* with emerging Alzheimer's disease should be encouraged to maintain their vocational interests for as long as possible. Individuals in middle or late Alzheimer's disease benefit from meaningful activities each day.

To be treated like an adult, not like a child

The *person* has led a full life, rich in experiences. Even late into the illness, the *person* will retain a sense of his or her personal history, achievements, and values, given cues. Activities and language should be age appropriate and meaningful. A former federal judge should not be asked to cut out paper dolls. People in their 70s should not be spoken to as if they were 7 years old.

To have expressed feelings taken seriously

Care providers, family members, and others know that many individuals with dementia want to discuss their feelings and sense of loss even if they cannot always fully articulate their concerns. Family members and professionals should be willing to listen and empathize. The authors hope that the growing trend of forming support groups for

individuals with emerging Alzheimer's disease will continue. They are a valuable service for the individual with dementia.

To be free from psychotropic medications, if possible

Mood-altering or psychotropic medications can be used to combat sleeplessness, anxiety, wandering, and aggression or other challenging behaviors. Although these medications can be helpful, they can also increase confusion. Most problems can be better managed by behavioral interventions or prevented altogether through improved education about the disease, better staff training in facilities, and use of the Best Friends model of care. Hugs are usually better than drugs .

To live in a safe, structured, and predictable environment

Whether it is a home or a long-term care facility, the living environment should be designed around the needs of the *person*. It should be safe and well lit, offer areas for walking or wandering, be uncluttered, and be pleasant. It should provide a structured schedule of activities and meals. Being structured and predictable does not mean boring—a rich environment that stimulates the senses (e.g. . fresh flowers on the table, the smell of baking bread) can still provide the *person* with a sense of security.

To enjoy meaningful activities that fill each day

Activities should be individualized whenever possible to take into account the *person's* abilities and interests. The *person* should be given a job to do. Activities that stimulate the senses with colors, fragrances, textures, music, and the tastes of healthy foods are ideal. Exercise such as walking, dancing, ball tossing, or stretching should be part of everyday life, if possible. Above all, positive, upbeat, and life-affirming activities are encouraged.

To be outdoors on a regular basis

Individuals with dementia should have fresh air and sunshine on a regular basis. Being outdoors can also lead to enjoyable activities such as observing flowers and birds or "people watching." Just feeling warm sunshine can boost morale and stimulate the senses. Outdoor activity is particularly important for people in facilities where most activities occur indoors. To have physical contact, including hugging, caressing, and hand-holding . Something as simple as a touch can reassure anxious individuals and bring great joy. A bear hug can distract someone about to have an outburst. If sexual intimacy is lost, hand-holding and caresses can help individuals with dementia and their loved one still feel close.

To be with individuals who know one's life story, including cultural and religious traditions

Knowing a *person's* life story and traditions enhances all aspects of Alzheimer's care. Communication is improved when caregivers can provide verbal cues. Likes and dislikes can be acknowledged. Also, appropriate activities that take into account the individual's interests and traditions can be planned. For example, it would be inappropriate to encourage someone to dance the polka if he or she belonged to a religion that prohibits dancing. To be cared for

by individuals who are well trained in dementia care Although family caregivers should learn as much as possible about dementia care, they have the right to *demand* competent care from professionals. Reading books on dementia care. participating in support groups, and attending workshops and conferences give families and professionals more tools for providing good care and improving quality of life for the *person*.

CONCLUSION

Like the U.S. Bill of Rights, the Alzheimer's Disease Bill of Rights is not absolute. To cite a famous example from constitutional law, the right of free speech does not allow someone to yell "Fire!" in a crowded theatre when there is no fire. likewise, the Alzheimer's Disease Bill of Rights must take into consideration each *person's* cognitive abilities and medical situation.

Yet, individuals, families, and professionals who adopt these rights will find that the result will be an improved plan of care and improved sensitivity to the *person's* needs. Facilities that adopt these rights will be informing families of their commitment to offer the highest quality of care for *persons* with dementia. Finally, it is the authors' hope that, until a cure for Alzheimer's disease is found, these rights may give comfort to people with emerging Alzheimer's disease. They can use this bill of rights as a tool to discuss their concerns and fears and to participate as much as possible in decision making regarding their future.