



# Serving Residents With Dementia:

Transformative Care Strategies  
for Assisted Living Providers

Kerry C. Mills, MPA

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**HCPPro**  
a division of BLR

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# About the Author

## Kerry C. Mills, MPA

**Kerry C. Mills, MPA**, has earned recognition in the field of Alzheimer's care as a former New York regional manager for a pioneering group in the study of caring for people with dementia.

In her 14-year career working with elders, 13 of which were spent directly serving people with dementia, Mills has done everything from being executive director of several Alzheimer's facilities to developing programs that provide a meaningful lifestyle for those afflicted with this disease.

In addition to writing a training manual for personnel who attend to the needs of people with Alzheimer's, Mills successfully completed an assessment of dementia care in all hospitals, nursing homes, assisted living facilities, day care programs, and homecare agencies in the London, UK, borough of Barnet. Her resultant treatment proposal was accepted by NHS England.

Mills also served as the dementia liaison for White Plains (New York) Hospital and is the current president elect of the Connecticut Geriatric Society. She is also a member of the Multi-Disciplinary Team, a coalition of nonprofit agencies, law enforcement, and private industry professionals for the prevention of elder abuse in New York state.

Whether Mills is participating in a symposium on healthcare at the United Nations, sharing her expertise with health professionals in China, moderating a state-of-the-art Alzheimer's program at Boston's prestigious Coolidge Theatre, guest lecturing to medical professionals in Hong Kong, training professional care partners in Toronto, or simply meeting with a family, she exhibits a high level of enthusiasm and encouragement and delivers a message of hope about this disease.

Mills' goal is to change the perception of the disease in the public square. She has witnessed many success stories firsthand and knows that much of the despair and anguish of families can be overcome through education and training.

Because of her commitment to changing the strategies currently applied to people suffering with Alzheimer's and related dementias, Mills decided, in early 2011, to open her own consultancy, Engaging Alzheimer's LLC, through which she offers her unique talents and experience to families that have loved ones diagnosed with the disease, as well as professional caregivers in nursing homes, assisted living facilities, hospitals, and homecare agencies.

More recently, Mills has received accreditation from several medical associations to teach her care strategies to healthcare professionals for CEU credits.

Mills coauthored the award-winning book *I Care: A Handbook for Care Partners of People With Dementia* and has appeared on the *PBS News Hour* with Paul Solman as well as CBS television with Dr. Max Gomez.

Mills holds an MPA with a specialization in health administration from Long Island University and a BS in international marketing from Arizona State University.

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*Do not withhold good from those to whom it is due, when it is in your power to do it.*

*—Proverbs 3:27*

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# Introduction

We are living in exciting times! Healthcare is changing rapidly before our eyes as we face the largest pool of people in the United States ever to require services at once. Indeed, Americans who are 65 years of age or older make up more than 14% of our nation's total population, a percentage that will continue to climb as baby boomers reach senior citizenship at unprecedented rates and provide us with renewed incentive to shape our healthcare system to meet their needs.

A cursory glance at how Medicare dollars are spent reveals that many Americans develop serious health conditions as they age. For some, these illnesses clear up quickly, but for many, the chronic nature of their disease necessitates long-term medical treatment. Beyond the health challenges that often accompany older age, many individuals also hit social roadblocks, including empty nest syndrome, retirement, widowhood, and the dispersing of longtime friends.

The need for more regular companionship, oversight, and medical assistance to cope with these coinciding life changes is what first gave rise to assisted living, an environment that has since blossomed into a staple of the healthcare continuum.

As the country's population of elders grows and their desire for autonomy continues even as they contend with increasingly chronic and complex diseases, assisted living residences are popping up more and more across the U.S. Many of these modern establishments have programs specially designed to meet the needs of people with dementia, who make up a significant portion of the setting's residents. Of the nearly 735,000 people who reside in assisted living facilities (ALF) across the U.S., 42% have Alzheimer's disease or a related dementia.

Herein lies the reason for this book: As our society continues to learn more about the conditions that cause dementia and effective interventions to mitigate its symptoms, traditional care approaches that prioritize bodily security over the human experience are becoming obsolete—as will, inevitably, the ALFs that stubbornly stand by them.

Cordoning off a locked section of a facility, scheduling staff to work in the enclosed space, and verifying that those who rent a room in this policed environment do have a dementia diagnosis will not result in a successful program for people living with cognitive impairment (CI).

It is time for a shift in mindset, a redirection of our focus from the limitations of people with dementia to the ways that we can build on their strengths and abilities.

Driven by this philosophy, *Serving Residents With Dementia: Transformative Care Strategies for Assisted Living Providers* aims to impart the most essential information about dementia to facility leaders and other influential stakeholders so that assisted living organizations can build—and continuously build upon—meaningful programs and spaces in which people who have dementia can thrive.

By design, assisted living residences are primarily social spaces rather than medical settings. However, because people with health issues are living in these facilities, there is a medical component to ALFs, albeit a smaller one than in other residential settings for elders, such as nursing homes, which strive first and foremost to provide exceptional medical care and secondly to replicate the comforts of home. Although these are important distinctions between the two settings, the term “assisted living” is not yet a household one, and many people confuse these establishments with nursing homes.

One important difference, though, is that whereas federal regulations play a large role in nursing homes, which receive significant funding from Medicare and Medicaid, this is not the case in the ALF sector, where 80% of residents pay for services privately. These circumstances provide states more freedom in developing their regulations for the industry. Some states are very advanced in their oversight, while others set minimal requirements and grant each individual organization free rein. But as ALFs grow steadily and government payer sources continue adding the care rendered in the setting to their list of eligible services, ALF regulations will become more standardized across the country.

Thus, in addition to its local aim of helping providers better serve their current residents, the global goal of this book is to help set industrywide standards of care in an increasingly, if still erratically, regulated space. To accomplish this, the text draws from the work and insights of a diverse community of professionals—including doctors, lawyers, program directors, nurses, social workers, and researchers—who make strides every day in understanding dementia and treating its symptoms.

Another key focus of the text is dispelling myths that undermine quality care. Organizations in the largely for-profit ALF sector too often focus on advertising their provision of “best practices” without taking the steps necessary to live up to this claim. Recognizing the power of certain buzzwords to get customers in the door is different than knowing why they are important or how to implement them safely and effectively.

