

The Neuropsychiatric Symptoms of Dementia:

*A Visual Guide to
Response Considerations*

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About the Guide:

This guide is a product of the collective experiences of those who have contributed to and reviewed this tool. It does not, nor could it, include all possible considerations or interventions needed to help a person with dementia. Each person with dementia brings their own history, personality, medical conditions, family, coping styles and many other issues that require attention, analysis and commitment in order to support quality of life through the disease process.

Following general definitions and information about the neuropsychiatric symptoms of dementia, subsequent sections will direct you to specific considerations. It is hoped that this guide will offer ideas and conversations to help people with dementia.

Contents:

SECTION I: General Behavior Information

This section describes the common behavioral challenges seen in the disease and the disease contributions that place individuals at risk for these challenges.

SECTION II: Possible Reasons for Specific Neuropsychiatric Challenges

This section allows you to go to the specific affective or behavioral challenge to be addressed and identifies some of the many possible reasons.

SECTION III: Interventions

This section provides possible interventions for many of the challenges identified in Section II.

SECTION IV: References and Resources

There are many valuable resources that address the neuropsychiatric issues of dementia and various interventions. This section identifies additional sources of information.

SECTION V: Alzheimer's Association Services

About Dementia:

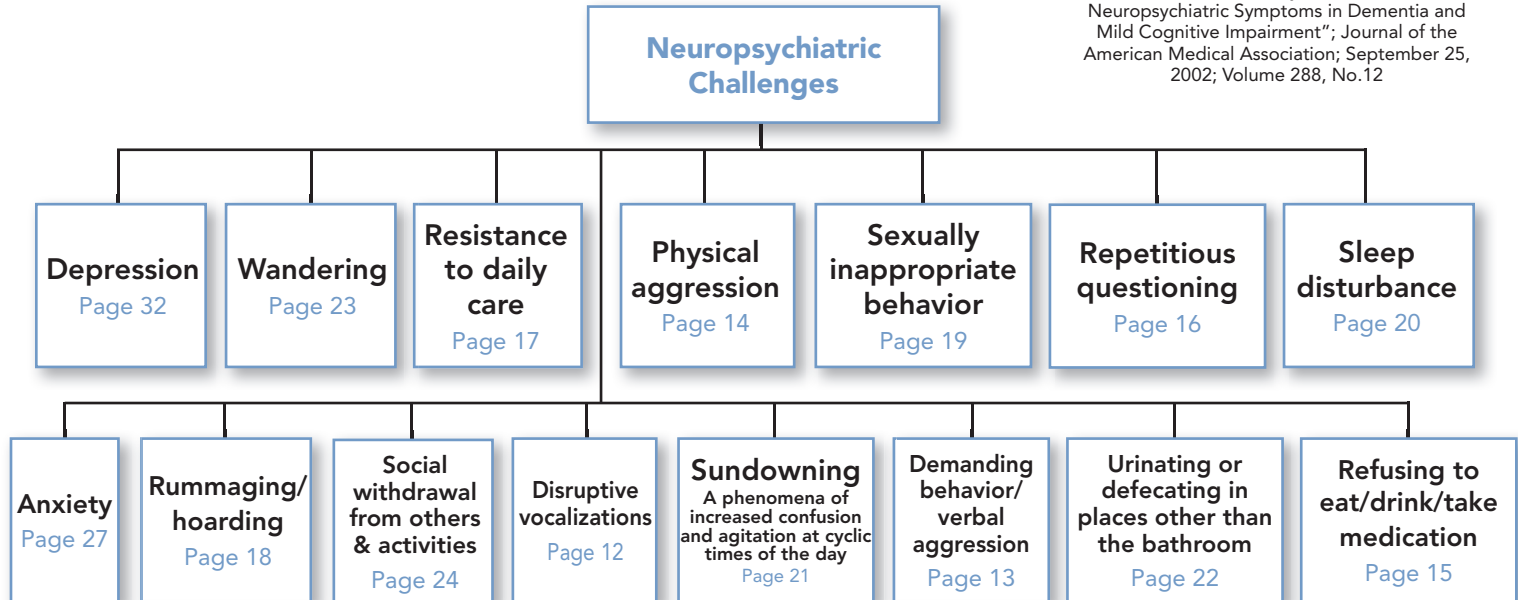
The term “dementia” simply means that a progressive neurological disease is present. There are many types of dementia. Alzheimer’s disease is the most common type. While the dementias may present with some common symptoms and may result in the same conclusion, how each of these diseases move through the brain can be different and requires caregivers to be informed in the unique type of dementia present. Informed and prepared caregivers often result in reduction or avoidance of foreseeable crisis. A thorough dementia evaluation can assist in not only narrowing the type of dementia, but also preparing individuals and families in how to live with disease. It includes a brain scan, blood work, lab work, cognitive testing and a complete clinical history. Physicians may order additional tests as well. While affective and behavioral symptoms, especially depression, can occur at any time depending on the medical and environmental context, the highest risk for the neuropsychiatric symptoms occurs in the middle stages of the disease and beyond.

