



Caring for a Loved One with Dementia

Dementia Caregiver's Guide

Interim
HEALTHCARE®
First in Home Care™

When Someone You Love Has Dementia

For every individual who suffers from dementia, there is a caregiver by their side, struggling along with them. As the life they always knew becomes increasingly unfamiliar, caregivers do their best to ease their anxiety and help them cope with the unexpected changes and confusion they are experiencing.

Our Dementia Caregiver's Guide provides valuable insight, resources and advice for those caring for a loved one living with dementia. The journey you are on is hard, but you're not alone. At Interim HealthCare[®], we're committed to helping you find the strength and support you need to be the compassionate caregiver they need.

Table of Contents

You Are Not Alone	4
What You Need to Know About Being a Caregiver	4
Your First Priority as a Caregiver	4
Don't Be Surprised By Negative Feelings	4
Care for the Caregiver	5
What You Need to Know About Dementia	5
What Dementia Is ... and Isn't	5
The Beginning Signs of Dementia	6
How Can You Be Sure It's Dementia?	7
Uncovering Dementia	8
How Dementia Affects Vision	9
Dementia Care Do's and Don'ts	10
A Proactive and Positive Approach® to Care	12
HomeLife Enrichment®	12
Adopt a CAN DO Attitude	12
It's Not Your Fault.	12
Caregiver Tip: Hand-under-Hand™	13
Understanding GEMS® States and How It Impacts Your Loved One	14
What are GEMS® States	14
Identifying the GEMS® States	14
HomeLife Enrichment®: A Holistic Approach to Care	16
Stimulating the Mind	16
Strengthening the Body	16
Uplifting the Spirit	16
Engaging the Family	16
You Don't Have to Walk this Road Alone	17
A P P E N D I X	
Caregiver Tips: Nutrition and Hydration	18
Caregiver Tips: Nutrition Guidance by GEMS® States	21
Caregiver Tips: Art Time	26
About Interim HealthCare	27

You Are Not Alone

Today, there are an estimated 5.6 million people living with age-related dementias in the United States and nearly 16 million people caring for them. It's a challenge many more of us will face, as either patients or caregivers, as the population ages. The diagnosis of dementia is life changing, both for the people living with it and those who care for them.

Dementia is complicated. It can affect all of the senses. It can impact memory and comprehension. It can cause anxiety, fear, and often, mistrust of other people, including caregivers. Knowing what your loved one is experiencing at each stage of dementia will help you keep them safe, comfortable and meaningfully engaged. It will also give you understanding into their condition and responses which will help you cope.

Caring for a loved one living with dementia is not easy, but we can shed light on issues that make it easier to understand. This guide for dementia caregivers was designed to provide you with the knowledge you need to care for them; insights about how it affects you and your loved one; and practical steps you can take to manage your role as a caregiver.

What You Need to Know About Being a Caregiver

Your First Priority as a Caregiver

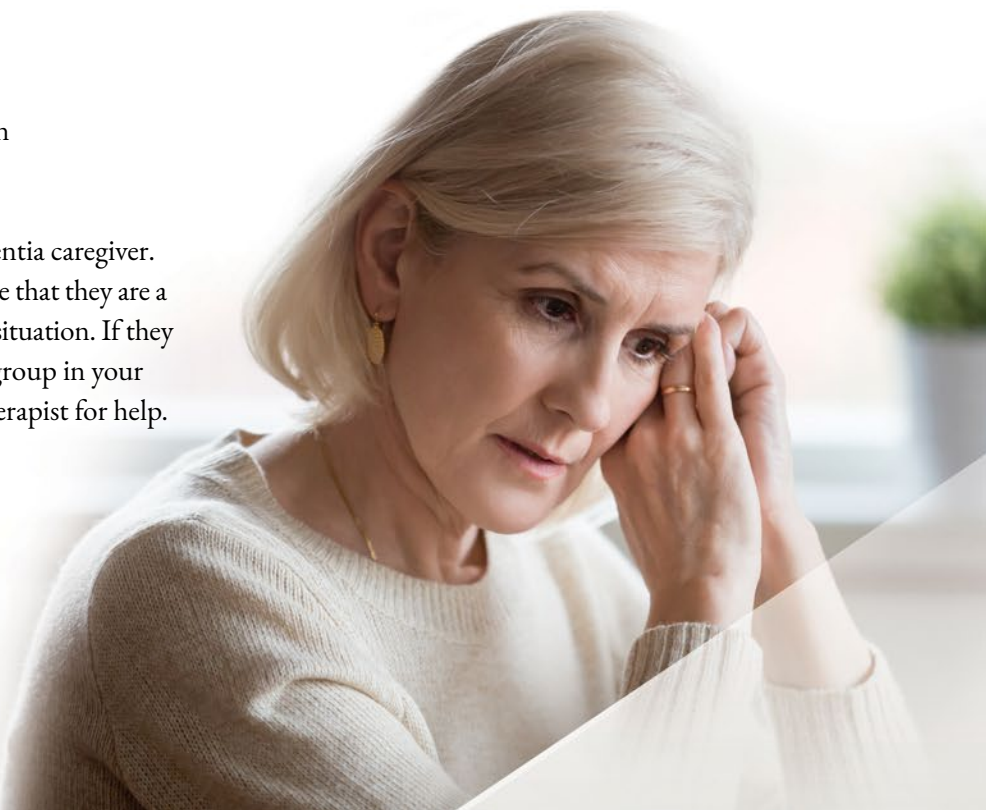
The first person any caregiver needs to care for is themselves. When you become a caregiver, you assume a responsibility that can be physically, mentally and emotionally draining. Being a caregiver may strain your patience, your finances and your time. It can lead to a range of feelings that can be, at a minimum, uncomfortable, and in the extreme, unhealthy.

Don't be Surprised by Negative Feelings

Caring for someone with dementia can take you for a ride on an emotional rollercoaster. Even the calmest individuals can experience a range of negative emotions. You may feel:

- Overwhelmed
- Depressed
- Desperate
- Trapped
- Angry
- Frustrated
- Confused
- Isolated
- Alone
- Guilty
- Grief-stricken

None of these feelings are unusual for a dementia caregiver. The best way to handle them is to acknowledge that they are a natural reaction to a stressful and challenging situation. If they persist, reach out to an Alzheimer's support group in your community, a family physician, clergy or a therapist for help.



