

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

..... 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*



CERTUS | Premier Memory
Care Living
where every moment matters

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.

.....

“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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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-trying 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

INTRODUCTION

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

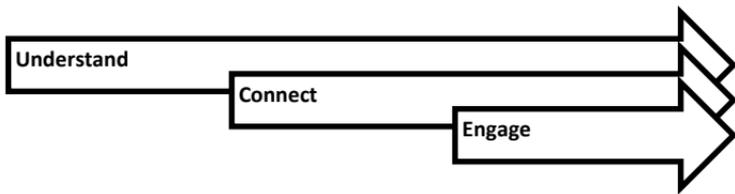
important way for people with dementia to maintain and build upon their skills. In turn, they can increase their level of stability, productivity, independence, and happiness.

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.



Know the Facts

The term *dementia* refers to a classification of signs and symptoms. There are more than 100 conditions that cause dementia, of which Alzheimer's disease and Vascular dementia are the most commonly diagnosed types. Currently, over 5.5 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

¹ Alzheimer's Association, 2014.

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

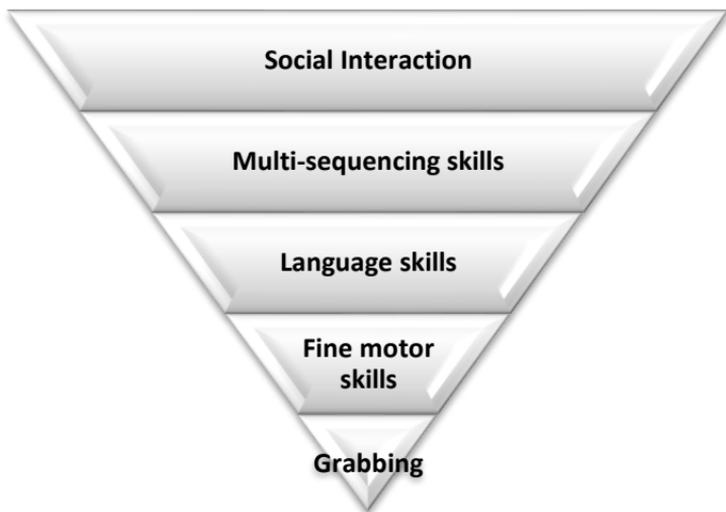
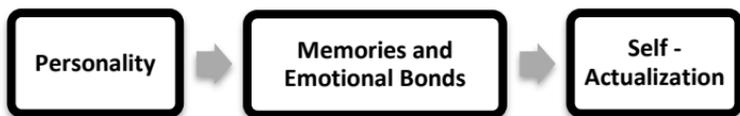
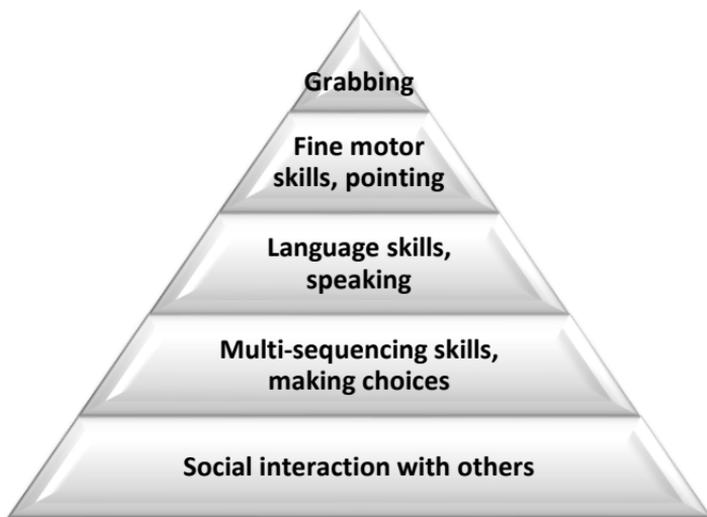
Fortunately, there is something that we can do to combat this problem through our work as caregivers. By increasing public awareness and improving caregiver education, we can help eliminate some of the detrimental stigmas associated with dementia. We must join the movement to change the way people with 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 FIVE

Symptom Progression

Did you know that as we age, we lose our abilities in the order opposite that which they are gained in childhood? This is exhibited most notably by people with dementia. A newborn baby will grasp your finger when it is in front of them, and this is an ability that is often retained even at the hour of our death. The first five skills we learn usually remain with us into the final stages of our lives.

Graphic on next page



It's important to know and respect people's capabilities. Not doing so can cause harm. Now that you have a better understanding of the signs, symptoms, and characteristics of the most common types of dementia, learning about the progression of dementia will help you identify someone's ability throughout each stage.

