

Dementia Care Guide

Understanding How to Provide
Compassionate, Effective Dementia Care



The Go-To Guide for Dementia Caregivers

Caring for a loved one with dementia can be both fulfilling and stressful. It's rewarding to be there for someone you care about but the care required can sometimes seem daunting. No matter what stage in the journey you're in, we're here to support you by providing strategies you can use to make day-to-day care easier. Whether it's learning how to handle a loved one's changing lucidity, finding new ways to communicate, or addressing the various symptoms of the disease, we're here to help.

If you're providing support to a loved one with dementia:

Find answers to common questions related to dementia care and gives you the tools you need to meet any situation head-on.

If you're feeling overwhelmed by dementia caregiving:

There may be times when you're unsure of the best way to support your loved one. Learn how to deal with some of the more difficult behaviors that come with the disease and how to promote your own self-care.

If your loved one has recently been diagnosed with dementia:

Take a proactive approach and learn what you can expect to encounter as your loved one's care needs evolve and how to stay mindful throughout the dementia journey.

Table of Contents

Can Dementia Come and Go?	4
.....	
Effective Communication in Early-Stage Dementia	9
.....	
Effective Communication in Mid-Stage Dementia	12
.....	
Effective Communication in Late-Stage Dementia	15
.....	
Strategies for Reducing Paranoia	18
.....	
Strategies for Dealing with Sundowning	21
.....	
How Vision Changes with Dementia	25
.....	



Can Dementia Come & Go?

By: Rob Wagner and Cheryl Popp

Nearly everyone who cares for someone with dementia has a story like this: *"Just yesterday, mom spent most of the day sitting quietly and barely said a word. When I brought her lunch, she looked at me like I was a stranger. This morning, she greeted me cheerfully and called me by name. A few minutes later she was working on a crossword puzzle. Could it be that she's getting better?"*

Dementia – once it has been officially diagnosed – does not go away, but the symptoms can come and go and the condition can manifest itself differently depending on the person. The symptoms and signs of Alzheimer's or dementia progress at different rates. There are different stages, but it doesn't ever "go away".

Dementia progresses rapidly for some people, while it takes years to reach an advanced stage for others. People with “mild dementia” may still be able to function independently, with memory lapses that have a minimal impact on daily life, such as forgetting words or where things are located.

While Alzheimer’s and other common forms of dementia are progressive in nature and cannot be reversed (not yet, anyway), sometimes symptoms fade and individuals can enjoy periods of relative stability. This happens for a number of reasons.

How Dementia Seems to Come and Go

In one study, charts of dementia patients were reviewed during a two-year period. The researcher scanned the charts for mentions of “good days and bad days.” The most common characteristics? Most of the patients lived with their caregivers (typically their spouse). Most were recently diagnosed with mild dementia. About half were taking cholinesterase inhibitors, a category of drugs used to treat Alzheimer’s. Good days most often involved enhanced mood, better concentration and improved ability to perform IADLs (instrumental activities of daily living). Bad days were characterized by increased verbal repetition, anger, irritability, forgetfulness, delusions and declining mood.

Why Dementia Symptoms Fluctuate

The common perception that symptoms come and go is an important area worthy of additional study. From what we know now, here are five considerations when thinking about why your loved one might

experience increasing and decreasing signs of dementia.

- 1. Your loved one is in the early stages of dementia.** The onset of dementia is confusing and frightening for patients and family alike. In early-stage dementia, memory problems and confusion come and go and may be accompanied by periods of completely normal behavior. As one writer puts it, “One day the person may be calm, affectionate and functioning well, the next, forgetful, agitated, vague and withdrawn.”
- 2. Co-existing medical conditions.** It’s very common for those who suffer from dementia to have other diseases that may worsen symptoms. For example, when an Alzheimer’s patient is also depressed, it may be that a deepening depression is to blame for emotional problems. Sometimes, treating the other condition will appear to “improve” Alzheimer’s. This is why it’s important for loved ones as well as the medical support team to not make any assumptions as to why the patient seems better or worse.
- 3. Maybe it’s not Alzheimer’s.** There usually aren’t major changes in cognitive function from day to day for Alzheimer’s patients. On the other hand, it’s common with another form of dementia called Lewy body dementia. This under-recognized and under-diagnosed dementia can result in an apparent improvement in symptoms.
- 4. Treatment with dementia medications.** Some patients respond favorably to dementia medicines. While the disease can’t be halted, certain medications can help sharpen the mind for a time, especially in the early stages of the disease. The top five drugs

for combatting dementia symptoms are Aricept (donepezil), Razadyne (galantamine), Exelon (rivastigmine), Namenda (memantine) and Namazric (donepezil and memantine).

- 5. Treatment with other kinds of prescriptions.** While non-drug options like counseling and support groups are the first line of defense, sometimes medications such as antidepressants, anticonvulsants, antipsychotics, anti-anxiety drugs and sleep aids can help correct emotional and behavioral issues. One elderly woman I knew went from mild cognitive problems to rapidly advancing symptoms in a single weekend, including wandering and hallucinations. Her doctor prescribed an antipsychotic medication that returned her to her previous state in short order. She lived contently for nearly a year before the symptoms advanced.

In short, there is no playbook for what is and isn't normal in dementia. In some forms of dementia, symptoms may appear suddenly or may come and go. People with dementia can often be very lucid, engage in perfectly normal conversations and seem to not have a problem with memory recall. The next day they are hallucinating and don't know where they are; they are walking around the house with the dog leash and think the dog is attached but the dog is outside. And then the next day they are doing the crossword puzzle peacefully. This can be challenging, if not maddening, for caregivers but should be understood, expected and met with compassion.

What We Know About Dementia

The National Institute on Aging (NIA) says that dementia affects approximately 3.4 million Americans, or 13.9 percent, of the U.S.

population ages 71 and older and is usually caused by brain damage associated with Alzheimer's disease, vascular dementia or Parkinson's disease. And in Canada, the number of people living with dementia is expected to rise 66% by the time we reach 2031. It is important to differentiate the various types of dementia; for about 70% of patients, a diagnosis of dementia will be accompanied by a diagnosis of Alzheimer's disease. Although these terms are often used interchangeably, Alzheimer's and dementia are not one in the same. Dementia is a loss of brain function that refers to a group of illnesses.

