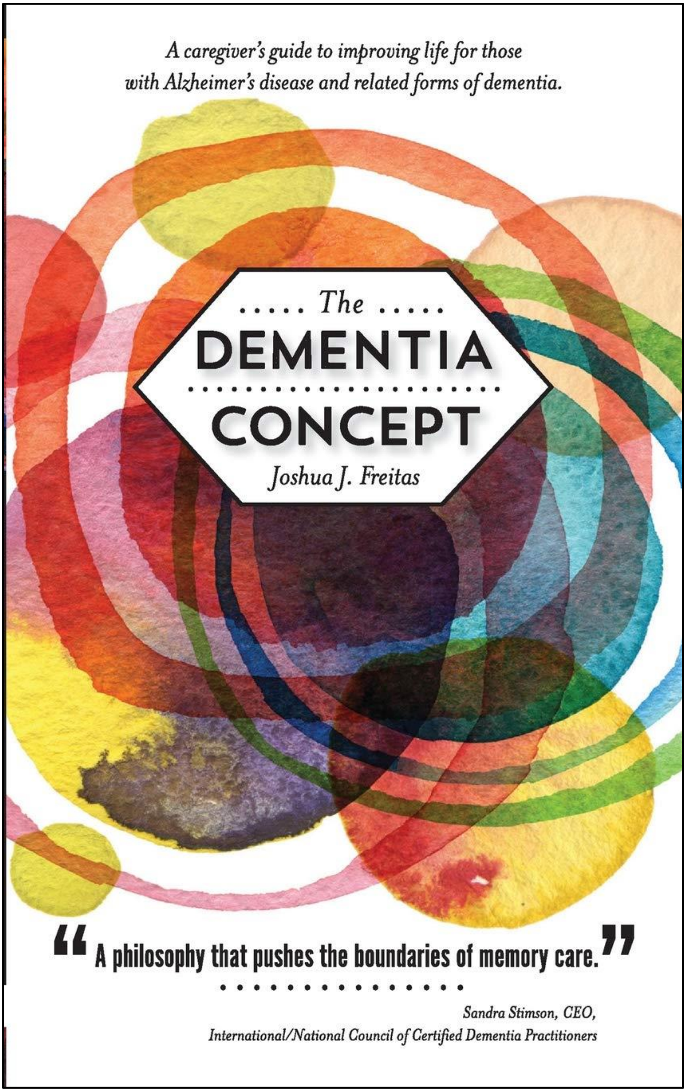

A caregiver's guide to improving life for those with Alzheimer's disease and related forms of dementia.

….. The …..
THE DEMENTIA CONCEPT

Joshua J. Freitas

> **"A philosophy that pushes the boundaries of memory care."**

Sandra Stimson, CEO,
International/National Council of Certified Dementia Practitioners

Words from our reading group…

"Joshua Freitas has channeled his considerable energy and passion toward educating the public about dementia and how our society can better understand this condition. This book is a wonderful tool for bringing compassion, as well as better and more effective practices to dementia treatment."

Laurie Ann Cozad, Ph.D., Professor at Lesley University

"Joshua Freitas is one of those individuals who you come across only once in a lifetime and who leaves an indelible mark on the world around them. Joshua has an incredible passion for exploring ideas and possibilities for improving the lives of memory-impaired individuals and their families. He implements his ideas in ways that make a significant and meaningful difference for all."

Barbara Lenihan, MS, RN, CNS, CDP

"Watching Joshua interact with memory-impaired residents is heartwarming, inspiring, and educational. His compassion, education, and commitment to excellent care are exceptional. His techniques continually create positive relationships. Working with Joshua has been an invaluable experience. I have benefitted greatly from adopting his techniques into my own day-to-day practice as an RN."

Matt Sakakeeny, RN

"I may be old, but Joshua keeps me going. I have known Joshua for about two years. Ever since I was diagnosed with Alzheimer's, he has made himself available to help me and my family. He has shown me that my diagnosis is not the end of my life, and in some ways, it is simply the beginning of a new life. His advice has freed me from worrying about what others will think and helped me to just do what makes me happy."

Anonymous

“I attended one of Joshua’s educational events and was blown away within the first few minutes of his presentation. His passion, dedication, and drive sets him apart from anyone I have ever seen when it comes to understanding and connecting within the field of dementia care.”

Emily Creig, Family Caregiver

“Through this timely book, Joshua Freitas has done the world in general, dementia studies in particular, and dementia research even more specifically, a major favor. His work offers an original, well thought-out, and successfully-tried approach to addressing dementia-related issues in society. The uniqueness in Freitas' methodology lies in its foundation of empathy and dignity for those who are struggling with dementia, as well as for their caregivers.”

Meenakshi Chhabra, Ph.D., Professor at Lesley University

“When I was first asked to be a part of the peer-reading group for The Dementia Concept, I thought the book would be full of medical terminology I wouldn't understand. It turned out to be quite the opposite. This book is for the everyday reader. It's insightful, educational, and easy to understand. Joshua’s passion for dementia care is evident in his writing, and his approach to improving quality of life is commendable. The world needs more innovative thinkers like Josh, and I am proud to call him my friend.”