Care for the Caregiver

Be a healthy caregiver. Take care of yourself, so that you can take care of your loved one.

DO:

- Join online or local community groups that can offer support and encouragement
- Build a strong support system of people who can help you and your loved one
- Barter time with others to ensure some free time just for yourself outside of the home, at least monthly
- Research [respite care](#) options
- Keep your medical appointments
- Maintain a healthy diet
- Exercise daily
- Get plenty of sleep
- Participate in hobbies and leisure activities when you can
- Ensure all legal and financial papers are in order, e.g., Power of Attorney
- Incorporate time in your day for things that bring you joy

DON'T:

- Neglect your own health
- Eat on the run
- Isolate yourself
- Let friendships falter
- Ignore other relationships
- Blame yourself or your loved one because of the disease
- Feel guilty for wanting a break
- Stop participating in things you enjoy
- Lose your temper
- Waste time reasoning or trying to convince your loved one of something
- Feel ashamed

What You Need to Know About Dementia

What Dementia Is ... and Isn't

Dementia is not a specific disease. It is an “umbrella” term that the [Alzheimer's Association](#) describes as “a group of symptoms associated with a decline in memory or other cognitive skills severe enough to reduce a person's ability to perform everyday activities.” The specific disease most frequently associated with dementia is [Alzheimer's disease](#). It accounts for 60 to 80 percent of all dementia cases. The second most common dementia type is [vascular dementia](#), which occurs when vessels supplying blood to the brain become blocked or narrowed. This can happen after a stroke, but not always. There are several other types of dementia that impact cognitive function, but they are far less common.

Dementia is not exclusively linked to age. Although it has often been referred to as “senility” or “senile dementia,” this reflects an inaccurate belief that serious mental decline is a normal part of aging. It is not.

The Beginning Signs of Dementia

Most people associate dementia with memory loss, but there are other overt signs that signal the early stages of dementia. These include:

- Speech and comprehension issues
 - Struggle to remember words, especially nouns
 - Difficulty putting a sentence together
 - Inability to understand what is being said, leading to responses of “huh” or “what?” (Reactions like these are often mistaken for a loved one being hard of hearing, but in reality, they simply are not catching and processing every third or fourth word.)
- Decline in hygiene
- Visual changes
- Lack of social awareness
- Trouble shopping
- Susceptibility to scams
- Anxiety about change
- Desire to stay at home and refusal to attend social events
- Difficulty starting a task and sequencing steps to complete it
- Locational miscues that can lead to getting lost while driving and traveling hours away from home



The Beginning Signs of
Dementia

How Can You Be Sure it's Dementia?

Regardless of age, we all have moments of forgetfulness at some point in our lives. So how can you be sure if someone you care about has a more serious issue? According to [Harvard Health Publishing](#):

Probably Normal Aging
They sometimes search for words.
It takes them a little longer than normal to complete tasks at work, but they can still finish them.
They can't find their car keys.
They need to focus a little more on conversations in a noisy environment.
They lose their temper a little more easily during an argument.
They misplace their house keys from time to time.
They forget what they ate for dinner last night, but they remember as soon as someone gives them a hint.
They have trouble deciding which entree to choose at a restaurant but ultimately make a choice.
They drive a little slower.
It takes them a little longer to answer the phone.

It's Time to Talk to a Doctor
They use the wrong words—"stove" instead of "table," for example.
They struggle to perform their job responsibilities.
They have trouble following a series of steps or instructions.
They can't remember how to drive.
They can't follow conversations at all when there is background noise or other distractions.
They scream, sometimes for no reason.
They always seem to be losing their keys and other everyday items, and they turn up in strange places—such as the refrigerator.
They forget what they ate for dinner last night, and no reminders can jog their memory.
They find it impossible to decide what to eat, choose what to wear or make other daily decisions.
They're very slow to react behind the wheel, and they often miss stop signs or red lights.
They don't acknowledge a ringing phone, nor the need to answer it.

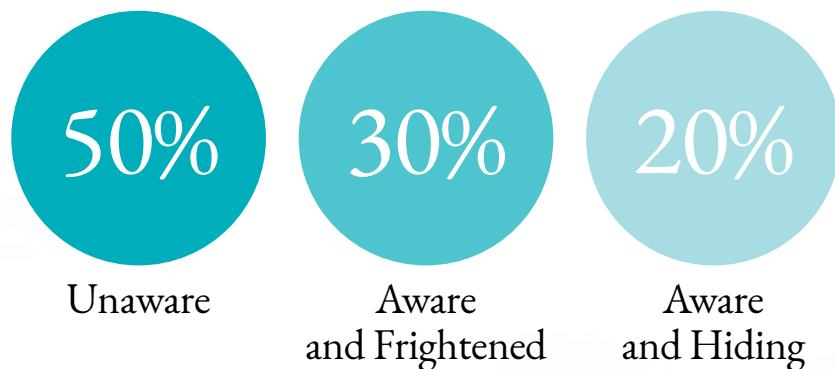
Uncovering Dementia

Unlike an upset stomach or a sinus infection, it's not always easy to recognize the early signs of dementia. Nor is it easy for people with dementia to acknowledge increasingly troubling symptoms. Those experiencing signs of dementia tend to fit in one of three categories:

1. **Unaware.** Half of people with dementia have no idea they have a problem. They do not recognize any deficits. If you point out an irrational or unsafe behavior, they may get extremely agitated or angry. These are the folks who will miss a road sign and drive miles out of the way. When they are “rescued,” they will insist the sign wasn't there, so they kept looking for it. They are not lying ... they really don't realize anything is wrong.
2. **Aware and Frightened.** Another 30 percent realize they are losing skills and are frightened by it. They know their memory is faulty. They hover over those they trust, clingy and highly nervous about upsetting or losing the people they know. They search for the skills they know they have lost. If you tell them you are going to do something at a certain time, do it. They get upset when things don't happen as promised. These folks can be overbearing and tend to quickly wear out a single caregiver, so it's good to introduce them to a team of people who can support each other.
3. **Aware and Hiding.** The last 20 percent are those who realize they are losing skills and don't want anyone to know, so they try to hide it. They might leave things like their mail out on a table to ensure they don't forget something, but as they keep piling items up in their homes, they still don't get things done. They often opt to stay home or away from people, because they don't want anyone to know about their deficits. And, they have a tendency to fire caregivers for this reason.

