



A VISUAL GUIDE::

Mood and Behavioral Challenges in Dementia

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ABOUT THIS VISUAL GUIDE ::

This visual guide is a product of the collective experiences of those who have contributed to or reviewed this tool. It does not, nor could it, include all possible considerations or interventions needed to support an individual with a dementia.

Each individual with a dementia brings their own history, personality, medical conditions, family, coping styles and many other issues that require attention, analysis, and commitment to supporting quality of life through the disease process.

This visual guide offers a way to think through mood and behavioral challenges and potential directions to respond to them. It is designed for those who care primarily for individuals who have moderate impairment.

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About Dementia

Dementia is a general term that indicates a loss of cognitive or behavioral functions to the point that it interferes with the ease or manner in which known tasks are managed or completed.

Most, but not all, dementias are progressive and the rate at which progression occurs can depend on the type or cause of the dementia, and also vary among individuals with the same type of dementia. Alzheimer's disease is the most common dementia. Other common types include Lewy Body Dementia, Vascular Dementia and Frontotemporal Dementia (FTD). Most of these dementias have subtypes.

Understanding the type of dementia expands the ability to manage the disease.

While there can be symptom similarity across various dementias, each has unique features including varying susceptibility and presentations of mood and behavioral complications. In FTD, for example, these complications may present earlier.

In Alzheimer's type dementia, the likelihood of these symptoms increases in middle stages.

SECTION 1

Common Mood and Behavioral Challenges

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COMMON MOOD AND BEHAVIORAL CHALLENGES::



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DEMENTIA IMPLICATIONS FOR MOOD AND BEHAVIORAL CHALLENGES::

While these dementias cause a variety of vulnerabilities, that does not mean that these mood and behavioral challenges are inevitable, void of external triggers, or hopeless. Instead, they present the necessity to explore a fuller picture of possible contributing factors and targeting of interventions based on the understanding of those potential contributors.

This is a key element in supporting QUALITY OF LIFE.

DAMAGE TO LIMBIC SYSTEM

The limbic system not only plays a role in memory and learning, but also emotions. When damage occurs in this part of the brain, mood can be affected, increasing likelihood of experiencing depression.

EXECUTIVE FUNCTION WEAKNESSES AND LOSSES

These losses include reduced capacity and losses in logic, reasoning, interpreting social cues and decision-making.

LOSS OF FILTER BETWEEN THOUGHT AND ACTION

As executive dysfunction increases, individuals lose the ability to interrupt or change reactions to their thoughts.

REDUCED COGNITIVE FLEXIBILITY

The brain is less able to accomplish timely task completion or to accommodate unplanned shifts in schedules or activities. It also is more difficult to respond to a multi-directional pace of conversation.

DECLINING ABILITY IN THE AREAS OF LANGUAGE

Expressive language is affected in the areas of word finding or word substitution. Individuals struggle more with sustaining conversation lines and can present as tangential. Receptive language is also impacted, creating challenges with understanding multi-step instructions or other information.

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DEMENTIA IMPLICATIONS FOR MOOD AND BEHAVIORAL CHALLENGES ::

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DECREASING ACCESS TO PRIOR COPING STRATEGIES

Everyone has certain ways that they cope with difficulties that are faced. In these dementias, it is often the case that individuals lose access to those coping strategies which can add to their distress load.

VULNERABILITY TO SLEEP DISTURBANCES

Several sleep disturbances can emerge as part of specific dementias including decreased time in deep sleep or specific REM disorder which can lead to more fatigue during the day.

LOSS OF DIRECTIONAL MAP

The mental map that supports getting from one place to another is damaged and eventually lost.

LOWER FRUSTRATION THRESHOLD

Due to the loss of filter between thought and action, there is less cognitive reserve to mitigate or subdue frustration.

LOSS OF NOISE FILTER

Individuals are less able to manage competing noises and voices.

DAMAGE TO SHORT-TERM MEMORY

Damage to and loss of short-term memory is a major feature in most of the dementias. This often leads to confabulation—the mind’s inclination to put things together that do not belong together. Long-term memory is typically sustained for a significant part of these diseases.

DAMAGE TO PROCEDURAL MEMORY

Individuals lose the ability to process the “how to” and the “next steps.”

VISUAL MISPERCEPTIONS

With limited exceptions, actual vision is typically not affected in Alzheimer’s disease or other dementias. The mind’s ability to translate what is seen is affected. Misperceptions can and often do occur.

WHEN IS A MOOD OR BEHAVIORAL CHALLENGE NOT A PROBLEM?

If SEVERITY is low.

If the behavior does not harm the individual with the disease or others.

If DURATION is limited.

If the behavior occurs infrequently or for brief periods of time.

If RESPONSIVENESS is high.

If the behavior can be easily redirected or ceases with appropriate interventions.

If DISTRESS is low.

If the behavior does not contribute to distress, suffering or negative consequences for the individual living with dementia.

Mood and behavioral symptoms are problematic when they interfere in quality of life, including the ability to absorb enjoyable elements, to receive support, and to utilize the strengths and abilities that individuals with a dementia continue to possess.

MEDICATIONS::

It is not inevitable that someone with a dementia will require medications to manage these mood and behavioral challenges, but the need for medications is common and often partnered with non-pharmacological interventions. Most individuals with a dementia will experience a level of depression. The most common symptom presentation includes anxiety and irritability.

Attending to presence of depression is central in supporting those experiencing these cognitive changes. Timing of integration of medications and non-pharmacological interventions depends on the severity of the presentation. For example, someone experiencing significant depression may be resistive to having help come in to the home or becoming involved in activities. In these cases, it would be key to start an anti-depressant first before triggering a negative response to interventions that may very well serve an important role once depression is at least partially remitted. Anti-depressants are often the first line of pharmacological intervention. **As with all medications, it is important to understand dosage, when potential benefits are to be expected, potential side effects, and any associated recommendations.**

TYPES OF PSYCHOTROPIC MEDICATIONS INCLUDE::

ANTI-DEPRESSANTS

This class of medications targets the set of symptoms that are associated with depression including anxiety, rumination/excessive worry, irritability, resistance, agitation, sadness, tearfulness, sleep disturbance, expressions of worthlessness/desire to die and appetite changes. Symptoms can include paranoia or other forms of psychosis.