Although dementia may be a symptom of Alzheimer's, it may have other underlying causes, such as Pick's disease, hypothyroidism or head trauma. While Alzheimer's is the leading cause of dementia, vascular dementia, which is often caused by stroke, accounts for about 17% of all dementia cases.

While people will experience dementia differently, most people with dementia share some of the same symptoms that may come and go.

Signs of Dementia

Symptoms may include the following in varying degrees based on how far the disease has progressed:

- Memory loss of recent events
- Getting lost in familiar places or misplacing objects
- Difficulty with problem-solving and complex tasks, such as managing finances
- Trouble organizing or expressing thoughts

- Asking the same questions repeatedly
- Being unable to follow directions
- Becoming disoriented with time, people, or places
- Neglecting personal safety, hygiene, or nutrition
- Difficulty recalling appointments they've made
- Trouble finding the right words to express themselves and organizing thoughts
- Trouble remembering simple steps in everyday activities (such as turning the stove off after cooking)
- Impaired judgment – ranging from dressing inappropriately to walking in the middle of the street
- Mood swings, personality changes, or loss of initiative

These wide-ranging symptoms are all memory related since dementia is a degenerative disease that causes a progressive decline in cognitive function including memory, attention span, and problem-solving skills.

Not all confusion and memory loss indicate dementia, however, so it's important to rule out other conditions. Some signs of dementia may be caused by physical problems versus mental. Urinary tract infections (UTI's), nutritional deficiencies (vitamin D and/or B-12), dehydration, possible side effects from medication, excessive alcohol consumption, insomnia, changes to routine, or even dental problems can have an effect on cognitive ability. Be aware that if these health issues arise for a



person already diagnosed with dementia, it can aggravate the condition. Dementia should also not be confused with common symptoms of aging like misplacing the car keys or forgetting what you were going to say.

Again, a healthcare professional should be consulted if these symptoms persist or get worse. According to the Family Caregiver Alliance (FCA), a diagnosis of dementia requires a complete medical and neuropsychological evaluation. The full exam allows the doctor to determine whether the patient has dementia and, if so, its severity and causes. From there, the physician can make treatment recommendations and assist the patient and caregivers in planning for the future.

Tips for Dementia Care

Dementia can be challenging for both patients and caregivers but knowing what to expect can help ease the journey. Caregivers may not be able to anticipate the level of dementia on a daily basis, but they can be prepared to manage the varying symptoms of dementia as they progress.

The different stages of dementia require different degrees of caregiving. With mild dementia, people may still be able to function independently, however, they'll experience memory lapses that affect daily life, such as forgetting words or where things are located.

People experiencing moderate dementia will likely need more assistance in their daily lives as it becomes harder for them to perform daily activities and self-care. They may hallucinate, get lost easily and forget where they are, and not remember what day of the week it is.

Someone with severe dementia will likely lose their ability to communicate and need full-time daily assistance with tasks such as eating and dressing. They may not remember their own name or the names of others. Physical activity and ability may be seriously impaired (walking, eating, bladder control) and they may be more susceptible to infections, such as pneumonia.

Regardless of the stage of dementia or how challenging it may be as the symptoms come and go, a person with dementia should be respected and treated as normally as possible while ensuring their health, safety and well-being. The more a caregiver can understand what to expect when a loved one has dementia and to accept the often-wavering levels of behavioral change, the more effective and loving they can be during difficult times. And finally, as challenging as it may be, try to maintain a sense of humor about the sillier, harmless things that can happen – like putting the milk in the microwave instead of the refrigerator – and not get upset. When it comes to a loved one suffering from dementia, they truly do not understand the error in what they do much of the time. Be kind and gentle.



Effective Communication in **Early-Stage** Dementia

By: Kyrié Carpenter

“People didn’t know how to talk to me even though I was the same person I was five minutes before I told them I had it. They just saw this big A on my forehead. They didn’t look at me as the same person – I was stupid, or couldn’t carry a conversation, or have a single thought on my own, which was very distressing for me.” – Anonymous person living with dementia

Receiving a diagnosis of dementia can be traumatizing. In a single moment, a word scribbled in a medical chart changes everything. This trauma is often assumed to be caused by dementia itself. In reality, dementia was experienced long before diagnosis. The change a diagnosis makes is not an internal one but an external one.

In this three-part series, we will explore how to best communicate within the early, middle and late stages of dementia. I will share what

I have learned about communication from the phenomenon of dementia. Dementia can (if we let it) teach us to communicate on a deeper, more human, level. As the late Dr. Richard Taylor, a fierce self-advocate living with dementia explains, "My relationships with my spouse, my family, and my friends have broadened and in some ways deepened. We spend more time really being together. We talk more, we hug more, we cry more, we laugh more and harder and longer together."

Yes, and... One of the most useful tools I have found in communicating through the early part of the journey of dementia is to borrow the improvisational theater concept of "yes, and...". Karen Stobbe is an improvisational theater performer and family care partner. She embodies and teaches the basics of improv for communicating within dementia.

"A basic tenet of improvisational theater. Don't argue the premise. Build on it. Don't say no. Say 'Yes, and...'." – Karen Stobbe

'Yes, and...' is powerful in the context of dementia. People living with dementia hear that their reality is incorrect all the time. "No, I'm not your sister." "No, it is not 1964." "No, you can't have ice cream. It's breakfast time." Reality is relative. Physics is proving this and our hearts already know it.

Take any two people living a day together, at the end of the day ask them about it and you will get two different stories. Every moment of the day we agree on a consensus reality. In actuality, we are all living our own personal realities. When we

get curious about the differences in our realities we come to know one another.

'Yes, and...' The 'yes' necessitates acknowledging another's reality. The 'yes' says 'I am here with you in your world. I am curious about it and want to be with you'. The 'yes' says 'I accept you exactly as you are'. The 'and' keeps the flow going and builds connection and relationship. The 'and' allows you to co-create a moment.

Drop Expectations

When communicating within dementia, drop expectations. This goes two ways.

First, drop the expectation for communication to be as it always has been. Stay open and curious about how communication is being transmitted and received.

Second, drop the expectation that a dementia diagnosis means one cannot communicate.