It is important to understand how loved ones are responding to symptoms of dementia, so that you can support them appropriately.




Three Responses to Dementia



These stats are sourced from Teepa Snow's Positive Approach® to Care educational materials.

How Dementia Affects Vision

One of the most significant changes you will notice in someone living with dementia is the fact that they cannot see as well. That is because dementia impacts peripheral vision, gradually diminishing it further and further as the disease progresses.

Change in Vision	Scuba Vision	Binocular Vision	Monocular Vision
			
When It Happens	EARLY STAGES	MID-STAGE	LATE STAGE
How It Affects Vision	Scuba vision blocks peripheral vision in the same way a scuba mask would restrict side views. It can be dangerous to drive with this handicap and difficult to walk (because you instinctively want to look at your feet instead of what's in front of you).	Binocular vision narrows the focus for each eye, creating what is called "social vision." It restricts the ability to see most things out of a direct line of sight. It also affects depth perception. This is why a person with dementia may eat food from a plate across the table rather than their own; they cannot see their own plate, unless they look down.	Monocular vision creates a sense of tunnel vision, with a severely restricted field of view. Even though it is so difficult to see the world around them, remember, your loved one's eyes will serve as their primary means of processing data.
Advice for Caregivers	Assume the driving duties and offer an arm for walking support.	Always approach from the front or side, rather than the rear, because you may startle them. Place objects they need, whether a plate or cup at meals or toiletries for daily grooming, directly in their line of vision.	At this stage, your loved one will need assistance with most activities of daily living. To communicate, be sure to position yourself directly in front of your loved one.

Positive Approach® to Care techniques, strategies, and overall approach to care were created, developed and are copyrighted by Teepa Snow and Positive Approach, LLC. © 2006-2021.

Dementia Care Do's and Don'ts

DO

DO:

- Be the calming constant for the person with dementia to temper their anxiety
- Be present in the moment with your loved one
- Encourage conversation and laughter; it may be slow in coming but don't give up
- Use your hands when talking to show actions, because words may not be enough
- Enjoy music, rhythm, dance, prayers and poetry together
- Walk along with them when they wander; they may have a need but are unsure how to meet it, e.g., they may want to find their bed, get a drink or go to the bathroom but cannot verbalize it
- Offer choices but limit them to just two at a time
- Help them get started with a task (because sometimes they forget how to start)
- Find friends, family and caregivers that they like to be around; it takes a team
- Let others take over care sometimes, so you can refuel yourself as the main caregiver
- Encourage drinking water and other liquids; dehydration is a problem
- Ensure a safe environment when your loved one is unaware of hazards, e.g., loose rugs, inadequate lighting, electrical sockets
- Ensure your loved one can swallow foods without choking; choking can indicate a need to change food textures to remain safe
- Understand that your loved one is going to change ... they are still the same person, but different
- Understand that you cannot grieve for your loved one in front of them; they are anxious and do not understand; be the positive and calm in their life
- Learn to say, "I am sorry; this is hard" and de-escalate their anxieties when they get upset; it's kinder and more respectful, so you both can move on

DON'T

DON'T:

- Attempt to reorient your loved one to the present, if they are in another time and place
- Feel guilty when you must stretch the truth to accommodate a potentially stressful or confusing situation
- Mistake dementia for stupidity; your loved one isn't stupid; they are just living with dementia
- Hesitate if it's time to take the keys away; your loved one would take them from you if your positions were reversed
- Feel selfish for taking time for yourself away from your loved one
- Expect your loved one to start following your directions if you weren't someone who gave them directions before; know that you may get your feelings hurt
- Be frustrated when your loved one cannot complete an activity today that they could do yesterday; sometimes each day is different
- Argue over trivial matters; understand what is happening and just let it go
- Change topics too quickly; your loved one is behind in processing what they hear, so they will respond slower and struggle to keep up
- Feel angry when your loved one swears or uses inappropriate words; they are using the abilities they still have
- Ask open-ended questions that require a specific answer; instead of "What do you want to drink?" say, "Would you like a hot or cold drink?"
- Speak in "baby talk" or high-pitched tones; use a calm, deeper version of your voice to reduce anxiety
- Tell a person living with dementia that someone they are looking for is dead; they will relive the grief each time. Many patients will ask, "Where is my mother?" Instead of saying she has passed, say "tell me about your mother" and give them the opportunity to talk about how that person made them feel

A Proactive and Positive Approach[®] to Care

HomeLife Enrichment[®]

For more than 50 years, Interim HealthCare has been a source of strength and stability to individuals with cognitive issues and other health conditions. As the nation's first home care company, we understand what it takes to care for someone living with dementia. It is not a static state, but rather an evolving journey for the patient and their caregiver. At Interim, our goal is to make that journey as personally engaging as possible. Our HomeLife Enrichment[®] signature standard of care was designed with that premise in mind. This holistic approach to care thoughtfully engages the mind, body, spirit and family to provide an optimal experience that enriches the lives of others. For those living with dementia, it is perhaps the most compassionate care there is.

Adopt a CAN DO Attitude

At the heart of HomeLife Enrichment[®] is a desire to care for the whole individual, not just one part. By nurturing every aspect of their being, we help patients live a more meaningful and enriched life. Founded on this holistic approach to care, our Cognitive Care Program addresses the specific needs and concerns of dementia patients and their families at each stage of the disease.