MOOD STABILIZERS

Medications in this class are given to assist with the management of agitation. While evidence regarding the significance of their benefit is limited, there are times they are used to minimize the use of anti-psychotic medication.

Careful monitoring of these medications is necessary. They often require titration, many require withdrawal protocol, and they may or may not be required for extended amounts of time. Medication should not be used as a substitute for good care, for activity or for medical assessment. Sedation is never the goal. **Decisions to incorporate such medications are based on the commitment to reduce suffering and to improve quality of life.** Incorporation of appropriate medication may extend the family's ability to care for the individual at home, reduce safety risks and prevent premature disability.

ANTI-ANXIETY/ANXIOLYTICS

Anti-anxiety medications may be indicated in short-term crisis situations, in individuals who have struggled with a long-term anxiety disorder or at end of life. Benzodiazepines, common anxiety-treating medications, do have the potential for negative side effects for those with a dementia, so most providers will attempt to avoid if possible.

ANTI-PSYCHOTIC

While rarely the first line of defense in mood and behavioral challenges, there are times when addition of an anti-psychotic medication is indicated. It is expected that anti-depressants and non-pharmacological interventions are attempted before moving to the addition of this class of medication. They do have potentially serious side effects so clear understanding of the risk or benefit profile should be known and discussed with family.

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31 / EXCESSIVE SPENDING/VULNERABILITY TO SCAMS

DEPRESSION ::



“ *Perspective is an incredibly powerful tool. It tempers how we receive information, and guides what we choose to do with it.*

T. A. SORENSEN

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UNWANTED SEXUAL EXPRESSION ::

Behavior, seemingly sexual in nature, may or may not have sexual intent. Further, sexual expression in an individual with Alzheimer's disease does not necessarily constitute inappropriate behavior.

It is important to limit reaction and to consider a range of possible contributors and responses.

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Loneliness or need for connection	65	Uncomfortable clothes—too tight, too warm	

REPETITIOUS QUESTIONING ::

Due to the prominent nature of short-term memory loss in this disease, asking questions multiple times is common and expected. It is important, however, to pay attention to specific features of the repetition.

How many times and for how long are the same issues or questions repeated?
What facial expression is displayed? What tone are you hearing?
Recognizing differences can help guide understanding and response.

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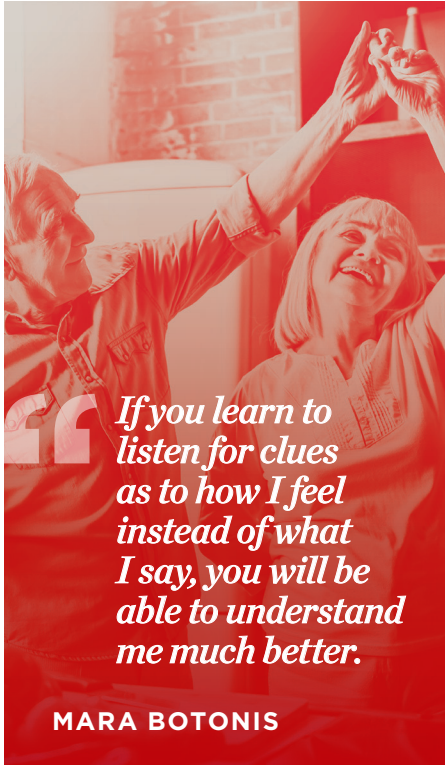
SUNDOWNING ::

Individuals with a dementia often experience a trend of restlessness, more confusion and increased agitation in the afternoon and evening hours.

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Unmet needs	

URINATING OR DEFECATING BEYOND THE TOILET::



“

Caregiving is a constant learning experience.

VIVIAN FRAZIER

PAGE

Delirium

44

Can't find the bathroom

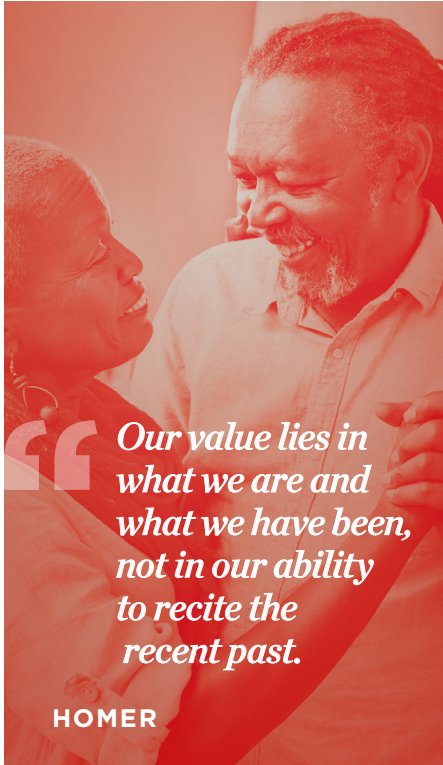
Lack of warning time

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RAPID ONSET CONFUSION ::



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Delirium

44

– Dehydration

– Environmental transition

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– Medication side effect

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HALLUCINATIONS/DELUSIONS ::

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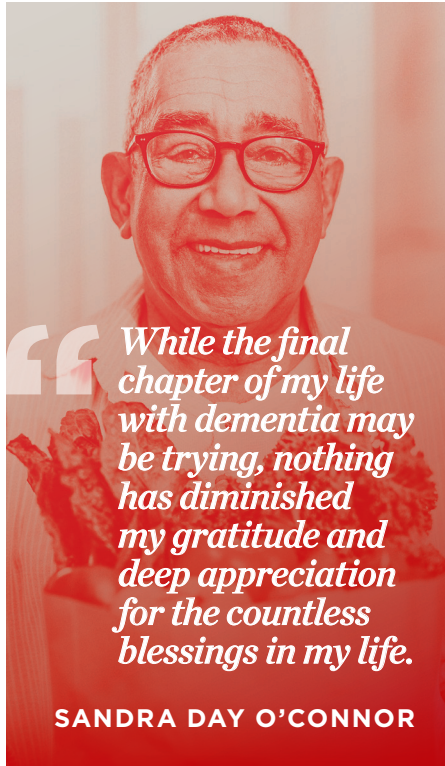
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EXCESSIVE SPENDING/VULNERABILITY TO SCAMS::