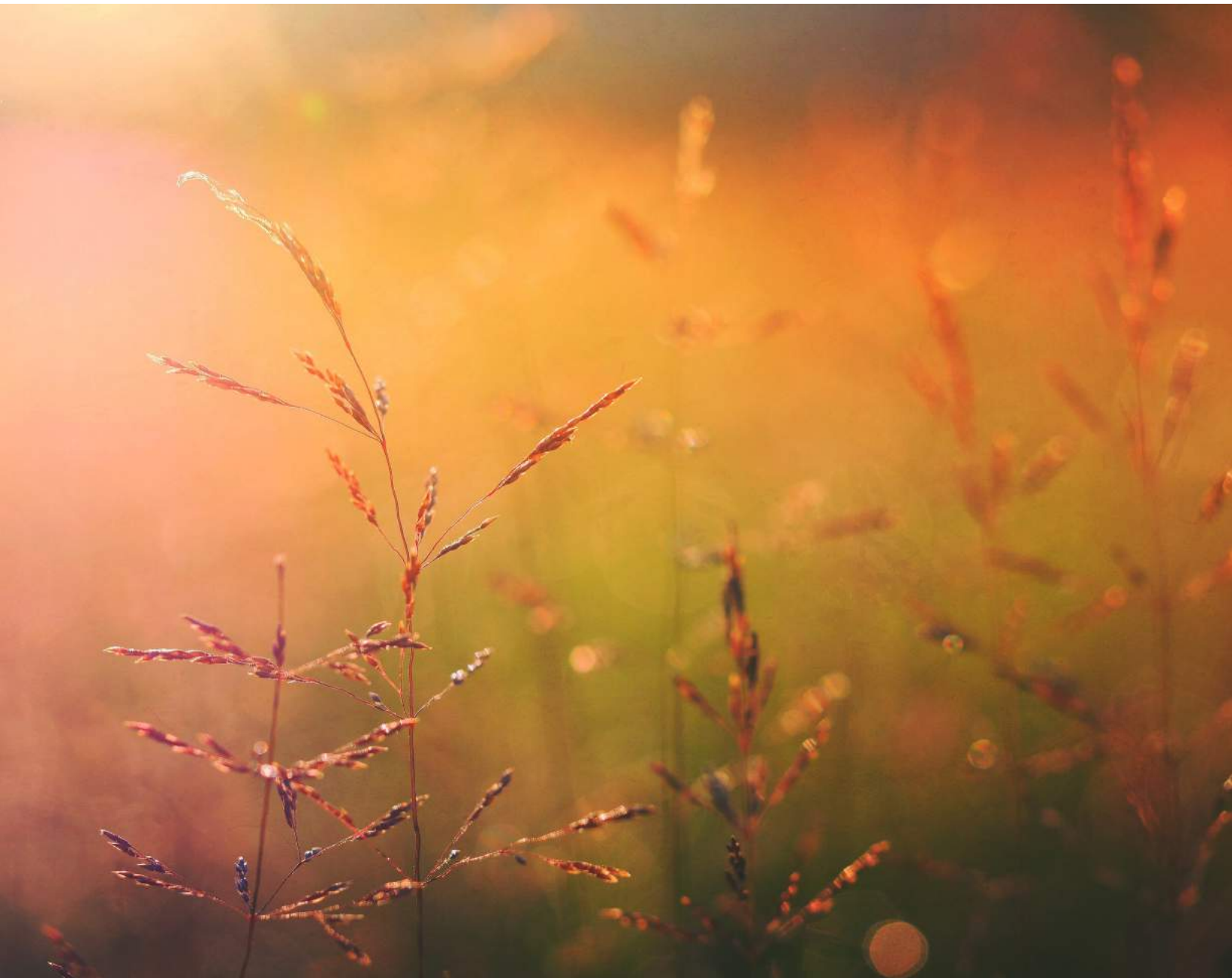


Being With

Set the intention for communication to 'being with'. The tradition of 'being with' comes from the existentialist movement. 'Being with' means that you are not coming in wanting something from the other person. 'Being with' means you do not want them to do something or be a certain way. 'Being with' means you want to be with them wherever, whenever and however they are. 'Being with' shows that you value who is here right now. I use these words of person-centered

psychotherapy founder Carl R. Rogers as a guide, *"People are just as wonderful as sunsets if you let them be. When I look at a sunset, I don't find myself saying, 'Soften the orange a bit on the right-hand corner.' I don't try to control a sunset. I watch with awe as it unfolds."*

We can all experience people (including, and especially, those living with dementia) to be as wonderful as sunsets. Be with each other, drop expectations and communicate using 'yes, and.'





Effective Communication in **Mid-Stage** Dementia

By: Kyrié Carpenter

Words? Who Needs Them?

“Many think it is the disease that causes us to withdraw, and to some extent, I believe this is true. But, for many of us, we withdraw because we are not provided with meaningful opportunities that allow us to continue to experience joy, purpose, and engagement in life.”
— Dr. Richard Taylor

Communication changes as dementia progresses. Half of the cognitive changes associated with dementia involve communication. We can see these changes as a barrier or an opportunity. The World Health Organization defines the middle stage of dementia as follows:

Middle stage: as dementia progresses to the middle stage, the signs and symptoms become clearer and more restricting. These include:

- becoming forgetful of recent events and people's names
- becoming lost at home
- having increasing difficulty with communication
- needing help with personal care
- experiencing behavior changes, including wandering and repeated questioning

We – those of us not living with dementia – can help ease the difficulty with communication associated with the middle part of the dementia journey. It all starts with understanding the changes.

How Dementia Changes Language

With dementia, communication changes the use of language in three ways. Expressive language, receptive language, and grammar and syntax are altered.

1. **Expressive language** is our ability to say what words we want to communicate in a given moment. The tip of the tongue phenomenon, when we know the word we want but cannot seem to find it, is expressive language. No one's expressive language is perfect. When one is living with dementia expressive language can shift, sometimes dramatically. Whatever word is available is often used as a substitute. For example, many objects become 'the thing' or an elevator becomes 'the up down up down'.
2. **Receptive language** is the reverse. It is our ability to take words and translate them into meaning. Receptive language happens when you hear the word fork. You know someone is talking about a pronged object used to eat food. Imagining you are learning a foreign language can be helpful in understanding changes in receptive

language. When you are learning a foreign language there will be words you do not know yet and cannot connect to their meaning.