To provide the most supportive environment possible, our caregivers and clinicians follow are educated in the [Teepa Snow Positive Approach[®] to Care \(PAC\)](#) model. One of the leading experts in dementia care, Teepa Snow developed PAC with the understanding that the more a caregiver learns about how to deal with challenging behaviors in a positive and constructive way, the less stressful and difficult the dementia journey will be. The approach emphasizes what those with dementia can do instead of what they can't do.

As dementia progresses, our focus is to preserve dignity and provide comfort while meeting evolving needs with skill, patience and compassion. Our care is tailored to each stage of brain change, according to the GEMS[®] States model developed by Teepa Snow. This allows us to meet people right where they are at each stage of dementia and tailor activities and care based on their abilities and challenges.

It's Not Your Fault

Dementia is not your fault and apologizing for it will not change the situation, nor will your loved one be likely to understand. Try to channel the natural tendency to assume blame with a more empathetic response. For example:

- I am sorry you are going through this; it's hard.
- I am sorry you are upset with me right now; this is hard.
- I am sorry today has been a troubled day; this is hard.
- I am sorry the bath made you feel cold; this is hard.



Hand-under-Hand™

Caregiver Tip: Hand-under-Hand™

Hand-under-Hand™ is a technique caregivers can use to reduce anxiety and calm a person with dementia. The base or heel of the hand is a highly sensitive area. Put a slight bit of pressure on that area by clasping your loved one's dominant hand. This technique works best if you put your hand underneath theirs. That gives them a feeling of control as well as calming them.

Hand-under-Hand™ is a trademark of the Teepa Snow Positive Approach® to Care

Understanding GEMS® States and How it Impacts Your Loved One

What are GEMS® States?

Interim HealthCare's Cognitive Care Program addresses the needs of those living with dementia using Teepa Snow's Positive Approach® to Care. The program incorporates the use of GEMS® States, a model which helps identify the current mental state of a person living with dementia.

Educated in the GEMS® States, our caregivers, nurses and therapists understand what individuals living with dementia are experiencing so they can provide a more supportive care plan. Moreover, our HomeLife Enrichment® signature standard of care includes care for the mind, body, spirit and family to help patients stay engaged throughout the day.



Identifying the GEMS® States

SAPPHIRE



My brain is “true blue.” I am aging normally and do not have dementia. It’s hard to find words, but I can describe what I am thinking so you understand. I may talk to myself because I am giving myself cues and prompts. I can learn new things and change habits, but it takes time and effort. Honoring my choices and preferences, when possible, is important. I need more time to make decisions. Give me the details and let me think about it before you need an answer. I am able to remember plans and information but supports are helpful. I like specific prompts such as notes, calendars and reminder calls. Health changes in vision, hearing, balance, coordination, depression, anxiety, pain or medication may impact my behavior, but my cognitive abilities remain the same.

DIAMOND



My brain is clear and sharp. I can be cutting and hard to deal with. I have many facets, so everyone sees me differently. This can cause conflict among my family or care team as it is hard to tell if I am just being stubborn or truly experiencing change in my abilities. I can socially chit-chat and have good cover skills. I want to keep habits and environments as they have always been, even when they are not working. I am often focused on finances or expenses and will resist most change including new expectations, routines or environments. I can become accusatory, thinking others are trying to trick or conspire against me. Short, brief visits will not expose my true struggles. Even if you are around all the time, you may not notice how much I am changing because instinctively you fill in the gaps for me.

EMERALD



I have little awareness of my changing abilities. You assume I can take care of myself, but my personal care is slipping, often resulting in poor nutrition and hygiene. I can chit-chat but struggle with words and understand only about three-fourths of what you say. I know you are unhappy with me by your tone of voice or expression. If I am lost in life, accept the moment I am in, listen and stay calm. Because I am easily frustrated, I often lose control of emotions and may blow up unexpectedly. When I feel afraid or confused I will want to “go home.” I remember strong feelings but won’t remember details. My brain sometimes makes up information to fill in the blanks, which makes you think I am lying. If you argue, I may become resentful or suspicious of you. I can’t be rational and will not want your help if you make me feel incompetent.

AMBER



I am caught in time and focused on sensation. I know if I like you based on how you look, sound, move, smell and respond to me. It may surprise you when I take, investigate, touch, smell, taste or take apart items, but it is a function of my brain processing information and it soothes me. I need to do things over and over and like simple tasks. I will resist what I can’t tolerate and I have limited safety awareness. I have no ability to stop myself and for safety reasons, you need to respond to me immediately. I am typically incontinent, may not feel hunger or thirst and can’t express my needs. My mouth, hands, feet and genitalia are highly sensitive due to changes in my nervous system. Therefore, activities like eating, taking medication, mouth care, bathing and toileting may distress me. Please notice my cues and stop if I am resisting. Wait a few minutes, connect with me and try a different approach.

RUBY



My brain is in late stage change. Transition is difficult for me. I like simple instruction and would rather you show me one step at a time instead of telling me what to do. My fine motor skills are very limited and I will need assistance with utensils, zipping, buttoning or brushing teeth. I tend to hold, pinch and manipulate items with my thumb rather than using my fingers. Because I can’t control the muscles in my mouth, I have difficulty swallowing. My vision has changed and I have no depth perception. I may misjudge distance, trip over large objects or get stuck behind doors. I have gross motor reactions and will have either a desire to move or an intense fear of falling. Pulling or pushing me feels like you are trying to hurt me and make me fall. Using Hand-under-Hand™ assistance helps me to feel safe and secure. I still have automatic verbal and rhythmic response. I enjoy music, your presence and a willingness to be quiet with me.

PEARL



My brain is losing its ability to control my body and I am at the end of my journey. Like an oyster, I am hidden in a shell, but will have moments when I become alert and responsive. Use our time to be with me, not just care for me. And please don’t talk about me as though I am not still here. I respond best to familiar voices and rhythmic gentle movements. I am ruled by reflexes and will startle easily. I appreciate it when you slowly and gradually shift me. When taking care of me, I am comforted when you place one hand securely on my body while using the other. I have trouble coordinating my swallowing and breathing and am prone to infection because my brain doesn’t organize a response. I may not be able to leave my body without permission from you. Your greatest gift to me is to let me know it is alright to go.