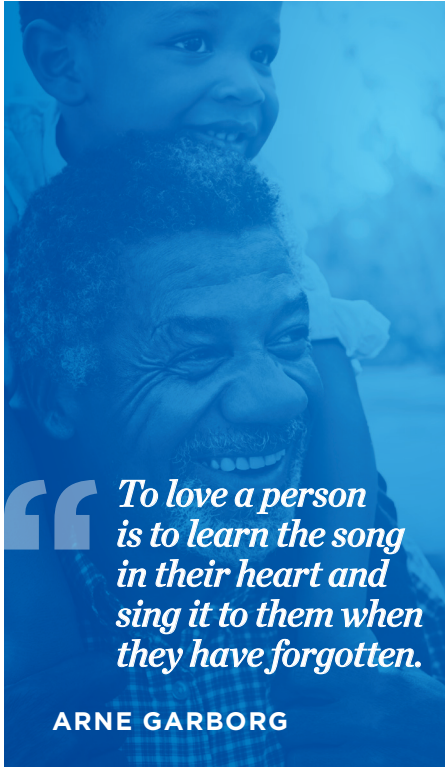
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ABSENCE OF INITIATION ::



Adjust expectations.

Create a routine that includes home care tasks, physical activity such as walks, appointments, and shared time with care partner.

Incorporate visual cues such as setting out items needed to set the table or setting out box of pictures.

Utilize a daily calendar with a limited number of tasks or activities for the day based on tolerance threshold.

ABSENCE OF “INITIATORS”—FRIENDS OR COMPANIONS WHO REACH OUT TO THE INDIVIDUAL::

Assist the individual in writing cards to send to others. Take time to discuss the person and their relationship with the individual. Affirm the value in sending a card to this person.

Consider activity-based groups.

Consider hiring a companion or an “assistant.”

Contact family, friends and others. Let them know of the individual’s need for social contact and create a regular rotation of visits or outings with those willing.

Encourage people in the individual’s life to send cards and short notes at regular intervals.

Encourage sitting on the front porch or set up chairs in the driveway to increase the chances of interaction with neighbors.

If the individual enjoys dogs, spend time at a dog park—even if he/she does not have a dog.

Partner with other care partners who have a loved one with a dementia to go out to eat, schedule visits at home or other social activities.

Schedule family virtual visits.

Support the individual in calling someone once a week.

Take walks at the park.

ADJUSTMENT TO TRANSITION ::

IF MOVING TO A FAMILY MEMBER'S HOME

Encourage visitors, but only one or two at a time. If the move is out of town, facilitate virtual visits to remain connected to friends.

Ensure some quiet space.

Find ways for the individual to help you.

Provide affirmations and reassurances.

Try to maintain some elements of prior day-to-day structure.

IF IN HOSPITAL

Consider completing an additional history with information regarding function/behavioral patterns. A social worker can assist.

Consider psychotropics as a last resort.

Facilitate a sleep regimen including noise-reduction measures and avoid nighttime awakening unless vital.

Find ways to identify the individual as a high risk for wandering. Possible options include subtle color code in room or on hospital ID and defined protocols.

Foster familiarity: encourage friends/family to stay at bedside if possible, maintain consistency of staff, minimize changes in room or roommates.

Frequently reassure.

Utilize a whiteboard for instructions and reassurances such as when a family member is coming.

IF IN A LONG-TERM CARE FACILITY

PAGE

Address depressive symptoms prior to transition if possible. Monitor and adjust as indicated.

45

Assign a management staff-person to the individual/family for first two weeks to spend extra 1:1 time, supporting the individual in adjusting to a new routine and providing the family detailed feedback during the transition.

Encourage family to bring activities to do together during visits.

Incorporate multi-sensory items such as talking photo albums, robotic pets, textured activity quilts or boards.

Instruct family to visit regularly and frequently, but to time visits so that individual can be escorted to an activity/meal at point of family departure.

Know historical coping strategies and explore ways to help adapt to the new setting.

Provide items that add a sense of security for the individual.

Provide sufficient activities and engagement.

Provide time outdoors. Utilize family if staff is unable to assist.

Schedule regular, but time-limited, visits that do not interfere with participation in activities/facility schedule.

Secure 10 "evening letters" written by important persons in the individual's life that follow a standard template. "I was thinking about you today and the time we did...or about what you taught me about..." The letter should include a loving close. The letters can be "delivered" daily. Incorporate a mailbox where the individual can be engaged to check for mail.

ANXIETY::

PAGE

Depression is one of the most common reasons for anxiety in an individual with dementia. Talk with a healthcare provider if this is suspected or if anxiety persists despite other efforts.

45

Assess for potential unsafe situations. If abuse, exploitation, or neglect is suspected, contact Adult Protective Services.

Break down instructions to one step at a time.

Consider a companion or “assistant.”

Consider a day program.

Consider specific environmental triggers and make adjustments.

Consider use of reassuring music that holds meaning. This often works best with noise-reduction headphones.

Enlist the individual’s help in an activity/project—working outside, meal preparation, sorting something, volunteer-related tasks, cleaning car, etc.

Integrate physical activity.

Limit time in larger group settings based on tolerance level.

Spread out activities with sufficient down time. Sometimes that means building a day in between events/appointments.

Utilize a daily calendar.



*And it is still true,
no matter how
old you are, when
you go out into the
world it is best to
hold hands and
stick together.*

ROBERT FULGHAM

A safety zone can be a person, item or place.

PAGE

Assess level of anxiety if away from primary caregiver or home. **36**

Manage depression. **45**

Assess if distress is higher with specific places.

Introduce others that can stay with the individual for small amounts of time when the primary caregiver is out. Gradually add time.

Share details about destination.
Provide reassurances.

Utilize written notes to inform of primary caregiver's time of return if the individual is able to understand.

BOREDOM::

PAGE

Create daily, weekly and routine schedules.