For example, many organizations boast that they “don’t use medication to manage behavior.” While minimizing the use of unnecessary drugs is certainly a worthwhile pursuit, the wholesale

removal of medication from the equation can be problematic. In many cases, managing behaviors is absolutely possible by engaging, fostering purpose, and initiating a whole host of other individualized interventions for residents. However, if a resident continues to show signs of distress after these nonpharmacological approaches have been exhausted, medication may be necessary to preserve his or her quality of life.



## Evidence from the real world

A number of years ago, I was part of a team that was invited by the UK government to perform an assessment of all dementia care programs in a borough just north of London. One of my assignments for the project was to visit various care environments (i.e., ALFs, nursing homes, hospitals, day programs, and home health agencies) to determine staffs' understanding of dementia interventions. In each home or organization that I visited, I asked the care team how they managed undesired behaviors. Nearly every time, they parroted back, "We don't use medication to manage behavior."

One particular day, I was standing in the dining area of one of the care homes while the residents ate lunch. Most of the residents were trying to concentrate on their meals but were becoming distracted by one woman who was alternately sobbing and screaming. I tried to listen to what she was saying and learned that she was very anxious. At that point, I asked the nurse manager whether the resident might benefit from some medication, to which she quickly replied, "We don't use medication to manage behaviors." Well, it turns out that they didn't do anything else to help, either.

Herein lies an example of the disconnect between recognizing a good practice and knowing how to apply it. Not only did the home's indiscriminate banning of medication leave a resident in extreme distress, but it also disrupted the lives of the other 25 residents who were sharing the dining space.

This book will fill in such gaps, allowing professionals across the assisted living industry to better serve people with dementia. In this way, it is intended for a range of key decision-makers, including managers of assisted living homes, program directors of specialty units for people with dementia, directors of wellness or nursing, and state governing bodies.

Whether you are in the process of opening your first home or your 20th, whether you have a program for 12 people with dementia or 120, whether you are starting from scratch or have an existing building in need of refurbishment, it doesn't matter. This book has something that you can use to make your work more effective and that's presented in a way that makes sense.

To that end, the text is structured to parallel the building of a quality dementia care program from the ground up. Chapters 1 and 2 provide background on the brain, how it changes during the progression of dementia, and what behaviors can surface as a result. Chapters 3 through 10 comprise practical advice that, if followed, can help readers develop a turnkey dementia care program. And although the majority of the book focuses on developing approaches, processes, and procedures to best meet the needs of individuals who are far enough along in their disease process to warrant residence in a dedicated dementia program, Chapter 11 focuses on care for those who are still living in a traditional ALF environment.

All chapters feature “evidence from the real world”—a series of anecdotes pulled from my own experiences to illustrate how key principles have been applied in the field. (You encountered the first one on the previous page.)

Finally, the book ends with a library of nearly 20 interactive tools that can help organizations circumvent the painstaking process of developing operational instruments themselves, thereby allowing them to kick off or retool their dementia care program more efficiently.

As we venture out to set the standard for what effective dementia care looks like, some practices should be present in all ALFs to give people with dementia the basics of good care. If organizations commit to this project on their own, great. If state departments opt to design their survey questions around the principles in this book, even better.

Regardless of your vantage point, the information in this text will help you improve your understanding of dementia and modernize your approach to caring for the growing number of individuals living with the disease.

In today’s person-centered healthcare climate, assisted living professionals are at a crossroads. Will we allow the future of our industry to change around—even in spite of—us, or will we be instrumental in its evolution?

## Chapter 1

# The Brain: How It Works, and What Symptoms Occur When It Becomes Impaired

The brain is the most complex, powerful organ in the body. Weighing in around three pounds and roughly the size of two fists pressed together, it is made up of 100 billion neurons. Like the rudder of a ship, it is small compared to the rest of the body but has a huge amount of power. For this reason, when the brain is not working properly, the whole body feels the effects.

How does this relate to dementia care in assisted living? To create an effective program for folks with dementia, we must start at the very beginning. A very good place to start indeed.

Dementia is a general term that describes a group of symptoms (e.g., loss of memory, judgment, language, complex motor skills, and other intellectual function) caused by the permanent damage or death of the brain's nerve cells, or neurons. In other words, dementia is not a diagnosis, but the expression that something is not working properly in a person's brain.

The goal of this chapter and the next is to help readers better understand the connection between the invisible cognitive changes that stem from dementia, unrelated and reversible stimuli (e.g., symptoms from other conditions, unproductive interactions with peers and care partners) that are often conflated with these changes, and the very visible behaviors that can result from these combined influences. In this way, these early chapters lay the groundwork for thinking about dementia care in a different way.

This shift in approach is important for assisted living professionals because good dementia care is not a way of doing; good dementia care is a way of thinking.

In other words, in order to know what kind of carpets to lay in your building, what color to paint the walls, how to staff your program, or what activities to schedule, you must first recognize the specific needs of your clientele.

Yes, it is true that we need to do things differently for individuals with dementia. However, a baseline understanding of the disease—including the variations in progression and symptoms that can exist from person to person—will guide a care team toward making program adjustments that are grounded in observation and based on the needs of the organization’s specific resident population rather than on the blanket application of a single, decontextualized line of research.



## Evidence from the real world

Research suggests that some people with dementia may be frightened by their reflection in a mirror because they don’t recognize the person looking back at them. Yes, this can be true; I have seen it firsthand. But I have also seen hundreds of people with the disease who are unfazed by catching a glimpse of themselves.

While working as the director of an assisted living facility (ALF), I had a resident—let’s call her Margaret—who actually made friends with her reflection. She would stand at the mirror and talk with her image. “They” would laugh together, and when one was sad, the other would assume her expression. You see, Margaret saw her reflection as someone who truly understood her.

But dementia care professionals aren’t always as attuned to such signs as they should be, especially if these observations conflict with popular findings or approaches.

For example, a brand-new memory care ALF opened up in my community last year. When I visited the premises during an open house event, I noticed that in all the bathrooms, where there should have been mirrors above the sinks, there were instead posters with nice sayings.