3. **Grammar and syntax rules** loosen in the middle stages of dementia. Nouns may be used as verbs. This change is usually the easiest for those of us not living with dementia to translate.

In communicating with dementia, not all three changes will always be present and they may be present in varying degrees.

- Someone can speak eloquently (expressive language) while having a hard time understanding what others say (receptive language).
- In contrast, if someone is having a challenging time finding the words they want (expressive language), this does not mean that they do not understand what is being said to them.

With changes in language, it is imperative to stay curious and not assumptive.

Double Binds

When communicating through dementia **intention becomes crucial**. The field of psychology has a concept called the double bind. A double bind is when our words do not match our sentiment. Think about when someone tells you everything is 'fine' but you can tell something is wrong. The more adept your intuition the more damaging double binds are. Being double bound, for any of us, feels confusing and can make us feel as if we do not understand reality. In the context of dementia, this can be extremely distressing. Make sure what you feel and what you say match.

Metaphorical Ears

Words become an increasingly unreliable form of communication in the context of dementia. Try listening with metaphorical ears (versus literal ones). I find it helpful to place my mindset as if I am listening to poetry. Allow all the words to flow in. Then let your intuition interpret their meaning and communication. These 'poems' often offer clues to unmet needs. For example, an elder I worked with was pacing and repeating "the up down, the up down." What was usually classed as 'word salad' when listened to metaphorically and in context became clear that they wanted to go somewhere in the elevator.

Communicating through Art

Communication is a way for us to connect with one another, human to human. This connection eases the existential angst inherent in our existence. Dementia has taught me that words are not required for this purpose. When words no longer serve us, **art**, which speaks to us throughout our lives, can be a medium for communication.

Songs communicate. When working in long-term care I crafted a playlist of favorite songs of the elders I worked with. Listening to a special song touches the heart. Listening (and sometimes singing along) with others helps us to feel seen, heard and held. Music can express a mood, or shift a mood and offer a point of connection. Play music from recordings. Make music in community with drum circles and other instruments available.

Any expression based medium works. Seek what connects you and the person you want to communicate with. I have found watercolor to be particularly helpful. Color offers mood and the strokes expression. Sometimes even clear content comes through. There are many support programs to connect through the arts. Check out TimeSlips and AliveInside as a starting point. The field of Expressive Arts Therapy is another great resource. Dementia does not have to be synonymous with withdrawal. Let us learn from Dr. Richard Taylor, quoted at the beginning of this article. The first step in providing 'meaningful opportunities to experience joy, purpose, and engagement in life' is to communicate beyond words.





Effective Communication in **Late-Stage** Dementia

By: Kyrié Carpenter

In this series, we have explored how we can learn from dementia to communicate better. Early in the journey with dementia, we learn to drop expectations. We learn to borrow from improv comedy the concept of 'yes, and...' and we began to cultivate our skills of being with. During the middle of the journey, we learn to rely on the arts as a bridge for communication and connection.

The World Health Organization describes the last part of the dementia journey saying, "the late stage of dementia is one of near total dependence and inactivity. Memory disturbances are serious and the physical signs and symptoms become more obvious." Communication changes drastically near the end of the dementia journey. We learn that words are not necessary for communication and have to develop other ways of connecting. **Communication is possible through the entire journey with dementia.**

The Superpower of Gist

In his non-fiction theater show, *Life's Most Dangerous Game* part of the ChangingAging Tour, Dr. Bill Thomas promises the audience after the show they will never have another 'senior moment'.

The audience participates in a game show style rendition of the work of Daniel Kahneman. The audience follows a set of instructions to come up with the next number in a sequence.

Research shows that younger people are able to do this faster than older people. Dr. Thomas offers one explanation being that, "the very beginning of wisdom is knowing a silly game when you see one and choosing not to play."

Thomas reveals that Kahneman and his colleagues went farther. They showed that older people were better than younger people at understanding gist.

What is gist? Gist is the story behind the story.

Look back on your teenage years. Are there moments where you wonder, "What was I thinking? How did I not see how that wrong boyfriend or bad job would turn out?" You couldn't know then because you didn't have your gist power yet.

Dr. Thomas explains that our brains are like filing cabinets. When we are young it is easy to keep it all organized. As we age it gets filled with the most interesting and random stuff. This makes it harder to do tasks such as the number prediction in the study but

offers us increased gist. At the end of the skit, Dr. Thomas asks the audience if they would rather have gist or be able to do math a little bit faster. The answer is always gist!

At this point Dr. Thomas offers the cure to the 'Senior Moment'. He says, "The next time you are out at dinner and you can't find the word you are looking for lean back in your chair and say, "That is my gist superpower working. Yeah, I am kind of awesome."

The gist phenomenon is present in the experience of dementia. **As one's cognition decreases, their intuition increases.** This effect appears similar to the phenomenon of when we lose one sense, such as sight, the others go into overdrive, such as hearing. The elders I have had the pleasure of spending time with had gist power that was off the charts! I have more anecdotes than I can count of times when an elder knew something no one had told them.

How to Communicate: Process vs. Content

Most of my work has been with people who have been living with dementia for quite some time. Process work is an invaluable gateway for connection and communication. Writing about how to communicate beyond language is inherently difficult. This work is much more something that you feel than know. I will do my best and hope the 'gist' comes across.

Anytime we communicate with each other there are two main elements to the communication, the content and the process. The content is what we say and the process is how we say it. Often times the

process carries even more meaning than the content. Think about a time when you were communicating via text message when the true meaning of what you were trying to say was misunderstood. The content came through but the process was lost. In the language changes associated with dementia (both expressive and receptive) often times the content is what changes. One says 'shoe' when they mean 'boat'. The process stays. I have had deep meaningful conversations where more than every other word was 'thingy'. Communication came through in body language, contextual clues, tone and my own felt sense, in short, the process.

I learned about process work through my studies in Depth Psychology. The founders of Process Oriented Psychotherapy are Arny and Amy Mindell. Often in the context of late-stage dementia I hear people who are not sure what to 'do' with their loved one. Process work offers a 'what to do' in a way that moves us away from doing and towards being. Arny and Amy Mindell even work with people near death and in comas using their method. It works no matter where on the journey someone is.