Stephanie Ladue, Peer-reader

“You may not be aware of this, but Joshua is dyslexic. Yet, his diagnosis has never held him back from accomplishing innumerable goals. I have worked with Joshua on a variety of projects. His drive, motivation, and enthusiasm for each task that he approaches helps him to overcome the challenges presented by dyslexia. I am inspired and impressed by all that he has accomplished thus far, and by what I know he will continue to achieve. Joshua is driven to make a positive difference in people’s lives no matter how great the challenge.”

Caitlin Dolan, Ed.M., CAGS

The Dementia Concept:

Understand, Connect, Engage

Joshua J. Freitas

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The Dementia Concept uses research-inspired philosophies, which may not work for everyone. Caring for, or working with persons who are living with dementia is by its nature potentially dangerous. Suggested approaches and techniques should be avoided if they put you or the person in your care at any harm or risk.

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The Dementia Concept is a collection of non-pharmacological, person-centric discoveries and approaches to dementia care. In references to specific resident examples, names have been changed to respect privacy.

DEDICATION

I dedicate this book to a man named Alan who changed my life. He was the kind of friend who seemed more like family, and he was an important mentor to me because of his tremendous, positive insights about hope and life. When I began working with Alan, he was in the early stages of his dementia diagnosis. At that time, most people could not yet tell that he was suffering from any form of memory impairment. When his condition declined, Alan could barely speak and he lost the ability to walk. He never lost his sense of humor or his warm smile, which I'll never forget. He smiled every time I talked to him until his final days.

My friendship with Alan taught me patience and showed me that I could improve the lives of others by treating them with respect and understanding. The positivity and resilience of people like Alan have inspired me to dedicate my life to improving the quality of dementia care. It's important to remember that every person is a complex, vibrant, unique individual who deserves genuine connection and engagement with life. Dementia caregivers have a profound opportunity to facilitate and improve that connection and engagement.

Alan once told me, "Each day is new. Each day is my reward." What an inspiring and hopeful insight to come from a man who, by some estimations, had lost so much. Every day in my practice, I remember his grateful attitude. It reassures me of the fact that the person I am working with is still there, even if some of their functional abilities have been diminished.

Alan, you were a great man even when you struggled. You taught me so much. I will never forget you. This book is for you.

* * *

"Though my mind may be going, I am still here.
I think; I live; I enjoy the company of those around me.
My only request is that everyone would stop asking if
I am okay. I am fine. I may even be better than fine
at this point in my life.

If I had to give advice to someone who has been
diagnosed with dementia, it would be to keep a sense
of humor. Life is too short to get caught up on
everything. If you get sick, you get sick, and that is that.
You just have to make the best of it."

Alan Hochberg

CONTENTS

PART 1: UNDERSTAND

PART 2: CONNECT

PART 3: ENGAGE

FOREWORD

Dear Joshua,

I am writing to you to let you know how much of an impact you had on my father from the day he met you until his last few hours. Even when he forgot his family's names, he still referred to you by name. Even when we gave up, you kept pushing him. His quality of life was sustained through your help, guidance, and dedication.

Although my father was not a singer, he would always sing with you. Even though he had difficulty talking, he was able to sing a whole song. When you got him to speak again through song for my daughter on her wedding day, it was one of the most remarkable things I have ever seen.

You are a bright and inspiring person. I have never seen anyone light up a room of people with dementia the way you do. You told me you were going to change the industry, and I'm sure you will. Just keep doing what you do.

Juliette Simmons

HOW TO USE THIS BOOK

This book is written primarily for caregivers of individuals with dementia. The information that is presented in this book can benefit anyone who wants to improve their understanding of dementia and the practical ways that we can improve the quality of life of those with dementia.

The Dementia Concept is structured in three parts. In Part 1, *Understand*, you will learn the signs, symptoms, and stages of dementia. This section provides an overview of the ways that those with dementia can maintain a vital connection to the world around them.

In Part 2, *Connect*, you will learn the core principles of connecting to individuals with dementia. Mindful interaction, conversation facilitation, creation of a routine, and the use of music as medicine can have profound impacts. Read examples of the successfulness of these methods.

In Part 3, *Engage*, you will learn to apply *The Dementia Concept* principles to even more specific events and interactions, and create a schedule to optimize each day. These holistic approaches to care have been repeatedly shown to benefit both individuals with dementia and the people who care for them.

Human nature drives us to continually seek new experiences throughout our lives. One of the most prevalent, false stigmas of dementia is that it signifies the end of learning. The reality is that people with dementia and other forms of memory impairment are capable of creating new memories and developing new skills. Although the type and severity of the dementia impacts these processes, there are ways to increase individual levels of success. The methods for interaction that are described in this book can be the difference between watching someone slip away and helping them remain engaged with their lives.