Already suspecting the answer, I asked the staff member who had been showing me around, “Where are the mirrors?”

“People with dementia are afraid of their reflection, so we didn’t put them up,” she replied.

I suggested that she dig out the mirrors because people were going to be asking for them, and sure enough, she said that they already were.

With this tendency to overgeneralize in mind, let's talk about the elephant in the room. People with dementia often have a reputation for being tough to care for and for demonstrating "difficult behaviors." I acknowledge that these challenges do arise and, at times, for unknown reasons. But more often than not, an unsavory exclamation or tendency to hit when frustrated is an attempt by a person with dementia to communicate something meaningful—a need, a desire, a feeling—that he or she can't necessarily put the right words or thoughts to anymore. For this reason, it's important for us to be educated and willing to investigate the why behind an action, rather than chalking it up to an inevitable consequence of disease. In taking this approach, we can address undesirable behaviors at their root, which is often a reversible or preventable external trigger rather than an inherent aspect of a dementia progression.

When a care team adopts this new mindset of discovery and, in turn, translates it into tangible approaches like the ones delineated throughout this text, they can effectively dissolve the stigma that too often surrounds dementia, opening their organization to a broader pool of people to empower—not to mention a healthier census.

To help kick off this culture change, this chapter will explore the brain and how it works, homing in on the adverse behaviors that this organ can fuel when it is impaired and the tailored interventions that can mitigate those challenges.

Note, however, that Chapter 1 is not intended to be an exhaustive study of the brain. It's instead composed of accessible and focused discussion on the behaviors we often encounter when caring for people who have dementia, as well as insight into the motivations and reasons that underlie those behaviors.

Throughout the chapter, we will navigate the seven parts of the brain that are often affected by cognitive diseases processes and whose impairment can produce behavior-altering dementia symptoms, exploring the shifting role each holds in an individual's life as he or she progresses through disease. These parts are:

1. Frontal lobe
2. Temporal lobe
3. Parietal lobe
4. Occipital lobe
5. Hippocampus
6. Hypothalamus
7. Amygdala

## The Frontal Lobe

The front lobe, which is where an individual's personality develops, is responsible for the following:

- Reasoning (e.g., “If it is raining, I should bring an umbrella”)
- Making complex decisions
- Impulse control, or the ability to identify and act on the right thing instead of the wrong or inappropriate thing even when the latter option is more appealing
- Problem solving
- Providing motivation to take initiative

This lobe also enables a person to learn “executive functions,” such as the following:

- Managing time.
- Multitasking.
- Planning, organizing, and executing a project. A task as simple as paying a bill requires a person to keep track of where to find the bill, as well as when and how to pay it.
- Staying focused, or maintaining an attention span.

As this part of the brain becomes damaged, there are many changes that can occur in the person with dementia. Let's take a look at how these changes affect some of the functions and abilities described in the lists above.

### Reasoning and decision-making

Reasoning and decision-making go hand in hand. Naturally, then, if you struggle to use reasoning skills, making complex decisions will become more difficult. It's important to understand this because, otherwise, in an effort to keep residents safe and to help them help themselves, staff may unknowingly ask residents to use reasoning in a way that they cannot.

As the anecdote on the next page illustrates, people with dementia—like most people—often respond best when they are treated well and addressed as capable adults rather than babied and told what to do. In other words, someone with dementia will respond best to the following:

- Validation
- Solicitations of help, advice, or positive feedback about their helpfulness
- Requests—rather than demands—that these individuals try out a task or activity



## Evidence from the real world

Over the course of a few weeks, Steve, an assisted living resident who was still able to dress himself, developed a habit of wearing multiple button down shirts at once. Each time he entered the dining room for breakfast, staff noticed that he had on more than one shirt.

At first, no one tried to intervene because it was springtime, and it was unlikely that Steve would grow too warm. However, as summer approached, and Steve started going outside in the sweltering sun, staff became concerned that he would overheat. To encourage him to remove the multiple layers, one member said, “Steve, it is so hot outside. You are going to burn up. Let’s take away one of these layers.” Another told Steve that he was red in the face, and he must be sweating, so “take the top off.” These dialogues were fruitless and frustrating for Steve and the assisted living staff alike.

After a few days of this unproductive back and forth, one staff member said, “Hey Steve, I love that shirt—it’s totally my color. Do you mind if I try it on? You have great taste!” Steve happily obliged, feeling proud about his sense of style and eager to do something for someone else.

Table 1.1 offers some examples of how assisted living staff commonly phrase day-to-day directives related to the care of residents with dementia and how the same instructions can be reworded to promote more enthusiastic participation from these individuals.

<b>Table 1.1</b>		<b>Alternative Communication Approaches to Promote Resident Participation in Care Tasks and Activities</b>	
<b>Activity</b>	<b>Traditional phrasing of task directive</b>	<b>Alternative phrasing</b>	<b>The difference</b>
Going to the bathroom	“Your daughter is coming, so let’s go to the bathroom.”	“Let’s get cleaned up. You always love to feel good when your daughter comes.”	The second phrasing provides validation and helps the resident feel in control of his or her own life by positioning the activity as his or her personal preference.
Exercising or walking	“You have to walk so your knees aren’t stiff, and then they won’t hurt.”	“I know your knees are bothering you. Can we try to walk just a few steps?”	The second phrasing provides validation and minimizes the resident’s chances of becoming overwhelmed by favoring an incremental approach to the activity.

<b>Table 1.1</b>	<b>Alternative Communication Approaches to Promote Resident Participation in Care Tasks and Activities (cont.)</b>		
Hydrating	"You have to drink your water so you don't get dehydrated."	"Will you help me and finish up this cup of water?"	The second phrasing repositions the directive as a request for help.
Taking medication	"If you don't take your medication, you aren't going to feel better later."	"I know you don't like to take medication. I don't either, but you do say that you feel better after you take it."	The second phrasing provides validation and helps the resident feel in control of his or her own life by positioning the activity as his or her personal preference.
Going outside	"You need to go outside and get some fresh air because it is good for you."	"Will you be my company for a walk outside?"	The second phrasing repositions the directive as a request for help and companionship.

