Caring for a Loved One with

Alzheimer's Disease

First hand experiences

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Natalia Valech Torres, Sandra Báez

IGCPHARMA

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ISBN libro impreso: 978-628-7695-31-3

ISBN versión electrónica: 978-628-7695-32-0

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Acknowledgment

We want to express our deepest gratitude to each of the family members who, with generosity and courage, shared their experiences in this book and granted us permission to publish them. Their stories not only allow us to gain a deeper understanding of the daily challenges of Alzheimer's, but also reflect the love, patience, and strength with which they support their loved ones. Thank you for opening your hearts, trusting this project, and helping to raise awareness and humanity around this disease. This book is, to a large extent, a testimony to your dedication and resilience.

IGCPHARMA

This book has been made possible thanks to the generous support of IGC Pharma and its executives Ram Mukunda and Claudia Grimaldi, whose unwavering commitment to Alzheimer's research and treatment brings hope to millions of families around the world.

To all those who refuse to give in to forgetfulness, who believe in purposeful science, and who work every day to restore dignity and memory, we offer our deepest gratitude.

May every page of this book be a step forward toward a future without Alzheimer's.

Sincerely,

Juan Carlos Arango Lasprilla, Valeria Villamizar,
Natalia Valech, Sandra Báez

Editors

Juan Carlos Arango Lasprilla

Dr. Juan Carlos Arango-Lasprilla is a renowned clinical neuropsychologist and internationally respected researcher, widely recognized for his work in brain injury and rehabilitation. He is an Ikerbasque research lecturer at the University of the Basque Country and has been an invited lectured at over 160 universities worldwide and has an extensive academic trajectory, including the publication of 24 books and more than 450 scientific articles.

Throughout his career, he has received over 30 international awards and honors for his contributions to the fields of neuropsychology and rehabilitation. His research has been fundamental in improving the quality of life of patients with neurodegenerative diseases and their families. His work has significantly influenced clinical practice and the development of intervention strategies.

Valeria Villamizar Mercado

Valeria is a psychologist with a deep interest in research and neuroscience. A recent graduate of the Universidad de los Andes in Bogotá, Colombia, she has continued exploring the neuropsychological processes involved in cognition, memory, and human behavior. Her passion for understanding how the brain works has led her to focus on topics such as Alzheimer’s disease, with the goal of contributing knowledge and tools to improve the quality of life for both patients and their caregivers.

Throughout her training, she has participated in academic projects addressing the relationship between cognition and quality of life. Her approach combines research rigor with the need to make neuroscientific knowledge accessible to society. Together with professionals, she has developed outreach projects aimed at providing useful resources for those facing the challenges of cognitive decline. She is currently engaged in ongoing professional development, with the aim of advancing the fields of neuroscience and psychology, promoting evidence-based approaches that foster a deeper understanding.

Natalia Valech Torres

Natalia is an adult neuropsychologist and psychogerontologist with significant experience in Alzheimer's disease and other neurocognitive disorders. She earned a PhD in Neuropsychology from the University of Barcelona, Spain, a Master's in Psychogerontology from the same university, and a Master's in Clinical Neuropsychology from the International University of La Rioja, Spain. She has worked in public hospitals and private centers, both in research and clinical care, within multidisciplinary contexts in Spain, Chile, and Canada. Alzheimer's disease and its impact on both patients and caregivers is one of her key areas of expertise, and she has collaborated with international organizations to develop psychoeducation programs and support resources for families of individuals with Alzheimer's. She is currently working at MHS Clinic in Bilbao, Spain.

Sandra Báez

Dr. Sandra Báez is an Associate Professor in the Department of Psychology at Universidad de los Andes (Colombia). She trained in Psychology at the National University of Colombia, holds a Master's in Neuropsychology from the Italian Hospital University Institute of Buenos Aires, and a PhD in Psychology from the Catholic University of Argentina. Her academic path includes postdoctoral training at the Max Planck Institute for Human Cognitive and Brain Sciences in Germany and at the Institute of Cognitive Neurology (INECO) in Argentina.

Throughout her career, Dr. Báez has investigated the neuroanatomical and neurophysiological correlates of social cognition in patients with neurological and psychiatric disorders. She has also analyzed how social factors such as poverty and inequality affect brain health and aging in vulnerable Latin American populations. She has published over 100 articles in high-impact scientific journals and has received prestigious awards, including the L'Oréal-UNESCO For Women in Science Award in 2019.

In recent years, she has focused part of her research on understanding the needs of MND caregivers, designing innovative interventions to improve their well-being. Her work has had a significant impact on developing strategies that support those who perform this essential role. Her interdisciplinary approach and commitment to applied research have generated crucial insights into improving the quality of life of caregivers and their families.

Foreword

Caring for someone with Alzheimer's disease is an act of unwavering love. It's a journey filled with uncertainty, challenges, and sacrifices, but also with moments of deep connection, instances when a glance or a smile says more than a thousand words. This book is born from those stories, from the voices of those who have stood by their loved ones throughout the course of this illness and who have shared in these pages their experiences, their pain, their hope, and their endless love.

When an Alzheimer's diagnosis arrives in a family, everything changes. What used to be routine becomes a new form of learning, a constant adaptation. You learn to communicate differently, to live in the present, to find beauty in simplicity. Most of all, you learn that love transcends memory; it does not vanish with forgetfulness but finds new ways to be expressed.

This book is a refuge for those who feel alone in the caregiving journey. It's a companion for those who have felt the emotional toll, the exhaustion, the hopelessness, but also the gratitude of being able to hold their loved one's hand for one more day. It's a reminder that every story is unique, yet each holds a common thread: compassion, resilience, and the desire to do the best possible for the person we love.

Here, you will find real-life stories, full of humanity of stumbles and lessons, of sleepless nights and silent embraces that speak volumes. There is no perfect manual for caregiving, but within these pages are experiences that can serve as a guide, a comfort, and a source of strength to keep going.

Alzheimer's disease confronts us with a difficult reality, but it also teaches profound lessons about life, patience, and unconditional dedication. It shows us that even as words are forgotten and memories fade, emotions remain—intact, resonating in the soul. It forces us to be creative in how we express affection, to find new ways of connecting beyond words, to discover the importance of touch, of a kind gesture, of a melody that sparks a light in our loved one's eyes.

This book is also a tribute to all those who have walked this path and who, through their testimony, remind us that life does not end with a diagnosis. Life goes on-with new challenges, new expressions of love, new ways of being present. And while Alzheimer's may change many things, it cannot erase who we are or the love we feel.

To every person facing this path today, we want to say: you are not alone. Others have gone through the same and found strength when they thought they had none left. This book is for you—the invisible heroes who give their patience, their time, and their boundless love each day. Your work is invaluable, your love immeasurable, and your dedication a gift that transcends time.

May these words be an embrace, a friendly voice reminding you that while Alzheimer's may steal memories, it can never erase love. May you find in these pages inspiration, companionship, and the certainty that every effort, every act of care, and every sacrifice holds deep meaning. Because on this journey, what matters most is not what is remembered—but what is felt. And love always remains, even when everything else seems to fade.

Juan Carlos Arango Lasprilla
Valeria Villamizar
Natalia Valech
Sandra Báez

What is Alzheimer's Disease?

As the name suggests, Alzheimer's disease is a disease not a natural part of aging, but a pathological condition that affects the brain.

This is an important clarification, as some people mistakenly believe that Alzheimer's is a normal aspect of aging. This confusion may arise because Alzheimer's often appears in people over the age of 65.[1] However, not all older adults develop Alzheimer's disease. For example, among centenarians (people who are 100 years or older) only about half have the disease.[2] At the same when he was time, Alzheimer's disease can also affect younger individuals, although this is much less common. The youngest known case is a man from China diagnosed at just 19 years old.[3]

Alzheimer's disease leads to a clinical condition known as major neurocognitive disorder. The term "dementia" has largely fallen out of use in medical and scientific contexts due to its negative and stigmatizing connotations. Historically, it was associated with insanity or a total loss of reason, often resulting in discrimination against those with such conditions. Today, the preferred term is major neurocognitive disorder (MND), which more accurately describes the progressive impairment of cognitive functions such as memory, thinking, and the ability to perform daily tasks. In fact, Alzheimer's disease is the most common cause of MND.

Cognitive functions are the mental tools our brains use to learn and make sense of the world around us. These include attention, perception, memory, language, planning, and reasoning. One of the first cognitive functions typically affected by Alzheimer's is recent memory—the ability to retain new information or recall events that occurred recently. Early in the disease, it's common to see that patients remember events from long ago, such as their wedding day, but struggle to recall a conversation from earlier that same day. This happens because the brain regions responsible for forming new memories are affected early on, while older memories are stored in other neural networks that remain intact for longer.[4] As a result of this impairment in recent memory, individuals with Alzheimer's often repeat the same questions or retell the same stories multiple times.

Other early cognitive symptoms include greater difficulty planning and organizing, slower and less efficient completion of daily tasks, poor decision-making, trouble multitasking, resistance to new or different activities, frequently misplacing personal items, increased disorientation in familiar neighborhoods, confusion about dates, increased distractibility, and difficulty finding words or connecting thoughts. While some of these issues are part of normal aging, in Alzheimer's they appear persistently, consistently, and with greater severity, significantly impacting daily functioning. Moreover, these changes worsen over time and become increasingly noticeable to others.

Alzheimer's also disrupts emotional regulation and behavior. This may be one of the most significant effects on quality of life and often strains social and family relationships. These issues are referred to as behavioral and psychological symptoms, and they are a primary cause of stress and burden for caregivers.[5] Common symptoms in this group include apathy (or emotional flatness), anxiety and irritability, depression, agitation (with or without aggression), sleep disturbances, and abnormal motor behaviors such as aimless walking or repetitive hand movements.[6] Although nearly all Alzheimer's patients experience at least one of these symptoms during the course of the disease, the specific symptoms and their severity vary from person to person and across disease stages.

Alzheimer's doesn't just damage brain cells; it also impairs the proper functioning of other systems in the body, since the brain is the main control center that regulates and coordinates organ systems. For example, the disease can affect the visual system[7] and other sensory systems,[8] the musculoskeletal system, and autonomic functions. Patients may have difficulty maintaining balance; combined with visuospatial deficits, this increases the risk of falls. Bladder and bowel control can also be affected, with urinary tract infections becoming more common. In advanced stages, basic functions such as swallowing become impaired, requiring special care during feeding.

Each person's experience with Alzheimer's is unique and depends on both individual and social/interpersonal factors. The pattern of symptoms, the rate of progression, and the impact on family systems vary case by case. Still, certain core features are consistent: it is a chronic, currently irreversible disease that significantly impairs autonomy, eventually leading to full dependency. It affects cognitive, behavioral, and emotional domains and disrupts family dynamics and personal relationships. Moreover, the experience of Alzheimer's has a profound impact on close relatives, particularly those who assume caregiving responsibilities. These primary caregivers are often referred to as "the second invisible patients," because they too require instrumental, practical, and emotional support to navigate the immense challenges of caregiving.[9]

Causes, Risk Factors, and Protective Factors of Alzheimer's Disease

There are two main forms of Alzheimer's disease: familial Alzheimer's and sporadic Alzheimer's. Familial Alzheimer's results from an autosomal dominant mutation in one of three genes: APP (chromosome 21), PSEN1 (chromosome 14), or PSEN2 (chromosome 1). Everyone with one of these mutations will develop Alzheimer's—typically at an early age. Their children have a 50% chance of inheriting the mutation. However, familial Alzheimer's accounts for only about 1% of all cases.[10] The vast majority of patients have sporadic Alzheimer's, meaning there is no known direct genetic cause.

Despite significant scientific and technological progress, the exact cause of sporadic Alzheimer's remains unclear. The brains of Alzheimer's patients differ from healthy brains in the accumulation of beta-amyloid plaques between neurons and neurofibrillary tangles within neurons. These structures are toxic and lead to neuronal death. These biomarkers are used to confirm an Alzheimer's diagnosis, either post-mortem or during life. However, it is still unknown whether they cause the disease or are a consequence of it.[11]

Sporadic Alzheimer's likely results from a complex interaction between genetic and environmental factors. One major genetic risk factor is carrying the APOE-e4 allele. Having one copy of this allele doubles the risk of developing Alzheimer's, while having two copies can increase the risk up to tenfold.[12] However, this gene is neither necessary nor sufficient for the disease.[13] In other words, some people with two APOE-e4 alleles never develop Alzheimer's, and some with Alzheimer's don't carry the gene at all.

A common question for healthcare professionals is whether having a family member with Alzheimer's increases one's own risk. Research shows that having a first-degree relative with sporadic Alzheimer's increases risk to 15–25%, compared to 10–15% in the general population.[14] So, while risk is elevated, it does not mean the disease is inevitable.

The most significant non-genetic risk factor is age. Prevalence of Alzheimer's doubles every five years after age 65. About 5% of 65-year-olds have Alzheimer's-related MND, rising to 13% at age 75, and around 30% by age 85.[15]

While neither age nor genetics can be changed, up to 40% of risk factors are potentially modifiable.[16] Knowing these risk factors is key to adopting healthier lifestyles that reduce the likelihood of developing the disease. Some estimates suggest that up to one-third of Alzheimer's cases could be prevented by minimizing risks and strengthening protective factors.[16]

Scientifically supported modifiable risk factors include: low educational attainment (especially lack of secondary education), hypertension, arteriosclerosis, obesity, high cholesterol, diabetes, uncorrected hearing loss, uncorrected vision problems, smoking, high alcohol consumption, depression, physical inactivity, social isolation, traumatic brain injury, and poor sleep quality.[16-18] Preventive actions include regular medical checkups, proper treatment of existing health conditions (e.g., high blood pressure, cataracts, hearing loss), healthy diets low in saturated fats and processed sugars, protecting mental health, managing stress, maintaining social relationships, promoting children's right to education, avoiding tobacco and substance use, maintaining healthy sleep habits, and using protective gear in high-risk activities (e.g., helmets when biking or playing contact sports).

There is less conclusive evidence on protective factors, though some promising ones have emerged. One is regular physical activity, which supports brain health both directly and indirectly. Exercise increases the release of substances that promote neuron health and connectivity and improves cerebral blood flow and oxygenation. It also reduces cardiovascular risk factors. Studies have shown benefits of exercise in both preventing Alzheimer's and slowing its progression in those already diagnosed.[19] The current recommendation is at least 150 minutes of moderate exercise per week.[20]

Another protective factor is the Mediterranean diet, rich in antioxidants and unsaturated fats. This diet emphasizes olive oil as the main fat, a high intake of vegetables, seasonal fruits, legumes, oily fish 1-2 times per week, eggs 3-4 times per week, whole grains, and low-fat dairy. It limits red meat, favors fruit for dessert, encourages hydration with water, and avoids processed foods, refined sugars, and salt. Nuts and berries are also recommended. Various studies have observed benefits of this diet for brain health and Alzheimer's prevention.[21]

Finally, lifelong mental stimulation appears beneficial. Activities that challenge cognition, such as card games, chess, learning a musical instrument or a new language, can help keep the brain active.[22] The World Health Organization recommends cognitive stimulation for older adults without cognitive impairment or with mild deficits to reduce their MND risk.[23] The evidence suggests that for these activities to be effective, they must be varied and challenging, rather than repetitive or overly familiar. [22]

Understanding modifiable risk and protective factors provides a powerful opportunity. While not all risks can be avoided and change is often influenced by access to healthcare and socioeconomic context, adopting a healthier lifestyle can at least delay the onset of Alzheimer's and slow its progression. Brain health should be nurtured throughout life, not only in old age. The earlier these habits are adopted, the greater their protective effect.

Stages of Alzheimer's Disease

A person does not go from being completely healthy to having a major neurocognitive disorder (MND) caused by Alzheimer's disease overnight. The disease begins to develop in the brain slowly and progressively, sometimes even decades symptoms significantly interfere with daily functioning.[24] Alzheimer's is therefore considered a continuum, beginning with subtle symptoms that may go unnoticed in standard cognitive tests and medical examinations. It then progresses to mild symptoms that are detectable through standard assessments but have minimal impact on daily functioning. Eventually, it reaches the MND stage, where symptoms significantly and visibly impair a person's ability to carry out daily tasks. Although significant efforts are underway to detect Alzheimer's in its pre-MND phase—including clinical trials testing disease-modifying agents—to date, we only have the tools to definitively diagnose and treat Alzheimer's symptoms once MND has already developed.[25]

MND due to Alzheimer's disease is further divided into stages based on the degree of cognitive deterioration and the patient's level of functional dependence. As mentioned, Alzheimer's disease is progressive in nature. The first stage of dementia in Alzheimer's disease is usually referred to as the "mild stage of MND." In this stage, patients show early cognitive deterioration and struggle with more complex activities of daily living. For instance, they may be unable to manage finances, plan trips or celebrations, remember appointments, or carry out formerly routine tasks such as playing games, cooking, using public transportation, managing medications, or operating technology. These more complex daily activities are known as instrumental activities of daily living.

Cognitively, individuals in this stage show clear signs of recent memory impairment, repeating questions and stories, frequently losing belongings, having trouble focusing on movies or novels, struggling to understand others, experiencing word-finding difficulties, and speaking more slowly and less fluently. These problems become noticeable to those close to the patient but may still go unnoticed in more casual social interactions. Patients may be fully aware of their deficits, have partial awareness, or lose the ability to recognize and remember their condition. Regardless, most people with Alzheimer's feel something is wrong. Their environment begins to feel unfamiliar, often triggering feelings of confusion, anxiety, disorientation, and fear.

At this and subsequent stages, it is important to implement behavioral strategies, make environmental adjustments at home, and establish daily routines to promote autonomy, engagement in meaningful activities, interpersonal relationships, and a sense of control. Rather than highlighting their mistakes, becoming frustrated by repetition, or doing everything for them, the goal should be to support a lifestyle that allows them to remain as independent, calm, and happy as possible. Before taking over tasks, caregivers should simplify activities and offer subtle supervision to encourage continued participation.

As brain damage progresses, patients move into the "moderate stage of MND." At this point, individuals require more assistance with daily tasks and become clearly dependent at home and in other settings. For example, they may need help choosing weather-appropriate clothing and may no longer be able to carry out complex home activities even with simplified routines and supervision (e.g., cooking, cleaning). Temporal and spatial disorientation is common; patients may forget their address or phone number and are at increased risk of getting lost, meaning they should always be accompanied when outside. In this stage, the individual can no longer live alone or participate independently in the community.

Eventually, the disease reaches the "advanced stage of MND," also known as the "severe stage." Here, the patient is dependent even for basic self-care activities like personal hygiene, using the bathroom, dressing, and eating. These are referred to as basic activities of daily living. Loss of bladder and bowel control is common. Patients begin to forget fundamental personal information and may struggle to recognize close family members. As the disease advances, verbal abilities decline, and basic psychomotor functions such as walking and swallowing are impaired. At this stage, non-verbal communication becomes vital for connection. Caregivers must pay attention to physical and facial cues indicating pain, thirst, hunger, and other needs. Music often serves as an effective form of stimulation and communication, allowing for continued shared experiences.

Healthcare professionals typically use objective scales to determine whether a patient is in the mild, moderate, or advanced stage of MND due to Alzheimer's disease.[26, 27] Understanding which stage, a loved one is in helps clarify their current needs and how to support their quality of life. The required level of assistance and the nature of their difficulties depend on the degree of impairment. Knowing how the disease progresses allows families to plan ahead and make decisions early—ideally, while the patient can still participate in those discussions.

Diagnosing Major Neurocognitive Disorder due to Alzheimer's Disease

Diagnosing MND due to Alzheimer's involves evaluating a clinical profile consistent with the disease and conducting thorough medical testing, including imaging and lab work. For a clinical diagnosis, the physician must confirm evidence of cognitive decline that significantly impacts the patient's functionality and is not due to other causes. Identifying and ruling out these other causes is essential, as some may be reversible (e.g., vitamin deficiencies, hydrocephalus, tumors). Therefore, the diagnosis should always be made by a healthcare professional.

The diagnostic process begins with a clinical interview in which the provider explores the history of symptoms to see if the pattern aligns with typical Alzheimer's progression. For example, they will ask when symptoms first appeared and whether the onset was gradual or abrupt. Unlike other causes of MND, such as strokes, Alzheimer's has an insidious onset. Often, patients and families have difficulty pinpointing when symptoms began and later realize that earlier signs were present.

Because Alzheimer's affects memory and self-awareness, patients should ideally attend the diagnostic interview with a close relative or caregiver, preferably someone they live with, who can offer detailed observations. Early consultation is ideal: as the disease progresses, brain damage spreads, making it harder to distinguish Alzheimer's from other MND types. Early-stage symptoms of different MND types are often distinct. For instance, frontotemporal MND typically presents with behavioral and emotional symptoms due to frontal lobe involvement, while Alzheimer's starts with memory problems due to medial temporal lobe damage. In advanced stages, distinctions blur as all brain functions deteriorate. Early diagnosis allows patients to make meaningful decisions about their future and gives families time to prepare and seek resources.

Beyond clinical history, objective evidence of cognitive decline must be shown through neuropsychological or cognitive tests. These involve asking the patient questions or assigning tasks to assess attention, memory, language, and other cognitive functions. Common screening tools include the Mini-Mental State Examination (MMSE)[28] and the Montreal Cognitive Assessment (MoCA),[29] among others.[30]

Ideally, patients should be evaluated by a neuropsychologist—a psychologist specializing in the assessment of cognitive, behavioral, and emotional symptoms related to brain disorders. Their expertise enables a more thorough analysis that supports accurate diagnosis. Unfortunately, neuropsychology is not always available in public healthcare systems and can be expensive. Greater recognition and funding are needed to improve access to these services.

Once cognitive decline is confirmed, it must also be shown to interfere significantly with daily functioning. This can be assessed through interviews or standardized functional scales. If cognitive decline is present but functional impairment is minimal, the diagnosis is mild cognitive impairment (also known as minor neurocognitive disorder). This may or may not progress to MND. If functional impairment is significant, the diagnosis aligns with MND. The next step is to rule out other potential causes, which requires further medical tests.

The classic workup includes a complete blood count and standard biochemistry, erythrocyte sedimentation rate, VDRL serology, serum folate and vitamin B12 levels, thyroid-stimulating hormone, and urinalysis. A chest X-ray and electrocardiogram are also common. Additional tests include brain images such as computed tomography (CT) scan or Magnetic Resonance Imaging (MRI) scans help rule out intracranial lesions, vascular events, or tumors and may reveal brain atrophy patterns supporting an MND diagnosis. Different MND causes show distinct regional atrophy patterns; for Alzheimer's, early signs include atrophy in the medial temporal and parietal lobes.

Multi-disciplinary diagnosing Alzheimer's disease is complex and requires collaboration among professionals, patients, and families. A detailed clinical history is key for ruling out alternative diagnoses, and family input is essential. Differential diagnoses include cognitive decline linked to depression or mood disorders, vascular cognitive impairment, alcohol-related cognitive decline, and other neurodegenerative causes like frontotemporal and Lewy body MND. Accurate diagnosis helps guide treatment and behavioral strategies to improve or maintain the patient's quality of life.

Myths and Realities of Alzheimer's Disease

There are many misconceptions about Alzheimer's disease, often stemming from outdated ideas or generalizations not supported by science. Dispelling these myths is essential for understanding the illness, adapting effectively, and creating MND-friendly societies where individuals with Alzheimer's can continue participating in their communities.