Let's consider symptom progression with an example of someone who loves to cook. In the early stages, the person might be able to cook almost entirely on their own. As they progress into mid-stages, they might be able to help by stirring or serving food if they are assisted with cues and support. A person in a later stage would need almost total assistance, but they may still enjoy the texture and the smell of something like cookie dough in their hands. Remember that people in later stages of dementia rely heavily on sensory-based knowledge and experiences, much as we do when we are very young. Although someone's role in activities may change, they can still enjoy aspects of the activity and the interactive experience.

Everyone is different, and people may experience different symptoms that progress at different rates. However, the industry standard is to identify the progression of dementia through 7 distinct stages that are based on a system developed by Barry Reisberg, M.D., clinical director of the NYU School of Medicine's Silberstein Aging and Dementia Research Center.

Dementia Stage 1

In this stage, information processing is primarily normal, and information is accessed from both propositional and sensory-based knowledge. Symptoms of this stage might be subtle enough that medical professionals do not see the signs or symptoms. A person in this stage may experience occasional confusion; increased anxiety; altered speech; mood swings; personality changes; wandering; changes in blood pressure and heart rate; mild delusions, and inaccurate recollection of the immediate past.

Dementia Stage 2

In this stage, a person will experience a noticeable cognitive impairment. This decline may seem to be part of the normal aging process, but its onset is sudden. Normal brain function and information processing continues through both propositional and sensory-based knowledge. A person in this stage of dementia may experience memory lapses; mild aphasia (difficulty recalling words); frequently losing or misplacing objects; slight social withdrawal.

Dementia Stage 3

In this stage, cognitive decline, although still mild, may become noticeable by friends, family, and coworkers. Medical professionals may be able to identify problems with memory or concentration through cognitive testing. Information processing may begin to shift to sensory-based knowledge as a primary method with the secondary support of

propositional knowledge. A person in this stage of dementia may experience mild to moderate aphasia and difficulty remembering new people's names; difficulty performing tasks in social and work settings; difficulty with reading comprehension; losing or misplacing valuable objects; difficulty with planning, organization, and sequencing.

Dementia Stage 4

In this stage, a person may experience moderate cognitive decline, which medical professionals can diagnose by observing specific symptoms in several areas. Information is processed primarily through the senses with the limited support of propositional knowledge. A person in this stage of dementia may experience short-term memory loss; long-term memory loss; inability to do basic math; inability to manage medication; moodiness and social withdrawal, especially in socially or cognitively challenging situations; changes in personality exhibited by new and uncharacteristic behaviors, such as singing or dancing in public.

Dementia Stage 5

In this stage, moderate to severe cognitive decline occurs alongside extremely noticeable forgetfulness. A person in this stage may begin to need help with the activities of daily living, such as putting toothpaste on a toothbrush or folding clothes, but they can still perform some tasks independently, such as feeding themselves and using the bathroom. Information is processed primarily through sensory-

based learning with almost no propositional knowledge.

A person in this stage may experience inability to recall their address, telephone number, middle name, hometown, or other details about themselves; increased confusion about where they are or where they have been recently; inability to tell time; need for assistance with daily planning such as choosing food, clothing, and activities; difficulty navigating their living environment, remembering where different rooms are, and where objects belong.

Dementia Stage 6

In this stage, a person may experience severe and progressive cognitive decline. Information is processed primarily through sensory-based experiences with little or no propositional knowledge. The person may need hand-under-hand assistance² with the activities of daily living and may experience an inconsistent ability to perform tasks. A person in this stage may experience major changes in sleep patterns; severe difficulty with motor-skill based tasks and dressing without supervision, commonly exhibiting self-securing behavior by putting on multiple layers of clothing. A person in this stage likely requires assistance with self-care such as meal planning, eating, bathing, and using the bathroom.

² The hand-under-hand assistance method is described in Chapter 11, Approaches to Interaction.

Dementia Stage 7

A person in the final stage of dementia experiences progressive and severe cognitive decline. Information is processed through sensory-based experiences with no propositional knowledge. A person in this stage loses the ability to respond to their environment and verbally participate in conversation. They will eventually lose fine motor skills, such as the ability to grasp, as well as mobility, including the ability to twist or turn (gross-trunk movement). A wheelchair is required. A person in this stage may experience the need for assistance to accomplish everyday tasks; inability to communicate verbally; difficulty eating, necessitating a soft or liquid diet; and increased need or desire for sleep.



Remember that quality of life can always be improved for people with dementia, even in the advanced stages. Although they may lose the ability to communicate verbally, they may like to be talked to. Although they may lose independent mobility, they may enjoy being taken for a walk in their wheelchair. They may no longer be capable of planning and coordinating their daily tasks and transitions, but they will benefit from a caregiver who offers compassionate support in these areas.

Use cues to lessen agitation when you are guiding someone through tasks and transitions.

Radiate an encouraging attitude. Consider the power of the words you choose, the tone you use, and the ability for music to soothe. These techniques will strengthen your ability to be the kind of caregiver and friend who can help others find happiness, even when they are struggling.