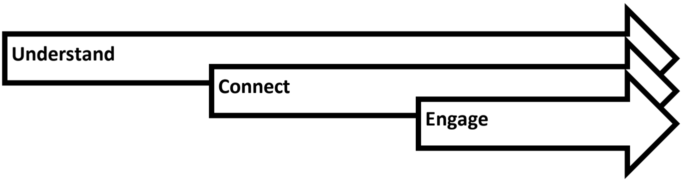
Caregivers and loved ones must recognize the importance of thoughtful and deliberate interaction. We must ask ourselves, "Who is this person? What do they love? How can we use our knowledge of what they love to help them engage with life?" It's not always easy to find a topic, object, or song that clicks with someone, but when you do, amazing things can happen. *The Dementia Concept* offers practical methods for engagement that serve to decrease agitation and increase success.

With consistency and repetition, we can help people with dementia to harness the power of Procedural Learning, which enables a new habit to be developed through the process of doing something over and over again. Procedural Learning is an important way for people with dementia to maintain and build upon their skills. In turn, they can increase their level of stability, productivity, independence, and happiness.

As caregivers, we often try to prevent people from making mistakes because we want to maximize their success. If we witness a person having trouble with something, we might decide it's best for us to do it for them. That approach effectively enables people in our care to lose their self-sufficiency. We might overlook the importance of daily self-care activities, commonly referred to as the Activities of Daily Living, such as getting ready for the day or making the bed, but these are essential elements of independence. We must allow time for people with dementia to attempt these tasks, even if they struggle. Doing so reinforces their skills and creates memories of new ways to approach challenges. If they struggle, we are there to provide support and guidance.

This book is based on a person-first approach to care. At its core is the understanding that people with dementia are still the same person they have always been, even though their needs and abilities are changing. Each person deserves a high level of respect and customized care. We must not reduce our perception of those for whom we care to the characteristics of dementia; we must continue to see them for who they are and tailor individualized care to suit their unique needs.

The Dementia Concept provides methods for engaging the whole individual, which results in a higher level of engagement. How can we use our knowledge of individual personalities to increase the quality of our connections? How can we make daily tasks and activities more enjoyable? *The Dementia Concept* describes approaches that make interactions more pleasant and successful by treating people with **understanding**, by **connecting** to what matters most to them, and by **engaging** them to be active participants in their own lives.


Understand
Connect
Engage

Part 1: Understand

The better we understand the form of dementia, its progression, and the available treatment options, the better quality of care we can provide.

CHAPTER ONE

Know the Facts

The term *dementia* refers to a classification of signs and symptoms. There are more than 100 types of dementia, of which Alzheimer’s disease and Vascular dementia are the most commonly diagnosed types. Currently, over 6.7 million Americans are living with Alzheimer’s disease, which constitutes 70 percent of the dementia population. This number is expected to triple within the next few decades.

Alzheimer’s disease is one of the leading causes of death in the United States. One in three seniors die with Alzheimer’s or another form of dementia.[1] Many researchers say that there is no cure in sight, and each year the number of cases grows worldwide. It is an epidemic that is soon to be classified as a pandemic. If a cure is not found within the next few decades, the rising cost of care could cripple the economy, and people living with dementia will

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[1] Alzheimer’s Association, 2014.

suffer from lack of funding for treatment options and caregiver education.

Fortunately, there is something that we can do to combat this problem through our work as caregivers. By increasing public awareness and improving caregiver education, we can help eliminate some of the detrimental stigmas associated with dementia. We must join the movement to change the way people with dementia and memory impairment are viewed and treated. *The Dementia Concept* offers a holistic, non-pharmacological approach to improving the quality of life of people with dementia. When this method is delivered with hopefulness and respect, it enables individuals to thrive. Increased understanding leads to better outreach and connection. In return, individuals with dementia can sustain and increase engagement with their lives.

CHAPTER TWO

Recognize the Myths

One of the myths associated with dementia is that it stops all new learning in its tracks. This myth overlooks the fact that Procedural Learning enables people with dementia to develop new memories. Human beings perceive and process information through two different avenues: propositional knowledge, which is the knowledge that we develop throughout our lives, and sensory-based knowledge, which is the information that we gain through our senses.

Dementia degenerates a person’s propositional knowledge, and when that happens, the person becomes more reliant on sensory-based learning. Many people in the early stages of dementia rely heavily on propositional knowledge about their identity, preferences, values, and habits of behavior. As the dementia progresses, much of this unconscious knowledge is lost due to a decrease in neural activity. People are then faced with the challenge of an unfamiliar world. The subtext of their surroundings is diminished and must be reinterpreted at face value.

Imagine seeing an apple as a shiny, round, red object as opposed to interpreting many meanings from it, such as fruit is a healthy, edible food, and eating is necessary for our survival. Understanding that people with dementia may perceive their surroundings without some of its subtext can help us in our work as caregivers. We must provide them with the right amount of information and support to increase their success and reduce their confusion. (Part 2 of this book, *Connect,* will give you practical tools for tapping into sensory-based knowledge to support the needs of a person with dementia.)