Here are seven common myths and the truths that debunk them:

Myth 1

Alzheimer's is just a part of getting old

It is not normal to lose memory and develop symptoms of Alzheimer's disease simply due to aging. Although Alzheimer's disease is more commonly seen in people over 65 years old, only a minority of elderly people actually suffer from it. Depending on the country and region, it is estimated that globally around 5% of people between 65 and 75 years old have Alzheimer's disease, increasing to 15% in those over 75, and up to 30% in people over 85.[31]

The false belief that cognitive impairment (CI) is an inevitable consequence of aging comes from the obsolete concept of "*senile dementia*", which still often appears even in clinical contexts. This term was coined two centuries ago to characterize the chronic loss of memory and judgment that occurred in previously healthy individuals, to differentiate it from transient delirium and congenital problems of judgment.[32] The scientific advances since then have been immense, and today we know there are multiple causes of CI that produce diverse symptomatic presentations. We know that Alzheimer's disease is one of these causes, and that it is a disease where there is a pathological accumulation of proteins that triggers progressive neuronal death. We know that the risk of developing Alzheimer's disease increases significantly with age, as is the case with most diseases, but this does not mean that age is the cause or that all elderly people will develop memory loss. For example, we know that the main risk factor for developing cancer is age: out of every 100,000 people under the age of 20, only 25 have cancer, compared to 1,000 people with cancer for every 100,000 people over 60 years old.[33] However, we understand that cancer is a disease and not an inevitable part of aging. In the same way, the risk of Alzheimer's disease increases significantly with age, but it is a disease, not a product of aging. That is why today we use the concepts of "dementia due to Alzheimer's disease," or "CI due to Alzheimer's disease." Furthermore, as previously mentioned in this chapter, there are cases of Alzheimer's disease in young adults.

This myth has negative effects, and it is important to dispel it. First, it can delay seeking medical advice, as memory difficulties may be assumed to be normal for the age. The later Alzheimer's disease is diagnosed, the worse the patient's quality of life will be and the greater the impact on their family. On the other hand, this myth undermines the diagnostic process, as it does not allow for clarification of the cause of the patient's symptoms. A poor diagnosis does not allow for proper intervention, and prevents patients and their families from dealing successfully with the disease. In order to respond appropriately to an event, it is necessary to understand it. This myth also encourages fear and a negative attitude towards aging in the population, creating anxiety about losing memory and becoming dependent as one ages. This leads to ageism, isolation, and the disengagement of older people from work and social environments.

Myth 2

If a parent had Alzheimer's, I will too

While it's natural to worry, fewer than 5% of Alzheimer's cases are due to a dominant genetic mutation. These "familial Alzheimer's" cases typically involve multiple affected family members or early onset. Most Alzheimer's cases are sporadic, caused by a mix of genetic and environmental factors.

Myth 3

There's nothing I can do to prevent Alzheimer's

There are people who believe that developing Alzheimer's disease is hereditary, or simply a matter of luck, and therefore that it does not matter what one does to prevent it. As we mentioned, hereditary forms of Alzheimer's disease are very rare. On the other hand, although there is still no definitive method to completely prevent Alzheimer's disease, modifiable risk factors and protective factors have been described that may play a role in its development. These factors were described in greater detail in the second section of this chapter. It is important to take responsibility for the care of our brain health throughout our entire lives. We should not only be concerned once we reach old age, when the negative effects of a sedentary lifestyle, poor diet, poorly managed hypertension, and uncontrolled diabetes may have already caused irreversible damage to our brains. We should not wait until it is too late. It is essential to know how to take care of our brain, and above all, to commit ourselves to practicing behaviors that keep it healthy.

Myth 4

Alzheimer's and MND are the same thing

We still have a lot of work to do in communicating knowledge about Alzheimer's disease and cognitive impairment (CI) to society. It is important that those of us dedicated to this field are able to share our knowledge so that everyone has an accurate understanding of what each term means, and thus be better prepared to face the disease themselves or help others do so. As we have mentioned several times throughout this chapter, Alzheimer's disease is one cause of CI. CI is a general term that describes a clinical condition in which a person progressively loses their higher brain functions (cognitive, behavioral, psychological functions). It is similar to saying "cold" or "flu." We all know that a cold occurs when a person experiences general malaise, cough, nasal congestion, sore throat, fever, etc. And we know that the cause can vary: it may be caused by rhinovirus, influenza A, influenza B, respiratory syncytial virus, metapneumovirus, etc. The same thing happens with CI. CI is when a person loses their higher mental faculties due to brain damage, and it can be caused by multiple factors.

The causes of CI are usually classified as irreversible or potentially reversible. Among the irreversible causes, the most common are: Alzheimer's disease (approximately 60% of all irreversible CIs are caused by this disease), CI due to Lewy bodies, vascular damage (or vascular dementia), frontotemporal CI, Parkinson's disease, Huntington's disease, Creutzfeldt-Jakob disease, and mixed dementia (when more than one of these causes are present). Among the potentially reversible causes of CI, the most common are: infections and immune disorders, low levels of vitamins such as vitamin B12 or thiamine, subdural hematomas, normal pressure hydrocephalus, brain tumors, and the effects of medications or substances.

It is important to know that the symptoms of CI can be due to different causes, and to perform a medical evaluation that allows us to differentiate between them and identify the underlying disease. It is essential to always rule out reversible causes that can be treated. Once these have been ruled out, it is recommended to identify the probable cause of irreversible dementia. Only in this way can we find the most appropriate intervention for the patient and their family, better understand the patient's condition, and seek the resources necessary to face their particular situation.

Myth 5

There are medications that cure Alzheimer's disease

Unfortunately, drugs that cure Alzheimer's disease, eliminate it, or reverse neuronal damage have not yet been developed. Nor have medications been created that can stop the progression of the disease. Currently, there are medications that help improve the quality of life of people with cognitive impairment due to Alzheimer's disease, aiming to slow its progression (the ones most commonly used are Galantamine, Rivastigmine, and Donepezil, which are cholinesterase inhibitors), or that target specific symptoms associated with the disease (for example, treatments to improve sleep quality or mood). In recent years, clinical trials (highly rigorous, complex, and controlled studies to verify the effect of a new medication or the use of an existing medication) have been conducted to observe the effects of new drugs in the earlier stages of Alzheimer's disease. Two of them (Lecanemab and Donanemab) have successfully passed the trial phases and have been approved by the United States Food and Drug Administration (FDA) and the European Medicines Agency (EMA). However, these medications have significant adverse effects and are currently being administered only to selected patients, under strictly regulated hospital protocols. The real impact of these drugs still remains to be fully understood.

Myth 6

Alzheimer's only affects memory

It is important to understand that, although recent memory loss (of things that happened the same day or a short time ago) is often one of the first symptoms, Alzheimer's disease produces a much more complex picture, with impairments in other cognitive areas (reasoning, language, attention, etc.), as well as difficulties in emotional and behavioral control. These difficulties are known as psychological and behavioral symptoms of cognitive impairment (CI), or sometimes as neuropsychiatric or non-cognitive symptoms. They often lead to noticeable changes in the person, and their family members may perceive them as no longer being the same as before. It is important to recognize that these symptoms are part of the disease, because if not, they can be misinterpreted as intentional acts by the patient to manipulate or annoy others. Understanding that Alzheimer's disease limits a person's ability to control impulses, tolerate frustration, understand their own moods and those of others, regulate their behavior according to social norms, and reason about the effects of their actions, helps people respond more positively to symptoms that can be challenging in individuals with CI due to Alzheimer's disease.

The psychological and behavioral symptoms of CI due to Alzheimer's disease may be triggered by direct effects of the disease (damage to neural systems related to the regulation of emotion and behavior), or by indirect effects. By indirect effects, we refer to the interaction between the disease and the patient's personality and environment. Cohen-Mansfield[34] and her team developed a model that is very useful for better understanding this: it is called the unmet needs model. In this model, it is explained that many of the behaviors of patients with dementia are the result of unmet needs (e.g., for safety, companionship, entertainment, or control), because dementia affects their ability to care for themselves, to autonomously satisfy their needs, and to communicate their needs to others. Thus, it is recommended that when facing an emotional or behavioral symptom that is causing conflict for the patient and/or their loved ones, efforts should be made to calm the patient and analyze the situation in order to identify what unmet need might underlie that symptom.

Myth 7

A diagnosis of Alzheimer's means life is over

Although Alzheimer's disease is progressive and currently has no cure, many people continue to live actively for years after diagnosis, enjoying meaningful moments and receiving treatments that can help improve their quality of life. There are both pharmacological and non-pharmacological interventions that can help people remain engaged in society and live a fulfilling life for as long as possible. Regardless of the stage the patient is in, there is always a way to connect with them—their emotions are still present, and we must continue striving for them to have the fullest, most active, and happiest life possible within their condition.

The list presented includes some of the most widespread myths about Alzheimer's disease. However, it does not cover all of them. The most important message of this section is to understand that we must properly inform ourselves about the disease, help others to better understand it, and seek scientific arguments or consult with professionals before accepting ideas or comments from others as true. We all must contribute to clarifying this disease, because only by being well-informed can we act in ways that positively support all those who are affected by it.

The Role of the Family

The family plays a fundamental role in the life of someone with Alzheimer's.[35] Family support provides emotional stability, reduces anxiety, and ensures a safer environment. Families are also central to treatment decisions and care planning.

The Role of the Caregiver

A caregiver—whether a family member or trained professional—is responsible for daily support, including hygiene, nutrition, mobility, and emotional care.[36] As Alzheimer's progresses, caregiving becomes more demanding and requires adaptability and resilience.

What It Means to Be a Caregiver

Being a caregiver means ongoing responsibility. It involves understanding the disease, providing constant support, monitoring symptoms, and often making difficult decisions. It demands both emotional and physical strength but can also be a deeply rewarding experience.

Caregiver Responsibilities and Challenges

Caregivers supervise safety, manage medications and appointments, assist with feeding and hygiene, and respond to behavioral changes. Challenges include coping with the patient's increasing dependence, stress, fatigue, and balancing personal life with caregiving duties.[37]

Essential Skills for Caregivers

Patience, empathy, organizational skills, emotional resilience, and effective communication are key. These skills help caregivers provide better care and maintain their own well-being.

Stages of the Caregiving Journey

Caregiving evolves with the disease. In early stages, patients maintain some independence but show signs of memory loss. In middle stages, assistance increases and behavioral symptoms emerge. In late stages, total dependence may occur, with loss of communication and mobility.[38]

Family Needs

Families of people with Alzheimer’s face multiple needs, including information and education about the disease, emotional and psychological support, financial assistance, and access to medical resources, as well as opportunities for respite for primary caregivers.[39]

Caregiver Syndrome

Caregiver syndrome refers to the physical and emotional exhaustion experienced by those who provide prolonged care to a dependent person. Physically, caregivers often suffer from chronic fatigue, sleep disorders, muscle pain, and tension due to constant effort and inadequate rest.[40]

Emotionally, caregiving can lead to stress, anxiety, depression, and guilt. Irritability, mood swings, and feelings of loneliness or isolation are common, especially as caregivers often neglect their own needs in favor of the patient’s well-being.[41]

Within families, living together can become strained, particularly when caregiving responsibilities are not shared equally, leading to conflict. It may also impact relationships with partners, children, and other relatives due to time constraints and emotional overload.[42]

In the workplace, many caregivers reduce work hours or leave their jobs to care for their loved ones, affecting their career and adding financial stress.[43] The cost of caregiving, including medications, home adaptations, and external support, can be high, especially if income is lost.[44]

Caring for the Caregiver's Physical and Mental Health

Maintaining Physical Health

Caregivers are at increased risk of physical health problems due to emotional stress and lack of self-care.[45, 46] Common issues include musculoskeletal pain, especially in the back, neck, and upper limbs, resulting from lifting and assisting patients. Lack of exercise contributes to joint pain and reduced mobility, and can lead to obesity and diabetes.[47] Caregivers also face a higher risk of heart disease, hypertension, chronic fatigue, and metabolic disorders due to prolonged stress.[48] Stress-related gastrointestinal issues such as ulcers and irritable bowel syndrome are also common.[49]

To prevent physical illness, caregivers should maintain a regular exercise routine. Walking for 30 minutes daily, stretching, yoga, or tai chi can relieve tension and promote overall well-being. Proper posture and ergonomic tools like adjustable beds and chairs help prevent injury.

Adequate sleep is crucial. Because caregiving often involves night-time interruptions, caregivers should try to maintain regular sleep schedules and seek support to share night duties. Nutrition is also vital: a diet rich in fruits, vegetables, lean proteins, and whole grains supports energy levels and immunity. Hydration, meal planning, and choosing nutritious snacks like yogurt and nuts can make a significant difference. Technology and telemedicine can also ease the physical burden by managing medication schedules, supporting health monitoring, and enabling virtual medical consultations.[50]

Mental Health and Emotional Well-being

Caregivers experience significant emotional strain. Chronic stress from constant vigilance can lead to burnout, which is a state of emotional, mental, and physical exhaustion.[51-53] Depression and anxiety are prevalent among caregivers, especially those without adequate support.[54] Anticipatory grief is common as caregivers witness the slow loss of their loved one's personality and independence. Social isolation compounds these effects,[55] as caregivers often reduce personal activities and social contacts.

Sleep disorders are another frequent issue,[56] impacting cognitive function and decision-making. Caregivers may even develop mild cognitive impairment due to prolonged stress and lack of rest.[57]

To counter emotional overload, caregivers should set boundaries and seek help when needed. Stress management strategies like meditation, breathing exercises, and expressive writing are effective. Maintaining social connections and joining support groups increases emotional resilience.

Rest is essential to mental health. Counseling and psychological therapy can help caregivers cope with distress. Support groups—online or in-person—allow caregivers to share experiences, express feelings, and receive guidance. Mental health professionals can provide tools to address anxiety, guilt, and grief.

The Importance of Rest and Self-care

Rest and self-care are not luxuries but necessities. Caregivers must integrate self-care into their daily routine to maintain physical and emotional well-being. Short breaks during the day, clear boundaries, and guilt-free downtime are vital for stress reduction.

Emotional self-care includes acknowledging emotions, validating feelings, and recognizing when help is needed. Activities like reading, listening to music, or spending time in nature can be restorative. When caregivers are healthy, they can provide better, more sustainable support to their loved ones.

The Importance of Social Support

Social support is critical. Having a network of family, friends, and professionals helps reduce caregiver stress. Strategies include joining caregiver support groups, consulting Alzheimer's organizations, delegating responsibilities, and using community services.[58]

With the right support and guidance, caregivers can provide dignified, high-quality care for both themselves and the patient.

Planning for the Future

As Alzheimer's progresses, patients' needs evolve. Proactive planning helps caregivers adapt and maintain quality of life. Advance care planning allows patients and caregivers to express preferences for future care and ensure those wishes are honored.[59]

Long-term Planning

Anticipating changes helps reduce stress. Advance care planning includes defining medical, legal, and financial preferences to avoid crisis-driven decisions. Many families lack guidance in this area, increasing caregiver stress.

Caregivers involved in planning experience less distress and greater resilience wishes with respect to resuscitation and palliative care.[60] Planning should include advance directives for medical care (e.g., CPR, palliative care) documented in legal forms like living wills or powers of attorney.[61] A solid financial plan is also essential, as MND care can be expensive.

Legal advice can help structure documents, manage assets, and prevent conflicts.[62] Building a support network that includes family, friends, and professionals is also crucial.

Finally, planning for the possible institutionalization of the patient is a decision that should be addressed ahead of time, with clear information about the available options. Many families experience feelings of guilt and ambivalence when considering admission to a specialized care facility, so researching the costs, services, and admission criteria in advance can help make the transition less abrupt. It has been shown that caregivers who prepare in advance for this stage experience less distress and have a greater capacity to adapt.[63] The lack of structured support in these areas has been identified as one of the main unmet needs for caregivers of people with Alzheimer's disease. Well-informed, early planning not only reduces uncertainty, but also improves the quality of life for both the patient and the caregiver.

Day Care Facilities and Transition to Long-Term Care

As the disease progresses, many families consider the option of day care facilities or long-term care centers. These settings can improve the patient's quality of life by providing specialized care and, at the same time, offer respite for caregivers. However, the adaptation process is not always easy. The transition to institutional care represents a critical moment for both the person with cognitive impairment and their relatives. For many caregivers, relinquishing direct responsibility for the patient's well-being and taking on a new role as visitors can lead to feelings of guilt.

Many caregivers feel that they have "lost" their loved one when the person is institutionalized, even when the patient is still alive.[64] This transition is accompanied by mixed emotions: on the one hand, relief in knowing that the patient is safe and well cared for; on the other hand, feelings of emptiness, anticipatory grief, and loss of purpose. The change in routine and the redefinition of the caregiver's role can contribute to isolation and depression, especially among those who have dedicated years to the exclusive care of a family member with Alzheimer's disease. Recent research reinforces that the sense of loss of control over the patient's well-being increases emotional stress in caregivers, which can affect their mental and physical health.[64]

One of the greatest challenges in this transition is trusting the institution's staff. Although care in specialized facilities is usually provided by trained professionals, many caregivers continue to actively supervise the patient's care and may feel anxious about not being present at all times. Those caregivers who receive guidance on how to redefine their role, establish effective communication with staff, and maintain a connection with their loved one experience better adaptation and less emotional burden during this transition.[64]

Access to day care facilities can be a useful alternative to facilitate this process of change. These facilities allow the patient to receive specialized care during the day while the caregiver has time to rest, work, or engage in personal activities, thus reducing overload and burnout. However, a major obstacle remains the lack of clear information about the availability and quality of these services. Many families are unaware of what options exist in their community, how to access them, and what the admission criteria are.

End of Life and Grief in Caregivers

The end of the patient's life is an inevitable reality that caregivers must face. As the disease progresses, many experience anticipatory grief, feeling the gradual loss of their loved one even before their passing.[65] This process of anticipatory grief is characterized by deep sadness and a sense of helplessness, as caregivers observe the progressive deterioration of the patient's identity and autonomy.

When the final stage arrives, emotions can intensify, especially if clear decisions about palliative care have not been made. The lack of planning in this area can generate anxiety and feelings of guilt in caregivers, who may question whether they did enough or made the right decisions in the patient's final days. The death of a loved one marks a profound change in the caregiver's life. For years, their identity has been defined by their caregiving role, and the sudden absence of this responsibility can create a sense of emptiness that is difficult to cope with. Many caregivers experience an emotional crisis after the loss, during which they must rebuild their identity and find new sources of purpose. This psychological impact can be aggravated by a lack of social and professional support, increasing the risk of depression and anxiety in the months following the patient's passing.

At this stage, access to support groups and psychological therapy can be fundamental in facilitating the grieving process. Caregivers who participate in post-bereavement support programs have a better capacity to adapt to the loss and a lower risk of developing long-term emotional disorders.[66] Although the transition is painful, it also represents an opportunity for the caregiver to regain aspects of their life that had been put aside during their loved one's illness. Finding new activities, reconnecting with support networks, and receiving professional guidance can help manage the loss in a healthier way.

Preparing for the Future

Preparing for the future in the care of a person with Alzheimer's disease involves anticipating changes, planning clearly, and accessing resources that facilitate decision-making. From establishing advance directives to financial and legal planning, early organization reduces uncertainty and relieves the caregiver's emotional burden. The transition to day care centers or long-term care facilities can generate feelings of guilt and loss, but with proper information and support, this stage can be managed more smoothly.

Available Treatments for Alzheimer's Disease

Alzheimer's is a neurodegenerative condition causing physical, cognitive, emotional, and behavioral challenges.[67] Though there is no cure, treatments—pharmacological and non-pharmacological—can manage symptoms and improve quality of life.

Pharmacological Treatments

Acetylcholinesterase Inhibitors: Drugs like donepezil, galantamine, and rivastigmine increase acetylcholine levels in the brain, improving cognitive function in mild to moderate stages.[68]

NMDA Receptor Antagonists: Memantine regulates glutamate activity to protect neurons in moderate to severe stages.[69]

Monoclonal Antibodies: New drugs like lecanemab and donanemab target beta-amyloid buildup and may slow early-stage progression. However, they may have serious side effects and limited availability.[70]

Non-pharmacological Interventions

Cognitive Rehabilitation

This refers to a set of strategies and techniques designed to improve or maintain cognitive functions in individuals experiencing decline due to conditions like Alzheimer's. The goal is not to cure the disease but to optimize preserved abilities and enhance the patient's quality of life.[71]

Cognitive Stimulation

This involves activities aimed at activating different brain functions, such as memory, attention, and language. Examples include word games, puzzles, category exercises, simple text reading, and music-based activities. Tasks should be adapted to the patient's cognitive level to avoid frustration and maintain motivation. Consistent and varied exercises can help reinforce neural connections and delay cognitive decline.[71]

Errorless Learning

This method reduces errors during learning by providing cues or guidance until the task can be completed correctly.[72] For example, if the goal is to help the patient remember a family member's name, a labeled photograph can be shown repeatedly in a positive context. The technique fosters memory through guided repetition and consistent support.[73]

Spaced Learning

This involves repeating information at gradually increasing time intervals. It helps reinforce memory, such as remembering the day of the week or the names of caregivers, and supports long-term retention of recent information.[71]

Visual Imagery

This strategy enhances memory by associating information with vivid mental images. For example, asking the patient to imagine a large, bright glass of water when they feel thirsty helps strengthen associations between concepts and memories.[74]

Generation Effect

Information is more easily remembered when the patient generates it themselves. Guided questions prompt recall rather than passive reception. For instance, instead of saying "today is Tuesday," ask "Do you remember what day it is today? Yesterday was Monday," offering hints if needed. This encourages deeper processing and active learning.[71]

Spaced Retrieval

This technique reinforces memory by prompting the patient to recall information repeatedly over progressively longer intervals. It is useful for helping patients remember personal data or daily routines, such as the names of loved ones or locations of important objects.[75]

Fading Cues

This method gradually reduces prompts as the patient improves. For example, initially providing a hint like "His name starts with M," and then slowly phasing out the cue helps the patient retrieve the information independently.[76]

External Aids

These include tools such as planners, alarm clocks, information signs, and mobile apps for task reminders. For patients with Alzheimer's, such aids help structure daily activities and maintain autonomy. Visual notes and alarms support time and space orientation and reduce anxiety linked to forgetfulness.[71]

When applying these techniques, personalization is key. Techniques should match the patient's cognitive status and involve caregivers in reinforcing learning. Patience, repetition, and positive reinforcement are essential. Combining methods can lead to better outcomes when tailored to individual needs.

Reality Orientation Therapy (ROT)

This therapy helps Alzheimer's patients maintain orientation in time, space, and personal identity, enhancing security and self-esteem.[71]

Session-based ROT: Conducted in small groups focusing on basic information such as date, location, and names. Discussions about recent events help maintain awareness.[77]

24-hour ROT: Implemented throughout the day by caregivers using large clocks, calendars, and signage to reinforce orientation. Studies show this approach can help preserve cognitive functions in individuals with MND.

Validation Therapy (VT)

This approach, particularly effective in advanced MND stages, emphasizes empathy and respect by validating the patient's feelings rather than correcting them. VT uses 14 communication techniques designed to foster connection.[78]

While more research is needed to fully confirm its efficacy, VT has shown promise in reducing stress, improving mood, and minimizing behavioral issues. Ongoing studies aim to better understand its impact on quality of life and cognitive functioning.

Reminiscence Therapy (RT)

RT helps MND patients recall personal history to reinforce identity and self-esteem. It uses prompts like photos, music, videos, and newspapers to trigger positive memories.[79]

Individual RT: Involves creating a "life book" to compile important personal memories.

