



A Dignified Life: The Best Friends Approach to Alzheimer's Care, A Guide for Family Caregivers

By Virginia Bell, David Troxel

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A Dignified Life helps combat the burnout and frustration that often accompany the task of caring for an Alzheimer's patient. Author David Troxel, an Alzheimer's expert and executive director of the California Central Coast Chapter of the Alzheimer's Association, maintains that at its simplest this approach is based on treating the person like a best friend and working from their strengths, not their weaknesses. He explains: "As family members, caregivers and professionals, we have to try to connect with them. People with this disease in some way need someone to be . . . attentive and empathetic--someone who really tries to walk a mile in their shoes."

A Dignified Life goes beyond the typical tips offered by most books and takes advantage of readers' instinctive desire to build friendships and taps into the intuitive aspect of caregiving that is part of our very nature. It provides a complete model for care built around creative and effective communication and meaningful activities and includes touching stories that demonstrate how the Best Friends method continues to improve the lives of both those who have Alzheimer's disease and those who care for them.

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Editorial Review

About the Author

Virginia Bell, MSW, developed the Helping Hand Adult Day Center sponsored by the Greater Kentucky and Southern Indiana chapter of the Alzheimer's Association in Lexington, Kentucky. The award-winning facility was one of the first dementia-specific adult day programs established in this country and remains one of the best. She received her master's in social work and served on two Kentucky Governor's Task Forces studying Alzheimer's care and service delivery. A frequent and popular speaker on aging, Ms. Bell has been directly involved with the annual conference of Alzheimer's Disease International for more than a decade.

David Troxel, MPH, is a recognized expert on the best practices in Alzheimer's care and is a popular keynote speaker at conferences related to Alzheimer's and aging services. Along with Virginia Bell and others, he established a statewide network of support groups and services in Kentucky for patients and their caregivers. Troxel is the executive director of the California Central Coast chapter of the Alzheimer's Association and is also the associate editor of *Early Alzheimer's*, an international newsletter sponsored by the California Central Coast chapter of the Alzheimer's Association.

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Chapter 4

A New Start

The Art of Friendship

Alzheimer's disease changes us all. Because of the associated memory loss and confusion, your mother, father, sister, brother, husband, wife, or partner may no longer know you or understand his or her relationship to you. Many caregivers are confused, frustrated, sad, or even angry about these losses. Your mother may have always been your closest confidante and strongest supporter; now, she does not recognize you. A spouse whom you counted on for many years to balance the checkbook, pay bills, file the income taxes, or cook three meals a day is no longer able to do these things. As a result, your relationship with the person changes whether you like it or not.

Adopting a Best Friends approach can help diminish this pain and loss and can have a powerful impact on the person with dementia. When you rethink, or recast, your relationships to individuals with dementia and become a Best Friend to them instead of just a caregiver, the person now feels you are on his or her side. In addition, friendship helps evoke some of the social graces or learned manners of the person with dementia. It helps put the person on his or her best behavior.

Caregivers using the Best Friends approach have made the Helping Hand day program of the Greater Kentucky/Southern Indiana Alzheimer's Association one of the most admired adult day programs in the United States. Many individuals with dementia in Helping Hand have been considered difficult and challenging by their own family caregivers. Yet at Helping Hand, because the staff and volunteers are acting as friends, they thrive. Families can have similar success using the Best Friends approach at home.

Rather than staying in a state of despair, caregivers can learn to work through the pain and focus on gaining maximum value from the present; caregiving is transformed from a terrible burden to a job that becomes meaningful and satisfying. The process changes from a series of failures to a series of successes. Recasting this relationship to become a Best Friend does not mean taking away love or loving the person with dementia any less. It simply means approaching the relationship differently.

One caregiver told us that he had always had a troublesome relationship with his father-so bad, in fact, that he ran away from home at age 16. He now cares for his father full time and says they have never been closer. They take a daily walk together, have an evening scotch and soda, and watch the grandchildren play soccer. They have found that they now enjoy each other's company. Because the father has forgotten much of the past and is often unsure of his relationship with his son, the son has realized that he, too, must let go of past slights and injustices. "What's the point of me dwelling on it?" the caregiver asks. "What's past is past."

Like many caregivers, the son never dreamed he would be in the position of taking care of his father, a father whom he admits disliking for much of his life. However, this family's approach to Alzheimer's care has helped heal not only the son's relationship with his father, but also wounds he has carried inside himself.

Being a Best Friend is not just about altruism. Caregivers who recast their relationships take advantage of the principles of friendship to gain new ideas for handling day-to-day care in a more natural, positive way; prevent problems before they happen; form a new relationship with a loved one based on getting the most out of every day; and replace the stress and strain of caregiving with satisfaction. Below are the key ingredients for success.