Currently, society views people with dementia as people who can no longer do anything for themselves. This perception indicates that there is nothing that can be done to build upon the person's capabilities. This leads to a decrease in productivity and independence among people with dementia, as well as caregivers who think they must do everything for the person. Instead, people with dementia must be empowered to try. When we view the person as someone who can no longer do anything, the dementia progresses faster. Individuals learn to rely on the caregiver, which nurtures many of the characteristics of dementia and promotes more forgetfulness and physical inhibition. Remember this golden rule: allow the person to do as much as he or she can before you provide support. When assistance is needed, provide just enough to help that person be successful.

Stigmas about a person's abilities can be detrimental and damaging to that person's sense of self. In a series of one-on-one interviews that I conducted with a group of people with dementia, I posed a series of questions and recorded their feedback. The following response that I received from a woman named Josephine highlights this issue:

"I know I have a form of dementia. It has not stopped me from learning and exploring new things. The biggest struggle for me is the way the disease causes others to stereotype me. I am, and have always been, an independent woman. I get upset when some people try to shelter me from life. It makes me feel weak and dependent when my daughter tries to do everything for me."

The prevalent stereotypes that are associated with Alzheimer's and dementia are some of the primary reasons that people wait so long to speak with a doctor about their symptoms. Some people might think that a dementia diagnosis is the end of an active and fulfilling life, but it does not have to be. Remember Josephine's perspective when you are working with a person who has dementia. Strive to empower and support them to achieve as much as possible.

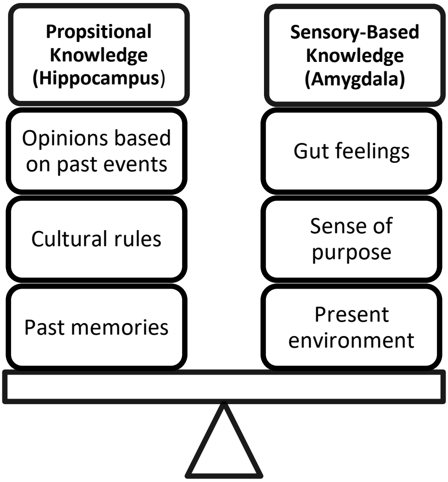
CHAPTER THREE

A Dementia Diagnosis is not the End

A diagnosis of dementia should not be viewed as the end of life. People can live with dementia for up to thirty years. We must empower people with dementia to continue to live purposefully. One major challenge is to educate the general public, healthcare providers, and medical personnel not to perpetuate the stigmas associated with dementia. We have the potential to improve quality of life through non-pharmacological, compensatory strategies for interaction. Although there is no cure for Alzheimer's disease or related dementias, in most cases there is a great deal that can be done to help people live active and fulfilling lives for a longer period of time.

The Dementia Concept offers techniques that treat the whole person, not just some of their symptoms. Through a combination of pharmacological and non-pharmacological interventions, we can help people sustain awareness and promote neuroplasticity. Doing so naturally elevates mood, reinforces skills, and increases confidence. Neuroplasticity also reinforces the hippocampus, which is the part of the brain that directs memory, enabling people to create new memories and retain them longer.

The following graphic illustrates some aspects of our lives that are governed by the hippocampus and the amygdala, which is the part of the brain that governs sensory-based knowledge. We normally process information by using a combination of these evaluative processes. As dementia progresses, this scale tips so that more information is processed through sensory-based knowledge and the amygdala. Thus, gut feelings, a sense of purpose, and present experiences become more significant.



Many people who are diagnosed with dementia express fear of losing their independence. For many years, the dementia care community has overlooked the right of those with dementia to be active participants in their own care. More and more individuals are coming forward and demanding to have a say in what happens throughout the course of their dementia's progression.

When all medical decisions are made by a healthcare proxy and all financial decisions are made by the individual's Power of Attorney, this takes away the choice and the voice of individuals with dementia. To counteract this problem, the Alzheimer's Bill of Rights has been drafted to help people with dementia to foster a sense of independence. This Bill of Rights strongly reinforces their rights to be informed of their condition, given opportunities for engagement, and given a sense of independence within a safe, structured, and predictable environment.[2]

The care we provide must uphold these values. We must recognize the importance of engaging with the individual and making them a vital participant in their own healing.

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[2] *The Best Friends Approach to Alzheimer's Care* by Virginia Bell and David Troxel. Copyright 1997, Health Professions Press, Inc.

ACKNOWLEDGEMENTS

The Dementia Concept has been years in the making, beginning with my education, through years of working directly with those affected by dementia. Thank you to my teachers and mentors for dedicating their lives, as I have, to improving the lives and the care of people with dementia. The insights we've shared have been integral to the development of this contemporary approach.

