

# THE LONG GOODBYE

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**Saying goodbye** to a loved one usually involves a nice long bear hug, followed by a warm statement of, "I'll see you soon." This is not the case when leaving a loved one afflicted with Alzheimer's disease. Goodbye is repeated over and over again, in hopes that the person remembers who we are, why we are leaving, and will they remember any glimpse of us when we return. Many families, friends, and caregivers express a deep sadness when saying goodbye. This June is Alzheimer's and Brain Awareness Month. Alzheimer's dementia is a devastating disease that slowly destroys the brains and lives of those diagnosed. The impact is broad-reaching as it pillages family and friends. This disease is often referred to as "The Long Goodbye," reflecting how families and friends must watch their loved ones slowly fade away.

The word dementia encompasses a range of conditions that affect the brain with deteriorating cognitive and cerebral functions. Under the dementia umbrella are several types of dementia-related memory loss, including Alzheimer's disease,

vascular dementia, Lewy Body dementia, frontotemporal dementia, and Parkinson's disease-related dementia. Alzheimer's disease accounts for 60-80% of cases for those affected with memory deprivation.

With the breakthrough in scientific-medical advancements, people are now living longer lives, but these advancements also increase the risk of Alzheimer's dementia. According

**You can't explain what it's like to mourn someone who is still alive unless you've experienced it firsthand."**

Jessica Seay-Soto

to Alzheimer's Disease International, "someone in the world develops dementia every 3 seconds." Age is the most significant risk factor for developing Alzheimer's Dementia (AD), increasing from 5% at age 65 to 33% after age 85. Currently, approximately 6.5 million older Americans are living with Alzheimer's Dementia, and it is projected to more than double by 2050.

Continued from page 1

The cost of care for a person with Alzheimer's is staggering. According to a report published by the Alzheimer's Association, "In 2022, Alzheimer's and other dementias will cost the nation \$321 billion." The predicted cost by 2050 is more than \$1 trillion. However, more shocking is these costs do not account for the billions of dollars in unpaid care that families provide for their loved ones who are affected by this desolating disease.

The average per-person Medicare payments for services to beneficiaries aged 65 and older with AD or other dementias are more than three times as much as beneficiaries without these conditions. Medicaid payments are more than 23 times. The prevalence of nursing home residents with AD or other dementias continues to grow with about one-half of all residents having a dementia diagnosis. Approximately 60% of long-stay (greater than 100 days) and 37% of short-stay (less than 100 days) residents have either AD or a related dementia diagnosis.

Remember, person-centered care focuses on the resident, supporting their choices, and providing them with a sense

of control over their daily lives. Several regulatory items speak to this, including OBRA Nursing Home Reform Act 1987, the





Scale (GDS), the Preferred Therapy Solutions Model “Do’s and Don’ts” associated with each state of dementia, purposeful rounding, extensive patient/caregiver educational materials, and therapist resources.

My Way Advanced Directive (Butler 2005) is a map for the care of dementia patients. Patients and families provide detailed information utilizing specific care preferences. This tool outlines crucial information on the Sleep/Wake Cycle, Self-Care Routine, Bathing, Toileting, Dressing/Undressing, Eating, Occupation, Leisure/Hobbies, and use with Assistive Devices. When using the My Way Advanced Directive, patients or loved ones remained at a functional level for longer periods.

### **The GDS is a standard tool that is easy to use.**

There is no cost associated with this model. Determining the stage of dementia allows caregivers to understand what functional capabilities the resident still has and if the resident is functioning at their highest practical level. A typical work

day in post-acute care is often not typical. From the unexpected to the everyday challenges often faced, we may not be able to provide dementia patients with the time needed to function at their highest level. The GDS method assists therapists and caregivers in identifying which activities of daily living a resident may be able to perform with less physical

assistance when allowed an additional time frame to complete an activity or task.

Caring for a loved one with dementia can be complicated, Preferred Therapy Solutions’ clinical teams witnessed these complications and believed we could do better. Their experience, drive, and determination led to extensive research and resources affecting those with dementia

# GDS

leading to the development of the “Do’s and Don’ts” associated with each stage of dementia. This program provides interdisciplinary teams and caregivers the insight into navigating these stages while allowing residents and loved ones to maintain their dignity and patient rights.

The Purposeful (hourly) rounding program has improved many aspects of the patient experience in the post-acute setting. Results associated with Purposeful (hourly) rounding are, decreased falls, increased patient satisfaction, including patient quality metrics with improvements in pain and incontinence.