Amy speaks to this work, "more than almost anything else in my life; being so close to people as they were going through these deep altered states, sometimes very near to death. I think I learned more about the essence of life and the essence of death from those experiences than anywhere else in my life; it was incredibly moving."

Process work is a moving and healing way of being with another person (with or without dementia).

The single greatest thing you can do to communicate through dementia (not around it) is to be present. Stay curious about what you can learn from dementia about communication. I have learned to listen with my heart as well as my ears. I have learned that a person's body and voice speak more loudly than their words. I have learned how to be with someone in their reality and to respect and delight in the differences. These lessons have helped me to be a better communicator with all people.



Strategies for Reducing Paranoia

By: Gina Roberts-Grey

Brain changes from dementia can cause hallucinations, delusions or paranoia. "Paranoia, or having false beliefs, is a common trait of later stage dementia," says Jared Heathman, MD, a Houston psychiatrist. "However, it can occur in all stages of dementia."

Paranoia in dementia feels very real for the person living with it. So says Susan London, LMSW, Director of Social Work at Shore View

Nursing and Rehabilitation. "There is often no evidence that will convince them otherwise."

As a caregiver, do not attempt to present "proof" a belief is false. Nor should you deny that the evidence is real. Both approaches could create an intense unfavorable emotional reaction from your loved one.

"Take the example of a woman looking for her deceased husband. She is certain that he is in the house. Telling her that he died a long time ago, or showing his death certificate,

will make matters worse," says London. She may not acknowledge his death to be true, and could be very hurt by that thought. The news could also cause her to re-experience the trauma of his loss. Or, she may strike out in anger, accusing this person of "killing her husband."

Rule Out Non-Dementia Causes of Paranoia

To understand paranoia in dementia, you need to understand its cause, says Heathman. Rule out possible causes outside of dementia. Schedule an appointment with your family member's physician to rule out treatable conditions.

"Paranoia can result from urinary tract infections, liver disease, systemic infections and anxiety disorders. In many instances, treating those may put an end to the paranoia."

If a physician rules out other medical causes, prescription drugs may reduce some symptoms of paranoia. Problematic side effects should be monitored.

Natural, Behavioral Techniques May Help Alleviate Paranoia in Dementia

Caregivers can provide reassurance and support that those suffering are safe and loved.

Do not fall into the trap that detailed explanations, or logical arguments, will help. Try these behavioral techniques to calm someone living with dementia, who is experiencing paranoia.

Remain Calm

"Remember that you are not to blame

for what your loved one is experiencing," says Heathman. "Although witnessing a hallucination can be scary, it's important to stay calm. Remember that arguing 'something is not real' is not helpful."

Instead, he suggests trying to stay as calm and collected as possible. Have a plan in place to prevent violence or call for help. If the situation escalates, act on your plan.

Be Cautious Before Responding

Assess the situation before responding to the person's delusions.

Is anyone at risk of harm?

If not, it's often best to ignore the behavior stemming from a false belief. "As long as the behavior does not become dangerous, you might not need to intervene," Heathman says.

Offer Reassurance

What if your loved one becomes agitated, or wants your help dealing with the delusion?

Heathman suggests reassuring him with kind words and a gentle touch.

"You could tell him 'Don't worry. I am here and will protect you'." You could also offer to hold your loved one's hand. Or shift their attention by lightly patting their back or shoulder. This can calm agitation.

Create a Distraction

"In some instances, it's possible to put an end to a delusion or for it to drastically subside if the person's attention is shifted," says Heathman. To help your mother snap back into reality, offer to take a walk with her or move to another part of the house.

"You can even try turning on lights or opening blinds. **Frightening hallucinations often subside in well-lit areas and if others are present.**" Try talking to your father about his favorite baseball team. Turn on his favorite song. Or suggest you both work on a puzzle together.

Ask Open-Ended Questions

Avoid being judgmental says Becky Siden, LMSW, CDWF a licensed psychotherapist in Birmingham, Michigan. "Asking questions that are open ended is very healing for everyone involved."

When communicating with a loved one with dementia, Siden suggests focusing on being understanding. She says some helpful things to say or ask include:

- How can I help you to feel safe?
- Let's look at this together and see how we can come up with a plan.
- I know the feeling of being scared and I am here to help.
- Tell me more about what this is like for you.

Remain Honest

If your spouse asks you about a false belief, Heathman says you should always respond with honesty.

If they ask if you see the person standing in the corner, you should respond by explaining you know that he sees something, but you do not.

Heathman says this approach does not deny what your loved one believes to be true. Honesty prevents you from having to lie and saying you also see something you do not. Heathman says this could increase the paranoia. Your loved one may become more

agitated if he thinks you also see something scary or unusual.

Modify The Environment

"It's very important to assess the reality of the situation," stresses Heathman.

- Glare from a window may look like snow to a person with dementia. Close the curtains to remove the glare.
- A dark area rug may look like a gaping hole your loved one believes she will fall into. Remove the rug to remove the hole.
- Your mother may see a scary stranger in her reflection in the mirror. Cover the mirror with a sheet.
- Turn on more lights to reduce shadows that could look frightening.

Summary – Do's and Don'ts for Paranoia in Dementia

Do:

- See a doctor to check for other causes of paranoia.
- Stay calm and honest.
- Ask open-ended questions.
- Acknowledge that you know that they are seeing or experiencing something.
- Say that you know the feeling of being scared, and are here to help.
- Modify the home environment to eliminate the source of scary objects.
- Have a plan in place/someone to call.

Don't:

- Don't be judgemental.
- Don't show "proof" that the paranoia is unwarranted.
- Don't respond with "logical" explanations.
- Don't deny the evidence is real.
- Don't say you see something which, in reality, you don't.



Strategies for **Dealing** with Sundowning

By: Rick Lauber

You are awoken at 2:00 am by the hallway light shining underneath your bedroom door and the sound of shuffling feet.

"Not again ...", you grumble. Your father is standing outside your bedroom door looking confused. "Dad? Where are you going?" you ask. Your father looks blankly, mutters something, and waves you off.