The GEMS® States model and Positive Approach® to Care techniques, strategies, and overall approach to care were created, developed and are copyrighted by Teepa Snow and Positive Approach, LLC. © 2006-2021.

HomeLife Enrichment[®]: A Holistic Approach to Care



Stimulating the Mind

Stimulating an individual's brain function helps them stay engaged. Our caregivers get to know each patient personally and integrate mind-sharpening activities such as puzzles, artwork and word games that they enjoy into their plan of care. Educated in the GEMS[®] States model, our caregivers can identify what stage of dementia a patient is in and adapt activities and care to their needs in ways that de-escalate anxiety.

Goal: *Encourage brain activity, increase engagement, reduce anxiety and promote joy*

Strengthening the Body

Each person has different physical goals. Whatever their age or diagnosis, our caregivers will work closely with patients to provide the personalized activities and support they need to meet them. Our plan of care combines daily activities and prescribed physical therapy routines to improve an individual's motor function while increasing their mobility, strength and independence. We can also assist with special diets, nutritional needs and medication regimens. See the appendix to learn how [mealtimes change with each GEMS[®] state](#) as well as helpful coping mechanisms.

Goal: *Encourage motor function, increase strength and mobility, and promote wellness*

Uplifting the Spirit

Care that uplifts the spirit of another facing challenges in life is the most compassionate care there is. At Interim, our caregivers look for unique ways to inspire their patients through music, poetry, videos, crafts and other creative outlets that bring fulfillment and joy to their lives. By tapping into their hopes and dreams, as well as their source of peace and happiness, we can connect with our patients on a deeper level, encourage their spiritual well-being and make every day more meaningful. See the appendix to learn how [art time](#) can be a relaxing, joyful and therapeutic experience.

Goal: *Uplift a person's spirit, increase fulfillment and add meaning to life*

Engaging the Family

Engaging family members in our plan of care is a big part of providing quality home care. Whether it's offering resources, support and advice or showing compassion and understanding to loved ones who care for them, our family-centered approach makes a difference to the people we serve. Our caregivers help family members understand what patients are going through, what to expect and how to support them. By providing the guidance and tools they need to manage daily challenges, we can decrease the anxieties of family members and create a stronger support system. And, when medical attention is required, we can help contact providers and coordinate the care they need.

Goal: *Engage family members, offer guidance, provide support and reduce anxieties*

You Don't Have to Walk this Road Alone

When a loved one is diagnosed with dementia, it can feel as though the world around you is changing. We understand how frightening this journey can be, but you don't have to face it alone. Interim will be right there beside you to support you each step of the way.

Experts in dementia care, Interim combines decades of specialized knowledge and experience with our HomeLife Enrichment® standard of care to provide an optimal experience for the patients we serve. Focused on the whole individual, we will tailor our plan of care to the unique needs of a person's mind, body, spirit and family to keep them engaged, comfortable and safe in their home. Our holistic approach to care includes caring for you, their caregiver. We understand how challenging this can be for you and we're committed to providing the guidance, support and relief you need to stay emotionally and physically strong while caring for your loved one.

If you are a caregiver to someone living with dementia, you need a good support system—Interim can be that for you. Reach out to one of our offices and find out how we can make the road ahead a little bit easier. Find an office near you at [interimhealthcare.com](https://www.interimhealthcare.com).



Caregiver Tips: Nutrition and Hydration

As we age, the need for a balanced diet becomes more important. Ensuring adequate nutrition and hydration may be more difficult for those living with dementia. There are several reasons that could lead to a deficit in nutrition and hydration for these individuals, but there are also helpful hints and possibilities to make nutrition and hydration an easier venture.

Timing of Medication Administration

- Often, those living with dementia are suspicious or skeptical about medications given to them. They may develop mistrust of the person offering the medication and refuse to take it. If these medications are given at mealtime, the medication refusal may cause the meal to be refused as well.
- Some medications are to be taken with meals; set them aside until after the meal so the medication struggle isn't part of mealtime.
- Clear all evidence of the meal and then offer the medication.
- Sometimes, eliminating the issues with taking oral medications can relieve many of the eating and hydration issues. Utilizing other medication types, such as liquid medication, patches or inhaled medication may yield benefits. Ask your physician or pharmacist if this is an option.
- New medications may alter or decrease appetite. Monitor them closely and notify a physician if there is a significant change.

Issues of the Mouth

- There may be pain related to eating for a person living with dementia. They may or may not be able to communicate this to you.
- Dentures that don't fit well may cause difficulty with chewing and make it uncomfortable to eat.
- It is important to visit the dentist on a regular basis to ensure any issues with teeth and gums are addressed.
- Some people living with dementia will complain about sensitivity around the mouth area that makes it uncomfortable to eat or drink.
- Offer a warm cloth to wash and wipe the mouth area before eating. Often, stimulating the mouth area with a cloth is beneficial to prepare for eating.
- For some, brushing their teeth is beneficial before a meal. Offer this option as well.
- Always test the food being served to ensure that the temperature is not too hot or too cold.

Appetite Changes, Taste and Smell

- With all the sensory and cognitive changes a person living with dementia experiences, you should expect that your loved one may experience changes in appetite and food preferences.
- Foods they have loved for decades may now have a negative smell or taste. Don't force these foods or argue over them. They may not remember that a certain food was a favorite and only know that it smells or tastes bad now.
- Offer a variety of balanced foods: vegetables, fruits, whole grains, low-fat dairy products and lean proteins.

- Offer small servings at first until you understand new preferences and realize they may change again. Offer no more than two choices at once. For example: Cold or hot to drink? Vegetables or fruit? Too many choices will confuse and cause anxiety.
- Depending on the cognitive impairment of your loved one, they may not recognize the food or know what to do with it.
- You may need to demonstrate picking up the food and eating it. Sometimes, people living with dementia need help getting started on a task.
- A visual demonstration is best for understanding.