I have a great appreciation for those who are living with dementia. I have been continuously amazed by how much they can still do. I'm so appreciative of all the residents and families who have shared their lives with me and trusted in my care. We have made so much progress together, and I hope what I have learned and documented in this book will help many others.

Thank you to my family, friends, and mentors. This book would not have been possible without your generosity and support. Thanks for your patience with my extreme focus on this project during all the time I have spent writing.

This book could not have been written without the work of my editor, Angela Simonelli, or the valuable feedback from our group of peer-readers. Your dedication to this book and all of your input is greatly appreciated.

5 Locations To Visit

Mount Dora

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☎ **(352) 385-1800**
✉ **EDMountDora@certusseniorliving.com**

Orange City

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OC, Florida 32763

☎ **(386) 775-3000**
✉ **EDOrangeCity@certusseniorliving.com**

Waterford Lakes

11120 Lake Underhill Rd
Orlando, Florida 32825

☎ **(407) 550-0021**
✉ **EDWaterford@certusseniorliving.com**

Vero Beach

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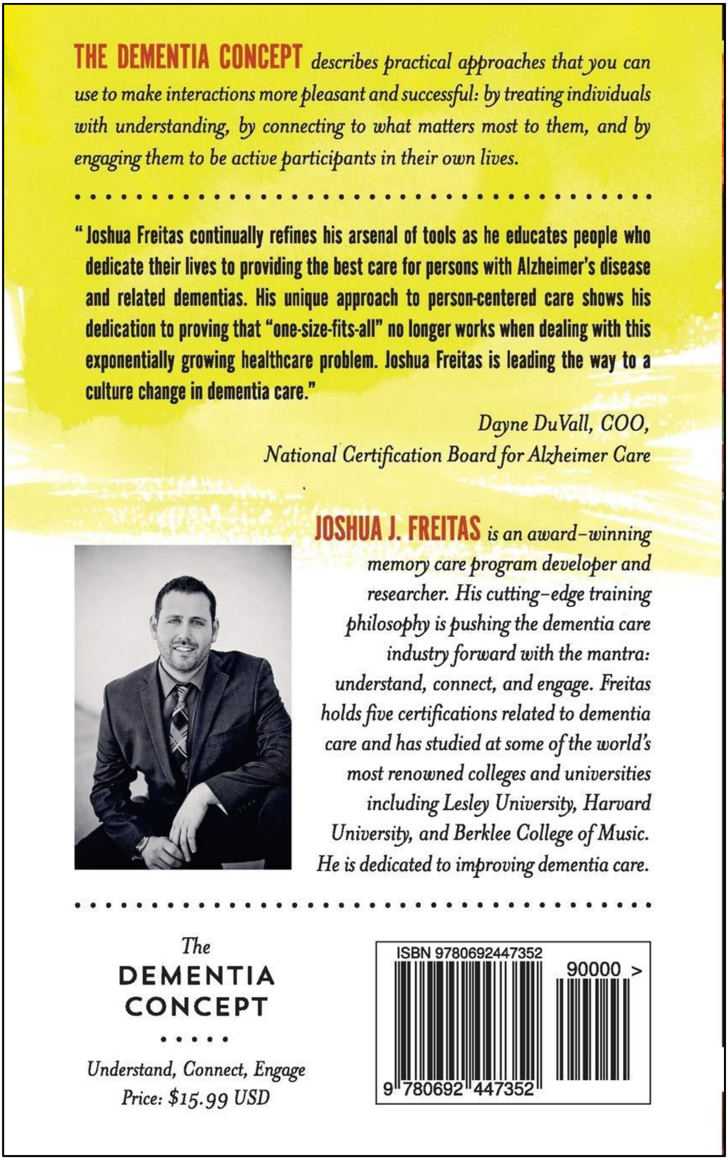
☎ **(772) 248-1222**
✉ **EDVeroBeach@certusseniorliving.com**

Dr. Phillips

7533 Conroy Windermere Rd
Orlando, Florida 32835

☎ **(386) 678-6010**
✉ **EDDrPhillips@certusseniorliving.com**

CERTUS
Premier Memory Care



THE DEMENTIA CONCEPT *describes practical approaches that you can use to make interactions more pleasant and successful: by treating individuals with understanding, by connecting to what matters most to them, and by engaging them to be active participants in their own lives.*

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> **"Joshua Freitas continually refines his arsenal of tools as he educates people who dedicate their lives to providing the best care for persons with Alzheimer's disease and related dementias. His unique approach to person-centered care shows his dedication to proving that "one-size-fits-all" no longer works when dealing with this exponentially growing healthcare problem. Joshua Freitas is leading the way to a culture change in dementia care."**
>
> *Dayne DuVall, COO,*
> *National Certification Board for Alzheimer Care*

JOSHUA J. FREITAS *is an award-winning memory care program developer and researcher. His cutting-edge training philosophy is pushing the dementia care industry forward with the mantra: understand, connect, and engage. Freitas holds five certifications related to dementia care and has studied at some of the world's most renowned colleges and universities including Lesley University, Harvard University, and Berklee College of Music. He is dedicated to improving dementia care.*

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The
DEMENTIA
CONCEPT
• • • • •
Understand, Connect, Engage
Price: $15.99 USD

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GLOSSARY OF TERMS

Acetylcholine: A neurotransmitter in the brain that is involved in learning and memory. Acetylcholine levels are greatly diminished in people with dementia.