The overarching point illustrated by Table 1.1 is that you shouldn't assume or expect residents who have dementia—and the compromised reasoning ability that it often signifies—to fully understand why you want them to do something, or to necessarily agree. Therefore, instead of emphasizing the rationale behind a course of action that you wish the resident to take, present your case in such a way that will make him or her interested in what you saying. This tactic helps to minimize stress for staff and diffuse situations that can otherwise become very tense.

### ***The difference between having opinions and making complex decisions***

Another important distinction that Table 1.1 highlights is the one between exercising choice and making overarching life decisions. Although each of the situations described in the table positions a dementia care professional as the initiator and manager of the given activity, the phrasing of each alternative approach as a question affords the resident the opportunity to consent, thereby safely facilitating his or her autonomy.

Although it is difficult for a person with dementia to make a highly complex decision, he or she will almost always be able to have an opinion or say in the events that make up his or her days.

Complex decisions involve navigating many different potential courses of action (e.g., determining what to include on a shopping list and actually purchasing those items at the store). But simple

choices, which still empower the chooser with control, necessitate only the selection between one, two, or three options. In minimizing the number of options, assisted living staff create the space for people with dementia to independently make a good decision. For this reason, Julia can make the call when you ask, “Do you want to go for a walk or join in a sing-along?” Don can decide what he’d like to eat when you ask, “Would you prefer to have cereal or toast for breakfast?”

## **Impulse control**

When we are young, and just learning to talk and make sense of the world around us, we say some of the most unfiltered things. We comment that people look fat, or point to those who have a lot of tattoos. We don’t say these things to be mean but rather to remark on sightings we find interesting in some way. As we grow, and get reprimanded for sharing certain observations in public, we learn which of our thoughts should not be said out loud or to strangers because they can be offensive.

The same holds true if another child is playing with a toy that is appealing to us. We often try to grab it away on at least several occasions before we learn to ask nicely and wait until that child is finished to play with the toy ourselves.

This coached restraint is defined as impulse control, which we use throughout life to reign in impetuosity and comply with social norms. However, demonstrating this control doesn’t mean that we cease to experience those urges that compelled us to point or grab as children; we just learn to stop acting on them. But as the frontal lobe becomes damaged during the course of disease, the ability to control these spontaneous words and actions diminishes, and the affected individual often begins acting more impulsively.

## ***Use of hurtful language***

A person with dementia will often be quick to state what is on his or her mind—even if sharing this thought defies social conventions. For instance, he or she might pat a person on the belly and say, “Looks like you are getting fat,” or tell a staff member that he or she looks very tired. This resident may refer to a female staff member as a man because she has short hair or comment that there is a blemish on someone’s face when in fact it is a large birthmark. When considering these examples, it becomes evident that someone with dementia is not looking to insult anyone by pointing out their imperfections; they are just stating the obvious.

The staff members on the receiving end of these comments may feel offended, angry, or saddened by the words of the individual with dementia, but are they truly surprised? If not, then the reason that people are upset is probably because the resident has brought to light something of which they are painfully aware and that makes them feel self-conscious.

Taking this line of thought a step further, is it a fair assumption that the rest of the folks on the dementia care team have also noticed these things? Of course they have—they just haven’t

pointed them out because it isn't socially acceptable to do so. Nevertheless, we still observe and think things that might not be flattering about others.

The difference is that the gate, the trap, that prevents these words from floating out of our mouths is faulty in the brains of people with damage to their frontal lobe, which means that they often say exactly what they see and think in an effort to share these observations with others—not to be malicious.

For this reason, dementia care professionals should make a concerted effort to not take personal offense when a resident with dementia makes a hurtful (albeit truthful) comment. For example, if the individual says, "You have a big mark on your face," a staff member can respond by saying, "Yes, I've had it my whole life."

Lastly, people with dementia may draw from a bank of words that are more emotional and less cognitive when someone is facilitating an unpleasant task, like washing their private parts or sticking them with a needle. These derogatory words are not meant to hurt the individual instigating the activity as much as they are an attempt to defend against the perceived affront.

When a resident calls a staff member a derogatory name—an occurrence that, again, is usually isolated to times when the individual feels scared or embarrassed—it is not helpful for the professional to respond to the words. For example, if during a trip to the bathroom, a resident deems the accompanying staff member a "dirty, filthy, stupid pig who is good for nothing else than cleaning me up," the care professional should refrain from saying, "Don't talk to me like that." Why not? Such retorts are likely to result in cyclical conversations that produce unnecessary frustration for both parties. This is because, due to his or her disease-related memory impairments, the resident will probably forget the staff member's admonishment, and, due to his or her lack of impulse control, will likely resort to the same type of language the next time he or she perceives a threat.

Instead, the care team member can acknowledge the emotion behind the resident's outburst by responding, "I know you're embarrassed. Let's get this done quickly," or "I'm sorry you feel this way. I don't mean to upset you." By using empathetic language, the staff member validates the resident's feelings and avoids assuming a defensive, threatening stance that could stoke more forceful rebellion from the resident. In this way, he or she prevents the situation from escalating.

The good news is that impaired impulse control doesn't only give way to the revelation of hard truths and the voicing of tactless expressions; it can likewise inspire individuals to share positive thoughts that they may have otherwise held in like, "You are doing a great job," "You work really hard," "I love you," or "Thank you!"

### **Uninhibited actions**

In addition to promoting the use of language that flouts social norms, damage to the frontal lobe can cause residents to take food off another person's plate or pick up a jacket they see laying on the couch in the common room. These individuals may not understand that the jacket is not theirs, and their lack of impulse control means that they may not hesitate to take it.

Individuals with dementia may also become less critical of themselves as a result of frontal lobe damage, which is one of the reasons that hygiene loses priority for some residents. This change in perspective has its perks, often making people more willing to participate in activities that they might otherwise shy away from. For example, if your facility organizes an event with live music, the residents with dementia often happily get up and dance; if you host a sing-along, these individuals are apt to chime in quickly and loudly.

Although damage to the frontal lobe comes with a host of care challenges, it also gives residents space to try new things and be less fettered by their past comfort zones. In developing a dementia care program, this is a great benefit and can go a long way toward creating a sense of community.