Distractions at Mealtime

- Offer a calm environment for mealtime; too much activity or interaction can be difficult for a person living with dementia to stay focused on eating the meal.
- Remove other objects from the table or food tray.
- If possible, turn the television off during the meal.
- Sit with the person who is eating, even if you are not. You don't have to talk, but it may be calming to have someone nearby.
- If mealtime is more of a social event for family to gather, your loved one may enjoy it more and be more willing to eat and drink.
- Arrange food on a plate that is a contrasting color; otherwise, visual changes may cause the person living with dementia to have trouble seeing the difference between the food and the plate.
- Give the person living with dementia plenty of time to eat. It may take over an hour for your loved one to eat the entire meal. Encourage independence by letting them finish their meal on their own, if they can do so safely.

Utensils, Chewing and Choking

- There may be times when your loved one cannot recall how to use a utensil. You can visually demonstrate usage, and this may prompt them to use a spoon or fork. You may need to put the utensil in their hand.
- To ensure safety, you may want to offer meals cut into finger food sizes so that your loved one can feed themselves, either with a utensil or by hand.
- Promoting independence is vital, so eating with your hands should always be acceptable.
- Avoid foods that require thorough chewing, as this may prove difficult for those living with dementia. Some examples of foods that require thorough chewing are tough meats, steaks, pork chops and raw carrots.
- Pocketing portions of food in the sides of the mouth might occur if your loved one cannot get it all chewed up and swallowed. This will eventually become a choking hazard.
- At some point, you might find it beneficial to serve ground or pureed foods to ensure they can be swallowed safely.
- If you have concerns about choking, start with some softer foods such as cottage cheese, yogurt, applesauce or scrambled eggs.
- Learn the [Heimlich Maneuver](#) in the event of choking.

Hydration

- Lack of hydration is a big problem for those living with dementia. Encourage and offer liquids often.
- Prompt fluid intake by having a drink along with your loved one. Modeling behavior is a good way to encourage intake.
- Sometimes, there is a fear of drinking water, typically related to a fear of choking. Use a dark colored drinking cup and enhance plain water with a flavored-powdered mixture.
- Offer hot or cold drinks. Sometimes, coffee is a great way to start the day. You might find that your loved one prefers room temperature drinks instead of ice cold. With the mouth sensitivity, cold may be too uncomfortable.
- Urinary tract infections are a big concern, so pushing fluids is important.
- Your loved one may not think of drinking during the day, so offer often and model drinking by demonstrating it for them.
- Offer foods that have a high water content as well. Some choices would be celery, berries, melons, cucumbers, apples, clear soups or broth.

Problem Food and Drinks

Certain foods may cause problems for your loved one, so if they are experiencing any issues, these could be the culprits:

- Caffeine
- Grapefruit
- Meats (pork, poultry, beef)
- Cheese or milk
- Fatty foods
- Salt
- Sugar
- Diet drinks



Caregiver Tips: Nutrition Guidance by GEMS® States

Based on guidance provided by Teepe Snow's Positive Approach® to Care instructional video.

Each stage of dementia can usher in new challenges for those living with dementia and their caregivers, especially in dealing with one of the most critical daily activities—nutrition.



Sapphire

Since sapphires are aging normally, they will not experience the same issues as those living with dementia, but they do have some changes and concerns that you should be aware of related to nutrition.

Common Concerns:

- Eating too much for their activity level
- Eating too little due to meds, health or emotional state
- Difficulty following a healthy meal plan
- Financial limitations for food options
- Lack of knowledge related to healthy choices
- Eating unhealthy foods based on old habits
- Feeling like they should be able to eat whatever they want

Possible Changes:

- Change portion size and activity levels
- Address underlying issues—modify meds, change textures, timing or amounts
- Partner up for meals
- Use a portioned plate
- Access local food banks, community co-ops or community gardens for healthy and affordable food options
- Consult a geriatric specialist

Diamond

Diamonds hold on to old habits. They will want to do as they have always done, as that's their comfort level. It is best to go with food choices they know and like. If introducing a new food, make sure to identify it as new over and over and encourage them to try it. At times, they may be more impulsive or more indecisive about food. They may behave differently in different social situations revolving around mealtime. They will be worried about cost. Expect complaints about taste, smell, temperature and presentation of the meal. "I am sorry; you are right" are important words to use when responding.

Common Concerns:

- Eating too much for activity levels
- Eating too little due to meds, health, emotional state
- Difficulty following healthy meal plan independently
- Worried about money and cost of meals
- Lack of food knowledge
- Poor food choice habits
- Feeling they should be able to eat whatever they want

Possible Changes:

- Do NOT battle over food
- Change portion sizes and activity levels in small steps
- Address underlying issues—modify meds, change textures, timing or amounts
- Make an effort to eat with your loved one
- Use a portioned plate
- Remind them of new foods repeatedly
- Provide positive encouragement for healthy eating choices

Emerald

Emeralds may see more issues related to nutrition and eating. They will not pick up internal cues and will need more specific external cues related to nutrition. At times, they may not realize they have just eaten and want something to eat, so you may see overeating during this stage. It's not uncommon for them to try to follow old routines for mealtime but they will not be able to complete them. They will not notice spills, drips and slips in their eating patterns. Using utensils is difficult for them so they may opt to use their hands and fingers. They are on the go and will not want to be delayed from eating when they want to eat. Emeralds do not like to be bossed around. They may be highly emotional and distressed. It may seem they are more sensitive to disliked flavors or tastes. Meal planning is vital for an emerald.

Common Concerns:

- Eating too frequently or rarely
- Eating too much or too little
- Eating too fast or too slow
- Sloppy eating technique
- Junk food—attracted to sweet and salty
- Diet issues
- Food preparation—adding condiments or cooking
- Trouble with menus

Possible Changes:

- Limit visual access—set food out and point to it
- Use smaller plates, half portions at a time
- Eat alongside your loved one and model eating, e.g. “Oh this is good ... try a bite, tell me what you think”
- Encourage loved one to assist in meal preparation
- Limit choices of food—use picture menus
- Use placemat as a cue to identify where to eat

Amber

Ambers are living in the moment and focused on sensation. They are interested in what it looks like, sounds like, feels like, smells like and tastes like. What can be done with items and space and sensation? Ambers explore without safety awareness. Their actions are based on sensory needs. Do I like it or not? Know the likes and work with those; stay away from known dislikes. There is no ability to delay needs or gratification for ambers. It’s more difficult to connect with an amber. Don’t take away items; offer a different choice. Substitute, don’t subtract!