What is a Best Friend?

FRIENDS KNOW EACH OTHER'S PERSONALITY AND HISTORY

A Best Friend becomes the person's memory.

A Best Friend is sensitive to the person's traditions.

A Best Friend respects the person's personality, moods, and problem-solving style.

FRIENDS do things together

A Best Friend enjoys activities with the person with dementia.

A Best Friend involves the person in activities and chores.

A Best Friend initiates activities.

A Best Friend ties activities into the person's past skills and interests.

A Best Friend encourages the person to enjoy the simple things in life.

A Best Friend remembers to celebrate special occasions.

FRIENDS COMMUNICATE

A Best Friend listens skillfully.

A Best Friend fills in the blanks.

A Best Friend asks questions that are easily answered.

A Best Friend recognizes the importance of non-verbal communication.

A Best Friend gently encourages participation in conversations.

FRIENDS BUILD SELF-ESTEEM

A Best Friend gives compliments often.

A Best Friend carefully asks for advice or opinions.

A Best Friend always offers encouragement.

A Best Friend offers congratulations.

FRIENDS LAUGH TOGETHER OFTEN

A Best Friend tells jokes and funny stories.

A Best Friend takes advantage of spontaneous fun.

A Best Friend uses self-deprecating humor often.

FRIENDS ARE EQUALS

A Best Friend does not talk down to the person.

A Best Friend works to help the person "save face."

A Best Friend does not assume a supervisory role.

A Best Friend recognizes that learning is a two-way street.

FRIENDS WORK AT THE RELATIONSHIP

A Best Friend is not overly sensitive.

A Best Friend does more than half the work.

A Best Friend builds a trusting relationship.

A Best Friend shows affection often.

Source: The Best Friends Approach to Alzheimer's Care.

Phil and Karen Zwicke renewed their marriage vows after 10 years of marriage. Surrounded by friends and family, the couple enjoyed the afternoon including champagne and wedding cake. Phil, 52, has been open with others about his diagnosis of Alzheimer's disease; both of them are determined to keep him active and enjoying life as long as possible.

FRIENDS COMMUNICATE

The best friendships often involve a lot of talking. Whether it is on the telephone or over the office water cooler, friends generally love to swap stories, gossip, share ideas, send e-mails and instant-messages to each other, and confide in one another. Friends are also there to listen to each other, in good and bad times.

A Best Friend Listens

In Alzheimer's care, it is important to try to be there for the person when he or she wants to talk about important feelings. Individuals with Alzheimer's disease should be given time to offer their feelings or ideas. Sometimes patience is rewarded with an insight.

Maria Scorsoni has spoken three languages in her lifetime: Italian as a child, Spanish when she lived in Argentina, and English after she moved to the United States. She now often mixes the three languages. Her in-home aides became her Best Friends by listening to Maria's words very carefully. When the aides cannot follow the exact words, they can usually still understand her by listening to the tone of her voice and watching her facial expression and other body language.

A Best Friend Fills in the Blanks

People with Alzheimer's disease begin to lose the structure of their sentences and language. When you can provide clues and cues, communication can vastly improve. Sometimes even filling in the blanks by supplying one or two words keeps the dialogue going.

Edna Edwards loves to converse but has major difficulty finding the right words. When Edna says "Those little ones, I miss them . . . at the school . . ." her Best Friend says "Picadome School?" Edna can continue, "Picadome, that's my school!"

Conversation can continue about early childhood days, her teaching, and her schoolchildren, all because her Best Friend brought up some familiar names of people, places, and things in Edna's life.

A Best Friend Asks Questions that Are Easily Answered

The person may become easily frustrated if asked questions to which he or she does not know the answer.

When Evelyn Talbott, a retired librarian, returned from a vacation, she would have been frustrated if someone had asked her to recall, "Where did you go on vacation," or "What was the name of the beach?" Instead, a friend asked skillfully, "Did you and your husband, Bob,

have a good time watching those big waves on the ocean?"

When her Best Friend provided some details within the question, it triggered memories and allowed Evelyn to share her joy from her vacation and participate in the conversation.

A Best Friend Recognizes the Importance of Non-Verbal Communication

Because verbal skills are diminished, body language becomes very important in Alzheimer's care. A Best Friend should greet the person warmly, smile broadly, and hold out a hand. The handshake still holds special meaning with older people who remember a time when everyone in polite company would shake hands. Almost always, the person will respond with a handshake. A mutual handshake is the beginning of a bond, a deep-rooted symbol that one is a friend, not a foe. Talking with your hands can also be effective. Gestures such as tapping the seat on a chair can help the person get the message to sit down.

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