MEMORY CARE RESOURCES

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Introduction

The thought of visiting a friend or loved one with Alzheimer's disease or another form of progressive memory loss can create a sense of unease and anxiety. Understandably, anyone can feel apprehensive about a situation or circumstance that is unknown or unfamiliar to them.

It can be especially difficult to witness the changes caused by memory loss firsthand and to accept the differences in the person you have known and loved. The concerns of friends and family members are frequently voiced in comments such as, "What if he doesn't know who I am?" "What should I say?" "How should I act?" or "I don't want to see her like this."

Experts in memory care, such as the Alzheimer's Association, tell us that various forms of personal interaction and social engagement, such as visits, are very important for individuals with memory loss. They say that positive connections with others have been shown to enhance the person's physical, emotional and spiritual well-being by reducing their anxiety and agitation while also improving their mood.

To better prepare you for a visit to our community this guide will provide information on common behavioral expressions, tips and strategies to make your visit a healthy and successful one, and who to contact when questions and concerns arise.

Common Behavioral Expressions

Alzheimer's disease and other dementias can cause people to act in different and unpredictable ways. Some individuals become anxious or aggressive. Others repeat certain questions or gestures. Many misinterpret what they hear.

These types of reactions can lead to misunderstanding, frustration and tension. It's important to understand that the person is not trying to be difficult and the behavioral expressions can be a form of communication.

Anger and Aggression: Aggressive behavioral expressions may be verbal (shouting, name calling) or physical (hitting, pushing). It's important to try and figure out what's causing the anger and try to prevent it from happening, when possible.

Anxiety or Agitation: People with dementia can become anxious or agitated for many reasons. It can help to learn what triggers this response by considering the person's surroundings, time of day and what has just occurred, and evaluating potential sources of pain, hunger, need for sleep and sudden changes.

Delusions and Hallucinations: Delusions (firmly held beliefs in things that are not real) may occur in middle- to late-stages of dementia. Confusion and memory loss – such as the inability to remember certain people or objects – can contribute to these untrue beliefs. A person with dementia may believe a family member is stealing his or her possessions or that he or she is being followed by the police. Although not grounded in reality, the situation is very real to the person with dementia. A delusion is not the same thing as a hallucination. While delusions involve false beliefs, hallucinations are false perceptions of objects or events that are sensory in nature. When individuals with dementia have a hallucination, they see, hear, smell, taste or even feel something that isn't really there.

Disinhibited Behavioral Expressions: Disinhibited behavioral expressions are actions which seem tactless, rude or even offensive. They occur when people don't follow the usual social rules about what or where to say or do something. Disinhibited behavioral expressions may include: tactless or rude remarks, bold behaviors (a person with dementia may inappropriately flirt with someone or make sexual comments), exposure (a person with dementia may take some, or all their clothes off at inappropriate times or in inappropriate settings), or fondling.

Forgetfulness and Confusion: A person with dementia may not recognize familiar people places or things. He or she may forget relationships, call family members by other names or become confused about where home is. The purpose of common items, such as a pen or fork, may also be forgotten.

Repetitive Actions: A person with dementia may do or say something over and over again – like repeating a word, question or activity. The person may also undo what has just been done. In most cases, he or she is likely looking for comfort, security and familiarity. These actions are rarely harmful but can be stressful for the caregiver.

Wandering and Getting Lost: It's common for a person with dementia to wander and become lost, and it can happen at any stage of the disease. They may try to go home when already there or attempt to recreate a familiar routine, such as going to school or work.

Trouble with Sleep: People with dementia may experience changes in their sleep schedule or have problems sleeping. Although the exact cause is unknown, sleep changes result from the disease's impact on the brain.

Ways to Make Your Visit a Healthy and Successful One

The Power of a Positive Attitude

Experts agree that your attitude, including body language, is extremely important when visiting with a loved one or friend with memory loss.

People with memory loss are said to be highly intuitive and are often able to "read" your mood. If you are feeling anxious, stressed or rushed they may become agitated as a result. And, like all of us, individuals with progressive memory loss can have their good days and bad days.

Bringing a positive attitude and a calm demeanor can result in a pleasant visit for both of you. Communication is how we relate to others, an integral part of our relationships, and the way we express our thoughts, wants, and needs.

The state of our brain heavily influences the way we communicate and interpret messages. Alzheimer's is a disease of the brain. As Alzheimer's disease and other forms of dementia progress, they severely impair a person's ability to communicate. Communication with a person suffering from Alzheimer's requires patience, listening, and understanding. Sometimes delivery of a message may have a different impact than what we intend.