Common Concerns:

- Playing with food
- Spilling or pouring food and drink
- Not using utensils
- Eating too fast or not eating at all
- Not drinking enough or too much
- Spitting things out
- Eating non-food items
- Taking food from others

Possible Changes

- Limit amount of food given at one time
- Cue to the food when offering it and use Hand-under-Hand™ to get started
- Offer more finger foods
- Limit number of utensils
- Use a smaller cup—lids or straws might be beneficial
- Go to softer foods versus dentures
- Limit thicker, denser meats
- Limit items that fall apart, such as tacos or sandwiches with too many items



Ruby

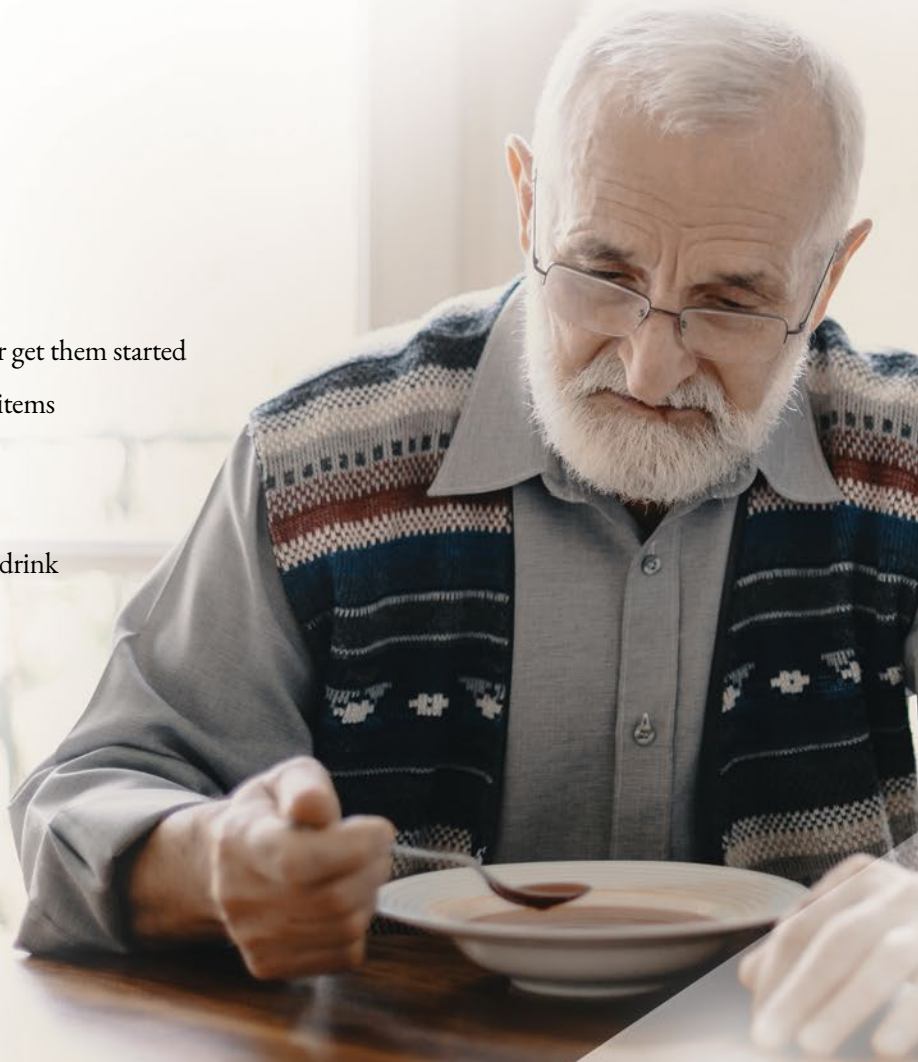
A ruby can make big movements, but lacks fine, detailed motor skills like safe chewing, using utensils or fingers. Rubies are likely to use their hands to feed themselves. They will have more dropping and spilling and will be less aware of their position related to their food. Rubies may be hyper-sensitive around the mouth and fingers. Vision is monocular, so offering food choices in their field of vision is vital. They will communicate needs through behaviors and not words. Rubies have trouble organizing chewing to swallowing, causing them to pocket foods, holding it in their mouth and not eating or drinking items.

Common Concerns:

- Weight loss
- Dehydration
- Fewer foods liked or wanted
- Refusals
- Spillage
- Not sitting down to eat
- Not waking up to eat
- Not able to feed self
- Pocketing food

Possible Changes

- Offer smaller snacks more often
- Typically, will eat sweets
- Limit food textures
- Use Hand-under-Hand™ technique to eat or get them started
- Utilize a spoon for thick liquids versus solid items
- Use cup lids and straws
- Switch to six to eight smaller meals per day
- Urge smaller bites—maybe five bites, then a drink



Pearl

Pearls are becoming immobile and may be curled into a fetal position. The loved one you knew is locked away most of the time. Their body and brain are failing, but they will still have moments of connecting. Reflexes are overwhelming or missing. Connections must be made slowly and cannot be maintained for long. Vision is monocular. Pearls need to be able to let go, we must let them know it's okay to go. They will have limited intake and drinking. There will be swallowing problems and pearls will have little interest in eating. If the pearl is alert, it would be appropriate to offer food, but not if they are not alert. Help them eat but resist the temptation to feed them. Often, we may put too much in their mouth and cause choking or aspiration.

Common Concerns:

- Will not open mouth
- Won't swallow
- Chokes/coughs
- Aspiration pneumonia
- Abnormal bite reflex, tongue thrust and grinding of teeth
- Contractures
- Increased sleeping

Possible Changes

- Hand to shoulder and hand under forearm or wrist for support
- Offer an empty bite to their mouth to prepare them
- May need a speech therapy consultation
- Limit nutrition offerings by mouth
- Try protein smoothies with fluids
- Consult an OT/PT for seating options and cues
- Love the person ... let them know you understand

The GEMS® States model and Positive Approach® to Care techniques, strategies, and overall approach to care were created, developed and are copyrighted by Teepa Snow and Positive Approach, LLC. © 2006-2021.