63

Consider a day program.
Calculate approach: day programs can be referred to as a club or a way to help others.

Consider hiring an “assistant” to assist in volunteerism, to help organize and complete tasks, to partner in physical activity such as going on walks or other engaging activities.

Develop activities based on past interests.

Ensure opportunities for change of place
—outside, grocery store, park,
faith community, restaurant, visits to
other family member’s homes, etc.

Incorporate other family and friends in developing a shared and more formalized support schedule.

Balance types of activities.

— Physical

— Productive
*home care, sorting, volunteer type tasks,
life questions*

— Social

— Relaxation
*music, time outside, seating with
movement such as a glider, watching
animal live cams options on the computer*

— Creative
*adult coloring books, magnetic quilt tiles,
time slips story creation—explore [timeslips.org](https://www.timeslips.org).*

— Spiritual
*if that has been an important part
of the individual’s life*

CAREGIVER COMMUNICATION/APPROACH ::

Acknowledge feelings and be reassuring.
— “I know it is hard but we can get through this together.”

Anticipate and acknowledge pleasurable times.
Make note of times that were enjoyable to both the individual and care partner.

Attend support groups.

Avoid statements such as “I have told you...” “Don’t you remember...” and “You have already asked me that...”
Instead, respond to questions, incorporate liberal use of “I’m sorry” even if an accusation is not reality-based.

Carefully consider necessity before telling bad news to an individual with moderate stage dementia.

Do not attempt to do difficult tasks at the end of the day or at times when either the caregiver or individual with dementia is fatigued.

Do not try to convince someone of something when the individual has moderate impairment. When the logic part of the brain is compromised, the expectation that logical explanations will be understood is unrealistic.

Expand the team. It is important to get respite care in the form of a companion, “assistant,” day programs, and/or direct care help. Introduce gradually.

In moderate stage, it is ethical and compassionate to integrate “therapeutic fibs” to explain things that the individual would not be able to process and accept.

Integrate the individual in daily tasks, such as putting away dishes. If put in wrong place, simply move them later. Do not point out mistakes.

Limit demands on the individual with dementia.
Sometimes tasks such as showering need to happen on a different day than an appointment or social event.

Provide regular reminders to the individual of their value.

Slow down. Accept and plan for time to accomplish activities or to prepare to go to an appointment or event.

Utilize step-by-step instructions with sufficient time in between steps.

CHANGES IN ABILITY OR OPPORTUNITY TO ENGAGE IN HOBBIES/ACTIVITIES::

Consider ways that the individual can continue in some aspect of the hobby/activity.

- Consider participation in teams such as playing cards or volunteering.

- Consider use of written and/or pictorial step-by-step instructions.

- Find ways to maintain connections with people who were part of past activities/hobbies.

- If the sport can no longer be played, watch or participate in a smaller part.
 - If the individual can no longer play golf, go to the putting range and hit balls or ride along in golf cart.

- Value the playing of a game or participating in an activity over accuracy. If the individual is no longer playing correctly or following rules, simply go along with it.

Consider activity-based groups or day programs.

Introduce new activities, even if you think the individual would not have been interested in that particular activity in the past. Things change. Do not limit yourself by what an individual would or wouldn't do prior to the dementia.

Keep doing what works.

CLUTTERED ENVIRONMENT::

Simplifying the environment can be helpful both to the individual diagnosed and to the care partner. It can support a level of independence, reduce frustration in lost items and help mitigate stress for the care partner.

Consider using friends or organizers to help.

Create specific zones in the garage.
Get rid of tools that may present danger.

Establish a consistent place for things like purses.

Integrate labels and/or pictures on cabinets and drawers.

Pare down clothes in closets.

Put outfits together and label by day of the week to reduce stress if the individual is having difficulty making decisions around clothing.

COMMUNICATION ISSUES/LACK OF ENGAGEMENT::

	PAGE	
Assess for depression, both in the individual with dementia and in the care partner.	45	Ensure environment is not busy, loud or distracting.
Address hearing issues through audiology, use of hearing aids, computer translation programs and the position and tone of those talking with the individual.	74	Incorporate nonverbal cueing and/or language as well as verbal. — Pointing or hand-on-hand strategy to get someone started.
If vision impaired, provide instructions to those around the individual on strategies to engage such as gentle touch, descriptive words or conversations, and use of texture.	74	Provide support in conversations with others, including integrating names in your dialogue to help the individual. If he/she stumbles with an answer, help in a dignified way.
Affirm participation.		Rather than asking, instruct with encouragement. — “We are going over to see Mary. She is really looking forward to seeing you.” “Time to go to the grocery store. You can help me with the cart.”
Attend to your own mood. Present in a cheerful fashion.		Reassure if the individual doesn’t feel safe in the environment or appears suspicious. Psychosis can be obvious or subtle.
Break down directions into single steps. — Instead of “wash your face”, start with “pick up the washcloth” and take it step by step.		Slow down.

CURRENT, PAST AND ANTICIPATORY LOSSES::



*I am seeking,
I am not lost.
I am forgetful,
I am not gone.*

KOENIG COSTE

PAGE

Attend to possible depression.

45

Provide structure and routine.

63

Acknowledge feelings and talk about meaningful memories attached to who or what has been lost.

Affirm the good things in the present.

DELIRIUM::

Indicators of possible delirium include: an acute state of increased confusion, inattention, sudden increases in agitation, new presence of psychosis and changes in sleep patterns.

Delirium has an acute onset—hours to a few days. The individual will have a fluctuating level of consciousness over the course of the day. Delirium is typically caused by something physical and, in 25% of cases, can be fatal if the underlying cause is not found. Thus, it is considered a medical emergency. If delirium is suspected, contact your physician immediately. Make sure healthcare providers understand the individual's baseline, timing of the changes and all information associated with the sudden change.

Alcohol/substance use?	New medications?	Delirium protocol <ul style="list-style-type: none">— Ensure the individual is drinking enough water. Offer sips of water throughout the day.— Explore with a healthcare provider if current medications are contributing and, if so, make appropriate adjustments.— Get the individual walking if possible (if appropriate to medical condition).
Constipation/impaction?	Over-the-counter medications?	
Contact a healthcare provider if any suspicion of delirium.	Recent hospitalization?	
Dehydration?	Taking medications inaccurately?	
Falls?	Urinary tract infection (UTI)? UTIs are common in this population and often are recurring.	