### **Evidence from the real world**

While I was working in an ALF as an activity professional, a gentleman named Matt, who was a former New York City police officer, moved in. At the time, we were debuting a weekly painting project. When asked to join, Matt responded, "I'm a cop. I don't paint." But staff encouraged him to participate because the ladies loved having him around. Although he needed convincing before each new session, Matt eventually began painting every week.

### **Problem solving**

Problem solving requires at least three other frontal lobe skills:

- 1. Reasoning.** First and foremost, problem solving requires an individual to reason through a given issue, identify potential solutions, and weigh the pros and cons of each.
- 2. Multitasking.** In order to determine the best course of action, a person must be aware of the facts, which are often multilayered and must be considered all at once.
- 3. Decision-making.** Finally, after assessing all of these factors, the person needs to decide which solution to pursue.

As the frontal lobe and these central functions become damaged, it will become harder for people with dementia to solve problems alone. They may seem to obsess about one particular aspect of a situation. They may appear to ignore the input of others. However, neither of these is typically

true: Instead, these individuals may be responding reflexively to the flood of information they are facing, which their condition makes incredibly difficult to sort through.

For example, consider the seemingly simple act of putting on shoes, which involves many steps:

1. Locate and look at the shoes, which could necessitate opening a closed closet door or solving another overlooked obstacle
2. Weigh all available options to determine which particular pair to wear
3. Decide on appropriate socks or other hosiery—would sport socks, dress socks, or panty hose best complement the shoe selection?
4. Put on the socks
5. Put on the shoes, which includes navigating the various closures (or lack thereof), such as laces, Velcro, or slip on

When broken down into individual steps, the task of putting on shoes is less straightforward than it seems at first glance—especially for individuals who have trouble problem solving. Given the many decisions they must make, it makes sense that we often see residents without socks.

To help these individuals remain independent but also successful, staff can narrow the scope of their decision-making without removing the element of choice completely. For example, a dementia care team member can show a resident two pairs of shoes and ask which he or she would like to wear. This approach allows the individual to demonstrate control over his or her body and outfit without feeling overwhelmed by a huge decision. Staff can then pick out the socks that are most appropriate and leave them on top of the shoes for the resident to put on by him- or herself.

## **Multitasking**

It has often been said that people with dementia don't adjust well to change, which means that alterations to living arrangements, hands-on care staff, and room assignments should all be minimized. However, this assumption isn't quite accurate. A person with dementia is just as equipped as anyone else is to make changes. However, he or she needs more time.

Take, for instance, a person with dementia who has been living at home for many years, until he falls. After being sent to the hospital, he does a short stint in a rehab facility and is finally sent to an assisted living home—all in a span of two months. This translates to four living spaces in two months. The average person would have trouble with that. But most people are less likely to experience such frequent disruptions to health, routine, and living environment than people with dementia, who are at the same time dealing with changes in memory and reasoning that further complicate the adjustment process. For this reason, we need to give these individuals more time to adjust than a person without dementia would need.

## Recap of care approaches to accommodate frontal lobe damage

As the frontal lobe becomes increasingly damaged during the progression of dementia, residents will have more trouble in each area of function described in the previous sections. The best practice for the dementia care team is to assess on a regular basis what each resident can do and update their interactions and approaches accordingly. They should also focus on residents' positive actions—the compliments and loving gestures—while at the same time striving to become less sensitive to the things that aren't so nice. Lastly, enjoy this chapter of residents' lives with them, as it might be quite different from the ones preceding.

## The Temporal Lobe

The temporal lobe is involved in helping a person to understand what he or she hears. Our semantic memory—our recollection of key dates, places, and things—is stored in this area of the brain, along with important details on experiences that we gather throughout the course of life.



### Evidence from the real world

When Tabitha, who did not have dementia, learned English as a second language, she struggled to understand American idioms like, “Kill two birds with one stone,” which she assumed referred to a particular hunting tactic. Or, if someone said, “I’m sick and tired of this,” she would ask the person how she could help, figuring that he or she was actually feeling ill. Tabitha’s eventual mastery of these tricky expressions took place in her temporal lobe.

The temporal lobe also contains our hippocampus, which plays a huge role in forming new and long-term memories. We will address this part of the brain in more detail later in the chapter.

The temporal lobe is also the part of the brain that allows people to comprehend words, phrases, signs, and symbols that are presented verbally and visually. There are three main changes that people can experience when their temporal lobe is damaged:

1. Their usage and understanding of words differ from those accepted by the general public
2. They understand others perfectly well, but they aren't easily understood themselves
3. They know what they want to say, but they can't get the words together

Let's discuss each of these phenomena in more detail.

## **Their usage and understanding of words differ from those accepted by the general public**

Picture a dog. Tell a friend the animal's fur color, as well as its sex, size, ear shape, and tail length. Ask your companion whether you correctly described a dog.

One hundred people could potentially conjure 100 different breeds, but any general description would likely convince the average person that the animal in question is, in fact, a dog. That is because our minds have in a sense, a visual representation—and/or an emotional response—to go along with our words. All of this processing takes place in the temporal lobe.

For this reason, when a person has temporal lobe damage, he or she has trouble matching the “visual” to the “word.” We see this most during mealtimes. A waiter asks Joanie, “Would you like chicken or grilled cheese?” to which Joanie answers, “Grilled cheese.” But when the waiter brings the grilled cheese, Joanie responds, “I didn't ask for this.” Joanie was likely picturing something else when she said “grilled cheese.”

When talking with a person who has temporal lobe damage, the best thing to do is to show him or her what you are talking about. The waiter can show Joanie two plates and say, “Joanie, which one of these would you like?” Then Joanie can make a decision that isn't based on words, but rather on the tangible considerations of visual recognition and appeal.

In this way, the best intervention for residents with temporal lobe damage is to minimize reliance on words and instead use showing, modeling, and cueing as methods for empowering these individuals to participate in care tasks and make decisions. The following sections provide some examples of each approach.

### ***Showing***

Displaying two plates of food or types of drink for residents to choose between is more helpful than asking them verbally which option they would like without including the visual. For instance, holding up containers of orange juice and cranberry juice allows the person with dementia to process visual signs of each and to make a choice that he or she is happy with. Facilitating the individual's successful participation in this decision can in turn reduce the burden that falls on staff when residents refuse or switch their original selections.