Caregiver Tips: Art Time

Self-expression is a means of communication. Whether painting, drawing or making a collage, art can promote joy and relaxation while decreasing anxiety. This is very therapeutic to someone living with dementia.

Once a person is diagnosed with dementia, their ability to act and live independently greatly diminishes. Typically, a caregiver directs all activities of the day, leaving them to follow someone else's agenda, even though it's for their benefit. Artwork allows freedom of expression and creativity. Over time, this freedom can be quite impactful.

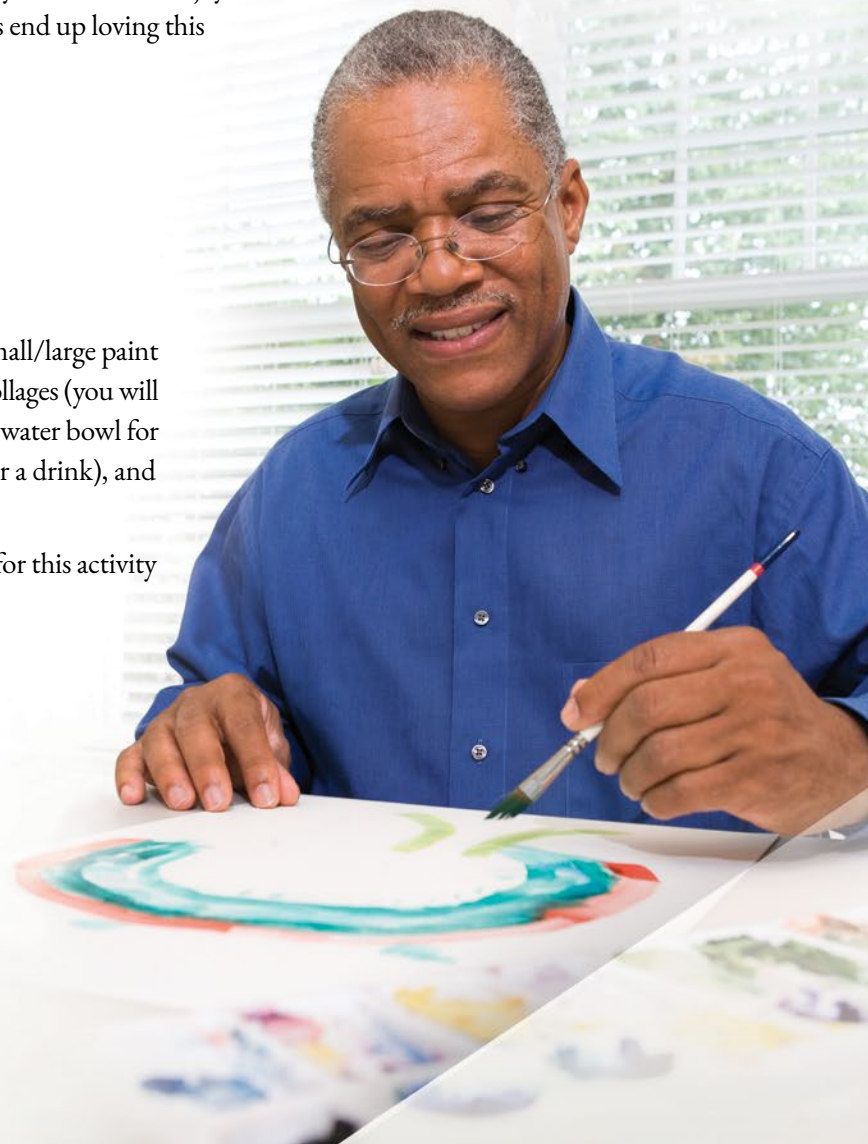
It's about the process; not the outcome. Artwork does not need to be beautiful, just enjoyable. The joy comes in the creating and in the completed project—not in their ability. Artistic activities can also lead to bonding and happy experiences for the caregiver and their loved one. So, join in and participate alongside them. You may need to put the brush or pencil in their hand as a reminder or actually model the painting or drawing action to get them started.

To begin, ask your loved one what they would like to create. If they are unsure, suggest something that makes them feel happy. There is no wrong answer; it's an opportunity to let them be in charge. Ask them to name their artwork and write it on the back (not on the front). Let the artwork be 100 percent theirs. Afterwards, look at the artwork together. Talk about what it means, what the colors represent or how the drawing makes each person feel. As a caregiver, you may want to write down your loved one's comments—some of them can be quite touching and telling.

Music is a joyful addition to this activity. Find music that your loved one enjoys and add this to the creative time. Even the biggest skeptics end up loving this activity and look forward to it each week.

Planning for Art Time:

- Set a weekly time for artwork
- Plan for about 30-45 minutes for the activity
- Gather art supplies: pencils, watercolor paints, small/large paint brushes, art paper or copy paper, magazines for collages (you will need to cut out pieces and place where directed), water bowl for rinsing brushes (no cups, as they may confuse for a drink), and paper towels
- Do not use children's coloring books or crayons for this activity
- Gather clean-up supplies for afterwards
- Select music for the activity



About Interim HealthCare

Founded in 1966, Interim HealthCare is the nation's first home care and healthcare staffing company. A recognized leader in their industry, Interim understands the importance of providing quality care in a place that's ideal for the individuals they serve. Distinguished by their HomeLife Enrichment® signature standard of care, they engage the mind, body, spirit and family in a personalized plan of care that ensures an optimal experience for their clients.

Operating through a network of more than 300 locally owned franchises, Interim offers a comprehensive range of home care, hospice and healthcare staffing solutions. From skilled nurses and therapists to aides and companions, they provide an average of 25 million hours of home care to 190,000 people every year.

interimhealthcare.com

First
in Home Care