The most common symptom of depression among those with a dementia is anxiety, including excessive worry and fear.

Other symptoms might include sleep changes, appetite changes, irritability, resistance, verbal or physical aggression, loss of interest in previously-enjoyed activities, withdrawing from others, exaggeration of deficits, self-deprecation, general negativity, tearfulness, sadness and expressing wishes of wanting to die.

	PAGE	
Connect to others —friends, family, appropriate group activities.	34	Affirm current strengths as well as past contributions made to family, community and others.
Provide positive care partner approach to communication and engagement.	39	Consider an anti-depressant.
Reduce environmental stressors.	48	Listen to feelings and provide reassurance.
Provide structure and routine.	63	

DESIRE TO FULFILL FORMER OBLIGATIONS::

The most common presentation is that the individual thinks they need to go to work.

Other examples include the need to attend to children, parents or other family members.

	PAGE	
Assess for boredom.	36	Attempt diversion. Ask if the individual can help you with something or that you need their advice.
Assess for delirium if rapid onset.	44	Be aware of visual or verbal triggers. — Is the individual at an open window to watch children walking home from school or school buses going by? Are there others in the house getting ready to go to work or discussing leaving for work?
Assess for depression.	45	Create a therapeutic fib. — “Your work called and said you didn’t have to come in today.”
Assess for lack of structure or routine.	63	Read or leave notes that give direction as to what to do or expect. — “Mom, we will be over to see you this afternoon.”
Affirm positive values reflected in the pursued obligation. — “Those patients were lucky to have you as their nurse. You always were so kind and went the extra mile for all your patients.”		Talk with the individual about his/her past experiences and perspectives. — “Tell me about how you decided to become a teacher.” Or “Were you more like your mother or father?”
Attempt delay. — “It’s late and already dark. Let’s stay here tonight and we can figure it out in the morning.”		

A SENSE OF BEING IN THE WRONG PLACE::

	PAGE	
Assess for depression.	45	If the individual is in a facility, do not talk about permanency. Instead talk about how the doctor feels it is needed for now to help with strengthening and supporting wellness in some way.
Address fear.	53	
Provide structure and routine.	63	If time and weather allow, take a short drive, then pull in to the driveway and say, "Here we are at home!"
Assess for hallucinations and delusions.	73	If time and weather do not allow, create a therapeutic fib. — "It's dark outside so let's just stay tonight and we can figure it out in the morning."
Bring in a task to do together.		
Ensure appropriate support in the home.		Redirect to reminiscence about familiar objects in the room.

ENVIRONMENTAL ELEMENTS AND CUES::

Utilize other senses including smell to increase interest in eating.

Keep the television off during meals, when others visit, or when trying to engage the individual in a task.

Do not talk about distressing things in front of the individual.

Do not sit in a different place than the individual with a dementia.

– If the individual with dementia eats at the table and you eat in front of the television, then he/she is more likely to leave the table.

Keep the table free of clutter.

If a tablecloth is used, it should be plain, without any pattern.

Use a solid-colored placemat that contrasts the color of the table to assist in indicating boundaries.

Simplify the place setting. All food should be able to be eaten with one utensil to reduce confusion.

Utilize music with a rhythm that correlates to taking bites.

Be patient with the length of time it might take an individual to eat.

Cover mirrors if the individual is reacting negatively in some way. If he/she is talking to the mirror and pleasant, leave the mirror alone.

Limit the number of people in the home or room at any one time.

Doors can present a cue to exit.

– Put a lock up near the top of the door.

– Add a cow bell, chimes or technology to alert care partner if door opens.

– Hang curtains across the door so that the curtains can be closed at night which will camouflage the door.

– Consider bookcase wallpaper or another type of mural to camouflage the door.

– Notes can work for a period of time. Try taping a note to the door such as, “Mary, do not open.”

ENVIRONMENTAL MISPERCEPTIONS::

PAGE

Assess level of distress.

– Assess for hallucinations and delusions.

73

– Do the environmental misperceptions interfere with sleep, care, fear or worry?

Be conscious of and observe the environment at different parts of the day.

– Consider the effect of shadows.

– Ensure sufficient lighting—consider using automatic timers to make sure lights come on before the sun starts going down.

Declutter and simplify rooms.

If the individual is misperceiving some object as a person or threat, explain that you have told the person or things to leave and you will make sure they do. Indicate you have taken care of it.

EXPECTATIONS AND CAPACITY DO NOT ALIGN::

This imbalance happens when we are asking—either directly or indirectly—an individual to do more than they are capable.

This type of stress can be triggered when an individual is living alone and no longer able to manage independently or is asked to complete a task that he/she can not figure out.

Generally, it is not a good idea to test an individual to see how much he/she can remember unless it is a clinical setting for a clinical purpose.

If fears or paranoia seem to be occurring at night, consider adding supports—hiring someone, moving in with family, a family member staying with the individual or transition to a long-term care setting.

Simplify communication.
Break down tasks into singular steps.

Give protective cues.

- If an individual is being asked what he/she wants to order in a restaurant, say, “I’m having the chicken, I bet you are going to order that too; am I right?” or introduce a person by name and relationship—“Look who came to see you, it’s Mary, your granddaughter!”

FATIGUE/SLEEP CHALLENGES ::

PAGE

Engage in physical activity during the day. **60**

Avoid over-the-counter sleeping aids that have “PM” attached as often these medications have anti-cholinergic properties and may provoke or worsen agitation and confusion.

Bathe or shower earlier in the day.

Encourage a one-hour nap in the afternoon.

Incorporate relaxing music with a slow rhythm.

Offer a back, leg, arm, or hand massage.

Offer warm milk or herbal tea at rest times.

Talk with a doctor about any alcohol or substance use. Typically, it is better to limit or avoid altogether.

Talk with a doctor about the possibility of introducing melatonin or other sleep-supporting medication.