Tips and Strategies to Improve Communication

1. Use positive body language and facial expressions.
2. Position yourself directly in front of the person at eye level and get their attention before speaking.
3. Say their name.
4. Demonstrate with actions and words.
5. Use familiar simple words in short sentences.
6. Ask yes/no questions: “Would you like some tea?” (while holding a teacup).
7. Take out “don’t,” “remember” and “no.”
8. Avoid questions that require short-term memory: “Did your son come to see you today?” Instead access the person’s long-term memory: “John is a wonderful son.”
9. Don’t talk over, through, or about them as if they aren’t there. They can hear, think, and feel emotions.
10. Give simple instructions one step at a time.

Get Support

Watercrest Senior Living associates are always available to welcome, to care, and to serve both you and your loved one. Our associates receive specialized dementia care training and are skilled in behavioral interventions and persuasion techniques that validate, redirect and comfort our residents during their times of need. Please do not hesitate if you find yourself in a difficult situation, to report the incident to a Resident Care Specialist, Wellness Nurse or Memory Care Director.

Resources:

Alzheimer’s Association www.alz.org
National Council Dementia Practitioners www.nccdp.org
National Institute on Aging https://www.nia.nih.gov/

Suggested Readings

An Absent Mind, by Eric Rill

Seventy-one, and a man used to controlling those around him, Saul struggles to make peace with his disconnected family before Alzheimer's consumes his sanity.

His ramblings, humor, emotions, lucid moments, and confusion are laid bare, as well as the thoughts and feelings of his loved ones: his wife, Monique, conflicted and depressed…caring, yet angry; his daughter, Florence, compassionate, yet proper and reserved; his son, Joey, self-centered and narcissistic, seemingly indifferent to his family's challenges; and his doctor, an Alzheimer's specialist, who cares for Saul until his final days.

From the beginning Saul and his family know how it has to end, because no one has ever outsmarted Alzheimer's. But as they navigate the meandering road that will eventually bring Saul's demise, they leave behind their once disconnected lives and come together to weather their difficult journey.

Heartfelt and moving, this lauded novel, winner of 2014 gold medals from the Independent Publisher Book Awards, Readers' Favorite Book Awards, and the Living Now Book Award for Inspirational Fiction, will appeal to fans of Lisa Genova's Still Alice or Nicholas Sparks's The Notebook.

Chicken Soup for the Soul: Living with Alzheimer's & Other Dementia 101 Stories of Caregiving, Coping, and Compassion, by Amy Newmark and Angela Timashenka Geiger

Caring for a loved one with Alzheimer's or another form of dementia? You are not alone. With 101 encouraging and inspiring stories by others like you, this book is a source of support and encouragement throughout your caregiving journey.

Alzheimer's disease and other forms of dementia affect millions of people, and this book is especially for caregivers. This collection, a joint project with the Alzheimer's Association, is filled with 101 stories of love and lessons from others like you, will support and encourage you as you care for your loved one.

Coach Broyles' Playbook for Alzheimer's Caregivers, by Frank Broyles

It wasn't always easy for me to find the answers my family needed about Alzheimer's disease, and at times I was frustrated and confused. I promised myself that one day I would share all that I had learned-from my research and my experience-with other families that were dealing with Alzheimer's. This dream came true when the Playbook was created and made available to my fellow Arkansans. We received calls and letters from so many people thanking us for sharing our story and information that I decided to make my dream bigger, and share the Playbook with people across our country. I gathered my team, and together, with the help and support of many Arkansan people and companies, we were able to generate the funding and expertise needed to make this Playbook for anyone wanting information on how to care for a loved one with Alzheimer's disease. It is my hope that you can benefit from my experience.

Creating Moments of Joy: Along the Alzheimer's Journey, by Jolene Brackey

Jolene Brackey has a vision: that we will soon look beyond the challenges of Alzheimer's disease to focus more of our energies on creating moments of joy. When people have short-term memory loss, their lives are made up of moments. We are not able to create perfectly wonderful days for people with dementia or Alzheimer's, but we can create perfectly wonderful moments, moments that put a smile on their faces and a twinkle in their eyes. Five minutes later, they will not remember what we did or said, but the feeling that we left them with will linger. The new edition of Creating Moments of Joy is filled with more practical advice sprinkled with hope, encouragement, new stories, and generous helpings of humor. In this volume, Brackey reveals that our greatest teacher is having cared for and loved someone with Alzheimer's and that often what we have most to learn about is ourselves.

Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease, by Joanne Koenig Coste

More than four million Americans suffer from Alzheimer's, and as many as twenty million have close relatives or friends with the disease. Revolutionizing the way we perceive and live with Alzheimer's, Joanne Koenig Coste offers a practical approach to the emotional well-being of both patients and caregivers that emphasizes relating to patients in their own reality. Her accessible and comprehensive method, which she calls habilitation, works to enhance communication between carepartners and patients and has proven successful with thousands of people living with dementia. Learning to Speak Alzheimer's also offers hundreds of practical tips, including how to:

- cope with the diagnosis and adjust to the disease's progression
- help the patient talk about the illness
- face the issue of driving
- make meals and bath times as pleasant as possible
- adjust room design for the patient's comfort
- deal with wandering, paranoia, and aggression

Lewy, Mom and Me: A Caregiver's Story, by Peggy Bushy

In her seventies, Peggy Bushy's mother, Francesca, started telling unbelievable stories. She claimed that people were invading her home and trying to kill her. She also became anxious and reclusive. For several discouraging years, Bushy searched in vain for a reason for her mother's behavior.