Section I

General Behavior Information

"80% of individuals with a dementia will experience neuropsychiatric (behavioral and affective) symptoms. The many serious consequences of these complications are greater impairment in activities of daily living, more rapid cognitive decline, worse quality of life, earlier institutionalization and greater caregiver depression."¹

¹ Lyketos, C., Lopez, O., Jones, B., Fitzpatrick, A., Breitner, J., DeKosky, S.; "Prevalence of Neuropsychiatric Symptoms in Dementia and Mild Cognitive Impairment"; Journal of the American Medical Association; September 25, 2002; Volume 288, No.12



Disease Vulnerabilities to Behavioral and Affective Challenges

While the disease exposes risk to these challenges, when they occur, it is never the case that we terminate further exploration and understanding simply because they have the disease. Instead, caregivers and clinicians must heighten their calculations of possible contributing factors and interventions. That is an important part of supporting quality of life.

Visual spatial deficits

Depth perception can be affected very early on in the disease. In middle stage, it can interfere with a sense of where one is in relationship to others.

Damage to executive functions

Logic, cognitive flexibility (ability to shift from one topic or activity to another), judgment, insight, decision-making, interpreting social cues.

Damage to the "filter"

Related to declines in executive functions, the "filter" between thought and action breaks down and people may say or do whatever comes into their mind.

Damage to communication centers

Word finding, word substitution and following a train of thought becomes increasingly challenging as does understanding the words spoken by others.

Decreasing access to historical coping strategies

Everyone has coping patterns, whether it be sitting quietly alone, reaching out to friends, work, etc. Many individuals in the middle and later stages of Alzheimer's disease do not have access to those strategies that have helped them cope with difficulties.

Damage to the sleep/wake regulator of the brain

Loss of directional map

The disease damages the part of the brain that helps one find their way around.

Loss of noise filter

Noises are not prioritized. Multiple noises meld together and can be distracting and distressing.

Inability to multi-task

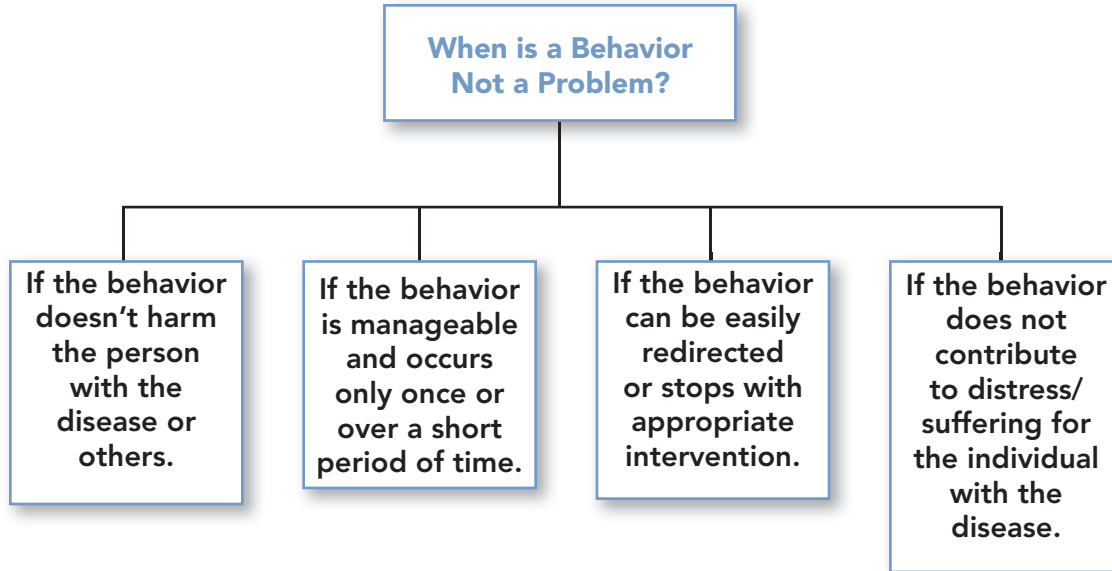
Alzheimer's limits the mind's ability to attend to more than one thing at a time.

