



MEET ME IN MEMORY CARE



WILL GRANDPA FORGET ME?
EXPLAINING DEMENTIA TO CHILDREN

*Dedicated to our residents,
past, present and future . . .*

*We honor their individuality
and celebrate their stories.*



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Introduction



When someone is diagnosed with Alzheimer's Disease or other dementia, everyone including the person diagnosed, their family and social circles can expect to realize a wide range of feelings and emotional impact. A new dementia diagnosis may bring the affected person a sense of disbelief, anger, or grief. It is certainly understandable that fear may take hold, and sometimes even an odd sense relief ensues, as he or she finally has an answer to questions relating to their recent symptoms.

Family members and friends often experience initial confusion, anxiety, distress and fear, followed by a determination to learn all they can about what to expect, how to handle expected symptoms and behavioral changes, and to create a plan that involves everyone who may potentially be of help.

In many cases, these plans do not include children, because after all, how can we expect a child to understand what we ourselves find so difficult to accept and grasp, let alone explain?

It is important for children to learn why their Grandma or Grandpa may forget them, acts strangely, or seems to be "not quite himself." They need to know that their loved one's behaviors are nothing to be ashamed of, afraid of, or cause for confusion. If a grandchild can benefit from appropriate explanation, they may be able to avoid being frightened or upset if their grandparent should accuse them of things they did not do or even disrobe in front of them, or feel guilty if they should cry without apparent reason.

It is important to explain things to children - and to answer their questions. How much and what kind of information you share depends on the child's age and relationship to the person with Alzheimer's or dementia.



Recognizing Your Child's Sensitivities



A child or teenager whose loved one is suffering from Alzheimer's or dementia may experience a wide range of feelings including confusion, fear, sadness, embarrassment, frustration, guilt, and even curiosity.

It's important to know that these feelings are normal, but recognizing them may not always be clear. For pre-teens and teens, imagine adding these emotional reactions to the typical adolescent challenges and physical changes they are already dealing with!

Your child may exhibit argumentative behaviors, reclusiveness, physical pain, headaches or other distress, and his/her school grades may begin to decline.

Take time with your child to explain what is happening to their loved one with dementia, in a way they can understand based on their age and capability for understanding. Assure them that you are always available for honest answers to their questions, and encourage them to write those questions down - or even keep a journal that can perhaps help them during your conversations.

Educate yourself as much as possible with the disease and understanding its symptoms and caregiving tips. This will assist you with age-appropriate conversations with your children. Assure them that their feelings are normal; that none of this is their fault, and there is nothing wrong with them. Comfort them with understanding and kindness. If they are not comfortable talking with you, suggest meeting with a school counselor or other trusted mentor. Speak with school personnel to inform them of the home situation.

If your child fears or is embarrassed by the person with Alzheimer's, don't force them to spend time together - give them the time and support they need to adjust at their own pace.

Communication with Children



Coping Strategies

As adults, we educate ourselves or seek support from professionals to help us cope with stressful situations. Our children rely on us to provide the help they need in understanding how to cope with Grandma's disease and the associated feelings they themselves are experiencing.

We covered some suggestions in the previous section of this publication. It bears repeating that taking time to communicate with your child cannot be overstated. Provide simple, honest answers to their questions without overwhelming, and understand that your child may not be comfortable in sharing negative feelings; these may surface in other ways.

Explain that Alzheimer's (or dementia) is a disease that affects how the brain works and memory loss, confusion, communication difficulties and mood or behavior changes will worsen over time.... and while there is no cure, medical progress continually advances, and the disease is not contagious.

Let your child know that Alzheimer's can cause bouts of confusion, fear or anger and sometimes it may be directed at others (including the child.) Assure them that no one is at fault, including Grandma. She is not responsible for the behaviors (the disease is), and your child is not responsible for causing it.

Be open in describing necessary changes in the household and even the balance of time spent together; assure them your commitment to their needs remains. Perhaps you may ask your teen to help a bit more with chores. Typically, children will follow a parent's example, so when they see the modifications you've made in your schedule, they may see the potential to feel more useful themselves.

Involvement in Caregiving and Dementia Techniques

Depending on your child's age, the stage of disease, and recommendations from physicians and medical professionals, your child may be able to participate in your loved one's care.

Allowing children have a role in daily routines can help them in understanding the symptoms of the disease. Depending on whether their loved one is living at home, with family, or in a memory care community, they can feel a sense of purpose in helping with household chores, sharing in activities, or simply providing companionship.

Discuss with the professionals involved in your loved one's diagnosis and care the best way to "coach" your child or teen in handling behaviors. For example, if a grandparent should shout or wrongfully accuse the child, it may be best to simply say "I'll be back to visit you later, Grandma" rather than to disagree in the moment. Remind your child they can ask you about it later.

Perhaps Grandpa believes he is working in his dad's garage. Your advisors may recommend that you validate that moment, rather than correct and reorient.

Remember, provide children with opportunities to help, but don't force them to do what they are not comfortable with.

It's important to keep in mind your child's need to be a child. Refrain from depending on them to be a full-time sitter. Assure they maintain their own hobbies, friendships, play time, school activities and homework.

Importantly, schedule time to spend with your child to avoid any perception that your dedication to your loved one with dementia has taken priority over their needs.



Tips and Ideas



Our publication “*Meaningful Moments and Engaging Activities*” describes the importance of creating special times with loved ones who suffer from Alzheimer’s and related dementias, and how sharing and participation in activities and programs can benefit everyone involved. This would naturally include children.

These are some ideas that can involve children, based on age and capabilities:

- Singalongs or playing musical instruments
- Browsing photo albums and scrap books
- Arts and crafts, puzzles
- Story time - reading from books, or telling real life stories!
- Gardening
- Watching old movies or favorite television shows
- Picnics, tea and cookies on the porch (or baking the cookies!)

Whatever the activity, remember that the goal should be to **See the potential . . . not the limitation.**



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. If you find yourself in a difficult situation when visiting a loved one in our community, please do not hesitate to report the incident to a Resident Care Specialist, Wellness Nurse or Memory Care Director.



Resources:

Alzheimer’s Association www.alz.org

National Institute on Aging 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 Surviving 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.

Alzheimer's Association Parent's Guide (leaflet)

https://www.alz.org/documents/national/brochure_childrenteens.pdf