### ***Modeling***

Similar to the game Charades, staff can act out what they want residents to do when words begin to lose their meaning. If a care team member wants a resident to brush his or her teeth and the individual doesn't appear to understand the request, the staff member should stop talking and use his or her finger to imitate brushing his or her own teeth. When words are no longer helpful, miming actions becomes a great replacement tool.

## **Cueing**

Using cues instead of words can help a resident with dementia navigate his or her home environment and recall important aspects of his or her life. For example, instead of printing the name of a resident's daughter next to her phone number, tape a photo there. Similarly, consider replacing or supplementing the nameplate on a resident's door with a picture of him or her, perhaps from an earlier and more memorable period of life.

As illustrated by these approaches, if a resident struggles to understand what you are saying, you should recognize that words are no longer helpful and seek other ways to communicate.

## **They understand others perfectly well, but they aren't easily understood themselves**

Some people with temporal lobe damage can understand others pretty well, but their communications come across as garbled. For example, certain individuals may fluctuate their tone of voice as anyone would when speaking at length during a conversation but instead of voicing a comprehensible thought, put forth a string of variations on a single word, such as “thing, the thingy, the thing-ity”—a disconnect that highlights their intention to communicate more than their words suggest. Others diversify their words and structure sentences in a more conventional fashion, but they still produce utterances that hold little meaning to others: “The blue chipmunk was on the train with the pizza in the park.” This sentence communicates something, but exactly what is unclear.

When communicating with people who are experiencing such verbal changes, it is important to respond to their body language. If a resident is happy, smiling, or laughing, then staff should respond happily. If the individual is upset, staff should be comforting. If he or she is angry, staff should look concerned and sympathetic.

Here's the other catch: This person, with all of his or her personal communication challenges, is likely still very much able to understand what others are saying. It is so important that staff recognize this distinction. Otherwise, they may conflate verbal challenges with comprehension shortfalls and treat an individual who has only the first impairment condescendingly or dismissively—a misstep that serves to further frustrate, upset, or anger the resident.

In the example on the following page, Lee's attentiveness toward Linda illustrates how important it is for staff to communicate with residents verbally, even if they aren't quite sure what an individual is saying. The more that a care team member listens to the people whom they serve—both verbally and by observing body language—the more effectively he or she will facilitate a meaningful exchange, not to mention forge a deeper connection, with this population.



## Evidence from the real world

Linda, an assisted living resident, verbally communicated very confidently. She sat up straight in her chair and participated in discussions, laughing at times, looking at who was talking, and even throwing out some short one-liners. She would also dominate the conversation when she had a lot to say.

But many times, no one knew *what* exactly Linda was saying. Her words were all over the place.

Eventually, those Linda was speaking with would zone out and sometimes even whisper to each other right in front of her, prompting her to stop talking. These exchanges were awkward for everyone. But that was before Lee, a personal care assistant, came into the picture.

From the moment that Lee started working with Linda, he really listened to what she was saying. After realizing how chatty she was, Lee also conversed with her regularly, allowing physical indicators of her mood to guide the conversation when he was having trouble understanding the meaning behind her words.

Through the simple act of paying attention and engaging Linda on a human level, Lee soon learned that Linda was very aware of how she was treated and felt terrible that her attempts to connect with others instead made them uncomfortable.

### **They know what they want to say, but they can't get the words together**

We all know that feeling of a word being “on the tip of the tongue.” This is exactly what communicating can feel like for residents who struggle to find words due to temporal lobe damage, but it happens on a much more regular basis. We also know how unhelpful it is when someone tries to spark our memory with lots of suggestions. What we need instead is to have a moment for our brain to relax and pin down the elusive thought.

The same is true for people with word-finding problems linked to their dementia. The best thing to say to these individuals during their mental hunt is, “I am right here. Let me know when you think of it.”

This approach takes the pressure out of the situation and lets the person's mind relax a bit. If you actually think you know what a resident is referring to during one of these events (e.g., a desire for more coffee with breakfast), then there is no problem asking (e.g., “Did you want more coffee?”). You can also ask the person to show you (e.g., by pointing to a nearby coffee pot), a

request that allows the individual freedom to communicate his or her needs independently, if not in the most traditional fashion.

When gesturing isn't an option, you can also try to supply the resident with a suggestion or two. Any more than that can upset the speaker. In fact, folks with this type of impairment tend to talk less and less not because of their disease, but because of frustration stemming from their inability to get their point across. It is important for the care team to help mitigate this frustration, which can extend beyond communication attempts and into daily activities.

Staff members can accomplish this aim by demonstrating sensitivity and empathy while at the same time encouraging residents to continue speaking as long as they can. The longer that residents can verbally communicate their thoughts, the longer that they will feel independent and able to connect readily with the people in their life.

Lastly, in an effort to get across his or her thoughts, a resident may say something that doesn't make sense when taken at face value but does make sense when considered in a broader context.



## Evidence from the real world

Lucy, an assisted living resident with dementia, often struggled to get her words out. One day, she worked hard and finally exclaimed, "The pear, the pear," prompting the care team to bring her fruit. Lucy wasn't satisfied. Staff figured that she just wasn't making sense and dismissed her. But later that day, Lucy's family showed up, including a set of twins (the pair).

As Lucy's story illustrates, a resident may sometimes only be able to come up with an approximate or less popular term for the message he or she is trying to convey. Listening and trying to understand the individual's perspective in these cases is extremely important.

## Recap of care approaches to accommodate temporal lobe damage

There are three different communication changes that occur most commonly in residents who have temporal lobe damage. These patterns don't make communication impossible but do require assisted living staff to change how they approach and interact with these individuals.

## The Parietal Lobe

The parietal lobe is responsible for our awareness of the space around us. Think of what it was like to drive before the advent of GPS: You had physical landmarks that helped you get around. Now, if you use your GPS, you may be much less aware of these signs because you aren't forced

to notice them; your device will reroute you if you drive past the big yellow barn that used to cue you to take a right-hand turn.

Similar to how reliance on GPS technology can diminish your familiarity with your surroundings, parietal lobe damage can hinder a person's ability to recognize where everything fits into his or her life. The parietal lobe brings the world into three dimensions. When it isn't working properly, depth perception can suffer. This can cause an affected person to trip on stairs (because they don't recognize the different heights) or stumble when walking outside (the sidewalk and street appear to be level with each other).