Activities of daily living (ADLs): Personal care activities that are necessary for everyday life, such as eating, bathing, dressing, and using the bathroom.

Adult day services: Programs that provide opportunities for older adults to interact with others, usually in a community or dedicated center.

Advance Directive (Living Will): A document written when in good health that informs family and health care providers of one’s wishes for extended medical treatment if such treatment becomes necessary.

Adverse reaction: A clinical term that includes any unexpected health or behavioral changes in reaction to a drug.

Aggression: Hitting, pushing, or threatening behavior. It is not uncommon for people with dementia to display aggression toward caregivers during assistance with daily living activities, such as grooming and dressing.

Agitation: Vocal or physical behavior, such as screaming, shouting, complaining, moaning, cursing, pacing, fidgeting, wandering, etc., which can be disruptive, unsafe, or interferes with the delivery of care.

Alternative and complementary therapies: Techniques that are used for treatment instead of, or as a complement to, drugs, surgery, or other conventional interventions. Common alternative or complementary therapies include the practice of meditation, exercise, expressive arts, reflexology, massage, and acupuncture.

Alzheimer's Disease: The most common form of dementia, which causes memory loss and damage to the hippocampus, where memories are stored.

Ambulation: The ability to walk and move freely.

Amygdala: Part of the brain located in the limbic system, which process memory through emotions.

Amyloid: An abnormal protein that the body deposits in various parts of the brain. Amyloid plaques are found in the brains of those with Alzheimer's disease.

Antidepressants, or Selective serotonin reuptake inhibitors (SSRIs): Medications that are prescribed for depression. SSRIs block a receptor in brain cells that absorbs serotonin.

Aphasia: Difficulty recalling and formulating words. Loss of language ability. Mild aphasia refers to occasional difficulty with word recall. Moderate aphasia refers to marked difficulty with word recall. Extreme aphasia refers to word recall that is limited to a few words or the complete inability to recall words.

Behaviors, challenging behaviors, and behavioral symptoms: Symptoms of dementia that are caused by difficulty processing emotions. These behaviors can include wandering, inappropriate sexual behavior, aggression, agitation, sleep disturbances, and other outward signs of depression and anxiety.

Beneficiary: An individual who is designated to receive something, such as money or property, following the death of a benefactor who has named the beneficiary in a document such as a will, trust, or insurance policy.

Binswanger's disease: A type of dementia that is associated with changes in the brain caused by stroke.

Biomarker: A marker that is used to indicate or measure a biological process such as levels of a specific protein in blood or spinal fluid. Detecting biomarkers that are specific to a disease can aid in the diagnosis and treatment of individuals with that disease as well as those who may be at risk but have not yet experienced symptoms.

Biotechnology: The use of biology (the study of living things) and biological processes to make goods or develop technologies for the benefit of humanity. Biotechnology is often used in the fields of food, drugs, and energy.

Blood-brain barrier: The selective barrier that controls the entry of substances from the blood into the brain.

Caregiver: Someone who is in charge of caring for another. A primary caregiver for those with dementia is usually a family member or a designated health care professional.

Care planning or Service plan: A written action plan that contains strategies for delivering care that addresses an individual's specific needs and challenges.

Case management: A term that is used to describe formal services that are planned by care professionals.

Cerebral cortex: The outer layer of the brain, which consists of nerve cells and the pathways that connect them. The cerebral cortex is the part of the brain in which thought processes take place. In Alzheimer's disease, nerve cells in the cerebral cortex degenerate and die.

Choline: A brain transmitter that enables cells to communicate with each other.

Clinical Social Worker (CSW): An individual who has specialized training in identifying, accessing, and assessing community resources, such as adult daycare, home care, or nursing home services, as well as individual and group counseling.

Clinical trial: A type of research study that evaluates the results of a new medical treatment, drug, or device.

Coexisting illness: A medical condition that exists simultaneously with another medical condition, such as arthritis and dementia.

Cognitive ability: Mental ability, such as judgment, memory, learning, comprehension, and reasoning.

Cognitive disorder: Psychiatric disorder that is manifested in memory deficits, altered or impaired perception, and difficulty with problem-solving.

Cognitive symptom of dementia: Symptoms that relate to impaired thought processes, such as learning, comprehension, memory, reasoning and judgment.

Combativeness: Aggression or agitation.

Competence: A person's ability to make informed choices.

Continuum of care: Care services that are available to assist individuals throughout the course of a disease.

Cortical dementia: Dementia that is associated with the disease that affects the cerebral cortex, causing impairments in abstract thinking, attention, memory, and reasoning.