Group RT: Encourages discussion about past experiences using meaningful objects or media. Studies show RT enhances cognitive function and quality of life in people with MND.[80]

Montessori Method

Adapted for MND care, this method enables independent activity through task breakdown and use of familiar objects. It promotes autonomy, self-esteem, and a sense of achievement. Research shows it improves attention, social interaction, and quality of life while reducing agitation.[81]

Intergenerational Therapy

This brings together older adults and younger generations in shared activities such as art, music, and storytelling. Benefits include reduced anxiety and depression in Alzheimer's patients and improved social attitudes and skills among the youth. Success factors include relationship-building, education on Alzheimer's, use of the Montessori method, participatory planning, and reflective journaling.[82]

Animal-Assisted Therapy

Animals are integrated into treatment to improve patients' physical, emotional, and social well-being. Interacting with animals can reduce anxiety, enhance memory and communication, and promote physical activity. It also supports better eating habits and decreases loneliness.[83]

Physical Activity

Regular exercise promotes healthy aging and may reduce Alzheimer's progression. While studies vary, some show physical activity improves daily function and slows cognitive decline. Aerobic exercise in particular may boost memory and executive function.[84]

Music Therapy

This uses music to enhance communication and emotional well-being. Sessions may involve singing, listening, or playing instruments. Music stimulates multiple brain areas, reducing anxiety, improving mood, and curbing disruptive behavior—even in late-stage disease.[71, 85]

Art Therapy

Art therapy uses creative expression to reduce anxiety, boost self-esteem, and aid emotional communication. Patients engage in painting, drawing, or sculpting under guidance. Research suggests it improves well-being and psychological symptoms, though more studies are needed to confirm effectiveness.[71, 86]

Virtual Reality (VR)

VR offers three-dimensional (3D environments for safe interaction and cognitive training. It helps assess and enhance skills like memory and orientation while simulating real-life tasks. Benefits include realism, safety, and increased engagement. VR holds potential for preserving cognitive function and improving quality of life in MND patients.[87, 88]

Home Automation

Technology that supports Alzheimer’s patients and caregivers in daily tasks. Home adaptations and assistive devices can improve patient safety and ease caregiver burden, which is particularly important as most patients live at home. However, home changes should be introduced early in the disease to avoid disorientation.[71, 89] Accessibility, cost, and caregiver awareness remain barriers to widespread use.[90]

Conclusion

Non-pharmacological therapies play a crucial role in care for a person with Alzheimer's disease. They help preserve abilities, reduce anxiety, and support emotional well-being. While pharmacological and non-pharmacological benefits may be modest and disease progression continues, individualized approaches can offer meaningful improvements in quality of life.

Pseudo-therapies: Identification and Prevention

In the emotional and physical challenge of caring for a loved one with Alzheimer’s, many families seek alternatives beyond conventional treatment. However, numerous “therapies” lack scientific support and may pose significant risks. Below we explain what pseudo-therapies are, their dangers, how to recognize them, and how to verify claims of medical effectiveness.

Risks Associated with Pseudotherapies

The use of pseudo-therapies in individuals with Alzheimer's disease can lead to a range of serious consequences:

Delays in Receiving Appropriate Treatment

Trusting in non-scientific treatments can cause patients to lose valuable time that could have been used to benefit from proven medical therapies.

Adverse Effects

Some alternative remedies may contain substances that interact dangerously with prescribed medications, potentially worsening the patient's condition.

Financial Exploitation

Many pseudo-therapies come with high costs, preying on the vulnerability and desperation of families seeking a cure.

False Hope and Emotional Distress

Marketing of so-called miracle cures creates unrealistic expectations that often result in emotional exhaustion, disappointment, and a sense of failure when the promised results are not achieved.

How to Identify and Avoid Pseudotherapies

To protect loved ones from misleading and potentially harmful treatments, it is crucial to develop the ability to identify not be based on scientific results pseudo-therapies. Warning signs that a treatment may lack scientific validity include:

Extraordinary Claims Without Evidence

Statements like “definitive cure for Alzheimer's” or “guaranteed results” are immediate red flags.

Lack of Scientific Backing

The therapy has not been supported by clinical trials published in peer-reviewed medical journals.

Reliance on Anecdotes

Testimonials and personal stories replace scientifically validated data.

Distrust of Conventional Medicine

Claims that mainstream medical institutions are hiding the truth or suppressing alternatives.

Sale of Unregulated, Expensive Products

Often marketed without proper health regulation, such as approvals from Official Institutions, and with inflated prices.

Resources for Verifying Information

To avoid falling for scams or ineffective treatments, always turn to reliable sources. The following tools can help verify whether a therapy is safe and evidence-based:

Official Institutions

Websites of the World Health Organization (WHO), the U.S. Food and Drug Administration (FDA), or the National Institute on Aging (NIA) offer trustworthy, updated medical guidance.

Healthcare Professionals

Before starting any alternative treatment, consult primary care providers, neurologists, geriatricians, pharmacists, or other licensed providers.

Scientific Databases

Platforms such as PubMed or the Cochrane Library contain peer-reviewed, scientifically validated studies.

Anti-Misinformation Platforms

Initiatives like "No Sin Evidencia" and the "Red de Prevención contra las Pseudoterapias" (Network for the Prevention of Pseudotherapies) work to debunk false claims and promote public education.

For English speakers, I recommend: webmd.com, Medscape.com and smartpatients.com looks interesting

Pseudo-therapies represent a real threat to the health and well-being of Alzheimer's patients and their families. The most effective defense is staying well-informed, critically evaluating claims, and always prioritizing scientifically validated care. When faced with a sea of conflicting information and empty promises, it is essential to remain grounded in the facts. The path toward supporting someone with Alzheimer's is not defined by miracle cures but by consistent, compassionate care.

Ultimately, what truly matters—more than any alternative treatment—is love, patience, and the daily act of being present. The next section shares firsthand experiences of caregivers who have accompanied their loved ones through this journey, overcoming hardship and creating lasting, meaningful memories along the way.

Life Stories

Mario

My name is Mario, I live in San Juan, Puerto Rico, and I am 77 years old. I am a retired pediatrician, having worked for over 30 years in my private practice. When my wife was diagnosed with Alzheimer's disease, I decided to sell my office and dedicate myself entirely to her care.

Before my wife was diagnosed, I was actively working in my pediatric practice. I focused mainly on helping mothers with breastfeeding, and since there weren't many pediatricians supporting this, families came from all over the island to see me. I met my wife at university; she is Spanish, later lived in Cuba, and eventually moved to Puerto Rico. After we got married, we moved to Spain where I studied medicine. We have four children—two born in Spain and two in Puerto Rico.

My wife was always incredibly active; she was the heart of our household. She planned all the birthdays and family events and handled all the finances for our home and my office.

I began noticing something was wrong when the electricity bill was delayed. She had never missed a payment before. We started arguing more often because she would contradict what I said, or I would have to repeat things to her multiple times because she wouldn't remember. One time, I found over ten or fifteen undeposited checks hidden in a closet. She had forgotten about them. These incidents escalated and she began acting aggressively towards us, even physically striking me. Despite being a doctor, I didn't recognize these as early signs of Alzheimer's.

We tried to take her to the doctor, but she refused, insisting she was fine. We eventually convinced her to see a psychologist who was a close friend of hers. The psychologist, a neurologist, my wife, and one of my daughters met while I waited outside. Suddenly, I saw my wife running out of the office. Apparently, she got upset when they asked her direct questions and left. The psychologist told us we would have to bring her in involuntarily to get a proper diagnosis and start treatment. Although it was hard, we followed through with a court order that allowed an ambulance to bring her to the hospital.

At the hospital, she calmed down, allowed the doctors to examine her, and even agreed to an MRI. The test results were normal, but during the psychological assessment, she conducted herself so well that the psychologist concluded she didn't need to be hospitalized. I disagreed, knowing how aggressive she could be at home. I asked a family friend who is also a psychologist to call and explain the full situation. When they told my wife she'd stay overnight for observation, her mood immediately changed. She tried to run away. Thankfully, the doors were locked. Nurses restrained her, and she began fighting them. That incident convinced the psychologist to admit her. She was sedated and transferred to another hospital for more evaluations, staying for five days. The neurologist reviewed the results and confirmed the diagnosis: Alzheimer's, due to dysfunction in the hippocampal area, and advised starting treatment immediately.

We were devastated. Even though I was a pediatrician, nothing had prepared me for life with someone living with Alzheimer's. I didn't know how to communicate with her. Fortunately, the hospital gave us guidance, although she resisted attending any follow-ups. Our psychologist friend gradually taught me how to manage her behavior. Later, I connected with a Puerto Rican organization that supports Alzheimer's patients and caregivers, where I learned even more. The director recommended a professional caregiver who has been a tremendous help, not only in looking after my wife but in teaching me how to care for her properly.

It's been hard, especially having to lie, which is something I've always disliked. I've had to use "white lies" and even words I usually wouldn't say to connect with her.

The most difficult part of caregiving has been the arguments. We never used to fight. But now we do, and I've learned to understand it's not her fault. She used to handle everything at home—I didn't even know how to pay the utility bills. Learning all of that was overwhelming. I came to realize that housework is a 24-hour job. I never used to cook, and now I've learned to make simple meals and do the grocery shopping. I'm amazed at how much she used to do without me noticing.

We were devastated

Amidst all this stress, I got sick and had to see a doctor. That was a wake-up call. I realized I needed to take care of myself too. I started eating healthier, walking, going to the gym, and taking art classes at my daughters' suggestion. That's helped tremendously.

This is a process, and I know it won't improve—the disease will continue to progress. She still recognizes me and talks to me. There are moments when she's agitated and others when she's calm. She's lost bladder control and I have to help her with that. Sometimes she feels embarrassed and tells me so. Some nights she wakes up a lot, has hallucinations or nightmares; other nights she sleeps peacefully. We've made home modifications: installed grab bars in the bathrooms, safety railings, and are considering a ramp to get her wheelchair upstairs.

She did so much for me that what I'm doing now is the least she deserves. Thankfully, my children are supportive, and the caregiver helps a lot with cooking and daily care. She's also taught me how to handle situations better.

Right now, I can say things are under control. I stick to a routine—waking her up at the same time, scheduled meals, bedtime rituals. Just last night, she suddenly held my hand and said, "I love you so much. You're so good to me, and you treat me so well." That made me incredibly happy—those moments didn't used to happen, but now they do. I'd say we're in a sort of honeymoon phase.

Relationships with others have changed. When we go to events, people greet her but don't want to spend time with us. They treat her like a child rather than an adult. Because they don't understand the disease, they withdraw from what they don't comprehend.

What worries me most now is the risk of her falling. She's lost mobility. She's already had a fall—thankfully no fractures—but I know the next one could completely incapacitate her. The best results have come from the therapy she receives at the local Alzheimer's center here. She didn't want to go at first, so they sent a therapist to our home. We even found a music therapist. But when she finally started attending sessions at the center, the change was immediate. She sings, dances, socializes—and even asks me to dance with her. It was a complete transformation. Seeing her laugh makes me laugh. We now go twice a week.

The caregiver helps a lot with cooking and daily care

The most positive thing about being her caregiver is that I've learned so much about Alzheimer's and how to manage it. And as I mentioned earlier, I now take better care of myself—my health and lifestyle have improved. Above all, I get to share so many meaningful moments with my wife. This illness has brought us closer. She wants to be with me, asks for kisses, and even though I know she won't get better, I'm committed to enjoying every moment.

To anyone just beginning this journey with a loved one who's been diagnosed with Alzheimer's, my advice is this: First, educate yourself. Without knowledge, you won't be able to manage this disease. It's tough. Second, love that person deeply and use humor. Humor is essential; you have to be able to laugh at situations because you can. And learn to lie-there's no way around it. They live in a different reality, and you have to enter that reality and know how to handle it. I've been to Alzheimer's support groups, but I don't like that everything discussed is always negative. That can be really depressing. There are positives in this process, too. Support groups are important, but they should also highlight what's good. There are many positive aspects to this journey.

María

My name is María, I am 56 years old, and currently live in San José, Costa Rica. I am a psychologist by profession. I cared for my mother for 16 years while she lived with Alzheimer's disease. She passed away nine years ago. At the beginning of her illness, I lived in a separate house but visited daily to care for her. At that time, my father and one of my brothers were living with her. Years later, after my divorce, I moved in with my daughter to live with my mom.

Before the diagnosis, my life was considered "normal". I was very happy raising my daughter. During her early years, I left work to focus on raising her. I spent time playing, attending school activities, managing my household, visiting my parents regularly, and seeing friends. Of course, like everyone, I had my share of problems. The bond I had with my mother was always very close-one of the most important of my life. I considered her my best friend and confidant. Before the disease, my mom was a truly brilliant woman: a Spanish teacher, always affectionate, an excellent communicator, joyful, strong-willed, and a wonderful mother and human being.

Among the first symptoms were subtle changes. She became forgetful and distracted, but it wasn't serious at first. A year later, her personality grew more apathetic. I noticed changes in her appearance and mood, and those concerned me.

She was diagnosed in September 2001. At that time, I didn't even know what Alzheimer's was. The doctor showed little empathy when breaking the news. He bluntly said, "In a few years, your mom won't know who you are or your names." We were completely ignorant of the disease. It was the first time we heard of it. That statement shattered me. It was devastating to think that someone I loved so deeply would change so drastically. My mom stayed silent. At home, my father, siblings, and I talked and tried to process the news.

Among the first symptoms were subtle changes

The first months were filled with denial. Then, just 15 days after the diagnosis, my father died from multiple heart attacks. That compounded my grief—I was mourning both my father's death and my mother's health. I felt frustrated, scared, and powerless. The doctor recommended we reach out to an association, where we began to learn more. My siblings and I organized to care for our mom, with the help of a household employee who became like a sister. Close friends supported me emotionally.

The doctor referred us to the Costa Rican Alzheimer's Association (ASCADA) for family support during that difficult time. I later ended up working there. He also recommended enrolling my mom in an adult day center for socialization, which helped for about two years. However, he didn't inform me much about caregiving, which I learned later through the association and by reading extensively.

The experience of caring for my mother through Alzheimer's was a profound act of love and a life lesson. It marked a before and after in my life. I took on the primary caregiver role freely and out of love. That role brought many sacrifices. My siblings were secondary caregivers—one was especially supportive—but all tried their best. As my daughter and nephews grew, they occasionally helped too, especially my daughter. When we received the diagnosis, my daughter was only four. My role as a mother was and remains deeply important to me. The family dynamic changed, especially my time as a mom—I had to multiply myself because I was never going to neglect my daughter. We understood it was our turn to care for my mom, just as she had cared for us. But the roles never reversed—she remained our mother despite her cognitive decline.

To meet her care needs, we made minimal home adjustments since the house had already been adapted for my grandparents, whom we had also cared for. We always made sure she had the medical equipment she needed as the disease progressed.

Aside from the moment of the diagnosis, the hardest part was when she lost her ability to speak due to a minor stroke early on. She could no longer say a single word. Over the years, it was painful and heartbreaking to witness her slowly fade away, like water slipping through your fingers.

Thankfully, the disease did not bring major financial burdens. We had the means at the time but needed good planning to manage expenses.

In the final years, I began feeling indescribable exhaustion. Alzheimer's lasted 16 years. There were times I couldn't get out of bed. My schedule was from 5 a.m. to 10 p.m., caring for her while also working. Emotionally, I was affected, but I always sought strength in God, because I had to be there for my mom and daughter. I experienced severe muscle pain, contractures, and occasionally needed medication for physical pain—but never for emotional burden.

My divorce wasn't related to my mom's illness—it stemmed from other issues. I kept most of my friendships, but a few drifted away during those years.

I went through every emotional state. As a primary caregiver facing divorce, surgery for hip replacements, and multiple losses, I often repressed feelings to keep going. Still, each time my mom declined, I allowed myself to cry—privately—feeling immense pain. I never saw death as a release for her. When it finally came, accepting it was very hard. Our family's goal was always to give her the best quality of life. I loved being her caregiver and was grateful when my family let me rest. But toward the end, that support dwindled, making things harder physically and emotionally.

A profound act of love and a life lesson

It's hard to pinpoint what worried me most, but perhaps when she couldn't eat anymore. We had to consider a Percutaneous Endoscopic Gastrostomy (PEG) feeding tube to avoid starvation, given the risk of aspiration. Another challenge was a heel ulcer, the only one she had. No one had warned us to avoid constant contact with the mattress. I cared for and cleaned it daily, difficult but possible through love.

Our family always gathered for special occasions. My mother was never without love and companionship. However, we never took time to express how each of us felt. We each coped in our own way. My communication with her never stopped (none of ours did), even when she couldn't speak. I would tell her about work, my daughter, only good things so she wouldn't worry. I read her stories, the Bible, prayer books. She enjoyed that. I never wanted her to feel underestimated. Our relationship was always strong and beautiful, but Alzheimer's deepened it even more.

Sadly, not all doctors are sensitive toward patients or families. As health professionals, they must communicate with empathy and compassion. The information families receive is emotionally overwhelming.

During this time, I also tried to take care of myself physically—I liked going to the gym. I went out with friends when possible, if a sibling could watch over mom. I never sought therapy or medication during caregiving.

I felt judged by society. Though not always negatively. When I took my mom out to eat, which I never stopped doing, some people didn't understand why I fed her. But that never stopped me from caring for her or enjoying those moments.

In the final stage, my mom was non-ambulatory, needed oxygen, and required daily nebulization. A respiratory therapist and two physiotherapists visited regularly. When they didn't, I handled exercises and massages they had taught me. I repositioned her every two hours to avoid ulcers. I believe she never gave up—her faith was stronger. She could still look us in the eye, sit with help, even when doctors said she medically shouldn't be able to, given her brain condition.

Her weakest point was respiratory. She often had phlegm. In her final month, the therapist visited frequently. When her breathing worsened, despite oxygen and nebulization, we took her to the hospital. She was developing pneumonia again. She had survived it once before. She was hospitalized for two long, difficult days. We siblings rotated to ensure she was never alone. She died while my eldest brother was with her, the last of us to visit that day. I thank God and my mom for the final six hours I spent by her side. She stayed awake, which was rare, and gave me the most loving, grateful looks. I thought she was improving and would come home the next day. When my brother arrived to take over, I kissed her forehead and said, “See you tomorrow, my beautiful old lady.” I left happy. It wasn’t a goodbye filled with sorrow—that was a gift. I now realize she was saying goodbye with all her love. That night, I slept peacefully, thinking she was recovering. Around midnight, my daughter and brother woke me. I immediately knew. I broke down, entered total denial. I thought she was fine. I cried uncontrollably, holding my daughter.

Today, with all I’ve lived and my psychology background, if I could change something, it would be respecting my own rest and caring for myself more. I always came last.

To cope with the demands and changes of her illness, I built emotional walls to keep myself strong despite my vulnerability. My life changed drastically after her passing. Anticipatory grief didn’t help me much. Her absence weighed on me daily. I missed her deeply. My walls collapsed. Life changed again. Thankfully, my uncles invited me to join a grief therapy group. It was a true gift.

To those just starting this journey with a loved one diagnosed with Alzheimer’s: surprisingly, there are positive things to rescue from this painful experience. First, your view on life changes. It’s up to you whether for better or worse, often bittersweet. You learn life is just one moment, and every opportunity for joy should be seized. My mom loved dancing with her in her wheelchair. When she couldn’t get up anymore, I played her favorite music and danced her wheelchair. You learn how fragile life is, and how quickly it passes. Say “I love you” often. It’s never too much. If there is communication, understanding, teamwork, and love, families can grow stronger. And lastly, you discover who your real friends are, those who stay by choice.

My humble advice: don’t go through this alone. Seek help from health professionals. It’s essential to have a team of doctors across specialties to face complications, your loved one’s or your own. And above all, seek psychological support during and after the journey. There will be confusion and grief along the way.

Respecting my own rest and caring for myself more

Libni

My full name is Libni, I'm 47 years old and I live in Costa Rica. I'm self-employed, and my mother is the one suffering from Alzheimer's disease. Her name is Bernardita Herrera García. I've been taking care of her for 15 years, ever since my father passed away, but the full-time caregiving began when she was diagnosed with Alzheimer's. It's just the two of us living in the house, and her symptoms began six years ago. From that moment, life became more difficult. It always has been, but her diagnosis six years ago made everything even more complicated.

When my father was alive, things were easier. I had time to go out with friends. But since I've been taking care of her-15 years since my father died-my social life has been a struggle. My mother would get upset when I went out, even when I left to go to work. When my father was around, I could go out, take a weekend at the beach without worry because my parents were together. I had, let's say, a normal life-going out, studying, those kinds of things. Back then, two of my brothers were also at home, but sadly, they've always been disengaged with my parents. There wasn't a good relationship between them and my parents. It was complicated.

My mother's symptoms became more evident and frequent six years ago. I'd leave meals ready for her, and she wouldn't eat. I noticed she was starting to forget to eat. That's when I realized she needed me at home more, so I started looking for a job that would allow me to spend more time with her. Over the years, I noticed my mom began treating me poorly. For example, I'd go out, and she'd get really upset, and the next day she wouldn't even remember it. That's when I knew something was wrong. It wasn't normal for her to treat me badly, for me to feel frustrated, and then for everything to go back to normal as if nothing had happened.

She also started repeating the same stories, stories about my dad, her childhood, adolescence, and youth. She talked a lot about her mother and a situation with her younger brother. Those stories became more and more repetitive. Over time, her anxiety worsened. She's never had an easy personality, but everything she already had became more intense with the years and the progression of the disease.

When I received my mom's diagnosis, I cried a lot. It's been an extremely hard and difficult process. At first, I tried to involve my siblings. I found a psychologist and told her, "I need my siblings to help me because I can't do this alone. She has five children, not just one daughter." It's been very painful to feel alone in this process. Even though I've come to accept her diagnosis, it hurts to see our mother, who gave everything to her children, be abandoned by them. That, along with witnessing the progression of her illness, has been incredibly hard. Her symptoms began ten years ago, worsened six years ago, and this past year has been the worst. When I was told her diagnosis, the doctors didn't give me much information. It was all over the phone and nothing was really clear.

Becoming my mother's caregiver was a decision I had to make because, of course, I would never abandon her. She gave me life, and if I abandon her, I don't know what would happen to her. Right now, she's completely dependent on me. I tried going back to work, and it affected her deeply.

At 47, I'm not married. It's been really difficult since my father passed, especially because my mother has always had an issue with me going out. She tried to control my life so much that she'd get angry just because I went out. So sometimes, I'd either go out for just a short while or not at all to avoid problems. The roles in the house have changed a lot. She used to do many things, and now she does fewer and fewer. I've taken over the cooking since my dad died. Sometimes I ask her to help in the kitchen just to keep her occupied, but I'm always very cautious that she doesn't use a knife. I try to include her and always ask if she wants to help. But it's no longer the same—she's slower, more tired, and most of the tasks around the house are now mine.

I contribute the most to our household income. That's why I used to work. If something's missing, I find a way to solve it. I dip into my savings to buy what we need. I always try to ensure my mom has her fruits, vegetables, and all the food she needs for good health. My sister sometimes buys groceries and pays for doctor visits and some medications.

Accepting the disease has been very difficult. Saying to myself, "I have to give up my life because she won't stay with a stranger, and I need my space," has been crushing. Sometimes I break down and feel like I can't take it anymore. It's tough because I want to continue living my life, but my mom needs me. I fall into this frustration where I just ask myself, "What do I do?" If my siblings won't help me, then what? Despite everything I've done, I feel peace because I've taken on their responsibility. I've never felt guilty. If anything, I blame myself for not making time for myself earlier. I feel peace because I know I'm doing the right thing, I'm being a good daughter, but I do worry about how this is affecting me. Psychologists and doctors have told me, "You can't just be your mother's caregiver. You

It's been very painful to feel alone in this process need space for yourself." One time, when I broke down, I thought no one needed me in this world. My siblings hate me so much and don't care about our mother, I couldn't make sense of anything. It frustrated me deeply. I had thoughts like, "Maybe if I weren't here, they'd be forced to take care of her." I never acted on those thoughts, but the frustration was so overwhelming I truly believed no one would miss me.

Being my mother's caregiver has impacted my personal life. Since my dad passed, I've been the one constantly by her side, always attentive, knowing her preferences-what food she likes, what she enjoys or dislikes. My siblings have basically abandoned her, so I've assumed their responsibilities to the point that I'm the only one who really knows her. We've spent so much time together that only I truly know my mom.

Her diagnosis and the progression of the disease have definitely worsened our family relationships. I get very sad and angry that they've turned their backs on her. I update them when she's unwell, and none of them come visit. None ask for time off work to see her or tell me, "Libni, take a break, I'll stay with Mom." Sometimes we don't even speak. My oldest brother used to blame me for her illness, saying she got sick because of me. It was just more denial, and I ended up being verbally attacked by my own brothers -their actions and words. Dealing with their aggression, rejection, and indifference has been horrible.

What I feel most is mental exhaustion. Since the pandemic, I couldn't understand why I had sleep issues, until a nurse friend told me, "That's because you're a caregiver. It's common among caregivers." During the pandemic, everything got worse. I didn't go out. Later, when I could, it was only to the pharmacy or supermarket. I had no social life. I met with friends over Zoom because I was afraid of infecting my mom. That really hurt my social life.