Approaches to Interaction

The way we approach people, guide them, listen, and respond to them influences the success of our conversations and interactions. Make compassion your primary intention, and use the following practical approaches to interaction when caring for someone with dementia.

Here are seven steps for mindful connection that help to create transitions, routine, and a sense of purpose.

- 1. Introduce yourself to the person, and provide prompting information.**

*"Hi, I'm Joshua, and I will be your caregiver today."
Or, "Hi, Mom; it's your son, Josh. I'm here to visit you."*

- 2. When communicating, make eye contact and communicate at the person's eye-level.**

3. Give a compliment, and then invite the person to help or participate.

“I bet you’re great at this activity. Would you like to join us?” Or, “I could really use your help with this; will you help me?”

4. When offering choices, provide no more than two or three options.

“Would you like to join us for morning exercise, or would you rather read the newspaper?”

5. Provide the person with something to hold for comfort.

The sensory experience of holding something releases dopamine, increase a sense of calm and comfort. Holding an object can also improve engagement and focus.

During activities, try offering a small pillow or another favorite object.

6. Sit groups in a circle or side-by-side.

Everyone should be a front-row learner. If you sit side-by-side with someone with dementia, sit on the side of their dominant hand.

7. Provide a clear ending to activities by thanking

the participants and creating an emotional and physical connection.

“Thank you for singing with me today!” Offer each person a handshake or a hug.



The following approaches offer more methods for achieving successful interaction. They prioritize kindness, compassion, and patience, which are qualities that can improve your relationship with anyone.

Give More Compliments

Compliment Therapy is the act of pointing out the positive attributes that you see in someone. When someone receives a sincere compliment, it reinforces positive self-esteem and increases positive behaviors. Compliments can cause endorphins to be released in the recipient’s brain. You will see a brightening of the expression, a lightening of the spirit, and an increase in energy. Even after a specific compliment is forgotten, an emotional bond endures.

When you initiate interaction by giving a compliment, you instill a sense of confidence, belonging, and trust. Start conversations with statements like, “Mrs. Smith, what’s your secret to staying so beautiful?” or “Joe, you have a handshake like a president!” Human beings are more likely to agree and comply with those who compliment us,

even if that compliment is as simple as someone remembering our name. Giving compliments makes it easier to manage difficult behaviors that might arise during an interaction.

Listen compassionately and validate feelings

We all have a desire for our feelings to be validated by others. When connecting with someone with dementia, it is important to validate how he or she is feeling.

Start conversations by acknowledging the person's countenance, for example, "*Hi, Mom; it's me, Josh! You seem happy today.*" Or, if someone seems markedly upset, validate that by saying, "*Hi, Mr. Smith; you seem sad. Would you like to talk to me?*" Let the person know that you are there to help.

Validating another person's feelings is a way of establishing a meaningful connection with them. Show the person that you care and are willing to listen. Use this connection to direct the conversation toward assessing what support they need and attempting to provide it.

Match emotion to emotion

If someone is feeling sad, you should match your emotion with theirs. Put yourself in their shoes. If you were visibly upset and a friend approached you with smiles and laughter without asking you what was wrong, might you feel disregarded and invisible? The same is true for someone with dementia, and

sometimes even more so, because verbal and cognitive obstacles can make it more challenging for them to express their feelings. We must match and mirror their emotional state: sad with sad and happy with happy. Connecting with their emotional experience is a form of empathy that gives you a chance to help redirect the emotion.

If Mr. Smith seems sad and lonely, walk over to him and validate his feelings. Ask if you can sit with him for a few minutes. Mirror his emotional demeanor when you speak to him. This will comfort him and enable you to begin asking more questions about how he feels and what might make him feel better. Throughout the conversation, you will notice that Mr. Smith will also start to mirror your emotional demeanor. Use this opportunity to lighten his mood and slowly bring the conversation to a happier place. Redirect the topic to something other than loneliness, and see if you can engage him in a connected social activity.

Appeal to All Five Senses

As dementia progresses, sensory-based learning begins to take a primary role in cognitive processing. Instead of focusing on a person's loss of propositional knowledge, we can leverage their ability to stay connected to the world through their senses.

Taste: Provide little tastes of food before dinner to communicate to the brain that dinner time is approaching.

Smell: Appetizing smells in the kitchen signify that the kitchen is a place for food. Encourage people to smell food before eating it. Encourage them to take deep breaths in the garden when you take them for a walk. Smell is highly linked to memory and keeping the nose engaged can help maintain connections to stored memories.

Touch: Sensory-based knowledge gives us a gateway for connection through touch. Encourage people to feel the objects they are working with, and provide them access to objects that they can manipulate.