Creutzfeldt-Jakob disease: A rare disease that is caused by prions that typically lead to rapid decline in memory and cognition.

Cueing: The process of providing cues, prompts, hints, and other meaningful information, direction, or instruction (such as adding labels to drawers) to assist someone with memory loss.

Deficits: Physical or cognitive skills and abilities that have been impaired or lost.

Delirium: A state of confusion, which may cause a sudden change in cognitive functioning. Delirium can have physical causes, some of which might be overlooked, such as dehydration, infection (most commonly a urinary tract infection), pneumonia, and medication.

Delusion: A false idea that is firmly believed and strongly maintained in spite of proof or evidence to the contrary.

Dementia: A term that refers to a decline in mental ability that is characterized by varying signs and symptoms such as memory loss and confusion.

Dementia umbrella: Dementia itself is an umbrella term that is used to describe various symptoms of a decline in mental ability. Alzheimer's disease, Vascular dementia, and Frontotemporal dementia are examples of different types of dementia that are categorized within the dementia umbrella.

Dementia-capable: Refers to a person who is skilled in working with individuals who have dementia and their caregivers, knowledgeable about the kinds of available services, and aware of which agencies and individuals provide such services.

Dementia-specific: Services that are provided specifically for people with dementia.

Dementia-specific care center: A facility that is solely dedicated to the care of people with dementia. This kind of facility can be free-standing or part of a larger campus.

Depression: A mood disorder that prevents a person from leading a normal life. Types of depression include major depression, bipolar depression, chronic low-grade depression (dysthymia), and seasonal depression (Seasonal Affective Disorder or SAD).

Diagnosis: The process by which a doctor or other qualified professional determines a patient's condition or disease. A diagnosis is achieved by studying the patient's symptoms, medical history, and physical or cognitive test results.

Differential diagnosis: Clinical evaluation to distinguish a condition or disease from other conditions or diseases that have similar symptoms.

Disorientation: A cognitive condition in which sense of time, direction, and spatial cognition are altered or impaired.

Durable power of attorney: A legal document that enables an individual to authorize another person, such as a trusted family member or friend, to make legal or financial decisions on their behalf if the individual becomes unable to make those decisions for him or herself.

Durable power of attorney for health care: A legal document that enables an individual to appoint another person to make healthcare decisions on their behalf, including choices regarding care providers, medical treatments, and end-of-life decisions.

Early-onset Alzheimer's disease: An uncommon form of Alzheimer's disease in which individuals are diagnosed before age 65. Less than 10 percent of those with Alzheimer's disease have Early-onset Alzheimer's.

Early stage: The first stages of dementia, during which an individual experiences very mild to moderate cognitive impairments.

Elder law attorney: A lawyer who practices elder law, which is a specialized area of law that focuses on issues that typically affect older adults.

Elopement: Another term for wandering.

Emotional Learning: A type of learning that occurs when a new skill is processed through the amygdala. This often occurs during life events that have emotional significance.

Experiential Learning: A type of learning that fosters focused attention through experiences. Experiential learning physically changes the brain, increases social participation, and generates multi-sensory stimulation.

Familial Alzheimer's disease: Alzheimer's disease that is hereditary (runs in families).

Frontotemporal dementia (FTD): A type of dementia that is categorized by the shrinking of the frontal and temporal anterior lobes of the brain. There are two major types of FTD: one is characterized by speech problems, the other is characterized by notable behavioral changes.

Functional capabilities: What a person is able to do.

Gait: A person's manner of walking. People in the later stages of dementia often exhibit a shuffling gait.

Glutamate: An amino acid neurotransmitter or nerve cell messenger.

Hallucination: A sense of perception (seeing, hearing, tasting, smelling, or feeling) for which no external stimulus exists.

Hippocampus: Located in the brain's limbic system, the hippocampus is where our memories are primarily stored.

Hoarding: Collecting and keeping things in a guarded manner.

Hospice: The philosophy and approach to providing comfort and care at life's end.

Huntington's disease: An inherited, degenerative brain disease that is characterized by mood changes, cognitive decline, and involuntary movement of limbs.

Incontinence: Loss of bladder or bowel control.

Instrumental activities of daily living (IADLs): Complex activities (as opposed to basic ADLs: eating, dressing and bathing) that are important to daily living, such as computing basic math, cooking, writing, and driving.

Late-onset Alzheimer's disease: The most common form of Alzheimer's disease, usually occurring after age 65. Late-onset Alzheimer's disease affects almost half of all people over the age of 85 and may or may not be hereditary.

Late stage: Designation given when dementia symptoms have progressed to the extent that a person has little capacity for self-care.

Layering: A self-securing behavior that involves unnecessarily wearing multiple layers of clothing.

Lewy body dementia (LBD): A form of dementia that is associated with protein deposits called Lewy bodies, which form in the cortex of the brain.

Living trust: A legal document that enables an individual (the grantor or trustor) to appoint someone else as trustee (usually a trusted individual or financial institution) to carefully invest and manage his or her assets.