Dad has Sundowners Syndrome (aka Sundowning or Sundown Syndrome). He can't tell the difference between day and night, and doesn't understand, "Dad, it's 2:00 a.m. and you should get some sleep!"

What to do When Someone is Awake All Night With Sundowners Syndrome?

Here are 12 tactics to try tonight if your mom or dad is up all night, or up from dementia-related sundowners:

1. **Turn on some familiar, calming music:** Soothing low-tempo music from your parent's younger days can sometimes help, and online playlists are easy to find.
2. **Massage:** A slow hand massage, foot massage, gentle head rub or back rub can soothe. Warm some lotion between your palms and then give a light-pressure massage.
3. **Aromatherapy:** Do you have lavender oil? Mix this with a little lotion or body oil – do not use straight from the bottle – and apply to the person's temple or wrist. Avoid putting on their fingers, as this can burn if they touch their eyes. Even a familiar perfume or cologne can help.
4. **Offer some Melatonin:** If you have this "jet lag" remedy in your medicine cabinet, and it's early in the night, give a moderate dose (0.3 to 1.0 mg). Melatonin is safe to use, however typical "drug store" dosages are very high – you can cut in half or a third to get under 1.0 mg. In an ideal situation, you want to offer melatonin 2 hours before bed time.
5. **Do NOT give antihistamines and nighttime medicines:** Over the counter drugs like **Bendaryl**, **Tylenol PM** or **NyQuil** are known to accelerate cognitive decline, which will make sundowning worse. They will also make your parent woozy, and then they are more likely to fall.
6. **Cool the room:** Lower the bedroom's temperature (to below 70 degrees), which can help your parent return to sleep. A cooler room may allow you to add another blanket; the weight of a blanket can help people feel calm.
7. **Distract:** Any distraction may be just what the person with Sundowners Syndrome needs to forget about

wandering through the house and getting back to bed. Pets can make for marvelous distractions as they never judge or question a person for still being awake at 2:00 a.m.

8. **Dim bright lights:** Bright lights can play havoc with a person's internal body clock. When it begins to get dark inside or outside, this can be a signal for a person to prepare for going to bed. If the lights are turned up, the body typically responds into believing that it is still daytime.
9. **Stay calm:** Although you've been woken up for the fifth time, it's important to stay calm. If you are on-edge, the person with Sundowners Syndrome may mirror you and become on-edge. Avoid arguing ... if your parent believes something is true – even when it's not true, there will be no trying to convince them of anything different.
10. **Offer food or water:** They could be legitimately hungry or thirsty. Offer some food or a glass of water. Perhaps a trip to the bathroom is required? Afterwards, steer Mom/Dad gently back to bed.



11. **Check for pain or discomfort:** Ask your parent/spouse if they feel any pain and to point out the area where the pain exists. It's also quite easy to look at their facial expressions and posture – both of which can indicate that a person is hurt.
12. **Be reassuring:** Mom/Dad may need to hear that everything is okay. A hug can be very soothing. If they need to pace, don't try to stop them. Instead, just stand by and be ready to intervene only if necessary.

How to Prevent or Reduce Sundowners Syndrome?

1. **Keep dinner light:** It can be helpful to adjust mealtimes (going to bed shortly after dinner is, typically, not advised as the stomach takes some time to digest fully) and reduce (or completely remove) caffeinated drinks.
2. **Keep the person busy:** Give Mom or Dad a job to do. The best approach is to assign any harder, more challenging work earlier in the day and then lighten the work load towards the evening. Try asking your parent to fold washcloths or ask if they want to do an activity with a grandchild.
3. **Simplify surroundings:** Consider everything in Mom or Dad's room. What purpose does each item have? Discard or donate the extra chair or the dresser they never use. Remove any mirrors from the walls as your parent may not recognize their own reflection and become startled by "an intruder."
4. **Keep things quiet:** Peace and quiet are more conducive to helping someone fall asleep and stay asleep. Ideally, you will be going to bed at the same time your loved one does; however, if not, excuse any visitors, wear headphones to listen to the stereo, and limit any banging around. Reduce the amount of noise in the bedroom. Is the room facing the front street with constant traffic flow? Perhaps the room is directly beside a noisy child's bedroom? Do whatever you can to make the room comfortable, livable and quiet.
5. **Stick to a schedule:** Creating a daily routine (where meals are served, activities are planned, and bedtime occurs at the same times each day) can also help reduce Sundowners Syndrome.
6. **Eliminate naps or take short naps:** If a person is awake throughout the night, that person will be tired throughout the day. Naps may become necessary; however, if the senior does show any sign of exhaustion, limit these naps (perhaps to a half-hour or an hour).
7. **Limit sugar intake:** Candies may be tempting but hide the bowl away in the evening. Similarly, restrict the amount of caffeinated and alcoholic beverages.
8. **Discourage strenuous activity:** Exercise is better done during the day, rather than just prior to bedtime.
9. **Discourage watching television:** Action movies can get the heart racing and the evening news can be disturbing. If the senior has a television set in his/her bedroom, remove it to reduce any temptation of tuning in while in bed. A good alternative can be any number of "family" DVDs – keep a good collection on-hand to choose from.
10. **Use baby gates:** Install baby gates at the top or the base of staircases to protect a senior from falling down (or falling up) the stairs. Block entry into the kitchen with another baby gate. This way your loved one can be kept away from the

stove and sharp utensils. You could also install a lock on the senior's door and/or window(s). Chosen wandering routes must be well-lit (even with a motion detector or nightlights).

- 11. See the doctor and check drug interactions:** A doctor can do a complete medical check to diagnose any problems and advise on current medications to see if any are causing sleeplessness. Caregivers should keep a list of medications their car partner is taking and dosage. Try to keep copies of the medical information provided by your pharmacist, which detail potential side effects. If you're in a rush, use your cell phone's camera to snap a photo of pill bottle labels and then show these pictures to the doctor.

What are Symptoms of Sundowners Syndrome?