I began to feel a lot of stress and anxiety. I consider myself strong, but this disease surprises you every day. You live through the changes, and all of it builds up until you collapse. So, I built a network of friends and told them, "Can I call you? I need someone to talk to. I can't do this anymore." I reach that breaking point and just say, "God, help me, because I can't go on." At my mom's last appointment with the geriatrician, he told me, "Libni, if you keep going like this, you're going to reach a point where you won't be able to take care of your mom anymore." I told my brother that yesterday. I told him I didn't think they wanted that to happen, that then they'd have to take over. But who would take care of me? I don't have

This disease surprises you every day

children, I don't have a husband or a partner. I'd end up in a psychiatric ward. And that's not fair after everything I've done for my mom—with love, yes, but also because my siblings didn't step up. They think that because I'm single and live with her, it's my responsibility.

I started seeking psychological help because I truly felt I couldn't manage on my own, and I needed a way to involve my siblings, to make them understand that taking care of our mom is everyone's responsibility. But that just made things worse. They started treating me even more harshly. That made the process harder because, sadly, even though the law says we are all obligated to care for our parents, they refuse to accept it. I've met with all four of my siblings face-to-face to try to distribute responsibilities. A psychologist even gave us two hours of her time for free to explain that they needed to care for the caregiver and to educate them about the disease. But they twisted everything, claimed there was no diagnosis because the doctor was someone I had found, so they didn't believe it. At another appointment with the geriatrician -which they didn't want to take me to- my brother was angry at me, but the doctor confirmed the diagnosis anyway.

What causes me the most anguish is how the disease progresses, because I don't know what will happen. Every patient is different, and the illness progresses differently in each case. I'm anxious because I haven't been given enough information. I've learned mostly by watching YouTube videos and reading. I dedicated a lot of time to that. That's how I've learned. Also, my psychologist and friend Mari, a former caregiver, has been a great support. There's an Alzheimer's association here that's helped me get informed, but honestly, even if you pay for a geriatric appointment, it's not enough time for everything they need to explain. I can't ask everything, and they assume I already know it all.

My relationship with my mother has improved in the sense that now it's rare for her to get angry at me. I don't know if it's due to a change in medication, but she's more tolerant, and I've become more understanding because I know now that it's not her, it's the disease. We're more at peace, but I still don't feel ready for what's coming, for facing the unknown. As for self-care, my psychologist has given me a lot of advice. When I can, I take time to go for a walk, to get some air, to go out with friends. I try to make space for myself even though it's hard to find someone to care for my mom for even a short time. Occasionally, my younger brother comes for a few hours so I can get out. I try to keep going with my life, but I wish I had more time. I wish I had someone to tell me, "Libni, from now on, every Saturday and Sunday you're free to go wherever you want. We'll take care of your mom."

One option I tried so I could work during the day was leaving my mom at an Adult Day Center. But she didn't like it. I noticed she wasn't comfortable, didn't like the people there. She felt secure at home and really didn't want to leave. So we dropped that idea. I just ask God to give me peace, strength, and health to care for her the best I can, because I know that if the roles were reversed, she would have devoted her whole life to me, just like she did when I was a child. So I always want to care for her. I want her to live many more years and to live well and to have a good quality of life. The psychologist told us that this is an expensive disease if you want to provide quality of life.

One of the positives of my mom's illness is the time we spend together. Even if I hear the same stories, I love her stories. I love hearing her talk about my dad. He was a great man. And those are stories I never get tired of, even if I've heard them a hundred times. And every time she tells them, I act like it's the first time I've heard them. For me, time with her is what brings me peace today. I know that when she's gone, I'll have even more peace because I'll cherish all this time. I know she's not the person she once was, but having breakfast with her, lunching together when I can, just being with her is a blessing. Having her is a blessing.

This isn't a job for just anyone. This makes you stronger. It forces you to mature and to help others. It's not the same watching it from afar as living it up close. This is a life story of an illness that makes you stronger. That's when I draw on all my patience and the love I have for my mother, bringing out the best in me. So yes, there are many positives despite the disease itself.

They're not the same person anymore

My advice to people who are or will become caregivers is this: First, hold on to God. He's the one who sustains you every day. He's been my ally, my friend, my confidant, my everything. In my weakest moments, I cried out to Him and rose again because I realized my mom needs me. Second, you need a lot of love. That's what my psychologist taught me. Without love, you can't endure this, because you're watching someone you love change. They're not the same person anymore. So only with great love can you carry a burden like this. Third, always seek out people to help you. You can't do it alone, no matter how much you want to. You need people to help care for your loved one so that you can also take time for yourself. As caregivers, we must care for ourselves; because to care for someone else, you have to be well.

Mesedonia

My name is Mesedonia, I am 76 years old and I live in Cipolletti, Río Negro, Argentina. I've always worked in domestic service. That's been my occupation. I am my husband's caregiver; he is 72 years old, and I've been caring for him for almost three years now. We live alone, just the two of us, though we have a couple of children who are already grown and have their own lives. We still stay in touch regularly.

Before my husband was diagnosed with Alzheimer's, around four years ago, we both worked while our kids were studying. My social life was like that of any housewife, mostly at home, but we stayed connected with our neighbors and chatted a lot. I also remember that I used to enjoy making clothing items to sell at small fairs. My husband and I would go to Neuquén to sell them at the market. My relationship with him has always been good; we've always gotten along well, and even after his diagnosis, everything has remained fine. I say things as they are. He has never been aggressive.

Up to now, everything has stayed mostly the same, even though my husband's companionship isn't quite what it used to be. Still, there are things in the home that remain the same. A normal day as a family used to be when we had Sunday lunch together, and we would celebrate birthdays at home in the usual way. That family dynamic is still pretty similar.

As for the time before the diagnosis, we started noticing that my husband was forgetting the names of things. He called everything "the thingy." He stopped calling bread by its name and would say, "pass me the thingy." When we saw this happening, we took him to the doctor because he's diabetic, and we thought it might be related. But when a psychologist saw him, we realized it was something else entirely. It wasn't the diabetes.

Sometimes I'd ask him, "hand me a glass," and he'd start pacing around, not knowing what a glass was. Other times, he'd try to make mate but wouldn't heat the kettle. He started forgetting little details like that. We also noticed he began forgetting birthdays, our children's names, and it was as if the words just wouldn't come out of his mouth. Luckily, I had previously cared for an elderly couple who had a different diagnosis, not Alzheimer's, and that helped me be more prepared to care for my husband.

When I learned of his diagnosis, the first thing I thought was that he was going to become aggressive, like the people I had previously cared for. I thought, "He's going to turn violent." But thankfully, that hasn't happened at all. When the doctor told us about the disease, I felt very sad, but I tried to handle it in the best way and move forward. Fortunately, I've always had the support of my children. I also currently have help from a young woman who assists me with some tasks—making appointments, running errands, buying medication. Her help has been very useful.

Of course, it hurts that I can't share the same things with him as before, like going out for walks in the park and such. Now when we go out, he wants to come right back. But both the psychologist and psychiatrist told me I needed to be patient and that this is a disease that will keep progressing and has no cure. They told me it's important that I take care of myself and get support through this process. They even informed me of available resources like MND associations and support groups, though I haven't needed them yet. At least now I know where to go when the time comes. For now, I don't feel the need; I understand what's happening with my husband, and we've handled it well so far.

Everything sounds perfect so far, but of course, I've had some problems. One day, on the way to the doctor, my husband wandered off and was gone for four hours, just wandering around. Since that day, he doesn't go out alone anymore; he's now afraid to go out by himself. When we do go out, he always wants to return home quickly.

There wasn't really a process for deciding who would care for my husband. As soon as we learned about the diagnosis, we both retired and did the paperwork so I could become his primary caregiver. It was automatic. Of course it was going to be me.

I take care of myself and get support through this process

Things at home have changed a bit, like the roles we each had. It's no longer the same to go out and do the things we used to do. Now I have to leave him home for short periods, go out, and rush back because he can't be alone for long. When I take him with me, he's anxious to return home. He gets nervous around crowds. So we no longer enjoy outings the way we used to. When I go out alone, I feel anxious too. I've found I can only leave him for about an hour if he's watching a movie, and that allows me to step out and come back. Sometimes, I go to the plaza just to clear my head, not to do anything in particular, just to people-watch. But I go and come right back. We used to go to the countryside a lot, and now he doesn't want to anymore. I'm with him all day, and the moment he senses I'm about to do something, he follows me to see what I'm up to. Whether I'm on the phone or going to the bathroom, he always asks what I'm doing.

We haven't made many changes in the house, though now he showers with a chair in the shower, and we sleep in separate rooms because he gets bothered when I snore. Even so, I stay alert from the other room. If I hear any noise, I'm already up.

So far, the hardest part of caring for my husband was when he had a fecal incontinence episode while watching a movie and didn't even realize it. I had to help clean him up, and that's been the most difficult moment for me. It only happened once, but since then I've been extra cautious. I tell him not to sit watching TV for too long without going to the bathroom. Thankfully, he's obedient. If I tell him to bathe, he bathes. If I tell him to sleep, he goes to bed. Luckily, he listens.

Since my husband's diagnosis, our finances haven't really been affected. We both retired. We had a car, but we sold it and put the money in the bank. It was too expensive to rent a parking space, so we sold it, though not because of his illness. Also, we haven't needed to buy adult diapers yet, but when we do, we were told our insurance would cover it.

Right now, my husband still dresses himself, bathes himself, does everything independently. He even irons his clothes. He's always been that way and still is. He's not the same companion he once was; he's in his own world now, but at least he's still independent. That's why I haven't had any physical strain, because I don't have to lift or move him yet.

My life is still quite similar to how it used to be. My relationship with my family remains unchanged. My kids' relationship with their father is the same, and my relationship with them is the same. My relationship with the neighbors is also unchanged.

Emotionally, I've noticed that since becoming his caregiver, I'm more sad and tearful. Sad because it hurts to see him like this, not being able to do things, not even realizing it. My sleep has changed too. Some nights he doesn't sleep, and I don't sleep either. I stay alert, listening to see what he'll do. I watch for when he wakes up and wants to watch TV, and whether it's three, four, or five in the morning, I get up to turn on the TV. I wake up frequently to check on him. I don't feel tired the next day because I nap during the day. I catch up on the sleep I lost at night. Usually, I feed him, put him to bed, and then I lie down too.

I've also noticed I sometimes forget things myself. For example, I once forgot that I'd already given him his pill and ended up giving it to him twice, but it hasn't happened often. Since becoming a caregiver, the roles at home have shifted. I feel more tired and weighed down because sometimes I ask him to help sweep the sidewalk or the stairs. He doesn't do it well, but he does it. So it keeps him entertained. But still, I feel more fatigued because I carry the weight of all the household chores now, and that's not normal. I have to do everything. Before he retired, he helped with everything. Now he doesn't.

As for receiving help or delegating the caregiving role, I was offered assistance once, but I haven't taken it because I haven't needed it yet. Right now, I can handle being his caregiver because I understand him. I understand what he's going through. In fact, what worries me most right now is something happening to me and him being left alone. I've been able to share these worries, challenges, and feelings with a niece. She once cared for her mother-in-law, who had a similar condition (Parkinson's). I used to tell her how I felt, and she shared her experience with me. I've never shared my emotions about the diagnosis with my husband because he wouldn't understand, and our relationship has stayed the same. He's not aggressive; if I talk to him, it's all good. Our relationship is still very similar to what it was before.

> *Still dresses himself, bathes himself, does everything independently*

Regarding professional care like psychiatrists and psychologists, I think it's been good. I wouldn't change anything. They've treated us well and told us what to expect and how things might change in the future. As for how others treat us, when we go out, people don't notice that something is wrong with him. They don't treat us differently or point fingers. He doesn't look like a sick man and people don't realize it.

Currently, I'm not receiving any psychological or pharmacological care. They recommended I get psychological therapy because of my caregiver role, but I don't feel I've needed it yet. I do sew, and that keeps me entertained. It's like therapy. Sometimes on a Saturday or Sunday evening, I go to the plaza. I invite my husband, though sometimes he joins me and sometimes he doesn't. But I always go. These are things I do to care for my physical and mental health. I still chat with the neighbors. My husband only greets them, but they talk with me.

If I could give advice to someone going through the same experience, caring for a loved one diagnosed with this disease, I'd tell them to treat them with love. Violence is no good; you have to treat them well. You also have to understand that they're sick, that this isn't some whim. I wouldn't suggest anything to the professionals; so far, everything is fine. They do what they can; more can't be asked of them. Though, I would say they should focus more on the caregivers, so the household doesn't end up with two sick people instead of one.

Iris Eunice

My name is Iris Eunice, I am 52 years old and I live in Coatepeque, Quetzaltenango, Guatemala. I am a clinical psychologist, a theologian, and also a homemaker. My mother-in-law suffered from Alzheimer's disease, and I was the one who cared for her over the last 15 to 20 years, sharing responsibilities with my sisters-in-law.

Before she was diagnosed with the disease, my life was independent from hers, but there was always a strong sense of family unity. I already had my children, so the typical care required for small children was also part of my everyday routine. I loved caring for my two sons. Together with my husband, we traveled a lot. As for my social life. I felt very happy because I am a sociable and extroverted person. I felt free—if I needed to go out or take care of my children, I had no problem, I usually took my kids with me. There are mothers with children everywhere—so I didn't see it as an issue.

Regarding family, we've always been very supportive of one another. There's a beautiful bond, both in my husband's family and mine. We would have family events like lunches and gatherings. It was always very pleasant.

I was the first person to notice that my mother-in-law was showing symptoms. At the time, I was studying psychology, and we had just started discussing degenerative mental disorders. I began to notice that many of the symptoms we talked about in class were showing up in her. At first, she couldn't clearly tell what day it was. For example, we would tell her we had plans on a certain day, and she'd insist it was already that day and want to go immediately, even though it clearly wasn't. On birthdays, she'd wonder why the date had come so quickly, as if time were altered or lost.

The family didn't take it seriously. They joked about it and didn't give it much importance. Eventually, she began talking about events that had never happened, and she'd get upset when we told her that wasn't true. She'd forget things that had really happened. Everything started mildly and gradually became more evident.

Getting a diagnosis was a bit complicated because there's no geriatrician where we live. So, my husband contacted a doctor in Guatemala City, who had a long waiting list. My sister-in-law had to take her to the appointment because we couldn't stay there. Physically, the doctor said she was generally well. Her blood pressure was a bit high, but otherwise fine. My mother-in-law must have been around 80 or 85 years old at that time.

When we received the diagnosis, it felt like a confirmation of what I already knew. The same was true for my husband because I had been preparing him in advance. For my sister-in-law, who took her to the doctor, it was extremely difficult to accept. She constantly insisted that her mother was just forgetful like anyone else. She would pressure her to try to remember things, which led to a lot of frustration for my mother-in-law. The doctor explicitly told her not to question her memory anymore.

When the doctors gave the diagnosis, it was my sister-in-law who was there, and she was in denial. So, transferring the information was difficult. She'd say the doctor suggested certain things, but always in a vague way, and she claimed her mother had nothing wrong. I already had an idea of what could be done or be expected. I told my professor at the time, who advised me to prepare as a family and align on decisions. She warned me how hard those moments can be and that the disease would become increasingly pronounced. I passed this on to my husband, who then spoke with his family.

The family didn't take it seriously. They joked about it and didn't give it much importance

Even though my sisters-in-law did everything they could for her, my mother-in-law preferred to stay at our home. Maybe because my sister-in-law pressured her a bit too much to remember things. There came a point when my mother-in-law didn't want to stay at her house anymore. She wanted to stay with us. And that's just how it happened.

The hardest part about caring for my mother-in-law was the exhaustion. In terms of understanding her, I knew what was happening and certain things no longer surprised me. But exhaustion wears you down. As the years went by my mother-in-law lived until 101 years and six months—it became increasingly draining. Eventually, she lost her sense of taste. She'd pick at food with her fork and then throw it under the table or spit it out in front of us. It became exhausting to constantly think about what meal might appeal to her. I remember buying things she liked with my husband, like desserts, ice cream, and local sweet breads called champurradas to eat with coffee. It was a way to get her to eat, knowing there'd be a "reward" at the end.

There were also long nights, since she had no sense of time. She'd sleep during the day, wherever she happened to be, and stay awake all night. Keeping up with her schedule was exhausting.

At the time, I didn't fully realize how tired I was. Maybe I was in a bad mood, but I tried to manage it. I tried to contain my irritability, but it was hard not being able to go have coffee with friends. I felt pity and compassion for her because she wasn't at fault for what was happening. Physically, I don't remember if I had any issues, but psychologically, definitely. There came a time when I cried, though never in front of her or my husband.

I never wished she were dead to end the suffering. Instead, I focused on stabilizing her memory with vitamins or by lowering her sugar intake. Later on, I began to wonder how I'd feel when she was no longer with us. Would it be joy, sadness, or nostalgia? That thought led me to feel guilty.

My intimate relationship with my husband wasn't broken, but it was affected. We were no longer just the two of us watching movies together or chatting in the living room. We were constantly looking after her. She was also afraid of being alone.

Overall, I never thought I was wasting my life caring for her. From my knowledge as a theologian, I know that in Judaism, caring for one's parents is seen as a source of blessing. For me and my husband, wherever my mother-in-law was, there would be blessing. I never once felt it was a waste of time.

Caring for her did lead to some memory issues for me. Once, I had to give a Zoom lecture to a group of women, and I had my mother-in-law beside me with an ice cream so I could keep an eye on her. She sat on the couch next to me, and during the talk, I kept checking on her to see whether she was eating or if she dropped the ice cream. Even though I had visual aids for the presentation, I couldn't remember anything and started mixing up what I was saying.

Another issue I developed during caregiving was trouble sleeping, since we were constantly alert. Because she had no awareness of time or space, she'd wake up at night or early morning, and sometimes she didn't sleep at all. As a family, it's important to talk about the care, the exhaustion, and the emotions involved. Everyone processes it differently. My husband's eldest sister, one of the main caregivers, would openly express how she felt. On the other hand, even though I'm a psychologist and familiar with the subject, I never admitted I was overwhelmed, even when I felt that way. I don't know why I didn't say anything.

Our extended family relationships actually improved beyond the already good connection we had. My sisters-in-law respect me deeply, and that moves me so much that thinking about it brings me to tears. My nephews and nieces also respect me immensely.

As for the doctors and how they handled the process, in Guatemala, there aren't many geriatricians. Fortunately, the one who treated my mother-in-law was very knowledgeable and extremely kind. No complaints at all. He addressed the issue very well and was attentive. It was comforting to know he was taking good care of her and showing her respect.

Regarding society and friends, I have a few anecdotes about how people reacted to her illness. We belong to a faith community, a church. Once, during a church service, my mother-in-law didn't like me sitting next to her. She only allowed my husband to sit with her. So we sat in different rows. That day, I was chatting with one of the women when I noticed another woman had approached my mother-in-law to greet her. Oh my, my mother-in-law was telling her that I was trying to poison her. I was mortified. I never knew what the woman thought after hearing that. Near the end of her illness, my mother-in-law often said things like that about me.

I oculd take time for myself

Society in Guatemala still takes good care of older people. Many of the people I interacted with had gone through similar experiences or understood that this could happen. Thank God, I was surrounded by a kind and understanding social circle. They would approach her and listen to her, even when she became repetitive. They handled it with grace.

There was a time when I could take time for myself, but there were also times when I couldn't, because she didn't like to be left alone. I had both experiences: taking care of myself and caring for her full-time. At one stage, we hired someone to help with her care, so I would go to the gym for an hour, no more than that, and then rush back home.

In her final days, unexpected things happened; things I never thought possible. One was that she had held a deep grudge against her husband, from whom she'd been separated for a long time. She used to refer to him as "that man," never by name. But in her last days, she suddenly began to mention him by name, saying things like, "If he were here, he'd know what to do," with a nostalgic tone. I couldn't believe what I was hearing. From that point on, all her anger disappeared, and she only remembered the good times they had shared.

Another surprising thing was that although my mother-in-law was very well-spoken and articulate, by the end she stopped speaking entirely. She would sit silently, and when someone approached her, she would simply look at them and smile. She had a very strong character and had been demanding, especially with her daughters, but not with my husband. Yet, at the end of her life, she stopped being demanding and just smiled at everyone.

There was a song she never forgot: Cielito Lindo. She forgot almost everything else, but never that song. I would greet her saying, "Good morning, sunshine! How's Cielito Lindo?" and we'd sing. I'd sing part—"Ay, ay, ay, ay"—and she'd respond, "Canta y no llores." And so on.

As for how she passed, one of her daughters wanted to take her to the United States. We realized her passport had expired. We took her to renew it. She became the oldest citizen in Guatemala to get a passport at age 101. The next day, she asked to go to the bathroom. My sister-in-law took her and mentioned they'd be traveling soon. Her expression changed. From that moment, she could no longer walk. My sister-in-law called for help. They managed to get her out with help from two people, but after three steps, she collapsed. She had a stroke.

When I entered the room and saw her, it was heartbreaking. I sat on the edge of the bed, touched her head, kissed her, and said, "I'm here, Doña Esperanza." I hadn't spoken about this before. I kept telling myself it had to happen eventually, especially given her age. I sang Cielito Lindo to her. And said, "Doña Esperanza, there are people here who love you. Don't worry—I will take care of Oscar [my husband]." She was unconscious for a week, then woke up once with the whole family her. We prayed. We thanked God for her life. She took a deep breath and passed away. I felt an enormous emptiness.

I cried at the cemetery, but that was enough. I didn't feel grief like others describe. I cried enough at the burial; it was the final goodbye. Life didn't go back to how it was. Having had this experience made me grow. It helped me understand fragility, not just the fragility of life, but of the mind. I was never the same. I now appreciate elderly people so much more.

One of the most beautiful things I learned from my husband's family through all this was the love they showed my mother-in-law. Such immense love and respect, even during her moments of crisis. The respect they had for her as a mother figure was profound. From my mother-in-law, I learned wisdom. And lastly, I learned about the fragility of the mind. People think fragility only applies to life, but I saw how this disease steals your memories, and in doing so, it steals your life.

If I could give one piece of advice to someone caring for a loved one with this disease, it would be the one thing that kept me going: faith. Faith in God, and the understanding that everything in the universe has a purpose, that none of this is meaningless, no matter how terrible it seems. There is always some gain in terms of wisdom, family unity, and the gratitude of being the one who got to care for that person. My advice: hold tightly to God. Faith will carry you through.

Claudia

I'm 56 years old. I'm from La Paz, but I live in Santa Cruz, Bolivia. I'm a physical therapist, and the person with Alzheimer disease is my father. He had already been diagnosed with MND for six years when he came to live here in Santa Cruz. The doctor did a CT scan, and by that time, he was already forgetting everything, and from there, it just kept progressing.

My mom and dad live alone in a small house in a gated community, and I live a few houses away in the same complex. They live well. I usually went to work every day; it was a daily routine of work, home, grocery store, and time with my two children. On weekends, I'd go out with friends. My life essentially changed the moment my parents left La Paz, based on the diagnosis and the altitude. They came to live with me, since I was already living here with my two children. Before my dad's diagnosis, my life was normal. I try to stay organized and ensure it doesn't interfere too much because my mom is a great support. She's 79 years old but doing pretty well.

It all started when one day, after work, when my dad was driving home. He got lost and had to pull over. Since he didn't know where he was, he called for help. Someone had to pick him up. That was the first sign that something was wrong. He was 77 years old at that point; now he's 84. After that incident, my sister, who was living with him in La Paz, decided he shouldn't drive anymore. But it happened again—he got lost and just stood there waiting for someone to come. I found him that time, and after that, he never drove again. Looking back, it seems like that's when he began to feel depressed. He didn't know the city, he was in a new home, everything in his world had changed. It was too abrupt. He no longer had his work routine, and he didn't want to go out. He liked having his drink, but when he drank, it got harder because he would take it out on my mom and say all sorts of things to her, so we had to put a stop to that.