FEAR::

PAGE

Alter your communication approach. **39**

Assess for depression. **45**

Assess for overstimulation.
Reduce noise and/or activity level. **70**

Assess for hallucinations and delusions. **73**

If potential abuse or neglect is suspected,
hotline to Adult Protective Services.

If the individual does not recognize people
around him/her, make positive statements
that affirm the relationship.

— “You have been an amazing uncle and I’ve learned
so much from you.” If you are a professional,
remind the individual you know his/her family.
“I just love your wife; she is such a kind person.” Or
“Your son tells me you have been quite the camper.”

If you are a respite care provider, have the
primary caregiver leave a note indicating
you will be visiting and when the family
member is expected back. Refer to the note.

Integrate visual cues of safety—
pictures of family and friends, keep
doors locked. Incorporate elements
of the individual’s faith tradition.

Monitor what is being watched on television.

Provide regular cues to go to the bathroom.
Support if the individual has been incontinent.

Slow down.

Try diversion. Involve the individual
in a task to help you, direct to a pet,
call another person, take a walk or drive.

EXCESSIVE OR UNNECESSARY SPENDING DUE TO FORGETFULNESS::

PAGE

Assess for anxiety.

36

Declutter the environment.

Delete any saved credit card information from online retailers.

Increase activities.

Label drawers.

Make weekly list of things needed and have the individual participate in checking things off the list.

Provide structure and routine.

Reduce credit limits on any active credit cards.
Cancel unnecessary or unused credits cards.

Unsubscribe to retailers.

Assess for depression.
Consider use of an anti-depressant if sadness is consistent over a period of time and unremitted by non-pharmacological interventions.

45

Acknowledge presence of feelings.
– “It has to be hard for you.”

Acknowledge strength in the individual, including the positive ways he/she has dealt with past losses.

– “You have been a model for us.
You have made it through so many tough things.”

Attend to the verbal and non-verbal feelings expressed.

Engage in a life review of times that have demonstrated the individual’s strength.

Modify past coping strategies.

– If work or being busy was a coping strategy, engage the individual in some task. If the individual coped through gardening or taking walks, then integrate these activities at times when the individual is more likely to struggle with emotions.

Offer avenues of projection.

– Read poetry or stories with the individual and discuss feelings.

– Time slips. Explore [timeslips.org](https://www.timeslips.org).

– Watercolor or other art-related projects.

HISTORY OF TRAUMA ::



Assess the value of getting connected to psychiatry.

Consider the need to incorporate psychotropic medication.

Ensure access to things that contribute to the individual's sense of security.

Pay attention to possible triggers and avoid or minimize if possible.

Reference a separation of the past and present.

– “You have survived so many things in your life, you are so strong, I’m so glad that is over and you are safe now.”

INABILITY TO KEEP UP WITH PACE OF CONVERSATION::

If in a large group and the individual distances himself/herself from the group, encourage others to go over one at a time to talk with the individual.

Introduce the individual's opinion when known and ask for confirmation.

- “Bob loves to swim, don't you Bob?”
“Hiking in Maine was Sue's favorite vacation, wasn't it Sue?”

Limit the number of people in the group if possible.

Make sure the individual is seated by someone who is aware of dementia and who he/she can talk to.

Monitor for distress and be prepared to leave a conversation or situation early if needed.

Slow down the pace of conversation.

INABILITY TO SIT FOR LENGTH OF TIME ::

PAGE

Assess for depression and treat accordingly. **45**

Assess for level of distractions in the environment.

Consider the comfort level of the chair. Look for indicators of physical pain.

Consider where the individual is going or what he/she is doing. If the inability to sit is about constantly getting up to peer out of windows, this could indicate psychosis. Respond accordingly.

If the individual is going to bathroom frequently, this could indicate constipation or UTI. Respond accordingly.

Incorporate noise-reduction headphones and music to reduce attention to external cues.

Make note of any patterns in terms of time, place or activity.

Provide nutritious finger foods.

Provide something with an interesting texture for the individual to hold.

Sit with the individual while eating to provide visual support for staying at the table.

The activities or tasks may not interest the individual. Alter to match interests and stages of the disease.

INADVERTENT CAREGIVER OR ENVIRONMENTAL CUE—CAREGIVER APPAREL, TELEVISION, ETC.::



If comments are made, find a reason that the individual should change the environment—room, aisle, errand—to assist in distraction.
— “I could use your help...” or “I just remembered we need to...”

If in public, direct the individual's attention or line of sight away from those who may have low-cut or revealing clothing.

Instruct visitors and hired caregivers to dress in a conservative manner.

Monitor what is on television and divert away from movies that might trigger an inappropriate reaction.

INSECURITY::

PAGE

Provide structure and/or routine.

63

Add support services.

Direct conversation into those areas where the individual feels confident.

Don't talk about the individual in front of him/her.

Engage in activities the individual is able to manage.

Space out appointments outside the home.

Utilize a whiteboard or large calendar to note the schedule for the day.

INSUFFICIENT PHYSICAL ACTIVITY::

Consider a fitness tracker to count steps and engage the individual in reaching a goal.

Consider walking distances when doing errands—park a little farther away or extend the number of aisles you are walking through.

Encourage the individual to do things around the house that require movement.

Engage grandchildren in doing chair exercises with the individual, which can add a positive experience for both.

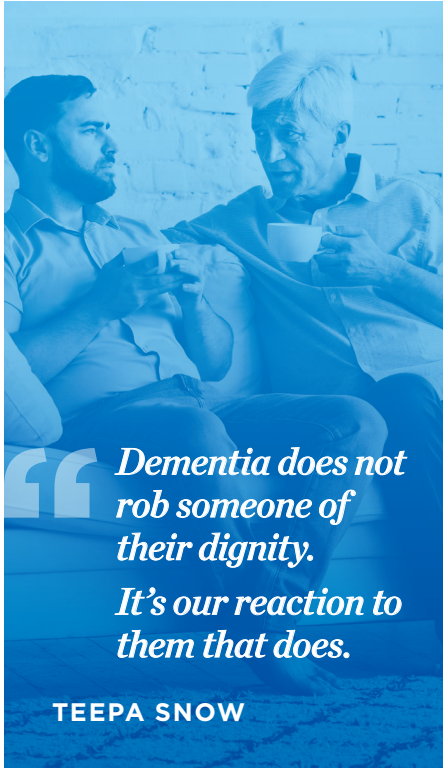
If dancing has been a past and pleasurable experience, play familiar songs and dance.