Sundowners Syndrome can be a tricky thing to put a finger on, as it is not just one thing. Any person living with Sundowners Syndrome will experience and/or show a number of symptoms. These symptoms will become more obvious and more frequent in the late afternoon and/or evening. Symptoms can include:

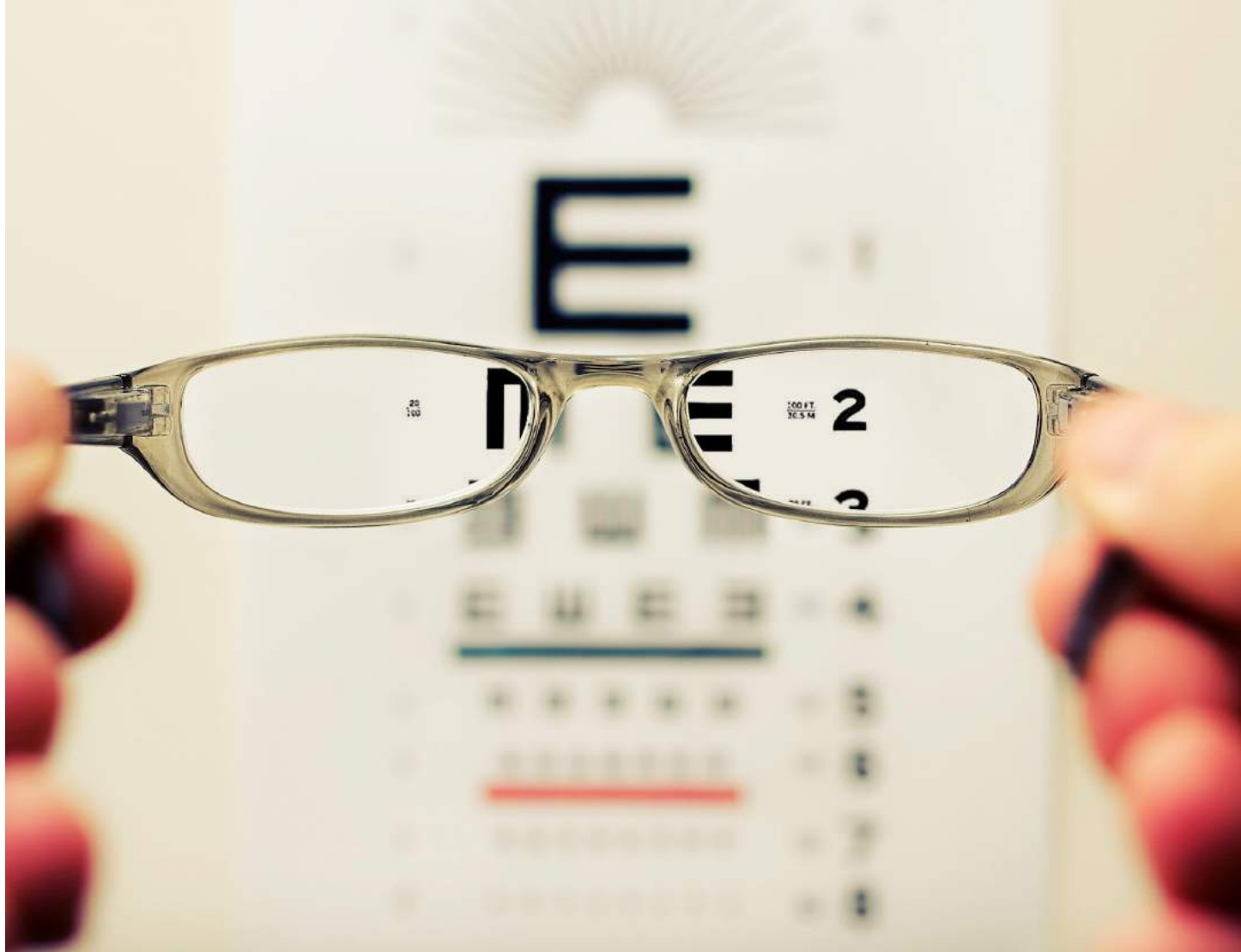
- Agitation
- Increased confusion
- Anxiety
- Pacing
- Aggressiveness
- Disorientation
- Mood swings
- Making demands
- Hallucinations

If your loved one is awake and wandering around the house at night, they will be awake. Logically, it is likely that you will be awake.

What Are the Medical Causes of Sundowners Syndrome?

No one, as yet, has been able to exactly determine the cause(s) for Sundowners Syndrome. Findings by researchers show that a person's brain works differently throughout the day. If you've ever found that you have more energy to tackle a project in the morning, you're not wrong to do so! The brain will – typically – work best in the morning (following a good night's sleep); however, it slows down and becomes more tired later. A tired brain doesn't always help a person with Sundowners Syndrome fall asleep. As the light dims, people with Sundowners Syndrome may display more symptoms (e.g. confusion, restlessness, and/or showing repetitive behaviors). We hope these tips for reducing sundowning help.





How **Vision Changes** with Dementia

By: Crystal Jo

The vision changes from dementia cause confusion and fear. You might notice strange behaviors and responses. Many people mistakenly think the odd behavior is a result of hallucinations. Understanding the changes helps you provide more compassionate care.

1. **Blurring.** Blurring is when one sees things less sharply. Faces and common objects can become harder to recognize. Blurring

can cause confusion and difficulty finding objects. Another challenge is not being able to read or write.

Caregiver tips:

- Make it clear who you are when interacting with a person with dementia. For example, don't say "it's me." Instead say "**Hi Mom, it's Bob, your son.**"
- When you give your care partner an object, state what it is. Such as "**here is your hairbrush.**"

- 2. Pupils reacting slowly to light.** Slow reactions to light make it hard to go from a light space to a dark space. When a person with dementia turns from looking out a bright window the room will appear dark. Going outside on a sunny day can be overwhelming. The light appears too bright until the pupils react.

Caregiver tips:

- Allow **plenty of time to adjust to different levels of light.**
- When waking up in the morning, keep the lights low. Turn on a small light first.
- Go slowly when entering from outside. Wait patiently inside the door until their eyes adjust.
- Encourage your care partner to shield their eyes from the sun, and wear a wide brimmed hat or sunglasses outside.
- Reduce glare and shadows in the house with blinds and adequate lighting.

- 3. Smaller visual field.** Your visual field is the area around you in which you can see things. Dementia causes this field to become smaller. With dementia the visual field can narrow to only 12 inches. Teepa Snow, a dementia educator, describes this smaller visual field as “like trying to move around while wearing binoculars.”