When he got to Santa Cruz, I took him to a doctor and asked for an evaluation. She did a CT scan and a psychological assessment. Then we were shown the results to understand what level he was at and what areas we needed to work on. I'm generally a positive person, so I thought, "Let's try everything." We used to go for walks, to the plaza. Until about three years ago, he would still go out with me. But one time, on our way back, he didn't want me to hold him and he fell. He was left in bad shape, and I started yelling, "Help, my dad!" A neighbor called an ambulance. At the clinic, they did another CT scan—it showed he had a minor stroke that had to be monitored. From that day on, his symptoms increased significantly. That day was terrible, especially with the head injury.

For his diagnosis, a psychologist recommended by the doctor visited me and my mom four or five times. She explained how difficult this would be for my mother and how much more support she would need. So I got organized. I loved it when they walked and went out, but they stopped wanting to do those things. I began doing my own routines. We were told we needed to stick to a routine, so my dad's day became structured, and that made things much easier. He gets up, takes a shower, and everything is done according to schedule to make things more manageable.

I was really happy when they came to live here in Santa Cruz—it was beautiful to have them here, just like I wanted. Right now, we have a helper on weekends. That's been for the past two or three months—it's a recent thing. It's helped a lot. Now I can sleep longer on Saturdays and Sundays and spend more time with my partner. I also wake up early because my mom had back surgery, and I help her get dressed and with various tasks we try to minimize for her. In the mornings, I do an hour of yoga and meditation. Sometimes the routine gets a bit exhausting because I have to rush home from work the three days I go in, and I have to do the same routine again. So I try to change it up—go home, sleep, or watch a movie, for example.

She becomes a bit unstable at times

Regarding my mom, she becomes a bit unstable at times and she completely loses patience. I think it's hitting her the hardest, especially because my dad takes things out on her. He's very docile with me—he accepts me 90% of the time. He's sweet, calm. But with my mom, it's different. He always says things that make her anxious. It's very complicated caring for your father. There are challenges that keep you from doing other normal things in your life, like maintaining a relationship or ensuring these issues don't affect your children.

I've adjusted pretty well. Thank God, my kids are 30 and 28, and they both live on their own now, so they're doing fine. Sometimes they help out on Saturdays. Every Sunday night, I've arranged with my partner that I won't be home before 8:30 or 9:00 p.m., and he has to accept that. Still, it does interfere a bit with us as a couple. It used to be different. Even though he knows I usually get home around that time, I still try not to be any later.

One of the hardest things as a caregiver is dealing with fecal incontinence. It's very sad to see him like that. Sometimes he realizes what happened and says, "How could this happen to me?" That really hurts me. I knew him as a very proud man who cared a lot about his appearance. It's hard to see him in this condition. He sometimes realizes it and blames himself. That makes him more depressed.

As a family, we talk every day. My sister is a trauma surgeon, so we talk to her occasionally, but we try not to tell her too much because she's far away and can't help. She feels frustrated, so we mainly talk among my mom, my kids, and me.

My dad has four friends who were his partners in a clinic. We've tried to get them together. One of them is a gynecologist in a wheelchair, and when my dad sees him, he recognizes him, he says, "Walker." That really moves me. We used to get them together more often since we lived nearby. Now that we've moved to a condo outside the city, surrounded by birds and greenery, it's harder to take him to the shopping centers like we used to. He used to enjoy going out for a beer and such, but now he has fewer friends.

During the week, I didn't go out much, and that hasn't changed. I just get home a little later on weekends. At first, I was a bit tired, but I still managed to meet up with my friends. I have five close friends; three of them also have moms going through this stage. So we go out to unwind and support each other.

I'm a yoga teacher, I do therapy, I meditate a lot, and I use Buddha in my meditation. This has really helped me cope with my dad's situation and the changes at home. Thank God I don't have any underlying health conditions and I don't take any medications. I believe that doing yoga in the morning and meditating—even just 30 minutes—has kept me steady, neither too high nor too low.

At the clinic where I work, I have three colleagues who are psychologists. Sometimes I sit down with one of them for a few minutes to have coffee and vent. She gives me advice. But I haven't felt the need to seek professional help. I sleep well. I go to bed early—between 10:30 and 11—and I'm up by five.

My father has deteriorated a lot. At first, he could walk alone. Now he only moves with a walker or with help. He used to have conversations—now he's quiet 80 to 90% of the day. He doesn't want to wake up or get out of bed until noon. It's a daily struggle to get him up. And when he does get up, he's often in a bad mood. We've started doing consistent things—he still eats by himself, and I try to make sure he does what little he still can every night. Not wanting to bathe is a major issue. He only bathes on Saturdays and only with help from the nurse. If I'm not there, he won't bathe for anyone. Once, I was away for 10 days, and my daughter nearly lost it because they couldn't get him into the shower. So, he didn't bathe that whole time. This disease brings many such difficulties. Sometimes, when we can, we take him out for a drive, but he doesn't really participate anymore. He doesn't get dressed or pick out his clothes. Thankfully, he still recognizes my mom and me quite well.

All of this frustrates me a lot because I knew a very authoritative, self-sufficient doctor. My dad was president of the Bolivian Society of Traumatology. He had his own clinic for years. Seeing him in this state is heartbreaking. Sometimes I think, “I wish he could rest.” I believe that when he becomes aware of what’s happening, it’s very hard on him. That’s what really makes me sad, more for him than for me. He’s no longer the man he was, and that hurts me deeply.

Sometimes I don’t even pray; I just say, “Lord, if all he wants to do is sleep, it’s because he’s tired.” He’s developed a small pressure sore, a type of skin ulcer, on his right leg near the hip bone, and we have to reposition him as much as possible. But my mom can’t move him because of her back, and it’s difficult for me too.

Through my dad’s illness, I’ve developed a lot of patience and empathy. I’ve come to understand that no one is immune to this. So, I care for him with a lot of love, and I’m grateful that I can do it myself. I know it’s more comfortable to be cared for by your daughter than by a nurse you don’t trust. All things considered, I’m thankful to be able to help him.

Every night I say, “Thank you, Lord, because You are truly here with me in this moment.” In the future, if my dad worsens, we’ll need someone to assist him at night. Sometimes he wakes up without a diaper and without his pajama bottoms. So we may eventually need a nurse to be with us through the night.

My parents used to live in a beautiful two-story house. Now they’ve moved to the condo where I lived—a small one-story home we’ve adapted for my dad. The only modified area is the bathroom. We installed grab bars everywhere—next to the toilet, in the shower (four or five bars), also for my mom, so she has support. So really, it’s been a change for both of them.

Thank you, Lord, because You are truly here with me in this moment

Expenses have gone up. We use a lot of disposable diapers and mattress protectors. We give him supplements, plus medication for diabetes and natural treatments. I’ve taken my dad off antidepressants and started giving him coconut oil. When I give him five tablespoons a day, he seems more alert. It may just be my impression, but I’m trying everything. We even play dominoes—he still plays, but getting him to the table is very hard. Some days he doesn't want to, and then we don't push it.

For anyone caring for someone with Alzheimer's, the first thing they need to consider is their own physical and mental health—because otherwise, they can't fulfill the caregiver role properly. My advice is to start meditating and reconnect with your inner self to grow spiritually. I think we've forgotten that part and also the importance of physical exercise. Caregivers need to avoid falling into a grinding routine and forgetting that they must come first.

To close, I want to say thank you for letting me be part of this. To those caring for a loved one with this disease: don't lose patience. Breathe deeply and remember, this person was once your father or mother. Now they are your angel, and you must care for them with patience and love. I truly believe that the more love we give, the more they feel it deep inside. I still look at my dad and see in his eyes the father he once was. So please—don't lose your patience, treat them with great affection, and when you're feeling overwhelmed, go out, breathe, and come back in.

Aída

My name is Aída, I am 69 years old and I live in Bogotá, Colombia. I'm not working at the moment because I was taking care of my mother. In 2024, she was the person I was connected to through Alzheimer's disease, and I cared for her for three and a half years.

Among my seven siblings, we took turns caring for my mother every eight days. I cared for her when it was my turn, from Monday to Saturday, along with my husband, in our home. However, before taking care of my mother, I worked as a professional hairstylist. I had an active social life—we went to the movies, exercised, went out to eat. I had lived in Venezuela for 35 years and always stayed well-connected with my family, visiting them annually. But when the pandemic hit, everything changed, and that's when I began taking care of my mom.

Her symptoms started after my dad passed away, about twenty years ago. I believe she developed the illness herself because she began saying she didn't want any memories of my dad. She asked us to remove his photos and to put away anything that reminded her of him. I think that emotional isolation really harmed her. She was very sad, very alone, and even though my siblings were attentive, they started to notice unusual symptoms. For example, she was given educational games, and when the instructions were explained, she would forget the rules right away. When it became more evident, we took her to the doctor and got the confirmation that she had Alzheimer's. It was devastating for the family—she had always been such a lucid woman, a reader, a believer in God. Watching her decline was terrible.

At first, I was still in Venezuela, so my siblings received the medical information. The healthcare provider (EPS) also recommended some places to go for guidance. One of my sisters, a psychology professor, was more involved in all of that. She bought educational games for my mom and constantly reminded her of her past—her parents, siblings, and anything she thought was essential for her. That sister lived with our mother, but then she passed away from an illness. The same thing happened again—my mom asked that her name not be mentioned, that we remove her university diploma and photos. It was just like when my dad passed.

Because of all that, my husband and I decided to move to Colombia. We lived in Medellín for five years, and later we moved to Bogotá, where I currently live. One of my sisters told me she wanted to become independent and asked if I could care for our mom. That's how I ended up staying with her in her house, where my husband and I moved in.

Days with my mom started very early. I would get up and give her medication for high blood pressure, diabetes, and other conditions. Then it was time for her bath and breakfast. She usually ate everything because she had a good appetite. After that, we would take her out to the balcony in her wheelchair to get some sun. That's when she often talked about stories of her father and one of her sisters.

We had to make some changes in the house to adapt to her needs. For example, we replaced her double bed with a single bed and added an extra one in case someone wanted to sleep with her. This helped a lot because she couldn't walk due to arthritis in her knees. The most difficult part of caring for my mom was helping her move, as her body was very stiff. Physical therapists came to give her therapy, and a speech therapist also visited. Lifting her worried me a lot, because even though my siblings bathed her once a week, I couldn't do it myself—but I did clean her daily and changed her diaper, which still required a lot of strength. Toward the end, she became very thin, and transferring her from the bed to the wheelchair was physically demanding. Sometimes my husband helped me hold her and move her when needed.

Seeing my mom so disoriented caused me deep pain. It was heartbreaking to see her so different from the strong woman she had always been—a matriarch who cared for the family. Remembering the elderly is very hard. Thankfully, I haven't had trouble sleeping or experienced physical fatigue, because I maintained a strict schedule: her meals were given at the same times every day for breakfast, lunch, dinner. Sometimes we stayed in her room to keep her company. My husband would also talk with her.

Taking care of my mother brought certain challenges. I became very tired, and in the end, I was so exhausted that I told my siblings. That's when I considered taking her to an elder care facility. But we felt bad—she was already used to her home, and moving her to one of those places, where people tend to die more quickly, just didn't feel right. We looked into what to do because I was truly overwhelmed, and my partner—who lived with me—noticed I wasn't doing well. He even told me that the situation had caused me to lose weight.

> *I would get up and give her medication for high blood pressure, diabetes and other conditions*

As the moment of farewell approached, I began to notice that she didn't want to talk anymore. Her gaze was distant. She had no strength in her left arm. I would try to lift it, and it would just fall. I mentioned this to her nurses, told them she was weak, wasn't eating like before, even though we were making her broths and meals. I ask myself if I ever wished she had passed instead of seeing her like that—and it's such a horrible thing to witness. So I simply said, "Whenever God decides, that will be the right time." My siblings and I were aware that she was going to leave us eventually.

One thing that helped was that my mom had a pension, and we had financial stability. The extra costs were shared between my siblings and me, so we never faced financial difficulties.

What stands out in our family is that we never drifted apart during my mother's illness. We maintained the same good relationship we've always had. We simply added caregiving responsibilities. If one person couldn't take their turn, another stepped in. We always supported each other.

My siblings and I are quite concerned that Alzheimer's might be hereditary. That's why we try to stay active, read, and avoid being sedentary like our mom. The disease has become so common that we haven't experienced social stigma or discrimination due to having a mother with Alzheimer's. The health insurance provider treated us very well, and we also had an additional emergency insurance policy for my mom. She saw four or five different specialists every month—a general doctor and several therapists.

I tried to take care of my own health too. I had a few failed attempts at exercising. I still try, since I've always liked jogging and staying active, even though now my knees are starting to wear down. To make up for the lack of physical activity, I researched proper nutrition and exercises for my knee pain online. This improved my health a lot. I also visited the doctor regularly, because in order to care for her, I needed to be in good condition myself.

My advice to anyone caring for someone with Alzheimer's is to do it with love, honesty, and sincerity; and if they can't, then it's better not to do it at all. This role comes from the heart, especially when it involves a loved one like your mother or father. I was raised in a home with strong family unity and a deep respect for our parents. My dad passed away 20 years ago, and not a single day goes by without me remembering him and saying a prayer for him.

So again, if someone is going to care for a person with Alzheimer's, they must do it with love and patience and keep a good attitude. Sometimes you'll say, "I'm tired," but that's not what it's about. If someone isn't ready from the beginning, it's better not to take on the responsibility.

From this experience, I learned patience, which is something very important. I learned to listen, because she would repeat things over and over.

We played music for her, and it brought back memories of her ancestors and beautiful times she had lived. We even took her to her hometown. We hired a bus because so many of us went, around 100 family members.

As a caregiver of someone with Alzheimer's, you have to know they're going to leave. So you must treat them as best you can while they're still with you, and try to give them the best quality of life possible.

My mother passed away on April 24, 2024. I screamed a lot—it was extremely painful. A nurse was cleaning her when I said I felt like something was wrong. I showed her my mom's arm—it was limp. She told me she had no strength and that they were already feeding her with a syringe because she couldn't swallow. That's when we took her to the emergency room. A doctor saw her and said she needed to be admitted. From January to April, we took turns staying with her at night.

My siblings and I already sensed she was nearing the end. She was very weak. Then one day, a doctor called me—as the eldest—and told me that she didn't have much time left. Of course, we didn't want her to suffer anymore, and we didn't want to suffer either, so we made the decision with the doctor.

I held her hand, spoke to her, and asked for her forgiveness for anything I may have done wrong. I thanked her from the bottom of my heart for giving me life, for helping raise my son, for the beautiful home she created with my dad and my siblings. I didn't know if she could hear me, but I felt I had to say it. One by one, my siblings also came to say goodbye. That night, my brother stayed with her. Around 5 or 6 a.m., the doctor came and told him that she had passed without him realizing. My brother called me—and all I could do was cry and scream.

After her death, the house has stayed the same. We haven't made many changes, but we are thinking about selling it. We also want to donate, sell, or give away her clothes—we're just not sure what to do yet. Her room has changed, of course. I open her door every day. My husband sits in her chair. I look at her bed—the last one she had was a hospital bed. The routine of life revolving around her is gone. Everything is different now. My siblings don't come over on Sundays anymore. Now we just talk by phone.

To close, I want to tell caregivers: the first step is to accept the disease. Accept it with humility and give these people all the love you can—because sooner or later, they will be gone. Even the smallest acts—combing their hair, dressing them, listening to them—make a big difference. My mom used to call me "mona," or sometimes by my name, and she talked a lot—even near the end—about the happy memories she had in life.

Margarita

What I've learned over these 12 years will be helpful to many others. My full name is Margarita, I live in the city of Aguascalientes, Mexico, and I was trained as a biology teacher. It's important to say that I donated my husband's brain for research purposes, and I've read extensively, attended conferences, and taken courses to be a better caregiver to my husband.

I decided from the beginning to be my husband's caregiver because I loved him very much. Eventually, though, I had to hire some help. I'm 75 now, and I was a caregiver for 12 years. I always cared for him myself, but in the final stages, I hired one person to help in the morning and another in the afternoon. I remember a caregiver course was available at that time, and both helpers took it—it was great because we would talk about what we learned and formed a sort of team. It was a blessing that they both took the course so they could care for him better.

The first years were lonely because when we got the diagnosis, it was shocking for both of us. He told me he didn't want anyone to know—not his family, not mine, not our neighbors or friends, not even our coworkers. He was completely against it. Eventually, his siblings, who lived in Mexico City six hours from Aguascalientes, found out. When they visited us once, I told them privately what was going on. Most of them offered their support. Others, due to distance or other commitments, said they couldn't help.

At the time, one of my sons, a psychologist, lived with us. He was the first to notice something was wrong. He told me, "Something's happening to your husband; you need to take him to a neurologist." And that's how the process. We visited doctors and did tests until the Alzheimer's diagnosis was confirmed with a CT scan and other studies. At that time, all I knew was that he would start forgetting things. I began the journey in the worst way, but I finished it in the best.

He and I were each other's second marriage. We met, fell in love, and were a very happy couple for 33 years. He was a joyful man—he loved telling jokes and was really good at it. He was a history teacher at a secondary school, and he made his classes fun. If students were tired, he'd tell a joke. He was noble and honest.

We worked together in educational institutions, spending around eight hours a day together. After work, we spent time with our children and pre-

> *He’d ask, “What day is it?” or “What time is it?” even though he had a watch. I’d tell him, but he preferred I say it out loud*

pared for classes. My husband loved traveling—we saw nearly all of Mexico, from north to south, east to west—especially its archaeological sites.

In general, our life together was happy. Before becoming his caregiver, I’d go to breakfast with friends, attend family gatherings—we were both very sociable. That changed when we started going to doctors, labs, and tests. It was all overwhelming. A niece gave me a book titled When the Day Has 36 Hours, but I cried just reading the first few pages. I’d read a little, then put it away. Eventually, I covered the book so my husband wouldn’t see the title. Later, I moved on to other reading and received support from the Alzheimer’s Family Foundation of Aguascalientes.

Thankfully, all this began after we had both retired. That allowed me more time for him. But without the right knowledge, the early stages were very painful for me. I cried often and couldn’t talk about it. Then I found a grief counselor who supported me for most of my husband’s illness and helped me see things differently.

His first symptoms were losing his car keys, his watch, his dentures, his wallet. He’d ask, “What day is it?” or “What time is it?” even though he had a watch. I’d tell him, but he preferred I say it out loud. I think retirement affected him deeply. At school, he had students and friends but outside of work, he had no social circle. He was happiest at school.

When he learned he might have Alzheimer’s, he froze and said, “But I’ve always had a great memory. Is this a punishment from God?” He cried, and I hugged him—we cried together.

When the doctor confirmed it was likely Alzheimer’s, I was devastated. I’d always seen my husband as the stronger one. I felt shocked. Later, we were able to cry and talk at home. I had always believed I’d die first, never imagined it would be him. Seeing him sick and changing was deeply painful for both of us.

In the months after the diagnosis, I felt very sad and told my son. He asked what I planned to do, and I said I was ready to stay by his side through it all.

My son was my most important support throughout this. Without him, I would've had no one. Eventually, others learned—friends, neighbors, and relatives—and they became very supportive, keeping my husband company and talking with him, especially in the final stages. The Alzheimer's Foundation of Aguascalientes was also a crucial support. I took my husband there, and we attended conferences with specialists. They taught us from experience—caregivers teaching caregivers—which helped me feel understood and not alone.

It was the neurologist who recommended the Foundation. They brought in experts from around the world, especially on World Alzheimer's Day, when they held international congresses. Later, we helped organize them ourselves. That's where I learned everything I needed to support my husband through each stage. I always wanted to learn more to be the best partner I could be.

Fortunately, I had people helping me, so I could spend quality time with him. He loved music—we'd listen and dance together. At home, we removed tripping hazards like floor clutter and cables. We installed bathroom grab bars when he needed help bathing. A talk I attended emphasized not leaving patients alone because they might fall, so I got him a bracelet with his name, address, phone number, and a note saying he had Alzheimer's, even though he didn't like it.

One day he went out to take out the trash and got lost. That's when I realized the bracelet was essential. Thankfully, I found him nearby.

The hardest part for me was the third stage: urinary and fecal incontinence. I had heard this would come, and knew I'd need to use diapers. The first time it happened, I woke up, smelled something strange, and saw tracks leading to the bathroom. I found him trying to undress, and everything from the bed to the bathroom was dirty. I didn't know whether to clean him or the space first—I was alone and overwhelmed.

As for costs, we initially covered everything with our pensions and his savings. He later sold a country house to help with expenses. But when those funds ran out, I used my pension—and my credit cards started piling up. Alzheimer's is long, expensive, and exhausting. Therapy—psychological and grief counseling—was also an investment I needed to make to relieve anxiety and pressure. I also went to church regularly to recharge and stay grounded.

Only after he passed was I able to take care of myself—fix my teeth, get hearing aids. There hadn't been time or money before.

My husband sometimes had episodes—he once tried to kick the night nurse. Luckily, she was experienced and understood it wasn't personal. He also had dark thoughts. He once said, "If I ever become a burden, I'll shoot myself." That scared me because he was strong-willed. That's part of why I saw a psychologist and eventually placed him in a care center where they could look after him better than I could. I feared the guilt that might come with his death.

His loss was very hard. I went through three years of grief and guilt, but my children and my grief counselor helped me move on. My counselor told me, "Margarita, death is not always the enemy." My family—though they live elsewhere—was very supportive. We stay close, especially at Christmas and birthdays.

Today, life is better. My husband left me his pension and financial security. Now I can travel to Mexico City to visit my siblings and son. I travel with them and have the freedom to do so. With everything I've learned, I love sharing knowledge. I even gift books on caregiving. Just last week, I gave one to my niece, whose father has MND.

There were painful moments—like the times he didn't recognize me. He'd call me "ma'am" and offer me a place to sleep. That happened about seven times, and it hurt deeply. But thankfully, he never hurt me, physically or emotionally. On the contrary—he would say, "Thank you so much for everything you've done for me."

I had trouble sleeping. I'd lie awake, worried he'd need something or start wandering. I had to take medication to help me sleep and calm down. One night I found him standing silently at the door, doing nothing. I gently said, "Come, let's go to bed," and he did. But that moment really shook me. I developed anxiety, and my internist advised therapy. My family also helped. My son, who doesn't live in Aguascalientes, would invite us to Acapulco or Puebla and take over caregiving so I could rest.

Despite everything, including the exhaustion and the challenges, if I had to do it again, I would. I'd care for him all over again. I don't cry when I remember him. We knew every therapy, every walk, was just to slow the disease. I always explained it to him: "We're doing this because..." and he'd say, "Okay." Even when he couldn't swallow anymore and needed speech therapy, he said yes.

My husband ultimately died from aspiration—food went into his lungs. He could no longer chew, and we respected his wish not to be fed by tube. The doctor prepared us for what could happen. When I was informed, I called his brother and my son. When I arrived, he had oxygen and other interventions I barely remember. I held his hand and said, "I'm here with you." I asked his forgiveness for anything I might have done and forgave him too. After he passed, I contacted the Alzheimer's Foundation president—we had arranged to donate his brain for research.

My grief counselor helped me through that day. When we went to the funeral home, I felt more at peace, accompanied.

Alzheimer's is long, expensive, and exhausting

Afterward, I received many messages of admiration—people said I had cared for my husband with dedication and love. Even his sister once told me, "No one would have cared for him like you did." That made me feel that I had done things right—not just in my eyes, but in the eyes of those around me.

To others, I say this: to care for someone with Alzheimer's, you must have love, above all else. You need to be informed, because at times they'll say hurtful things. Once, my husband accused me of trying to poison him with medication. It hurts, but it's part of the disease. That's why I give people handouts from the conferences and even gift books—I just gave one away last week.

To caregivers, I say:

Love deeply.

Don't give up.

Stay informed.

Get emotional support by consulting see a psychologist or grief counselor. I did for six years, and again after his death. You can't wait until you collapse, taking care of your mental and physical health is essential.

One thing I wish I had done differently: not be ashamed to tell people. I wish I had taken him out more, traveled, gone to the park—without hiding it. If people stared, so what? I was caring for the person I loved.