If the individual has Lewy Body Dementia, consider programs like Rock Steady.

Integrate neighbors, friends and others in walking with the individual.

Schedule time to walk and indicate it is a part of therapy. It is!

LACK OF APPROPRIATE PHYSICAL AFFECTION ::



Hold the individual's hands—which supports appropriate physical affection while limiting the ability to inappropriately touch.

If the individual is aware you are there, hug from behind.

Pat or briefly rub the individual's back at times such as when he/she sits down to eat.

Provide gentle touch through use of hand or foot lotion.

LACK OF PURPOSE ::

PAGE

Provide structure and routine help.

63

Ask the individual's opinion about something.

Consider "an assistant" to support the individual in simple volunteer tasks.

Find tasks to sort or organize.

Incorporate language about helping you or others in everyday tasks.

Make homemade dog treats together and take them to the dog shelter.

LACK OF STRUCTURE AND ROUTINE ::

Ask friends/family to routinize their visits.
Many individuals cannot visit weekly but would be willing to do so on a monthly basis.
Make one morning or afternoon the “visitor day.”

- Wednesday afternoon is scheduled for friends.
One friend comes the first Wednesday of the month, another comes the second Wednesday of the month, etc.

Create a weekly schedule that includes everyday tasks, social events, and physical activity.

Go to bed and get up at about the same time.

Make sure to schedule something that you anticipate would be enjoyable to do together.

Schedule rest periods or naps.

LEVEL OF CAREGIVER FATIGUE OR DEPRESSION IMPACTING RESPONSES::

Address caregiver depression which can affect one's ability to sleep.

Consider support groups.

Do not attempt difficult tasks, such as helping with baths, when you are worn out.

Expand the care team!
Incorporate respite assistance earlier rather than later.

If the individual you are caring for is up at night or not sleeping, talk with a healthcare provider.

In some cases, it is a time to consider placement options.

Make a list of things that you would like to do if you had the time and make a plan to do at least one every week.

LONELINESS::

There are two types of lonely: social loneliness which refers to lack of interaction with others and emotional loneliness which refers to a longing for something/someone.

PAGE

Assess for possible depression.

45

Add activity and/or structure.

63

Consider adult day programs.

Create and use DVDs of family/friends talking about good memories.

Encourage routine visits from friends and family on a structured, realistic basis.

Ensure access to the individual's faith-based practices.

If the individual is unable to have a pet, have pet visitors or visit petting zoos.

Incorporate talking photo albums.

Offer appropriate affection.

LOSS OF ABILITY TO CONTROL IMPULSES::

Various dementias damage the part of the brain that serves as the filter between thought and action. In Alzheimer's disease, this occurs in the middle stages.

PAGE

Monitor for depression.

45

Reduce environmental stimuli.

70

Monitor for hallucinations and delusions.

73

Create and use a business card that says, "My companion has a dementia; please be patient." and discreetly give the card to people who may be confused or react to the individual's behavior.

– This might include restaurant servers, airline attendants, grocery store clerks, etc.

Divert away from circular conversations. Do not continue to try to convince the individual of something.

– "Whoops, time has gotten away from me, I need to get started on dinner." or "That makes me think of the time you tried to teach me to..."

Do not scold or correct.

Monitor environmental cues.

Practice good communication skills.



The first two rules of becoming a caregiver: One, it will be difficult. Two, it will be worth it.

LAURA FINNEY

PAGE

Monitor for depression.

45

Provide structure and routine.

63

Ask the individual's opinion about safe things.

Do not ask "Do you want to..." if no is not the answer you want. Instead, give statements of instruction in an encouraging way.

- "I've got lunch all ready for you. Come sit with me and keep me company."

Integrate language about the individual's long-standing opinions about how to do things.

- "I know you always want to look your best when we go to Mary's, so I've got everything laid out."
"You have always taught us about family helping each other and I want you to know I listened, and we are going to do this together."

MISIDENTIFICATION OF CAREGIVER::

PAGE

Assess for depression.

45

Divert the conversation to who the individual perceives you are.
“Tell me about how you met your wife.”

Integrate name and relationship upon greeting.
“It’s me, Mary, your daughter.”

Redirect into conversation about a task that needs to be done.

Voice recognition is sustained longer than visual recognition. Go into another room and call the individual and indicate that you arranged a person to stay with him/her and you will be home soon.

MODESTY ::

Discuss things important to the individual while engaged in bathing or helping with toileting, such as family, stories about the past or memories of something fun you did together.

Introduce washable incontinence underwear early on when problems first present, then convert to incontinence products when the situation worsens.

Talk through individual steps.

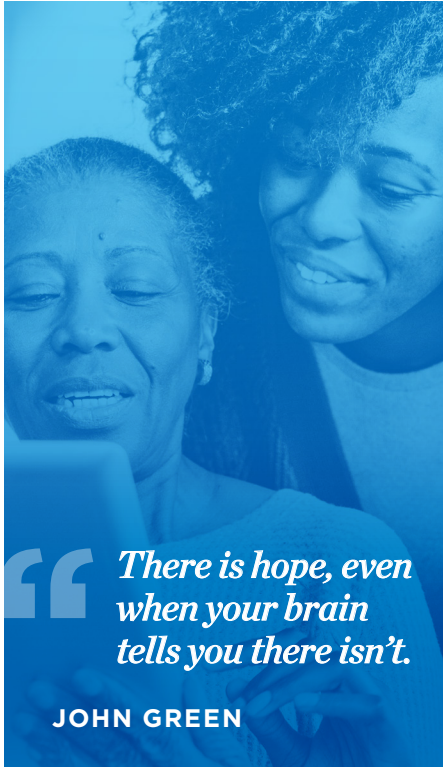
Use language about doing personal care together.

Use medical-sounding language to de-personalize.

– “The doctor told me we need to use this special soap to help with your skin integrity.”