Finally, Francesca was diagnosed with Lewy body dementia. Although it's the third-most-common cause of dementia, Bushy was unable to find much information on the disease, and the medical community was frustratingly unhelpful.

Lewy, Mom, and Me is the book that Bushy wished had been available when her mother was first diagnosed. It details her personal journey of discovery, with all its challenges and revelations, and is written in a compassionate, empathetic style that will comfort any reader dealing with a parent's decline.

Bushy explains how she learned to accept the changes in her mother and to support Francesca emotionally as she grappled with her frightening illness. She also describes what was involved in caring for her mother first at home, then in long-term care, and finally in hospice.

Part memoir and part survival guide, this compelling testimony offers support and information for family caregivers of aging parents.

My Two Elaines: Learning, Coping, and Surving as an Alzheimer's Caregiver, by Martin J. Schreiber

Former governor of Wisconsin Marty Schreiber has seen his beloved wife, Elaine, gradually transform from the woman who had gracefully entertained in the Executive Residence to one who sometimes no longer recognizes him as her husband. In My Two Elaines: Learning, Coping, and Surviving as an Alzheimer's Caregiver, Marty candidly counsels those taking on this caregiving role. More than an account of Marty's struggles in caring for his wife, My Two Elaines also offers sage advice that respects the one with Alzheimer's while maintaining the caregiver's health. As two-thirds of those with Alzheimer's are women, he offers special guidance for men thrust into an unexpected job. With patience, adaptability, and even a sense of humor, Marty shows how love continues for his Second Elaine.

Still Alice, by Lisa Genova

From New York Times bestselling author and neuroscientist Lisa Genova comes the definitive—and illuminating—novel about Alzheimer's disease. Now a major motion picture starring Oscar winner Julianne Moore!

Alice Howland is proud of the life she worked so hard to build. At fifty years old, she's a cognitive psychology professor at Harvard and a world-renowned expert in linguistics with a successful husband and three grown children. When she becomes increasingly disoriented and forgetful, a tragic diagnosis changes her life—and her relationship with her family and the world—forever. As she struggles to cope with Alzheimer's, she learns that her worth is comprised of far more than her ability to remember.

At once beautiful and terrifying, Still Alice is a moving and vivid depiction of life with early-onset Alzheimer's disease that is as compelling as A Beautiful Mind and as unforgettable as Ordinary People.

Surviving Alzheimer's: Practical tips and soul-saving wisdom for caregivers, by Paula Spencer Scott

The book recommended by dementia experts and family caregivers as the most complete, practical guide to Alzheimer's and other dementia – now updated and expanded through end-of-life care.

This new edition of Surviving Alzheimer's offers the best, most current thinking on how to help a loved one with memory loss and related symptoms without sacrificing YOU. You'll learn:

- What's behind odd, frustrating behaviors like repetition, wandering, personality changes, bathing resistance, and aggression – and what you can do
- How to defuse resentment, guilt, and family friction
- What to say for better communication and more cooperation
- Special advice for spouses, out-of-town caregivers, and other specific situations
- 100's of confidence-raising solutions from top doctors, social workers, dementia specialists, and family caregivers

The 36-Hour Day: A Family Guide to Caring for People Who Have Alzheimer's Disease, Related Dementias, and Memory Loss, by Nancy L. Mace, MA, and Peter V. Rabins, MD, MPH

The most trusted guide for caring for persons with Alzheimer's disease, memory loss, and dementia disorders-now revised and updated with practical and legal advice and compassionate guidance for families and caregivers.

When someone in your family suffers from Alzheimer's disease or other related memory loss diseases, both you and your loved one face immense challenges. For over thirty years, this book has been the trusted bible for families affected by dementia disorders. Now completely revised and updated, this guide features the latest information on the causes of dementia, managing the early stages of dementia, the prevention of dementia, and finding appropriate living arrangements for the person who has dementia when home care is no longer an option. You'll learn:

- The basic facts about dementia
- How to deal with problems arising in daily care-meals, exercise, personal hygiene, and safety
- How to cope with an impaired person's false ideas, suspicion, anger, and other mood problems
- How to get outside help from support groups, friends, and agencies
- Financial and legal issues you must address.

Comprehensive and compassionate, The 36-Hour Day is the only guide you need to help your family through this difficult time.

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