Today, I have no challenges or difficulties. My mother has passed, my father too, half my siblings are gone, and now my husband as well. That has made me strong. I love sharing my experiences with others who might need it. That's what I want to do now—help others.

Hernán

My name is Hernán, I'm 73 years old, and I live in Barranquilla, Colombia. I'm currently a small business owner and also my mother's caregiver. When I was in my twenties, I had an accident at the company I worked for, which caused me to lose a kidney, and I spent three days bleeding out. That injury prevented me from continuing to work in formal companies. I have children, but I'm currently single, and I have a grandchild. My relationship with my mother is good—it always has been. Before her diagnosis, our life together was very harmonious and happy. My mother and I have lived in this house our whole lives; we've never moved.

I began to notice something was different about my mother 12 years ago, after my father passed away. Six months after his death, she was at a gathering when she suddenly screamed and said she felt like running. It wasn't normal for someone to experience something like that during a social event. She described it as feeling like a "shot" inside her. After that, she started constantly saying she was losing things. She'd go through her drawers obsessively, claiming her money was missing, and she began repeating and asking the same questions over and over. Then I started noticing she was confusing people; she mistook a nephew for her brother, and even confused me for her brother. I'm the one she still recognizes the most.

When her symptoms began, we took her to a medical center where she was diagnosed with Alzheimer's through our health insurance provider. Initially, the doctors didn't think she had the disease and sent her back home. That caused us to lose valuable time until we returned with more evident symptoms—and that's when she was diagnosed. A significant detail is that her family has a history of this disease; her siblings and other relatives also suffered from it.

When I received my mother's diagnosis, I was already expecting it, knowing the family history. I even believe I might have a bit of it myself. But I didn't feel alone when I got the news because I had a good brother who supported me a lot. Fortunately, I already had some knowledge of the disease from watching other family members go through it. But no one at the clinic explained what the disease was, how it progressed, or what to expect. They didn't mention support groups or associations. I learned of such resources through family or random chance. For example, I once visited a university and heard there was a talk by an Alzheimer's group, but I never followed up.

No one at the clinic sat down with me to explain what was happening with my mother or how to help her. The decision about who would take care of her happened naturally. I had always been with my parents and cared for my father too, so I simply assumed that responsibility without anyone asking or discussing it.

As a caregiver, I've received no treatment or support. I even asked for it, because I've suffered from stress-induced memory lapses and serious sleep loss. My blood pressure has gone up, and I struggle to sleep, worrying that my mother might fall or that something might happen to her. For the past two or three years, I've only been sleeping five to six hours a night, and that leaves me fatigued and exhausted. I feel I'm losing cognitive abilities—my memory and focus are affected. Since I have to lift her, I've developed body pain. Carrying her aggravates my hernia and sometimes causes pain in my kidneys. It's usually temporary, but significant.

Emotionally, I've become more irritable. I sometimes rush through the streets, bumping into people due to the stress. Watching my mother stressed out and not being able to help makes me more stressed. It's an overwhelming cycle.

I am always the one who takes care of my mother. If I have to go out to get medication or run errands, a family member helps, but I always try to return quickly so she isn't alone for too long. When I feel overwhelmed, I look for friends or people I can talk to. Since becoming her caregiver, some friends have been very supportive, while others tell me not to take it so seriously. They share stories of caregivers who didn't stay involved long, who weren't so committed. But I'm different. I tell my mom, "You are the fragrance of my life." As long as she's okay, nothing else matters to me.

When my friends tell me not to give her so much love, I just stay quiet. I keep my feelings to myself and I don't share my sadness with others. But I've felt very supported by my neighbors; they're considerate, and I like chatting with them about other things, just to distract myself.

I know I've neglected my own health. Still, I try to follow my doctors' advice carefully and look up information online, because the health insur-

> *Emotionally, I've become more irritable. I sometimes rush through the streets, bumping into people due to the stress*

ance system is slow and inefficient when I need attention quickly. I try to be proactive about my health.

What worries me most about my mother's condition is that she's slipping away more each day. I notice she's slower—her steps aren't what they used to be. Another big concern is that I have a hernia, and the pain becomes unbearable when I have to lift and move her around the house. My relationship with her has always been good, but as time goes by, she becomes more distant and I love her even more. It's very painful to think about the day she will leave me. I try not to think about that day—it's too hard.

As for the doctors, they've been good. The real issue is with the health insurance company; they make everything difficult. You have to go in as an emergency to get care. I once arrived at 1:00 p.m. and didn't leave until midnight.

At home, I haven't made any major modifications. I did install a rocking chair for her arthritis and adapted a piece of furniture to help her move around. In terms of finances, our household spending has definitely increased. It's impacted our economy, but we've managed.

Despite everything, there are positive aspects to caring for my mom. I feel satisfied with what I'm doing. I feel like I'm giving back everything she did for me, such as every time she rocked me to sleep in her arms. On a spiritual level, it has been fulfilling. I feel full and grateful for what we've shared. Spending so much time with her has allowed me to truly know her. She tells me stories, old sayings, anecdotes—it's been beautiful getting to know that part of her.

To other caregivers, I'd say: cling to God or to a higher power that can help you. Faith gives you the strength to endure, because this journey is very hard. I would describe this process as difficult, distressing, stressful, and exhausting. I would advise healthcare professionals to support patients more, to see how hard this is for caregivers. They should be more connected, more attentive to how things are progressing in the homes of their patients.

Gloria

My full name is Gloria. I'm 81 years old and live in Mexico City. I'm a homemaker, and the person diagnosed with Alzheimer's disease was my husband. He's no longer with me as he has been living in a nursing home for two years now, very far from here. His symptoms started in early 2019, around the time of the pandemic.

My husband was already retired by then, and we were both living here. I used to practice alternative medicine; I was a therapist and had a clinic, but when he got sick, I had to close it down because I had to care for him. Our life used to be very different. We used to travel by plane, and he would even drive me to the clinic. By then, we had grown apart—our relationship was no longer loving. He had always been very flirtatious and unfaithful. We didn't fight anymore, we slept in separate beds, but we were able to coexist.

One time, he congratulated our daughters-in-law on their birthday—on a day that wasn't even their birthday. That was the first red flag. Then I started noticing more odd behaviors. When we went out, he had no sense of money. He'd hand over a bill and walk away without waiting for change, or he'd give too little. When we drove to my son's house, he'd get lost, take wrong turns, and we'd end up driving around in circles, although we always made it eventually. He'd get angry when I told him we were going the wrong way. Eventually, he decided himself that he shouldn't drive anymore—he realized he couldn't remember the directions properly.

We took him to neurology, and in the consultation, when they asked him some basic questions, he couldn't answer them correctly. That's when they diagnosed him.

When we got the diagnosis, I felt angry because I had to close my clinic. He also didn't want me to bring patients to the house. When some did come, he would ask them too many questions or talk excessively to the young women, which made them uncomfortable. So I stopped seeing patients entirely. That's when I realized I needed to be fully present for him, to keep a close eye on him.

When we were given the diagnosis, the professionals gave us some advice. They recommended taking him to a daycare center for Alzheimer's patients—leaving him there during the day and picking him up afterward. But it was difficult for me to manage that, because I had to drive and handle everything at home too.

Caring for my husband was hard. The most difficult part was bathing him because he didn't like to be touched. He'd grab my hands and tell me he didn't want that. He'd get upset easily. The hardest part overall was always needing to be alert, making sure he didn't climb onto the roof, didn't grab the house keys and try to leave, all while also keeping up with housework.

At night, he'd wake up and turn on the TV, and I could hear it from my room. One night, I woke up because I smelled smoke. He had gotten up, taken a piece of cheese, tried to cook it, and it burned. I went downstairs and found him asleep on the couch while the cheese was burning in the kitchen. After that, I put a bed in his room to be closer, and I installed a bell on the door to alert me if he left the room.

Thankfully, I never had trouble sleeping. I was so exhausted that I'd fall asleep instantly. That's why I didn't always hear him get up. Sometimes I'd wake up to check on him, make sure he was in bed, then go back to sleep.

Even though caring for him was exhausting, when my children told me it would be better for both of us if he lived in a care home, I became very sad. I cried all the time. When I fed him there, the tears would just fall, and he noticed. I wanted to admit him, but once I did, I was overwhelmed with sorrow and guilt just seeing him that way.

He has a good pension, and I thank God for that peace of mind. It's enough to pay for his care home. The home requires things like diapers, a wheelchair, and medications, and his pension is enough to pay for them. But for myself, I live modestly. I've never been into luxury, so I get by.

As for his family—they hardly ask about him. In an entire year, they've only visited him once at the care home. Occasionally a sister or brother stops by, but nothing consistent. He never really had close friends, so he hasn't missed anyone socially.

Money-wise, he was never generous with me. I didn't even know how much he earned or what he did with his money. When he got sick, he started telling me about his accounts and giving me his passwords. The hardest part was having to take over everything because he hadn't told me anything. Suddenly, bills started coming in, like the insurance on the truck, and he had

> *I'm grateful that he's doing well now and that he's in a place where they're caring for him properly*

accounts in several banks. I didn't know any of it. He stopped paying those things and never said a word. Managing all of that was extremely difficult.

Everything started during the pandemic, so we stopped going out, even to his doctor's appointments. We both got COVID—his case was mild, mine was severe. At that time, I received no help for either my physical or mental health. There was no access or opportunity for support.

I'm grateful that he's doing well now and that he's in a place where they're caring for him properly. That's the most positive thing. He's gotten thinner, but I'm at peace knowing the doctors are checking on him and giving him the best care. I also thank God that he was never aggressive. He got stressed during bath time, but never violent.

A piece of advice I'd give to other caregivers like me is: give them lots of love and treat them well. What else can you do? Seeing him so sick made me very sad. I'd constantly wonder what was going to happen to him—and what would happen to me. All you can do is speak kindly to them, make sure they're okay, and keep them calm—just like he is now at the care home.

Vilma

My name is Vilma. I'm 57 years old, I live in Cipolletti, Río Negro, in the Republic of Argentina, and I'm a lawyer. The person with MND is my mother, and I've been her caregiver since 2020.

Before my mother's diagnosis, a typical day for me involved getting up, having breakfast, going to work, taking my daughter to and from school, going to the gym, and meeting up with friends and family. I had a fairly active social and professional life. My mom and I have always had a very close relationship—we were like partners in crime. I saw her once a week since we didn't live together but we lived close by. Our relationship has always been one of deep attachment and love.

At first, we thought her forgetfulness was due to aging. But we started noticing something else was going on—she kept repeating everything, became disoriented, suddenly stopped doing things, didn't want to leave the house or see friends or siblings. When we went to the doctor, they said it was depression. It's quite common to confuse MND with depression. What she actually had was apathy—no energy, no interest in anything. She'd lie on the couch watching TV all day. One day, we were walking and she got lost. That was in 2017. That same day, I made an appointment with a neurologist. He said she was having memory lapses and suggested she carry a notebook to write things down so she wouldn't forget. She wrote on everything—receipts, her cigarette pack, everything. Then in 2020, when the pandemic started, things worsened. She became dependent on me and my brother. She couldn't handle money, couldn't find things, couldn't remember where she parked the car. From that point on, she lost her autonomy and she could no longer carry out daily activities without help.

My brother and I shared care duties. She'd stay at my house for a while, then at his. In 2022, after cognitive tests, we were given the official diagnosis: MND. I wasn't surprised—I had seen it coming—but it was still heartbreaking. At that time, I received a lot of information about what the diagnosis meant and what to expect. The doctor invited me to attend group meetings about the topic, and I gradually learned more and more.

Among the five siblings, I'm the one who's most involved in caring for our mother. I was the one taking her to doctors, so I became the main person in charge. My brother admitted he found it too difficult, so I ended up taking on more. At home, we got a special chair to help with bathing her, because it was getting hard. Bathing was complicated—she insisted she had already bathed. That was tough, especially because I have a younger daughter. Giving up her room for my mom wasn't easy.

What's been hardest is accepting that the person my mom used to be is no longer here. She lost her identity and gradually lost other things too—she forgot how to cook, didn't want to bathe, didn't want to see her siblings, forgot about people who had passed away. For us, it was hard accepting that she had become someone else, even though I knew her love for me would never change. Watching her deteriorate has been painful. I've grieved the loss of our mother-daughter relationship—we can no longer have a conversation. I've experienced the full weight of being a caregiver. Alzheimer's marks a clear "before" and "after" for a family member. That's how I'd define it. It affects your sleep—you worry constantly. Sometimes they wander at night. One time, she even escaped the house. If you follow the doctor's recommendation to increase her meds so she'll sleep, she might fall out of bed. They hide things or eat in the middle of the night. Then the next day, you can't function due to lack of sleep and emotional exhaustion.

Emotionally, the recurring feelings are guilt—wondering if I'm doing enough—and frustration: "Why me?" It brings on a sense of anguish. Not depression, because I don't even have time to be depressed, but a deep anxiety and disorientation, not knowing how to move forward, knowing this is irreversible.

Since my mom's diagnosis, my life has completely changed. If I'm not with her, I'm doing something for her. Even when I'm with my husband, my kids, or friends, her care is always on my mind. You have to take her to neurologists, psychologists, psychiatrists, manage her meds, adjust dosages—it all eats up your time. I've distanced myself from my social life. I still see my best friend from high school, but the rest have drifted away. My mom's siblings also drifted away because they couldn't handle the situation. I hardly go out for coffee, to the movies, to dinner, or to birthdays—my social life has been cut more than in half.

Sometimes, I'm so overwhelmed I forget things like papers, for example. Thankfully, I haven't needed medication to get through this. I try to care for

I'm grateful that he's doing well now and that he's in a place where they're caring for him properly myself—I exercise, or have a beer with my husband on a Friday. I've seen other families grow stronger during this process, but that's not the case with mine. In our family, it's always been dysfunctional, and my mom became like a hot potato—everyone just wanted to pass the responsibility. Her illness didn't bring us together. It did the opposite.

To be honest, I've thought how sad it is to end your life this way. After everything she did in her life, she deserved to grow old with dignity and a sound mind—to enjoy life. I love her as she is now, and I don't want to lose her. But what worries me most is that she's entering the final stage of the disease. I dread the moment when she'll need diapers, because it'll hurt so much. Or the day she stops speaking. Right now she still talks a lot, and even if she doesn't make sense, she keeps talking. The medication makes her legs weak, so I worry about her mobility. And I fear the day she no longer recognizes me.

She's been in a care facility for a few months now—on medical advice. It had become impossible to care for her at home. She was completely dependent on me. I stopped going out, stopped working, stopped exercising—I just stayed home with her. I only went out for groceries. I never hired a caregiver—I did it all myself. And if I left the house, it was like leaving a baby—I'd run out and come back quickly. It clearly couldn't go on that way.

Admitting her wasn't easy. First, you have to research and find a suitable place. Waiting lists are long. There's a lot of demand and very little supply. Not all homes are good or a good fit. Plus, you feel like you're abandoning your loved one. I talk about this a lot with my younger brother, who lives with me. My mom's illness has triggered a lot of family conflict. I used to talk about it with my brother and my mom's twin sister—but not anymore. Now no one asks about her. They've forgotten her.

Alzheimer's is an expensive disease. It's not for low-income families—and not even for the middle class. It has financially impacted us greatly since placing her in the care home. She has her own income, and her medications are covered. I never hired caregivers at home, but if I had, her income could have covered it. But the residence costs are crushing—we've had to take out loans.

In my opinion, there are very few psychiatrists and psychologists truly prepared to treat Alzheimer's patients. You can go to the right psychiatrist, but I say this because early on, when my mom was feeling down, they filled her with meds, thinking it was depression. But it wasn't depression—it was apathy, part of her condition. What failed was the initial diagnosis. Once we had the right diagnosis, we acted fast. But we lost valuable time.

People in general are ignorant about what Alzheimer's really is. There needs to be more awareness—it's incredibly common. When people hear "Alzheimer's," they think "senile," like it's just some memory loss. There's

> *People in general are ignorant about what Alzheimer's really is*

also a certain discrimination. People start excluding you because they don't know how to deal with someone who has it. Even my mom's own siblings stopped inviting her to things. You get pushed aside. That's discrimination based on ignorance.

Still, there have been some positives. I've learned to relate to my mom in a different way. You cultivate patience, compassion, mercy, empathy. You learn to value moments of peace and appreciate your loved one. Alzheimer's isn't a death sentence. You can still live with your loved one. There are even funny moments, which shows the importance of humor. It's not all bad. You simply have to reorganize your life with a person who has Alzheimer's. It's not that your life is over—you just have to shift the pieces. You learn a lot, and in the end, that experience makes you grow.

To families starting out on this journey, my advice is: love—love deeply, because without love, you can't do this. Even if your loved one doesn't recognize you, they still love you. That love doesn't disappear with Alzheimer's. My mom doesn't always know who I am, but she still tells me she loves me. My advice: love each other deeply, be patient, and transform this disease into an act of love. Accept your loved one as a new person—a new mom, a new dad, a new partner. Part of them may be gone, but the love is still there. And when you reach your limits, ask for help from professionals or support groups. But above all: love, patience, and grace.

Lorena

My name is Lorena. I live in Mexico City and I am 52 years old. I work at an elder care home. My relationship with people who have MND-dementia began when I was very young—since I was three years old, I observed how my mother took care of my father. Later, four of my siblings were diagnosed with Alzheimer's disease. Currently, I am caring for my sister, and in the house where I live there are 14 other residents, three of whom also have Alzheimer's.

Before dedicating myself to caring for people with Alzheimer's, I was a model and worked with Televisa doing commercials. I mainly modeled clothing, so my life back then was completely different from what it is now. I traveled a lot and had no experience or knowledge in caregiving. I didn't get married, although I almost did—with my boyfriend. I also completed a degree in pedagogy because I wanted to open a school focused on early childhood education. But my world changed completely.

As a family, before the disease appeared, we were very united. We got along well and enjoyed doing exercise and activities together. My mother was devoted to our home—she bathed us, cooked for us, and took care of everything. Among my nine siblings (three women and six men), we played volleyball, basketball, swam, and really enjoyed our time together. However, when four of my siblings developed Alzheimer's, our family dynamic was completely disrupted.

Right now, I'm caring for my sister, who is younger than I am. Her first symptoms began at age 39. She started feeling extremely sluggish about doing anything, which was unusual because she had always been very active. She began waking up later, stopped doing the dishes, making her bed, and completing other daily tasks. We initially thought it might be depression, even though she kept reading—which she loved. But then her behavior changed drastically: one day, she forgot to take her daughter to school, got disoriented, and we spent the entire day looking for her.

We finally decided to take her to a neurologist. Based on our family history, they performed genetic testing and confirmed that she had Alzheimer's. I remember them showing me scans of her brain—several areas were already affected. They also did genetic testing on me, but due to the lab's policy, I was never given the results.

During this process, I met a doctor who had studied Alzheimer's in families from Jalisco, where the disease is more prevalent due to intermarriage among relatives. He showed us a genealogical tree of my family, clearly displaying a hereditary pattern. According to that study, I am currently among the group not presenting the disease—along with two of my older siblings.

When I learned of my sister's diagnosis, I was devastated, especially because she has two small children. It's the kind of news that's difficult to process, but thanks to working with psychologists, I came to understand that life is a journey and that we must face illness with attention and love. I began attending support groups and learning more about Alzheimer's so I could better support my sister.

Caring for my siblings has been challenging but has also taught me valuable lessons. With the help of neurologists, we've used workbooks with cognitive exercises to try to slow the progression of the disease. Spending time with other families going through similar situations has comforted me and reminded me that I'm not alone.

I chose to care for my siblings of my own free will, although there were times I felt overwhelmed. A psychologist helped me understand that I shouldn't expect gratitude for what I was doing and that I needed to act from love and not expect anything in return.

Each of my siblings experienced Alzheimer's differently: one spent all day sweeping, another lost the ability to speak but communicated through gestures. These differences taught me that the disease doesn't affect everyone in the same way, even with the same genetic background.

The hardest part has been seeing my sister during moments of lucidity when she realizes her condition and cries, asking, "Why me?" Those are the most painful moments for me.

At one point, I was taking care of all four siblings at the same time, and I physically collapsed. I had to seek professional help to manage the physical and emotional stress. That's when I decided to open a care home, because I knew I couldn't do it all on my own.

The home I created is small but focuses on providing quality care to people with Alzheimer's. We charge a low fee because many families have limited resources. We have trained staff, motor skills activities, and monthly medical check-ups. My partner and a close doctor helped me launch this

> *She started feeling extremely sluggish about doing anything, which was unusual*

project. It was born from my desire to give others what I learned from my own siblings: to care with love, patience, and dignity.

Today, I understand that life is fleeting and that everything we do should be focused on love and understanding. I've learned not to question people with Alzheimer's, but to follow their pace and respect their perception of reality.

This journey hasn't been easy, but it has strengthened my family relationships and taught me to cherish each day. Despite the challenges, caregiving has given me a sense of purpose I never imagined.

I sometimes speak with others, especially members of support groups. I listen and encourage them to read, to open themselves to new opportunities, and to seek out other support groups. When they start having trouble, I tell them they must learn to let go—that nothing belongs to us. We're only here in this world to be happy. That's what I learned from my siblings: everything is fleeting, everything lasts only a moment.

Society discriminates against people with Alzheimer's. They're not included, people feel ashamed of them, and terrible things happen. But it shouldn't be that way. It's a gift to be able to help another human being. If you do it selflessly and from love, it shouldn't matter what people say. Unfortunately, discrimination is still very common.

There was a time when I was afraid that the disease would come for me too. But with the help of my psychologist, I learned that if I lived imprisoned by that fear, I wouldn't be able to enjoy life. Everything is fleeting. I could die tomorrow. I couldn't let myself spend every day wondering if I was going to get Alzheimer's.

What life has taught me is to move forward and not complain about meaningless things or treat them as problems. Life is not a problem. What happens to me every day are just circumstances—whether I have to pay the electricity bill or fix a leak in the house, all of it should be handled with love, because life is about living in the present. I can't change things, and I've learned to live with that—just as they are, here and now.

My advice to people just entering this world is that life is a process—and it's filled with changes. And now, that change has arrived. You have to acquire knowledge to help others and yourself. It's not something outside of reality—things happen to everyone in life. But the more informed you are, the easier it is to handle everything. In the end, this process will leave you with a life lesson. When you let go of yourself and help others with your heart, the experience becomes something wonderful. And at the same time, you must let yourself be helped by others. You have to find people who are willing to do their part. There are institutions that are ready to help too.

Nuria

My name is Nuria, I'm 45 years old, and I live in Tegucigalpa, Honduras. I currently work in mental health, specifically in art therapy, but by profession, I'm a visual artist and graphic designer. I was the caregiver of my grandmother, who passed away three months ago and had Alzheimer's disease. While caring for her, there were eight of us living in the same house and sharing the responsibility of her care.

Before my grandmother's diagnosis, I was still in school and really only focused on myself. I was 18 years old, and at 19, my life changed drastically because my parents left to work abroad, and we were informed that my grandmother had Alzheimer's. At the time, I had no idea what that disease really was. My life then revolved around my studies—I was finishing my senior year of high school and preparing for university. I was introverted, quiet, not very social. It was the same with my family; I preferred being in my room, drawing and listening to music. My parents (who were always strict about responsibilities) both worked, and back then, my grandmother was around and often took care of us, but she didn't yet live with us. Those early experiences shaped my role later as a caregiver.

As loving grandchildren, we were always close to her, so I noticed she started complaining about her memory. She had been a special education teacher for the blind, and I remember one day she got disoriented in a place she had passed through daily on her way to work for many years. She didn't know where she was. That was one of the first warning signs we observed as a family. At that point, she was about 70 years old. My grandmother was very organized and wrote down a lot of reminders in her notebook. She wasn't emotional by nature; she was calm and composed. I remember one time she lost her coin purse—which she usually hid somewhere—and couldn't remember where. That was the first time I saw her cry. I now understand it was probably out of frustration and pain. I remember going to her and telling her it was something that could happen to anyone. After that, more incidents of losing things and telling stories that hadn't happened began to occur.