Use towels to help cover the individual so he/she does not feel so exposed.

OVERSTIMULATION ::



Allow quiet time between activity or events.

Limit choices.

Limit the number of visitors, including young grandchildren.

Reduce noise and bright lighting.

Slow down and do not rush the individual.

Support the individual retreating to their room when needed.

OVERWHELMED BY NUMBER OF PILLS OR FOOD CHOICES ::

Consider reduction of optional pills, such as vitamins, in consultation with a healthcare provider.

Explore if medication can be spread over time. Instead of eight pills at one time in the morning, perhaps give three pills at 9:00 a.m., three pills at 9:30 a.m. and two pills at 10:00 a.m.

If there is an imbalance between morning and afternoon medications, see if any can be divided differently.

Explore if medication can be divided and given in different locations.

—Some pills given when first awake, some at the breakfast table and some given once the individual moves to another chair or room.

Give pills one or a few at a time while sitting with the individual watching television. Commercials provide a good opportunity for pill-taking.

If the individual is not eating, try giving one food item at a time.

Ensure that the food served can be eaten with the same utensil.

Transition away from asking what the individual wants or if he/she is hungry.

In restaurants, provide cues for the individual as to what he/she might order.

PAIN::

Pay attention to nonverbal cues of various types of pain (accurate verbal reports may or may not be possible). Types of pain include:

- Intermittent
headaches, virus, GI reflux, etc.

- Dental
dentures not fitting, cavities, infection, sores, etc.

- Acute
angina, compression fractures, bowel impaction, urinary tract infections, etc.

- Chronic
Back pain, sciatica, arthritis, restless leg syndrome, etc.

Give the individual water after bites of food.

Have dentures checked regularly, especially if weight loss has occurred.

Offer a warm bath.

Pay attention to the length of time the individual is sitting in one position.

Position cushions.

Provide a quiet environment.

Seek guidance from a healthcare provider.

Utilize prescription-strength fluoride toothpaste.

PSYCHOSIS: DELUSIONS AND HALLUCINATIONS::

Delusions refer to beliefs that are not based in reality. Hallucinations refer to the experience of seeing, hearing, or smelling something/someone that no one else sees, hears or smells.

At times, psychosis can be accepted and is not a negative experience. At other times, it is distressing and frightening.

Consider criteria on page 9.

PAGE

Assess for depression.

45

Assess for delirium caused by urinary tract infections or other medical condition.

Assess for prior mental health issues.

Assess the environment.

Is there furniture or items that are being misperceived, such as a person for a coat rack or an animal because of clothing on the floor. If so, either remove or camouflage.

Be aware of the television shows the individual is watching.

Reduce or eliminate news, crime shows or talk shows if contributing. Replace with shows the individual is familiar with, sports, musicals, positive documentaries or Hallmark-type movies. All of these limit the need for understanding storylines or remembering new characters.

If abuse or neglect is suspected, hotline the concern to Adult Protective Services.

Make sure the individual is capable of what is being expected of him/her. For those living alone, psychosis can be a sign that he/she no longer feels safe or secure living independently.

No family arguments should occur in front of the individual. Family members should not put the individual in the middle of disagreements.

It is common for family to see things differently—encourage family meetings away from the individual with dementia to discuss issues about care, support and grief.

Reassure the individual that he/she is safe, and you will be there for him/her.

SENSORY IMPAIRMENT::

For vision impairment.

- Attend to potential shadows.
- Consider talking books.
- Ensure sufficient lighting.
- Integrate music.
- Integrate tactile activities.
- Talk through what is happening or who is around in a way that can be understood.
- Use contrast.

For hearing impairment.

- Face the individual when you speak.
- Know if one ear is better than the other.
- Speak up so the individual can hear.
- Use physical gestures.
- Utilize a dry erase board or technology to assist in communication.

INABILITY TO IDENTIFY SCAMS/SCAMMERS::

Block websites.

Cancel credit cards, as appropriate.

Increase supervision in the home.

Look for clues of worrisome acquaintance or stranger behavior.

— Add cameras in the interior of the home.

— Monitor unrecognized expenditures.

— Utilize cameras at the front door or frequently-used entrances to understand who is visiting.

— Watch for missing checks.
Limit checks available to the individual.

Make sure a trusted person has durable power of attorney.

Make sure the durable power of attorney or a family member has a copy of the will.

Place the individual on “no call” lists.

Place the individual’s social security card in a secure place.

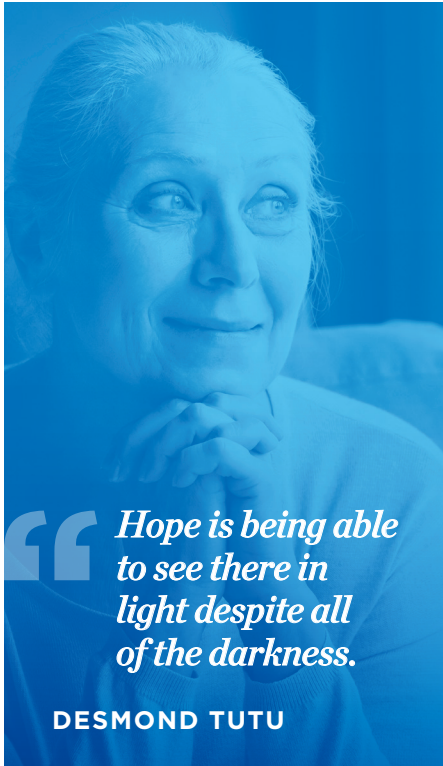
Reduce limits on credit cards, as appropriate.

Review calls received on individual’s cell phone and block calls not recognized.

Switch bank accounts—maintain only a limited amount in account being used by the individual with dementia.

Unsubscribe to store or company emails.

VISUAL-SPATIAL CHALLENGES::



Ensure color differentiation between the toilet and the surrounding floor.

Reduce glare.

Reduce or eliminate patterns on chairs, flooring, tablecloth, etc.

Use colored painters' tape to help define steps.

Use solid-colored placemats to differentiate the plate from the table.

Use verbal cues.
— “Step up just a little more.”