Damage to short-term memory

Short-term memory is primarily found in one area of the brain. It is the area the disease attacks early on and is progressively impacted. Long-term memory, which is dispersed all over our brain, is preserved through a significant part of the disease.

Damage to emotional center

Individuals with Alzheimer's are at high risk for depression, as well as mood instability unrelated to depression. Individuals therefore have a lower threshold for becoming frustrated.



Affective and behavioral symptoms are problematic when they interfere in quality of life, including ability to absorb enjoyable elements around them, to receive care, and to utilize the strengths and abilities that they continue to possess.

Medications

While environmental interventions and therapeutic care may reduce or negate the need for pharmacological intervention, there are times incorporating medication as part of a treatment plan for individuals going through behavioral and affective challenges is necessary. It is important to understand general types of medications utilized in order to avoid an automatic default to anti-psychotics and anxiolytics. There may be circumstances where an individual's medical status or long-term belief system precludes incorporation of pharmacological interventions. Further, all medications carry with them potential side effects. Dialogue with families about risk/benefit profile should occur around the use of any medication. When prescribing such medication, those with less potent side effects should be attempted first; often that means antidepressant trial. Careful assessment of these drugs is always important. At times, primary physicians may prescribe such medications. However, in situations where multiple psychotropic medications are on board, intolerable side effects occur, or challenging behavior persists, securing opinion from a geriatric psychiatrist may be indicated. Further, medication response may change or decline over time necessitating re-evaluation of medications. The need for medications should be reevaluated on an ongoing basis.

Types of psychotropic medications include:

- ***Antidepressants***

Antidepressants target the set of symptoms that constitute depression — such as irritability, negativity, anxiety, resistance, agitation, sadness, sleep disturbance, expressions of worthlessness/desire to die, and appetite changes. Symptoms of depression can even include paranoia and other forms of psychosis.

- ***Mood Stabilizers***

Mood stabilizers, such as Depakote and Neurontin, are given in this population to assist in management of agitation and aggression. While evidence regarding the significance of their benefit is lacking, their use is often associated with attempts to minimize or avoid use of the antipsychotic medication.

- **Anti-anxiety Agents**

Anti – anxiety agents may be indicated in short-term crisis situations, in individuals who have had struggled with long standing generalized anxiety disorders in their life prior to dementia, end of life situations and in people with Parkinson’s disease or other movement disorders. They can provoke paradoxical effects, increase fall risk, increase confusion, and negatively impact function.

- **Anti-psychotic Medications**

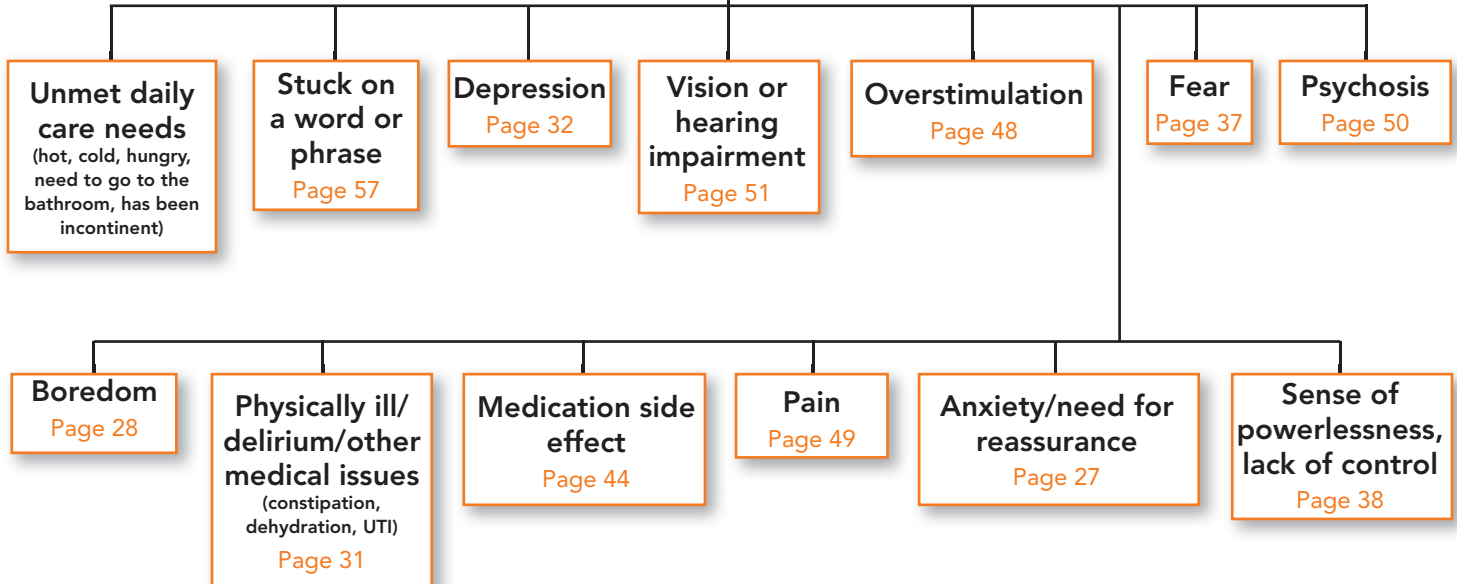
The newer anti-psychotic medications such as Risperidol, Zyprexa and Seroquel may be utilized as part of the treatment for the behavioral consequences of dementia. While their use may be unavoidable, all other possible interventions should be attempted first in order to minimize or negate use of this class of medications. They do have serious potential side effects including increased risk of death and, as with any medication, risk/benefit profile should be discussed with family.