My aunt, who is my grandmother's daughter-in-law, noticed that her behavior was changing: social withdrawal, difficulty with coordination, disorganized speech, sleep disturbances, and appetite changes. She decided, with the support of my grandmother's children, to take her to a neurologist. That's when she was first diagnosed with possible Alzheimer's in 2006. By then, she was getting very disoriented, had angry outbursts, and would walk off alone. We were worried she'd get lost, so we took her for a formal evaluation.

Hearing the diagnosis made me incredibly sad. I broke down in tears at the doctor's office—it was really hard. I remember the doctor telling us it wasn't advisable for us to take on the caregiving responsibilities because we were so young. I was 23 and still studying, working, and caring for my grandmother and younger sister. I had a migraine crisis and went to see a neurologist, who told me I was carrying too much weight on my shoulders. At that point, I still didn't fully understand what Alzheimer's was—it was a painful and confusing time.

Because I was so close to my grandmother, I didn't want to let her go. I begged my uncles and my mom to let her stay with us, and my siblings supported my decision. Despite the doctor's recommendation, we kept her at home. The clinic staff also told us to seek support from the Honduran Alzheimer's Association, which gave us more information. I was the grandchild who stayed with her the closest—for nearly 25 years.

Of all those 25 years of caregiving, the most difficult part was the introduction of palliative care, though it lasted only a few days. It's the hardest memory for me to erase. When she turned 90, we began focusing entirely on quality-of-life care. The final years—especially after COVID—were the hardest. We didn't have nursing help because we couldn't afford it, and also because my husband and I preferred to keep it in the family. I didn't want to hospitalize her because I didn't want her to feel alone, and hospital care was also too expensive. As her caregiver, my biggest fear was that she wouldn't be comfortable or would be alone. I refused to see her hooked up to machines in an emergency.

Once her physical condition began to decline, we started modifying the house. I became very focused on this. I started reading more from the Alzheimer's Association and learning on my own. I shared everything I learned with my family so they could understand what was needed—like adapting the bathroom with shower chairs, installing grab bars, switching her to a higher bed with railings, adding pressure-relief cushions, and reinforcing gates to keep her safe while still allowing her to feel connected to her environment. She always had the full love and support of our family—we tried to meet every need she had.

> *As her caregiver, my biggest fear was that she wouldn't be comfortable or would be alone*

After her passing, everything came crashing down. Over the years, I developed cervical and lumbar injuries from carrying her. I now live with chronic fatigue and depression, my sleep is disrupted, I've gained weight, and I'm still dealing with all of that. I never had children—my husband and I weren't avoiding it, but I think the stress kept it from happening. I've had migraines that were treated by a neurologist and psychiatrist who also prescribed me medication.

My husband was incredibly supportive. As he saw me becoming more affected, he got more involved—he helped me bathe and dress her. My grandmother became like a daughter to us.

Today, I've had to scale back my activities because I'm so exhausted. At one point, I was given hormonal treatment to help with pregnancy, but it caused terrible side effects—anxiety, mood swings, self-harm—so we stopped.

There were many moments when I felt frustrated—when I didn't know how to help her eat, how to give her instructions. I knew it wasn't her fault—it was the disease—but I still felt anger. I'd ask myself, "Why am I feeling this way?" My biggest fear was disrespecting her or becoming abusive toward her. It wasn't until I got professional help that I realized this is common for caregivers. These intrusive thoughts are warning signs that it's time to delegate, and that was something very difficult for me to do.

I was deeply frustrated that my life didn't look like my siblings'. I saw them pursuing their goals while I struggled to maintain mine. I often felt alone, even though I wasn't. The last few years, I shut myself off a lot.

I felt guilty—people told me I shouldn't—but I felt I never did enough. When the day came that I had dreaded for so long, God allowed me to be by her side. I got the chance to say goodbye days before, even though I didn't know it was the end. I opened my heart to her, told her what she meant to me, and how painful her absence would be. She passed away peacefully, without suffering.

I usually kept my feelings to myself, sharing only with my husband. But even then, I didn't always tell him everything—I wanted to protect him. Especially in her last two years, I stayed quiet because things got very difficult.

I tried to take care of myself—getting up earlier to make the most of the day—but it always felt like there wasn't enough time. It was hard to prioritize myself.

As for the medical professionals who helped us, I think there's a lot of room for improvement—especially in the public sector. Communication needs to be better. One doctor didn't know how to treat my grandmother—he didn't explain anything, violated her space, and made her anxious. That left all of us very unsettled.

This journey was a shared learning process. I got to speak with other caregivers, share daily tips, and exchange experiences. To anyone stepping into a caregiver role, I'd say: to take care of someone else, you must care for yourself. Don't forget yourself. Always create space for you. Stay active with your loved one—that's part of giving both of you quality of life. Have patience, seek information, and learn to truly listen.

When my grandmother was about to pass, her way of thanking me was through a gentle touch. The next day, she passed away, peacefully, just like I had prayed. I was surrounded by my siblings and husband. In that moment, I said, "Mission accomplished." I couldn't have done more. I had cared for her for 25 years, and when she left, everything changed. Some days I don't feel like doing anything—but I'm continuing a mental health project I started for her. That gives me purpose. I've cut back on work hours to focus on it. My daily routine used to run from 5 AM to 7 PM. We never had a nurse; my husband and I did everything ourselves.

I always feared the grief—wondered if I'd be able to let her go. But this grief has been different. I kept doing the things I love, especially painting. I've made three paintings so far, talking to her and painting through her. That's helped me heal.

I know now that I have to take care of myself, because healing is up and down. Learning to delegate is crucial, and so is letting others guide you. Let others share your burden. Let yourself be supported.

Marta

My name is Marta. I was born on October 25, 1948. I'm 76 years old and an architect. I worked for over 20 years in an architecture firm in Miami, USA. During that stage of my life, I met Patricio, with whom I shared 27 years. I had already been separated from the father of my two children. My life with Patricio was wonderful. Sadly, when we returned to Chile, his illness began to manifest. Patricio passed away on April 29, 2024.

I'm currently retired, but still very active because I'm hyperactive by nature. I live alone, but I'm always busy between my succulents on the balcony and gardening at my son's house. I also love to cook. Most importantly, I dedicate a lot of time to my three wonderful granddaughters—they are the core of my emotional world. When we arrived in Chile, we took care of the oldest, who is now 15.

I was Patricio's caregiver for eight years, until I reached a breaking point because I had no help. The hardest and most painful decision I ever made was having to move him into a care facility in July 2019. Alongside the pain came overwhelming guilt. But I felt I had no way out. As the disease progressed, Patricio caused several fire hazards in the apartment. What finally pushed me to make this decision was when he began wandering off, getting lost for hours. That final episode forced my hand.

At that stage of the illness, I had help from a woman who came Monday through Friday for about six hours a day. That gave me a small but vital break, during which I could go out. This was critical for me because I was attending psychotherapy and Alzheimer's caregiver workshops—support offered by the Memory Clinic, created and led by a neurologist.

Patricio had five children from his first marriage; two sons and three daughters, all adults. We had no children together. I did everything I could to seek their support. Financially, I never received any help from them, but my own children, Pilar and Rodrigo, did assist me. I tried everything to get them to help me with time, which was crucial because I needed some space to breathe in order to keep going. But that support never came either, and I'm convinced that's what accelerated my decision to move him into a care home. My children helped financially, but they also had very demanding jobs and couldn't offer more. What I needed most during that painful time was attention, empathy, care, and someone to listen to me. That's why I say, even now, that the Memory Clinic's team, especially my psychologist, saved my life.

> *He still helped in the kitchen, though with less enthusiasm. His role in raising Amalia, our oldest granddaughter who was only one when we arrived, was essential*

Before Patricio's illness, my life was very different. I felt I was going through the best stage of my life. Our relationship was harmonious, we were a team, we helped each other with everything. Each of us had our own job, but come Friday, we shared activities together. We had an active social life. Every Saturday, we'd host a dinner and invite friends. We loved cooking and entertaining. On weekends, we'd go on outings or spend time with my visiting children. Patricio was always a gentleman—he made me feel like a princess. He supported everything I loved and was always there for me. We truly did everything together.

Returning to Chile was a drastic change—especially for him. I think it was tougher for Patricio than for me, perhaps due to how men in Chile are raised. After retirement, he seemed lost and disconnected, while I remained busy. He still helped in the kitchen, though with less enthusiasm. His role in raising Amalia, our oldest granddaughter who was only one when we arrived, was essential.

The first clear symptom appeared in 2012 (we moved back in 2011). We were preparing food to take to my son's house. I went to get my purse, and when I came back, he asked, "Martita, where are you going?" At first, I thought he was joking. Later, I realized it was the first sign of short-term memory loss. Looking back, maybe it started earlier—around 2010—after a surgery requiring general anesthesia. The doctor was concerned about his recovery, as he was very disoriented for a long time. He also stopped participating in shared decisions, leaving me to handle everything alone. I was so caught up in preparing the move back to Chile that I didn't notice. I also remember one night, while driving, he hit a curb and popped the tire. His response was, "I can't drive anymore," and he never drove again. One month later, we were in Chile. That, too, may have been a symptom.

I sensed something was changing, but I couldn't figure out what it was—like trying to pinch glass. I didn't know if the change was due to the move...

At that point, I took him to a neurologist. Without conducting any tests, he diagnosed Patricio with "severe depression in an older adult" and added

"Alzheimer-like symptoms, but it's not Alzheimer's." He prescribed antidepressants, increasing the dosage at each visit. But I, living with him, knew this wasn't depression. After two desperate years of maximum-dose antidepressants and no improvement, I took him to another neurologist, who immediately ordered blood tests and a brain MRI. The results showed clear neuronal damage. The diagnosis changed to nonspecific MND, and the antidepressants were stopped.

I felt relief knowing he would now be treated correctly, but this new doctor—though highly recommended—was arrogant and cold. I decided I didn't have to put up with that. I was already going through so much. I took Patricio to a geriatrician, who maintained the diagnosis of nonspecific MND. Eventually, we reached the Neurology Department at Hospital Salvador, referred by my family health center (CESFAM). There, a neurologist diagnosed Patricio with Alzheimer's disease. She clearly explained that it was a degenerative brain disease with no cure. Patricio didn't grasp the gravity—he was already very out of touch—but I was devastated. The doctor also invited us to join a research study, and I agreed immediately, hoping to contribute to better understanding and treatment.

Receiving the diagnosis brought mixed feelings. Relief that we finally knew what it was, but deep anguish because it was incurable. I wish someone had explained the disease's progression, how it would manifest in behavior, and how I should respond. As the disease advanced, I felt overwhelmed. I would get angry at Patricio, then feel guilty and powerless.

Soon after, the Memory Clinic was established. I felt welcomed and was assigned a psychologist who supported me through the worst phases. Patricio was losing all cognitive and functional ability, falling often, leaving appliances on, and smoking indoors.

About a year into the Clinic, workshops for Alzheimer's caregivers began. I attended them all. It was like group therapy—everyone going through similar but unique journeys. We cried, shared fears, gave advice. That group work was a turning point for me.

Being Patricio's caregiver wasn't a choice—it was obvious. I knew I couldn't rely on his children. My children helped financially, but I was always alone. Caring for him was my duty. They respected and loved him because of how well he treated me.

We didn't have to make many changes at home—just logical ones like removing rugs and labeling drawers. He would wander at night, leave things on, smoke. I moved him to another room so I could lock the door and sleep safely.

On March 5, 2019, around 9:00 PM, Patricio wandered off and walked aimlessly for two hours. With the help of the police, we found him. I was terrified and emotionally drained—at my breaking point. My children sat me down and told me it was time to make a decision. I began searching for a care home with a trained team and a safe environment.

The first home we tried was good, and I highly recommend gradually transitioning your loved one into care. Patricio started going twice a week, then three times, and finally stayed. Having that time to breathe helped immensely—it was the relief I never got from family. I also continued therapy, which was essential. I was physically and mentally exhausted.

When Patricio became incontinent and began smearing feces, it was unbearable. Despite using adult diapers, the messes happened often. Cleaning him, the room, and everything else was one of the most painful parts. I felt sadness, rage, guilt. I still sometimes feel ashamed I lacked the patience I should have had. It's important to prepare early—go to workshops, learn how to respond to these situations. Those workshops saved me.

The diagnosis deeply affected my mental health. I suffered from depression and needed medication because therapy wasn't enough. I was referred to PROVISAM, where the wait for a psychologist was long, but I got lucky. I got an appointment quickly—and that saved me. Therapy saved my life. I often wanted to disappear.

Caring for Patricio made me give up many things I loved—gardening, cooking, socializing. Alzheimer's is like a tsunami—it drains your energy, takes away your joy, and leaves you needing silence and rest.

When he moved to the care home, I had mixed feelings. I could rest, but I felt guilt and sadness for taking him out of our home—the one we built together, every piece chosen together. I visited him often, lay next to him, sometimes even napped with him. We'd go outside to smoke. I made friends with other residents. Our relationship changed—he became affectionate, and I no longer had to be the one managing his "episodes." He'd hold my hand tightly. On Sundays, I'd bring him to my son's house, where he loved being with the girls and the garden. He always enjoyed a whiskey.

During the pandemic, that care home deteriorated, and Patricio's condition worsened rapidly. I regret not moving him sooner. Eventually, I transferred him to a smaller, more personalized home, where I believe he was well cared for.

> *When he moved to the care home,*
> *I had mixed feelings*

Throughout these 12 years, beyond professional help and medication, I also found comfort in a chosen family—friends who became closer than relatives. I took a Bach Flower Therapy course that included weekly meditations, which helped me relax and brought me peace. I loved it so much I repeated the course years later. It gave me spiritual strength and a sense of belonging.

To anyone beginning the caregiver journey, I say: seek professional help immediately. Join groups or workshops, find relaxation and meditation spaces, and build a healthy support network, especially if your blood family isn't present. Keep a journal of your emotions—it's therapeutic even if you cry while writing. I wish I'd been taught from day one about the variations of Alzheimer's, not just told it was incurable. Knowing what to expect would have made a huge difference.

From this painful experience, I gained profound personal growth. Seeking professional help was transformative and still sustains me. Finding workshops and loving friends made me feel supported and enriched.

In the end, it wasn't Alzheimer's that took Patricio, but cancer—a prostate cancer detected in 2010 that returned in 2021. By then, his Alzheimer's had advanced so far that no treatment could be done. When he died, I felt deep sorrow. I still cry, a cry that comes from deep within my soul. I've learned that grief is energy that must be released

I miss him terribly—even when he was almost unresponsive. I'd visit, play his favorite Elvis videos, bring him home, share a drink with him. Those were our final ways of communicating.

What helped me endure this ordeal were the memories. I felt blessed by the love he gave me. We made sure he didn't suffer, that he was at peace. That gives me comfort.

Since Patricio passed, I feel a void, but also more time and fewer worries. I'm now dedicating myself to my granddaughters. Maybe I just have a caregiver's soul. With more free time, I laugh at things I used to overlook. Some joy is returning. My social life is still fragile, but I'm working on it.

Elena

My name is Elena, I am a 71-year-old woman and have been José's partner for 37 years. Together we built a blended family with three children each: four daughters and two sons who feel like siblings. I am a clinical psychologist and continue to work with great affection and commitment to my profession.

The person with Alzheimer's I care for is my husband. He worked until 2019, and even then, there were signs something was changing. José is also a psychologist. Toward the end of that year, his projects were winding down, the pandemic began, and he lost his job. At that point, we moved to the countryside, where José began to isolate himself, while I stayed socially active. I continued meeting with my friends however I could, but José withdrew and became depressed. That's when it became clear something was happening. In 2020, he was diagnosed with mild cognitive impairment, and the doctor explained it could be the onset of Alzheimer's. At the start of 2022, he was formally diagnosed with Alzheimer's.

Three years ago, I obtained a general mandate to represent him, and two years ago, I had to close his bank account and take full charge of organizing and supporting both our lives. For the past year and a half, I've been his full-time caregiver. We live alone, and our dynamic has clearly changed. Before the diagnosis, we both enjoyed a lot of freedom. We worked during the week, often apart when José worked abroad, and reunited on weekends at our countryside home, enjoying our life as a couple or with family.

My social life was very fulfilling. I frequently saw my friends, traveled to visit my children and grandchildren, and we planned our lives freely and carefully. Our relationship has always been respectful, kind, and loving. While our independence was important, we were close friends and wanted to be together.

The biggest change is that we used to build life together. José had goals, desires, plans, and shared interests. We had a fun family life and enjoyed doing things together. Today, I build our life alone. I invent, decide, generate, and organize everything on my own.

When José was first diagnosed with mild cognitive impairment, he already had forgetfulness, strange ideas, and actions he couldn't explain. He made up excuses, denied things, and behaved unlike the man I had known for over thirty years. He often forgot commitments, events we shared, or conversations we had. He got frustrated when I confronted him. José knew something was wrong, and it made him angry and sad. Receiving the Alzheimer's diagnosis brought some relief. I could see the changes, but I had to pretend nothing was happening to avoid making him feel attacked. He was still in denial and very afraid.

Initially, I couldn't talk to him about the diagnosis. Today, we process it together. José appreciates that I ask and talk about what he's experiencing. In the beginning, he would always find an excuse for forgetfulness or mistakes, and got angry when I tried to clarify. Fortunately, I have sisters, and even though we had no experience with cognitive decline in the family, we would talk and share our experiences. Having an outside perspective was important. I often felt terrible, as if I were the one making José look bad. I knew I wasn't a bad person, but it was hard being the one to recognize something was wrong. I needed external validation and companionship. It's incredibly painful and desperate to watch your life partner disappear, dissolve, fade.

As a psychologist, I understood the diagnosis. I had supported patients and families with Alzheimer's before. I read books, watched films, and sought information to be better prepared and avoid getting angry. But none of that removed the sorrow or anxiety. I often feel overwhelmed.

I work with a psychologist who helps me accept reality and respond in the best way. Being José's caregiver wasn't a choice. After 36 years with a man I love deeply, I will continue being his caregiver as long as I can. When it becomes harder, I will seek support. Today, he can sit for hours watching TV but cannot tell me what he saw.

A hard part is José's heightened sensitivity. Anything not said lovingly makes him sad and teary-eyed. He was always sensitive, but now it's intensified. He feels misunderstood and powerless. He loses things, can't find what he's looking for, and doesn't recognize many items. It's painful to witness. He knows he can't do many things and says, "I am no longer who I was."

One gift I received was this advice: "Don't search for the man who is no longer there, look for the child and play with him." That changed everything. I now treat him like I did my children when they were sensitive—sweet voice, affection, distraction. It helps both of us. He no longer writes or reads. He asks me to be his voice. We're still great friends and companions.

My needs haven't changed. I still need air, others, to nourish my heart and mind. I have a meditation group and a bodywork circle of women I love deeply. I do yoga weekly and continue working, carefully scheduling it when José naps. Work allows me to do something for myself, like traveling to Spain to visit my sister once a year. Thankfully, we have the financial means, which gives me peace.

My personal life is more restricted. My sexual life is fading, though we share tender intimacy. He's very affectionate, and I enjoy being close to him. Without Alzheimer's, our sexual life would likely be different. Still, I'm not unhappy. I know this is part of life. I seek company and balance to stay healthy. Being well is necessary to care well. What's changed the most is my lack of internal silence. I'm constantly thinking about José's needs. It's like having young children—always alert.

I feel blessed. It's not common to have so much support and children who help you breathe and nourish your soul. José pushes me to be gentler and less self-centered. I'm still myself but learning to be softer because he matters. This challenge broadens my perspective. I see myself as a small part of a greater universe. Life feels lighter and more impermanent. Stability equals death. That reminds me to be present and appreciate today, because tomorrow may be worse.

Being a caregiver is physically, emotionally, and intellectually demanding. It's a multi-level challenge. I take a small dose of antidepressant to help. This will end with death. We talk about life and death often, especially after losing family members. I know José will die. I've imagined life without him. I don't want him to live forever, especially not completely dependent, bedridden, incontinent. That will be hard, even if he's unaware. But I will be there. It's my loyalty to the man I lived life with. And I know that if it had been the other way around, he would sit by me every day.

Sometimes he shares his feelings. I listen. When he despairs, it saddens me because he thinks it's his fault. If I told him how hard this is for me, he would cry, and I wouldn't know how to comfort him. At first, I could share my feelings with him, but not anymore. His distress doesn't help me. I talk to others about my experiences, about the profound loneliness, but not to him. I want to spare him unnecessary pain.

If I could give advice to someone starting this caregiving journey, I'd say: be aware this is a process. Nothing is stable. Today is better than tomorrow. Enjoy what there is, even if it's little. It's exhausting, and you will want to run. So take care of yourself. Ask for help. If there are children, ask them to take one afternoon a week. You can't give everything. Caregivers need care too.

As for professionals, I wish they spent more time explaining what to expect. That would help with preparation. I was lucky to have two close friends who had gone through this with their husbands. They are an invaluable source of support.

Alzheimer's is common and will become more so. It's not an unknown disease. We should talk about it at the dinner table because more people will deteriorate before they die. Making it part of life helps everyone learn how to support and understand it—including our grandchildren. That's the value of sharing and learning.

Conclusions

Caring for a person with Alzheimer's disease is a profoundly transformative experience. The life stories shared in this book reflect not only the challenges but also the love, dedication, and resilience of those who accompany their loved ones through this journey. From these narratives, we can extract some key takeaways that may be helpful for other caregivers and their families.

The Emotional Impact on the Caregiver

One of the first things evident in these stories is the significant emotional toll that an Alzheimer's diagnosis has—not just on the person diagnosed but on their entire family. Caregivers express feelings of sadness, fear, and uncertainty as they witness their loved one change due to the disease. However, they also share how, over time, they learned to adapt to this new reality, finding moments of connection and love in small daily interactions.

Experiencing emotional ups and downs, including moments of frustration and exhaustion, is completely normal. Recognizing these feelings and seeking support is crucial for maintaining the caregiver's well-being. Many stories highlight the importance of accepting these emotions without guilt, understanding that the care process is demanding and requires great mental and emotional strength.

The Importance of Patience and Understanding

Alzheimer's is a progressive disease that affects memory, language, and behavior. In many of the stories, caregivers recount situations where they had to repeat the same answers over and over, deal with mood changes, or manage episodes of disorientation. Facing these challenges with patience and empathy makes a significant difference in the quality of life for both the patient and the caregiver.

A recurring theme in the testimonies is the importance of avoiding confrontation. Instead of constantly correcting the patient, it is more beneficial to accompany them in their reality, find ways to comfort them, and create an environment of trust and safety. Adapting to the new dynamic can be difficult, but learning communication and behavioral management strategies helps make daily life more manageable.

The Role of a Support Network

The life stories show that the caregiving journey should not be walked alone. Caregivers who have the support of family, friends, or support groups tend to have a better quality of life and are less at risk of developing "caregiver burnout." Delegating responsibilities, accepting help, and taking breaks not only benefit the caregiver but also enable better care for the patient.

Additionally, sharing experiences with other caregivers in similar situations can be a source of comfort and learning. Connecting with others who understand the challenges of Alzheimer's helps reduce feelings of isolation and provides practical tools for daily life. Some stories highlight how support associations and community resources were essential in navigating the caregiving process.

The Need to Care for the Caregiver

One of the most important messages these stories convey is that to take good care of someone else, you must first take care of yourself. Physical and emotional exhaustion can lead to health issues, making it essential to find time for rest, recreation, and self-care.

Many caregivers emphasize the importance of maintaining personal activities, even amid caregiving demands. Small actions like going for a walk, reading a book, or simply having a conversation with a friend can make a big difference in emotional well-being. It's also important to seek professional help when needed, whether through therapy or medical care to address stress-related health concerns.

The Value of Happy Moments

Despite the challenges, a common thread runs through all the stories: love and shared moments of happiness. People with Alzheimer's may forget names or events, but they don't forget emotions. A hug, a smile, or a song can bring joy and strengthen the bond between caregiver and patient.