Living Will (Advance Directive): A legal document that expresses an individual's decision regarding the use of extended care options or artificial life support systems.

Long-term care: A comprehensive range of medical, personal, and social services that are coordinated to meet the physical, social, and emotional needs of people who are chronically ill or disabled.

Long-term memory: The brain's system for permanently storing, managing, and retrieving information for later use. In healthy brains, information that is stored in long-term memory can remain there indefinitely.

Memory: The ability to process information that requires attention, storage, and retrieval.

Mild Cognitive Impairment (MCI): Refers to memory problems that are noticeable to others. People with MCI may or may not have other cognitive problems. Those with MCI alone may be able to meet typical daily challenges without major difficulty. Some people with MCI progress to

develop Alzheimer’s disease or other forms of dementia.

Mini-Mental State Examination: A mental examination that is commonly used to measure a person’s basic cognitive skills, such as short-term memory, long-term memory, spatial orientation, writing, and language.

Multi-Infarct dementia: Another term for Vascular dementia.

Neurodegenerative disease: A type of neurological disorder that is marked by the loss of nerve cells. Examples include Alzheimer’s disease and Parkinson’s disease.

Neurological disorder: A disturbance in the structure or function of the nervous system resulting from developmental abnormality, disease, injury, or toxin.

Neuropathology: The branch of medicine that studies nervous system diseases.

Neuroplasticity: The brain's ability to restructure its neural pathways through changes in behavior, environment, and cognitive processes such as thoughts and emotions. Plasticity refers to the brain's ability to reroute information in order to bypass damaged parts.

Neurotransmitter: A chemical that is released from a nerve cell which transmits an impulse to another nerve cell or a muscle, organ, or other tissue. A neurotransmitter transmits neurological information.

Non-pharmacological or Non-drug: Refers to a treatment approach that does not involve drugs.

Novelty learning: A type of learning that refers to learning new things, which creates new neural pathways throughout the brain that can bypass injured areas.

Onset: Defines the time when a disease begins (early-onset, late-onset).

Pacing: Aimless wandering, or walking back and forth, that is often triggered by an internal stimulus, such as pain, hunger, or boredom, or by some distraction in the environment such as an agitating noise, smell, or temperature.

Paranoia: Suspicion and mistrust of others or their actions that is not supported by evidence or justification.

Parkinson's disease: A progressive, neurodegenerative disease with an unknown cause characterized by the death of nerve cells in a specific area of the brain. People with Parkinson's disease lack the neurotransmitter dopamine and have symptoms such as tremors, speech impairments, physical difficulties, and often dementia in later stages of Parkinson's disease.

Pick's disease: A type of dementia in which abnormal amounts of certain proteins cause degeneration of nerve cells and shrinking of the brain's frontal and temporal lobes. Pick's disease causes dramatic changes in personality and social behavior but does not typically affect the memory until later stages of the disease.

Physical Learning: A type of learning that is achieved through exercise and behavioral tasks. Physical Learning can increase blood flow and foster more neural activity. Repetition of a physical action reinforces muscle memory, making physical tasks easier to perform over time.

Praxis: The ability to plan and execute coordinated movement.

Prognosis: The probable outcome or course of a disease; the estimated probability of the opportunity for recovery.

Procedural learning: Learning that is achieved through the repetition of a process or action.

Propositional knowledge: Foundational knowledge that is stored in long-term memory. This type of knowledge is governed by the hippocampus.

Pseudobulbar Affect (PBA): Occurs secondary to a variety of otherwise unrelated neurological conditions and is characterized by involuntary, sudden, and frequent episodes of laughing or crying. PBA episodes typically occur out of proportion or incongruent to the patient's underlying emotional state.

Pseudo-dementia: A person’s exaggerated indifference to their environment without impairment due to cognitive capacity. Implies dementia symptoms.

Quality of care: A term that is used to rate the level of care and services. High-quality care enables the recipient to attain and maintain their highest level of mental, physical, and psychological function in a dignified way.

Quality of life: A term that is used to rate a person’s ability to enjoy normal life activities. Quality of life is an important consideration in medical care. Some medical treatments can seriously impair quality of life without providing appreciable benefit, while other treatments greatly enhance quality of life.

Serotonin: A natural brain chemical that affects the mood and works as a neurotransmitter.

Sensory-based learning and sensory-based knowledge: Learning that is achieved through the senses. This type of knowledge is governed by the amygdala.

Short-term memory: A system for temporarily storing and managing information that is required to carry out complex cognitive tasks such as learning, reasoning, and comprehension. Short-term memory is involved in the selection, initiation, and termination of information-processing functions such as encoding, storing, and retrieving data in the brain.

Sundowning: Unsettled behavior or increased agitation that is evident in the late afternoon, early evening, or overnight.

Trigger: Something that either sets off a disease in people who are genetically predisposed to developing the disease, or causes certain symptoms to occur in someone who has a specific disease or condition.

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