Hearing: We must often speak louder to be heard by older people, but remember to use a loud, clear talking voice rather than a yelling voice. A gentle, mellow tone can be calming, and a hostile or impatient tone can be threatening and agitating.

Sight: Use color deliberately to create a more welcoming, stimulating, or calming environment.³ Use lighting to convey cues about the time of day.

The 15-minute rule

Have patience. It takes a person with dementia about 15 minutes to become acclimated to his or her surroundings, after which the windows of opportunity for meaningful interaction will begin to widen. The average brain tends to process information differently about every 15 minutes, and

³ The use of color is further described in Chapter 18, Engaging Through Color.

interestingly, the average attention span of a person with dementia is typically about 15 minutes. Remember to give people 15 minutes to acclimate to new surroundings and another 15 minutes to begin to participate. Your patience during transitions will truly help them engage with the next activity.

If a person with dementia starts to exhibit a concerning behavior, give him or her about 15 minutes before attempting to redirect the behavior. This allows the brain to process the information you are giving them with a different set of neurotransmitters.

Hand-under-hand

When you must guide someone physically, the approach matters. The *hand-under-hand* approach for physical assistance uses your hand to perform a task while the person you're guiding rests their hand on top of yours. This enables the person you're guiding to feel what your hands are doing, so that they can perform the action with your support. This is a non-invasive method to hands-on helping that assists rather than forces.

The *hand-under-hand* approach can be used as a meaningful method to social connection while also giving assistance during tasks such as dining and the many other activities of daily living. The use of this method can be particularly effective during bathing to reduce anxiety and resistance.

Hand-over-hand

The *hand-over-hand* approach helps a person complete a task with forced direction. The caregiver

guides a person's hand to complete an action with limited help from the person. This is an invasive approach that forces rather than assists. Remember to handle people gently and offer them lots of supportive reassurance. When used correctly, this technique can lead to a positive emotional result. It can create a memory of having completed an action that has become impossible. This technique uses the healing power of touch to bypass the parts of the brain that have been damaged by dementia.

CONCLUSION

In the words of the poet Maya Angelou, “People will forget what you said, people will forget what you did, but people will never forget how you made them feel.” *The Dementia Concept* offers tools to impact the quality of your care in a way that makes people feel valued, appreciated, and acknowledged. This, as I hope you will witness in your own care practice, can have a profound impact on individual levels of success.

With a better understanding of dementia and practical tools for how to meaningfully connect and engage with others through care, you are ready to put *The Dementia Concept* into action. The next time you are working with someone with dementia, remember these tools, which are now yours to customize into the most caring and personalized approach for each individual in your care.

Through an improved and mindful approach to interaction, conversation, expressive arts therapy, and the creation and maintenance of a regular daily schedule, you can greatly improve the life of someone with dementia. You can bring more positivity, light, and love into patient-caregiver relationships in ways that are scientifically proven to positively affect the brain. Individually, these changes might seem small, but when you put them all together, amazing things are possible.



Thank you for joining the movement to improve dementia care.

May compassion, peace, and inspiration guide you on your journey.

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.

RESOURCES

Alzheimer's Association

919 North Michigan Avenue | Suite | Chicago, IL
60611-1676 | Helpline 1.800.272.3900 |
www.alz.org

Alzheimer's Disease Education and Referral Center (ADEAR) | National Institute on Aging

P.O. Box 8250 | Silver Spring, MD 20907-8250
1.800.438.4380 | www.nia.nih.gov/alzheimers

Alzheimer's Foundation of America

322 Eighth Avenue | New York, NY 10001
Helpline 1.866.232.8484 | www.alzfdn.org

Family Caregiver Alliance | National Center on Caregiving (FCA)

785 Market St. | Suite 750 | San Francisco, CA
94103 | 1.973-729-6601 | www.caregiver.org

Family Caregiver Network

1130 Connecticut Avenue NW | Suite 300 |
Washington, DC 20036 | 1.202.454-3970 |
www.caregiveraction.org

National Alliance for Caregiving

4720 Montgomery Lane | Suite 205 | Bethesda, MD
20814 | www.caregiving.org

**National Association of Professional Geriatric
Care Managers (GCM)**

1604 N. Country Club Road | Tucson, AZ 85716-
33102 | 1.520.881.8008 | www.aginglifecare.org

National Family Caregivers Association (NFCA)

10400 Connecticut Avenue | Suite 500 |
Kensington, MD 20895-3944 | 1.800.896.3650
www.ninds.nih.gov

National Certification Board for Alzheimer Care

3170 N Sheridan Rd | Suite 1008 | Chicago, IL
60657-4882 | www.ncbac.net

National Institute for Dementia Education

6501 Arlington Expressway B105 #2051
Jacksonville, FL 32211 | www.nid.education

International Caregivers Association

P.O. Box 193 | Mapleton, ME 04757
1.207.764.1214 |
www.internationalcaregiversassociation.com

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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