Making the most of every moment of clarity and connection is one of the greatest lessons from these stories. Adapting to the changing reality of the disease doesn't only mean managing difficulties, but also learning to find beauty and meaning in every shared moment. Many families have learned to enjoy new forms of communication—like music, art, or simply mutual presence—transforming the caregiving experience into an opportunity for love and closeness.

Preparation and Planning Are Essential

One of the most valuable lessons from these stories is the importance of being prepared for the future. Alzheimer's is a progressive disease, and caregivers who plan ahead often face fewer difficulties along the way. Having legal documents in order, researching available resources, and learning about the stages of the disease allows for informed decisions and prevents crisis situations.

Planning also includes adapting the home for the patient's safety and exploring care options as dependency increases. Many caregivers found relief in having emergency plans and strategies for difficult situations.

In Conclusion

The caregivers' life stories reflect the hardship, but also the deep humanity, of the act of caring. Although Alzheimer's is a disease that robs people of memories, it can never erase the love and dedication of those who stand by the patient. Every caregiver, through their challenges and learnings, leaves an indelible mark on their loved one's life.

If these stories teach us anything, it's that we are not alone on this path. Seeking support, taking care of ourselves, and cherishing every moment are key to navigating this experience in the best possible way. And above all, remember that even if memory fades, love always remains. With a combination of patience, support, and preparation, it is possible to provide dignified and loving care while preserving the caregiver's own well-being.

APPENDIX

Organizations and Associations

Across the world, there are various organizations dedicated to supporting caregivers and individuals with Alzheimer's disease. These organizations offer a range of services, including family guidance, cognitive stimulation programs, caregiver training, and emotional support. It is recommended that individuals contact these associations directly for detailed information about available programs and services, as well as requirements for affiliation and participation. It is important to clarify that we cannot guarantee or vouch for the quality, effectiveness, or conditions of the services offered by these organizations, so we suggest interested individuals conduct a careful evaluation before accessing them.

Below are some of the organizations and associations available in Latin America:

Ibero-American Alzheimer Association (AIB)

Founded in 2003, this association brings together organizations from Ibero-American countries with the goal of jointly combating the negative effects of Alzheimer's disease. It promotes collaboration and the exchange of experiences among associations in the region. Website: fundaciontase.org

Alzheimer's Association

Based in the United States, this organization offers resources in Spanish and provides a 24/7 helpline for individuals facing Alzheimer's and other MND. It offers emotional support, information, and access to local resources. Website: alz.org

Pan American Health Organization (PAHO)

This organization offers the iSupport program, a self-help tool for caregivers, family, and friends of people with MND. The iSupport manual is designed to provide practical guidance to caregivers. Website: paho.org

▶ Argentina

A.L.M.A. (Association for the Fight Against Alzheimer's Disease and Similar Conditions)

Founded in 1989 and based in Buenos Aires, A.L.M.A. is a nonprofit organization that provides advisory services—both in-person and virtual—alongside support groups, caregiver training programs, therapy workshops (including cognitive stimulation, music therapy, and movement), and a helpline. They organize "Café con A.L.M.A." sessions and educational events to improve care quality, reduce stigma, and enhance caregivers' and patients' dignity. A.L.M.A. is a founding member of Alzheimer Iberoamérica (2003) and has belonged to Alzheimer's Disease International since 1990.

Website: alma-alzheimer.org.ar

Alzheimer Argentina

Established in 1998 in Buenos Aires, Alzheimer Argentina is a leading nonprofit focused on research, teaching, diagnosis, and treatment of Alzheimer's and other cognitive disorders. Their services include neuropsychological evaluations, cognitive rehabilitation, psychotherapy for patients and families, occupational therapy, legal advice, caregiver support groups, and webinars. They also publish an annual scientific journal and host the Argentine Congress on Alzheimer's and Cognitive Disorders. Dr. Luis Ignacio Brusco, a founding member and president, spearheads collaborative studies with CONICET and various universities.

Website: alzheimer.org.ar

National Registry of Home Caregivers (Argentina)

Managed by the Argentine government, the National Registry of Home Caregivers is a public system that certifies and supports trained residential caregivers—many of whom specialize in elder care and MND. Registered caregivers receive access to educational resources, standardized training, and official recognition to ensure quality of care in private homes across the country.

Website: argentina.gob.ar

▶ *Bolivia*

Alzheimer Bolivia Association (AAB)

Founded in January 2008 in Cochabamba, the Alzheimer Bolivia Association (AAB) is the country's leading non-profit devoted to supporting people with Alzheimer's and other MND, along with their caregivers. It operates across seven regional chapters—Cochabamba, Santa Cruz, La Paz, Potosí, Sucre, Tarija, and Oruro—offering tailored training, workshops, peer support groups, and caregiver guidance to help both patients and families cope with emotional and practical challenges elpais.bo+11alzint.org+11lostiempos.com+11. In 2017, AAB became a member of Alzheimer's Disease International and Alzheimer Iberoamérica, expanding its collaboration within global MND care networks alzint.org. The organization has also been instrumental in advocating for public policy reforms, including the 2009 Bolivian Law 4034 for Support Centers for MND Patients—although implementation remains pending.

Website: asociacionalzheimerbolivia.blogspot.com

▶ *Brazil*

Brazilian Academy of Neurology (ABN)

The Brazilian Academy of Neurology (ABN) is the leading professional body for neurologists in Brazil. It provides clinical guidelines, continuing education, and research dissemination related to neurological disorders, including Alzheimer's and other MND. ABN organizes national congresses, offers specialized training (like the AD Class on Alzheimer's), and publishes consensus documents on diagnosis and treatment standards, playing a crucial role in advancing MND care and neuroscience in the country.

Website: https://abneuro.org.br

Brazilian Alzheimer Association (ABRAz)

Founded in 1991 in São Paulo, the Brazilian Alzheimer Association (ABRAz) is a nationwide nonprofit organization that supports individuals with Alzheimer's disease and other MND, along with their families and caregivers. It operates through over 20 regional branches and dozens of support groups, reaching thousands of people across Brazil. ABRAz offers caregiver education, public awareness campaigns, emotional support networks, and promotes public policies to improve care for older adults with cognitive impairments.

Website: https://abraz.org.br

Brazilian Association of Geriatric Neuropsychiatry (ABNPG)

Established in 1998, the Brazilian Association of Geriatric Neuropsychiatry (ABNPG) is a multidisciplinary organization that brings together neurologists, psychiatrists, geriatricians, and researchers to improve the mental health of older adults. It promotes scientific exchange, organizes conferences and seminars, and supports studies on psychiatric and neurological conditions such as MND, with a strong focus on improving diagnostic and therapeutic strategies for aging-related disorders.

Website: https://abnpg.com.br

▶ *Chile*

Corporación Alzheimer Chile. The Chilean Alzheimer's Corporation

Corporación Alzheimer Chile, established in 1990 and legally recognized in 1992, is a nonprofit headquartered in Santiago. As a member of Alzheimer's Disease International since 2007, it supports families and caregivers of individuals with MND through a wide range of services: caregiver education, counseling, telephone helpline, day care, respite care, memory café, volunteer training, workshops, and advocacy for national policy change. It also promotes scientific research and public awareness to improve MND care throughout Chile.

Website: gerontologia.uchile.cl

Community Support Centers for People with MND

Chile's government has established Community Support Centers for People with MND, integrated into the National Plan for MND. These centers provide comprehensive services—including medical follow-up, caregiver training, socialization activities, memory assessments, and day care—to support individuals and families affected by dementia throughout the country.

Website: chileatiende.gob.cl

GAFA (Support Group for Families of Alzheimer's Patients & Other MND)

Founded in Viña del Mar in 2016, **GAFA** is a Chilean nonprofit and self-managed support group for informal caregivers of Alzheimer's and other MND patients. GAFA strives to make caregivers visible as rights holders, offering peer support, community outreach, training, and advocacy. It is recognized by Chile's Ministry of Social Development, with active participation in national collaborative working groups on caregiver issues.

Website: apoyosycuidados.ministeriodesarrollosocial.gob.cl

▶ *Colombia*

Asociación de Familiares y Cuidadores de Personas con Alzheimer (Barranquilla)

Serving the Atlántico region, the Association of Families and Caregivers of People with Alzheimer's in Barranquilla offers peer support, practical resources, and emotional guidance to caregivers navigating the challenges of Alzheimer's care.

Colombian Association of Gerontology and Geriatrics (Bogotá)

The Colombian Association of Gerontology and Geriatrics, headquartered in Bogotá, brings together professionals and families to provide educational events, clinical guidance, and resources for improved elder care and MND management.

Fundación Acción Familiar Alzheimer Colombia (AFACOL) (Bogotá)

Based in Bogotá, the Family Action Alzheimer Foundation Colombia (AFACOL) provides caregiver education and support through training programs, guidance services, and informational resources aimed at improving both caregiver skills and patient well-being.

Website: alzheimercolombia.org

Fundación Alzheimer Colombia (Cali)

Located in Cali, the Alzheimer Foundation Colombia focuses on delivering specialized clinical care, caregiver education, and research initiatives to advance knowledge and treatment of Alzheimer's disease in the region.

Website: fundalzheimercolombia.org

Fundación de Alzheimer del Eje Cafetero (Pereira)

The Alzheimer Foundation of the Coffee Region, based in Pereira, provides comprehensive services—including caregiver workshops, counseling, and patient support—to families affected by MND throughout Colombia's Coffee Triangle region.

Neuroactivo – Specialized Alzheimer and MND Day Center

With over 12 years of experience and ten centers across Colombia, Neuroactivo is a specialized day center dedicated to individuals with Alzheimer's and other MND, offering therapeutic programs, daily care, and family support services.

Neuroscience Group of the University of Antioquia (Medellín)

The Neuroscience Group at the University of Antioquia in Medellín focuses on academic research, postgraduate training, and public outreach in neuroscience, with a strong emphasis on Alzheimer's research and MND education.

► *Costa Rica*

ASCADA (Asociación Costarricense de Alzheimer y Demencias Asociadas)

ASCADA is a Costa Rican nonprofit organization dedicated to improving the lives of people affected by Alzheimer's and related MND. It focuses primarily on providing education and emotional support to caregivers, helping them develop the skills needed to care for their loved ones with dignity and compassion. ASCADA also offers workshops, counseling services, and community outreach programs to raise awareness about MND in Costa Rica. Caregivers can access resources and participate in support groups designed to reduce caregiver burden and improve quality of life.

Website: ascadacr.wordpress.com

FundAlzheimer Costa Rica

FundAlzheimer Costa Rica is a leading organization that provides comprehensive education programs, volunteer opportunities, and partnerships with institutions to strengthen MND care across the country. Their mission includes promoting research, improving patient care, and supporting families affected by Alzheimer's. Through public campaigns and training sessions, FundAlzheimer raises awareness about MND and advocates for policies to enhance social and health services for patients and caregivers. The organization also collaborates with health professionals and universities to advance scientific knowledge and best practices in MND care.

Website: fundalzheimer.com

La Casa del Cuidador

La Casa del Cuidador is a collaborative project aimed at supporting the needs of caregivers who look after individuals with Alzheimer's and other chronic conditions. This initiative focuses on providing emotional support, educational workshops, and respite care services to reduce caregiver stress and prevent burnout. By fostering a community where caregivers can share experiences and access practical resources, La Casa del Cuidador helps improve caregivers' well-being and capacity to provide sustained care. The project also organizes training programs to enhance caregiving skills and promote self-care among family members.

Website: hogarbellohorizonte.com

▶ *Cuba*

Alzheimer Patient Care Reference Center

The Alzheimer Patient Care Reference Center in Cuba specializes in the diagnosis and comprehensive management of Alzheimer's disease. It provides integrated care services designed to address the complex needs of patients and their families, including medical evaluation, therapeutic interventions, and caregiver support. The center aims to improve quality of life through multidisciplinary approaches and tailored care plans. Additionally, it plays a role in training healthcare professionals and promoting awareness about MND in the Cuban healthcare system.

Casas de Abuelos

Casas de Abuelos are community-based day centers for elderly individuals, including those living with MND. These centers provide a safe and supportive environment where seniors can participate in social, recreational, and therapeutic activities designed to maintain cognitive and physical function. They offer respite for family caregivers and promote social inclusion for older adults.

Website: alzint.org

▶ *Dominican Republic*

Dominican Association of Alzheimer's and Similar Conditions (ADAS)

Founded in 1994 by Maritza Cedano de Guerra, ADAS is dedicated to supporting caregivers and individuals with Alzheimer's disease. It has been a member of Alzheimer's Disease International (ADI) since 1998.

▶ *Ecuador*

Fundación TASE

Based in Ecuador, Fundación TASE specializes in the **diagnosis, care, and support for individuals with Alzheimer's disease**. The foundation provides clinical services, cognitive evaluations, and family education programs aimed at early detection and effective management of MND. Fundación TASE also promotes research and community outreach to raise awareness and improve understanding of Alzheimer's within Ecuadorian society.

Website: fundaciontase.org

▶ *Guatemala*

The Ermita Alzheimer Group Association of Guatemala

Founded in 1996 and headquartered in Guatemala City, offers a full suite of MND care services including recreational therapy, non-pharmacological treatments (such as music therapy, guided exercise, tai chi, manual crafts), medical evaluations, and counseling. Their day center operates weekdays from 8 am to 4 pm, providing respite care. They also offer accredited training programs for caregivers (including a diploma in Alzheimer's care with Galileo University), support groups, helpline, workshops, and community outreach to promote MND awareness and solidarity

▶ *Honduras*

Honduran Alzheimer Association

The Honduran Alzheimer Association (ASHALZ) is a non-profit and non-political organization based in Tegucigalpa. It was founded in 2005 by professionals, family members, and volunteers committed to supporting individuals with Alzheimer's disease, other MND, and their caregivers. https://www.alzheimerhonduras.org/

▶ *Mexico*

Alzheimer México, I.A.P

Alzheimer México, I.A.P is a nonprofit organization dedicated to providing comprehensive care, education, and support programs for individuals affected by Alzheimer's disease and their families. Their services include cognitive stimulation therapies, caregiver training, psychological support, and community outreach to raise awareness and improve quality of life. The organization also promotes research and advocates for public policies to better address MND care across Mexico.

Website: alzmx.org

Mexican Federation of Alzheimer (FEDMA)

The Mexican Federation of Alzheimer (FEDMA) acts as an umbrella organization that unites 22 Alzheimer associations across 16 Mexican states. FEDMA coordinates efforts to standardize care, promote training, and facilitate access to resources for patients and caregivers nationwide. They organize conferences, awareness campaigns, and collaborate with health authorities to enhance MND-related services and public policies.

Website: fedma.mx

Mexican Alzheimer's Disease Association

This association provides educational resources, workshops, and support groups tailored to patients and caregivers living with Alzheimer's disease. Their programs focus on improving understanding of the disease, offering practical caregiving advice, and creating networks of emotional support to reduce caregiver burden and improve patient outcomes.

INAPAM Memory Clinic

Part of the Mexican government's National Institute for Older Adults (INAPAM), the Memory Clinic offers **specialized diagnostic services, cognitive evaluations, and treatment planning** for MND patients. The clinic also provides caregiver guidance and referral to appropriate social and medical resources to improve MND management in older adults.

Website: gob.mx/inapam

National Institute of Neurology and Neurosurgery – Support Groups

This prestigious medical institute provides caregiver support groups and educational programs designed to assist families managing Alzheimer's disease and other neurological conditions. They offer clinical expertise, psychosocial support, and facilitate connections with rehabilitation and therapeutic services.

Website: gob.mx

▶ *Nicaragua*

Alzheimer Foundation of Nicaragua

The Alzheimer Foundation of Nicaragua (FADEN) is a non-profit organization based in Managua, founded by family members, professionals, and volunteers dedicated to improving the quality of life for individuals with Alzheimer's disease and other forms of MND. https://falzheimernic.wixsite.com/misitio

▶ *Panama*

Support Association for Families of Alzheimer Patients (AFAPADEA)

Founded in 1996 and based in Panama City, AFAPADEA provides assistance and support to families of people with Alzheimer's disease and other MND. The association offers guidance, workshops, and peer support to help caregivers better understand the disease and manage the care process. In 2024, AFAPADEA became a member of Alzheimer's Disease International (ADI), further integrating into global efforts to improve MND care.

▶ *Peru*

Peruvian Association of Alzheimer's Disease and Other MND (APEAD)

Founded in 1999 and based in Lima, APEAD is a national nonprofit that supports individuals with Alzheimer's and their families. As a member of Alzheimer's Disease International since 2000, they offer caregiver meetings, counseling, MND training, educational workshops, webinars, a helpline, newsletters, and printed resources. Their support services include peer support groups and meaningful engagement activities designed to enhance quality of life.

FOCCADI (Fortalecimiento Creativo de Capacidades Distintivas)

Established in Lima in 2013, FOCCADI focuses on training professional and family caregivers for older adults with MND, offering a 3–4 month certification program that includes legal, neurological, and clinical evaluations. With support from medical and psychological experts, they provide evidence-based education, advocate for caregiver rights, and are recognized by Peru's Ministries of Health, Education, and Labor. FOCCADI has also partnered internationally, including with Alzheimer.

Website: foccadi.org.pe

▶ *Puerto Rico*

Alzheimer Association of Puerto Rico

Founded in 1983 and a member of Alzheimer's Disease International since 1991, this San Juan–based nonprofit provides education, support groups, and advocacy for individuals with Alzheimer's and their caregivers. With over 30 support groups across the island, it offers workshops, public awareness campaigns, and professional training in collaboration with health institutions.

Website: alzheimerpr.com

Organization for the Care of People with Alzheimer's

OPAPA PR is a therapeutic center offering cognitive stimulation, speech pathology, physical and recreational therapy for individuals experiencing memory loss or MND. Their ECO program also includes caregiver education and family counseling sessions to empower both patients and carers. Based in San Juan, they aim to maintain quality of life and cognitive function through multidisciplinary methods. Address: 719 Av. Escorial, Caparra Terrace, San Juan, PR.

Website: opapapr.org

De Frente al Alzheimer, Inc.

Active since 2015, this nonprofit provides financial assistance, educational campaigns, and organizes events like the "Run to Remember" series. Their "Padrinos por un Cuidado Digno" sponsorship program helps low-income families fund Alzheimer's care costs. Based in San Juan, they also lead awareness initiatives, including public runs and fundraising campaigns island-wide.

Website: defrentepr.com

Cuidador Alzheimer

Cuidador Alzheimer is a dedicated caregiver support initiative in Puerto Rico. Their mission is to **develop and sustain support services, education, and self-care for Alzheimer's caregivers**, helping them remain healthy while caring for loved ones. They provide training workshops, resources, and community networks.

Website: cuidadoralzheimer.org

Programa Amigos Mayores Acompañantes (PAMA)

Run by OPPEA (Office of the Advocate for the Elderly), PAMA mobilizes volunteers aged 55+ to provide respite care—4 hours a day, 2–3 days a week—in the homes of Alzheimer's patients in early to moderate stages, offering companionship and practical care support.

Therapeutic Center for Advanced-Age Alzheimer's

Part of OPPEA's programs, this Guaynabo-based day center offers nursing care, social work, medical support, meals, and therapeutic activities for older adults with Alzheimer's. It's one of several such centers across Puerto Rico, offering structured day services and relief to caregivers.

▶ *Salvador*

The Association of Relatives of Alzheimer's Patients of El Salvador

Is a **non-governmental, non-profit organization** based in **San Salvador since 1994,** and a member of **Alzheimer Ibero-America** and **Alzheimer's Disease International** since the year **2000.** https://www.alzint.org/member/asociacion-de-familiares-alzheimer-de-el-salvador/

▶ *Spain*

Spanish Alzheimer's Confederation (CEAFA)

The Spanish Alzheimer's Confederation (CEAFA) is a national nonprofit founded in 1990 that brings together over 300 local Alzheimer's associations across Spain, coordinating advocacy, public policy efforts, and professional training programs. With a membership of more than 80,000 and a volunteer workforce of over 5,400, CEAFA works to elevate Alzheimer's on the political agenda, organize Spain's National Alzheimer Congress, lead rural caregiver training, and promote biomedical and social research—all under a framework of governance recognized publicly since 1997.

Website: ceafa.es

Alzheimer Spain Foundation (FAE)

The Alzheimer Spain Foundation (FAE), established in 1991, is a government-sanctioned, nonprofit organization based in Madrid that aims to improve the quality of life for patients and families affected by Alzheimer's. Operating under the patronage of Spain's Ministry of Health, it offers impartial support services—such as information, guidance, and training—led by a multidisciplinary board that includes both professionals and family members.

Website: alzfae.org

Associations of Relatives of Alzheimer's Patients (AFA)

Local AFAs are independently run organizations across Spanish regions (e.g., AFEA Madrid), typically managed by families and volunteers. They provide practical support, cognitive stimulation activities, and community engagement, such as theater workshops, care guidance, and resource networks, all tailored to their local members. Example: afeammadrid.org

▶ *Uruguay*

The Uruguayan Association of Alzheimer's and Related Disorders (AUDAS)

Is a **non-profit organization** founded on **May 10, 1991,** and legally recognized since **1994**, based in **Montevideo, Uruguay**. It is composed of family members, friends, and professionals, and its mission is to **support individuals with Alzheimer's and other dementias**, as well as their families, in order to **improve their quality of life** and to **promote awareness and knowledge** about these conditions. https://www.audas.org.uy/

▶ *Venezuela*

Alzheimer Foundation of Venezuela

Nonprofit offering psychological counseling, caregiver training, and cognitive stimulation activities.

Website: alzheimervenezuela.org

Alzheimer Foundation Zulia

Located in Zulia state, this foundation offers guidance and support to older adults with Alzheimer's and their caregivers.

Books and Practical Guides

- The 36-Hour Day – Nancy L. Mace & Peter V. Rabins (Spanish version: Cuando el día tiene 36 horas)
- Alzheimer. Guía práctica para conocer, comprender y convivir con la enfermedad – Dr. Carlos Hernández-Lahoz & Dr. Secundino López-Pousa
- Manual for Caregivers of People with Dementia – In collaboration with CEAFA
- Guide for Families of Alzheimer's Patients – Published by FIAPAM
- Alzheimer's Disease: What If There Was a Cure? – Mary T. Newport
- Learning to Speak Alzheimer's – Joanne Koenig Coste
- Creating Moments of Joy Along the Alzheimer's Journey – Jolene Brackey
- A Loving Approach to Dementia Care – Laura Wayman

Apps

- For medication reminders and organization: CareZone, Medisafe, Dementia Clock
- For monitoring and location tracking: GPS SmartSole, Safe365, AngelSense
- For communication and assistance: Talking Mats, My Therapy, Dementia Guide Expert
- For cognitive stimulation: Lumosity, MindMate, Reminiscence Therapy
- For caregiver emotional support: Headspace, Alzheimer's Caregiver Buddy, Caregiver Stress Check

Additional Available Resources

ALZConnected

An online community from the Alzheimer's Association that offers a space for caregivers and family members to share experiences and connect.

Banner Health

Through their podcast Dementia Untangled, they provide practical advice and support for Alzheimer's caregivers. They also offer educational videos on their YouTube channel.

Caregiver Action Network

Offers an online support community with various forums, including one specifically for caregivers of individuals with Alzheimer's disease.

CaringKind

This organization provides free programs and services for caregivers, including support groups, educational workshops, and resources in Spanish.

Dementia Caregiver Solutions

Offers practical strategies and solutions for managing challenging behaviors and common situations faced by dementia caregivers.

eCare21

Provides 24/7 remote care monitoring, allowing caregivers to track a patient's activities, medication, nutrition, and vital signs.

ForoAlzheimer (Facebook Group)

This Facebook group is designed for caregivers and family members of people with Alzheimer's disease to offer mutual support.

National Institute on Aging (NIA)

Offers detailed guides on how to get help for caring for a person with Alzheimer's disease, including daily care strategies and how to find community support.

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Esta obra ha sido publicada por
Editorial El Manual Moderno (Colombia) S. A. S.
se terminaron los trabajos de la
primera edición en octubre de 2025,
en los talleres de Imagen Editorial S. A. S.
Fue compuesta en caracteres
Source Sans Pro y Gandhi Serif

Bogotá, D.C., Colombia