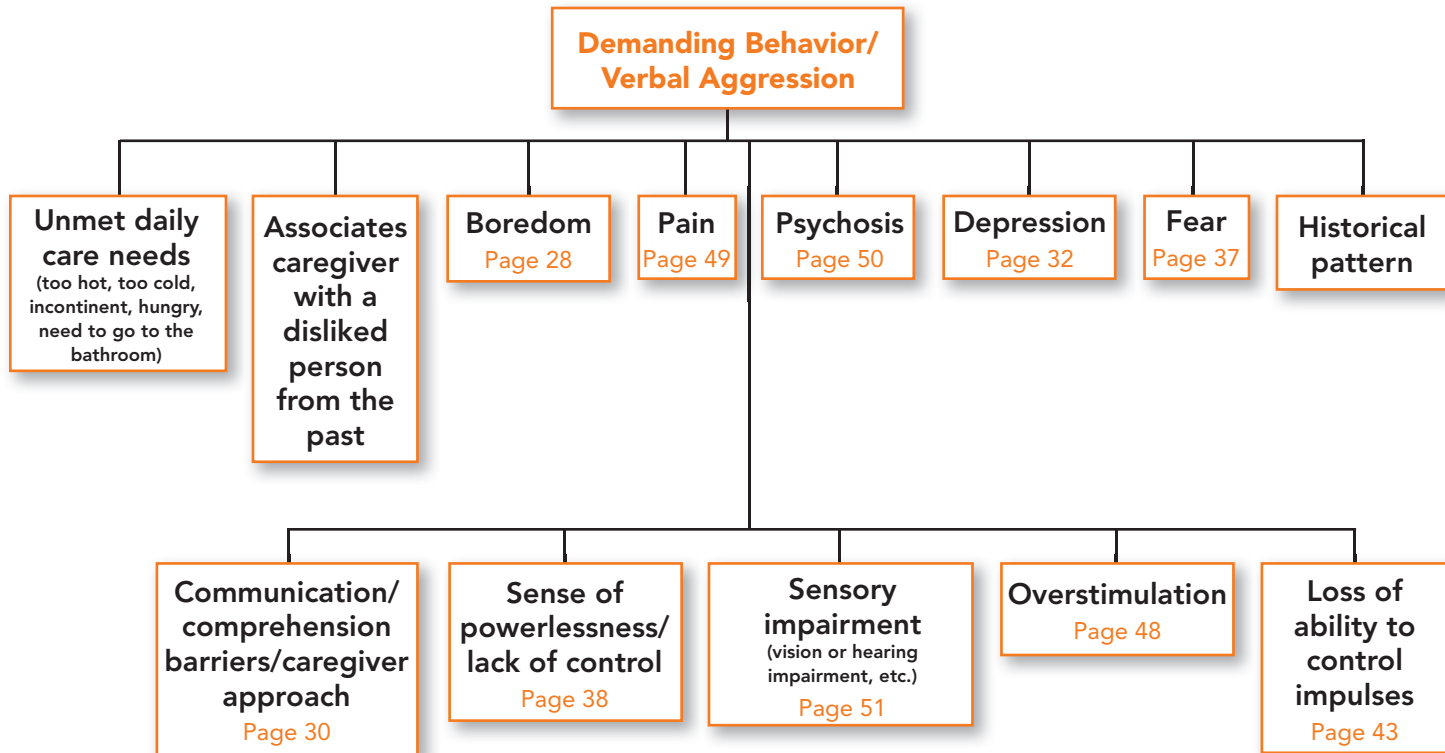
Careful monitoring of these medications is always necessary. They often require titration, many require withdrawal protocol, and they may or may not be required for extended amounts of time. Medication should not be used as a substitute for good care, for activity or for medical assessment, nor is the goal sedation. Decisions to incorporate such medication are based in the commitment to reduce suffering and improve quality of life. Incorporation of appropriate medication may extend the family’s ability to care for the person at home, may reduce safety risks to the person and others and may prevent premature disability.