### **Implications for mealtimes**

In assisted living, parietal lobe damage often comes into play when residents are eating. If there is little contrast between the plate and tablecloth (e.g., both are white), an individual may not see where the plate ends and the tablecloth begins, finishing his or her meal with a lot of food around the plate and creating the impression that he or she requires additional dining assistance. But if the facility instead swapped the white plates for a bright red variety that stood out against the white tablecloth, this resident would immediately demonstrate more independence, registering the border of the plate and keeping his or her food better contained.

### **Implications for using the bathroom**

Another area of the assisted living facility where the effects of parietal lobe damage surface is the bathroom. Bathrooms are often painted white, with white floors and white fixtures, a design scheme that can be very confusing for residents who have trouble with perceiving dimensionality. Male residents in particular will often use the garbage can instead of the toilet because it is a round, open space in the bathroom. Replacing white toilet seats with ones in a contrasting color can minimize this issue. Removing the garbage can wouldn't hurt, either.

### **Implications for numerical comprehension**

The parietal lobe is also responsible for helping us process numerical values and situations, especially those related to time and money.

A person with dementia may retain the ability to add or subtract but experience waning recognition of numerical values. For this reason, staff should rethink how they engage residents in number-based situations, such as when they relay event times to residents and attempt to help them understand how much money they have on hand.



## Evidence from the real world

Jill, an assisted living resident with dementia, was always worried about what time her daughter would come to visit her. She knew that she saw her daughter regularly but was often hesitant to get involved in the facility activities she loved because she didn't want to miss her daughter's arrival.

At first, the care team responded to Jill's repeated questions about when her daughter would visit by saying some variation of, "She is coming at 5:00 pm for dinner. It is only 11:00 am now, so you have all day." Each time Jill asked for a subsequent update, staff would respond in this vein, relaying a specific time that Jill could expect to see her daughter, not realizing that Jill couldn't grasp how this intangible numerical value corresponded to the actual events that made up her days.

Eventually, staff realized that Jill needed reassurance that she would get to visit with her daughter more than she needed a specific time frame, and began to tackle Jill's questions from a different angle, saying, "Jill, I promise that when your daughter comes to visit, I will get you immediately. I know how important it is to you to see her, and I will make sure that happens." Jill was much more satisfied by this new approach, which used phrasing that made sense to her and showed her that the ALF team also viewed her daughter's visits as the priority they were.



From the time George started earning an allowance, he never left home without his wallet. Even after he moved into an assisted living facility in his early 90s, keeping his wallet in his back pocket was still very much a part of George's daily routine.

However, when George first joined the ALF, staff there suggested his family empty this signature wallet to avoid incidents of lost or stolen money. But, every time George opened his wallet after his family had complied with this recommendation, he became very upset, stating that someone had stolen his money.

George was particularly vexed by this apparent theft because he had always been a great tipper and was continually humiliated to find, at the end of a meal in the ALF dining room, that he had no money with which to "tip" the wait staff.

Eventually, staff arrived at a solution that would protect George's hard-earned money while allowing him to preserve his dignity and sense of propriety. Staff directed George's family to put 15 dollar bills in his wallet. While his appreciation for the value of the money had changed, he was sure to recognize a wad of cash when he saw one. Staff were then directed to return any tip money George left after meals to management so they could replenish his wallet. The strategy worked, restoring George's confidence and sense of security.

## Implications for reading comprehension

Similar to the targeted declines residents with dementia may experience in the numbers realm, these individuals may continue reading well into the disease process but begin to have trouble understanding the bulk of what they read.



### Evidence from the real world

Thomas, an ALF resident with dementia, read his newspaper without fail every morning, finding satisfaction in the rote and familiar act, even as his ability to comprehend the information in the articles diminished over time. Despite this obvious limitation, the care team recognized the joy Thomas got from reading the paper was far more important at that point in his life than his comprehension of its contents and ensured that he continued receiving a copy every day.

## Implications for other aspects of life in the ALF

The challenges residents with parietal lobe damage face can extend far beyond a specific room or activity, affecting many different aspects of daily life. These individuals will be more likely to misjudge where the edge of the chair seat is and end up on the floor. They may regularly bump or walk into things because their ability to assess the space around them is impaired.

For these reasons, damage to the parietal lobe requires ALF providers to make environmental changes that allow affected residents to function more independently. Keep in mind the old adage “out of sight, out of mind” when initiating these steps.

For example, because similar coloring can make unlike objects that are in close proximity to one another appear “flat” or blended to individuals with parietal lobe damage, painting the facility exit doors the same color as the neighboring walls can minimize the attention that residents pay to this area—and the chances that they will attempt to leave the building against staffs’ wishes. By this same logic, providers should consider designing spaces that they want residents to engage with—such as the doorway to the dining room or the secure, outdoor courtyard—with big, bold architectural elements and bright colors that contrast with surrounding areas.

## The Occipital Lobe

The occipital lobe interprets and makes sense of what the eyes see. When this part of the brain is damaged, a person may have trouble interpreting what they are seeing, meaning that he or she may be looking straight at a favorite sweater in the closet but do not recognize it as the article of clothing for which he or she has been searching.

In addition, research shows that, like individuals with dementia, those with damage to the occipital lobe may experience visual hallucinations. The number of people with dementia who also have occipital lobe impairment remains unknown, but it is not uncommon for a person with dementia to experience hallucinations at some point during their disease process. It is unclear, however, whether the hallucinations in individuals with dementia stem from damage to the occipital lobe or a change in a different area of the brain.

The best way to respond when a person with dementia describes something that is not real is to provide validation. If Ginger is fed up with “the kids who won’t stop yapping” in the next room, offer to ask them to quiet down (and follow through if Ginger responds favorably to your proposition). Successfully getting the children to be quiet is a moot point; there are no children, and the noise is not real. What’s pivotal here is that you are validating Ginger by acknowledging that her emotional response, while triggered by a hallucination, is itself real and doing what you can to help her.