This means that when a person with dementia is moving around they see much less than you do. A bathroom door in “plain sight” might not be seen. It is normal to have a smaller visual field as you age. But with dementia, the visual field is much smaller.

Caregiver tips:

- You can use **large pictures** to help a loved one with dementia find common things. A large picture that is easy to see

can help identify where to find a mug.

- Another idea is to use bright colors. **Contrasting colors** are easier to see. A bright colored plate on a light-colored table will be more noticeable. Contrasting colors make it easier to see the food as well.

- 4. 4. Loss of peripheral vision.** Peripheral vision is when you can see things that are not directly in front of you. You see things “out of the corner of your eye.” A loss in peripheral vision causes difficulty seeing objects around you. This vision loss can lead to falls, tripping over chairs, or bumping into door frames.

A person with dementia will not see you if you come up to them from behind or the side. Without peripheral vision they will not see a plate of food in front of them.

Caregiver tips:

- Keep in mind that the person with dementia may only see things directly in front of them. You will startle and frighten them if you approach from behind. Try to stand directly in front of them before you speak.
- Serve finger foods at meal time. These are easier to recognize. If helping with feeding, try to direct the person to look at the food before offering a bite.

- 5. Problems with depth perception.**

Advanced dementia can cause the brain to see from only one eye. What they see becomes too much for the brain to process. To cope, the brain only uses information from one eye. This affects the ability to know how far you are from an object. The difference between a flat surface or a raised surface may not

be clear. You might notice your care partner steps too highly over a change in flooring. They could try to go around a shadow. Without depth perception, the dark spot may look like a hole.

A loss of depth perception can cause strange behaviors. For example, you might think a person with dementia is hallucinating. They may pick at the air around them. They are actually trying to touch something but can't tell how far away it is. When they pick at the air in front of them, they may be trying to turn off a ceiling light.

Caregiver tips:

- Avoid placing dark rugs on the floor.
- Paint the edge of the stairs to make it easier to see each step.
- Increase the amount of lighting. A dark corner may appear frightening.
- The behaviors that look strange are a result of how they see the world.

What Is Posterior Cortical Atrophy?

Posterior Cortical Atrophy (PCA) is a form of dementia that causes visual problems. Typically, the symptoms involve difficulty seeing more than one thing at a time. Memory and cognitive problems may be milder than Alzheimer's disease. Although the disease also causes loss in memory and cognition.

Most people will seek help for vision changes caused by Posterior Cortical Atrophy. PCA is a brain disease, not an eye problem. Other symptoms often include:

- Memory changes
- Behavioral changes
- Anxiety

- Irritability
- Apathy
- Depression

PCA often occurs at a younger age than Alzheimer's disease.

How to Help a Person Cope with Vision Changes

Visual difficulties can cause frustration for the caregiver. Understanding the why behind strange behaviors will help you. Look at how you can rearrange the environment to make it safer for the person with vision loss or dementia.

Become familiar with the normal changes in vision that occur. If you notice any vision changes, see either an ophthalmologist or optometrist for regular eye exams.

Allow for extra time to complete regular activities. Slow down and offer plenty of encouragement. See the world through the eyes of a person with dementia.



Meet the Authors



ROB WAGNER

With over 20 years of experience writing for leading healthcare providers, Rob is passionate about bringing awareness to the issues surrounding our aging society. As a former caretaker for his parents and his aunt, Rob understands first-hand the experiences and challenges of caring for an aging loved. Long an advocate for caregiver self-care, his favorite activities include walking on the beach, hiking in the coastal hills of Southern California and listening to music.



CHERYL POPP

An accomplished freelance writer and editor, Cheryl is passionate about healthy longevity and how to bolster our resilience as we age. Her compassion and understanding for caregiving stems from acting as a caregiver for her mother, who struggled with dementia, and her father, who suffered from Parkinson's.



KYRIÉ CARPENTER

As a radically age and dementia positive coach and thinker, Kyrié calls herself a crone in-training because she believes our world needs elders and we need to train to become them. Her passion for story led her to a career in film, studies in Depth Psychology, and ultimately her work with aging. She is a book author and blog contributor for multiple platforms.

Meet the Authors



GINA ROBERTS-GREY

For over two decades, Gina Roberts-Grey has pored over studies and interviewed leading health experts on topics ranging from healthy aging, caregiving and longevity. Having been an active caregiver to her grandparents who lived into their 90's, Gina is passionate about supporting caregivers through their journeys.



RICK LAUBER

As a former co-caregiver, Rick Lauber helped and supported his own aging parents. His mother had Parkinson's and Leukemia and his father had Alzheimer's. Rick learned that caregiving is challenging and used writing to personally cope. His stories became two books, *Caregiver's Guide for Canadians* and *The Successful Caregiver's Guide*. To learn more about Rick and to connect with him, please visit www.ricklauber.com.



CRYSTAL JO

As a freelance writer, Crystal Jo enjoys educating and inspiring seniors, and those who love them, to choose a healthy life. She is a Registered Nurse who is passionate about helping older adults live happy, healthy lives at home.

About Home Care Assistance

At Home Care Assistance, we provide customized care to older adults so they can live happier, healthier lives at home. We champion the needs of seniors with a positive, empowering approach to aging that celebrates independence, dignity and quality of life. Our caregivers receive exceptional training, support and resources to deliver an unmatched care experience.

High Quality Care

We go above and beyond to deliver concierge-level care for clients who want, and expect, the very best for their aging loved ones.

Committed to our Clients

We believe the best way to deliver exceptional care is to focus on building long-term, trusting relationships between caregivers, seniors and their families.

Elevated Quality of Life

Our Balanced Care Method emphasizes healthy mind, body and spirit. We believe that with the proper care, we can help older family members live happier, healthier and more fulfilled lives.

Trusted Care Expertise

We are experts in all aspects of home care, from family dynamics to nutrition, around-the-clock care to dementia. And we train our caregivers accordingly.

Total Peace of Mind

We understand the trust you place in us, and do everything possible to ensure that the home care experience is worry-free for all concerned.

Connected in the Community

We are the trusted partner of reputable care professionals in the communities we serve. We pride ourselves on connecting our clients to the care solutions they need - even if it's outside our service offerings.



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OUR MISSION

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