Beyond hearing phantom noises, another common hallucination among residents with dementia involves a stranger coming into their room at night. Rather than denying the occurrence of the event, staff should simply say, “Wow, I am sorry that is happening. Does it bother you?”

Again, because the episode is not real, you don’t have to take active steps to fix it, but you should gauge how the experience affects the individual’s emotional state. If it does bother the resident, assure him or her that you will ask staff to keep an extra close eye on the room at night.

Finally, there are many times when a person with dementia may not interpret what is happening around them realistically but will remain convinced that they are.



## Evidence from the real world

Tina moved into an assisted living home and, as any good Italian lady would, adorned her room with lots of tchotchkes and framed photos of her family. As she moved these keepsakes around on the bookshelves and lifted them up to show staff, some began to break, spraying glass shards and wooden splinters across her floor.

In an effort to keep her safe and preserve her belongings, Tina’s family was asked to remove the items, which they did during a visit a few days later while Tina was away from her room. When she realized that the decorations were gone, Tina became convinced that someone had stolen them. Eventually, she began to accuse the housekeeping staff of taking her belongings because they went into all the rooms and exited with “big bundles.”

From Tina’s perspective, this conclusion made total sense. Overnight, her most cherished possessions went missing, and she saw people who were taking things out of people’s rooms.

It is important for staff to acknowledge residents' theories and analyses surrounding events that affect their lives. Even if these perceptions are flawed, they are often grounded in some kind of discernible logic around which interventions can be built to alter interpretations and improve the overall quality of life for people with dementia. In Tina's case, her family returned her belongings, with the understanding that they could become damaged. To preserve her safety in such an event, staff checked the room each morning while getting Tina out of bed to see if anything had fallen, broken, or seemed to pose a danger to her.

## The Hippocampus

The primary functions of the hippocampus are long-term and new memory formation, as well as the classification (or organization) of information.

Similar to the hard drive of your computer (or nowadays, the cloud), the hippocampus stores a lot of information in different files and folders.

Back on the hard drive, you not only have files that you have intentionally saved, but those that the computer has stored temporarily, or "autosaved," such as working documents in your word processing program whose most recent changes may have otherwise been lost when your laptop shut down unexpectedly.

Our brain does the same thing. If you go for coffee with a friend, and she gives you all the juicy details about what is going on in her life, you will remember a lot of this because you are, in a sense, purposefully storing the data. But, if while you are listening to her, it suddenly occurs to you that you need to pick up a carton of milk, and you actually remember to buy that milk during your stop at the store on the way home, you retrieved this information from your temporary files. This was your hippocampus at work.

When the hippocampus is damaged, it is hard to create new memories, which is why people affected by this impairment will repeatedly ask the same question and wrongfully accuse family members or staff of failing to tell them something (e.g., the time of a doctor's appointment) that they have been informed of many times. Contrary to our first impulse, repeating information in a loop and attempting to convince people that we have in fact shared this data is unproductive. If the brain is impaired, we need to take a different course of action altogether.

To help someone who is losing the ability to remember, care staff should:

- **Write things down.**
- **Avoid arguing if the resident claims you didn't tell him or her something.** Simply apologize and agree that it is frustrating when you are not told things in advance. Assure him or her that you will try to do a better job next time.

- **Avoid telling the resident things that will cause him or her anxiety too far in advance.** This person might forget the information and ask about it more frequently, becoming upset anew with each reminder. This cyclical anxiety can be avoided by telling the individual pertinent information closer to the time of the occurrence in question. For example, tell Larry about his upcoming doctor's appointment the morning of the event, or a couple hours in advance, rather than the night before.
- **Help the resident cope with the realization that he or she is losing memory.** Most people recognize when they are beginning to forget more frequently. Whether they choose to admit it is another story. Some people are open about their memory lapses, others do their best to conceal them, and still others direct the blame elsewhere (e.g., "You never told me that"). Staff should adapt their care and conversation approaches according to each resident's specific coping strategy.
  - » *For residents who acknowledge their declining memory,* engage them in a conversation about the experience. Ask them how they feel about it. Some won't be bothered; others will be anxious. Rather than responding with tired clichés, assure these individuals that you are on their side and are here for support. Also offer to help them find any additional assistance desired.
  - » *For individuals who prefer to conceal memory lapses,* let them. If they let their guard down and admit they are having trouble, simply align yourself with them, letting them know you care about them and are happy to help them in any way you can. Also offer to help them find any additional assistance desired.
  - » *For those who choose to blame others,* just accept it. Arguing with them will only add fuel to the fire. They are blaming you, not because they think you are a bad person, but because it is their way of coping.

The good news is that damage to the hippocampus does not affect the memory associated with the ability to learn new motor skills, sometimes referred to as "procedural" or "muscle" memory. This is why it is so important for care staff to keep residents as involved physically in their personal life as possible. Walking, zipping jackets, buttoning buttons, using utensils, brushing teeth or hair, and singing are all examples of procedural memories. The longer and more frequently residents practice these actions, the longer they will retain their ability to do so.

Furthermore, if, upon a resident's move to the dementia care program, staff realize the individual hasn't been practicing these skills regularly, they can often help him or her relearn certain aspects. The icing on the cake is that residents can also learn skills they never knew prior to their diagnosis, such as how to count in a new language or dance a new step.

# Serving Residents With Dementia: Transformative Care Strategies for Assisted Living Providers

Kerry C. Mills, MPA

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Assisted living facilities (ALF) have historically been governed by disparate regulatory structures and have consequently experienced a lack of connective care standards. But as the industry continues to grow rapidly, attract the attention of federal regulators, and cater to an ever-expanding population of Americans with dementia, ALFs that want to remain competitive must heighten their focus on providing individualized, transformative care using consistent, compliant strategies—actions that can often be hard to coordinate if not approached with the proper tools and mindset.

***Serving Residents With Dementia: Transformative Care Strategies for Assisted Living Providers*** is a dynamic and comprehensive manual that addresses these critical considerations. Written in an engaging conversational style and infused with numerous anecdotes from the author's own international experience as a dementia care partner and pioneer, this book empowers key decision-makers across the assisted living sector with the guidance, processes, and tools they need to develop a dementia care program that's robust enough to accommodate the diverse and evolving needs of residents in all stages of disease progression.

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