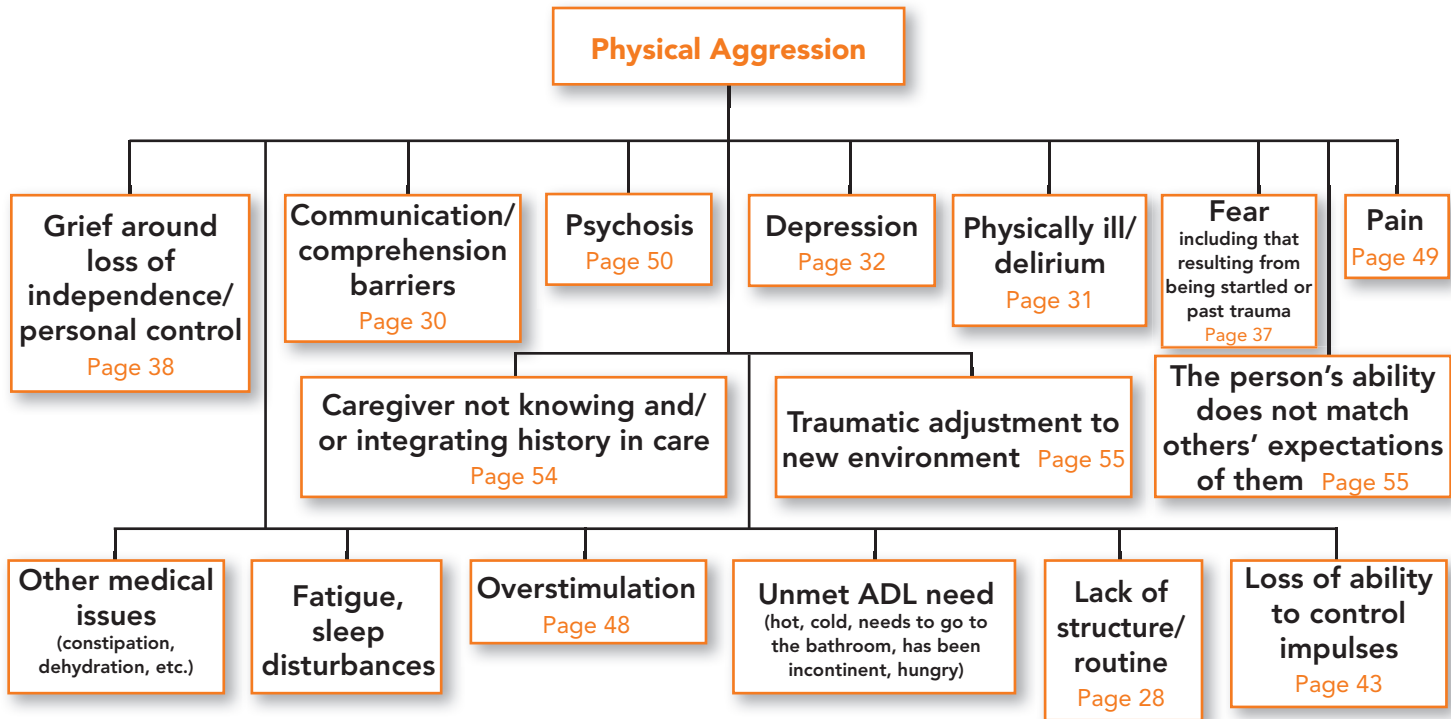
Section II

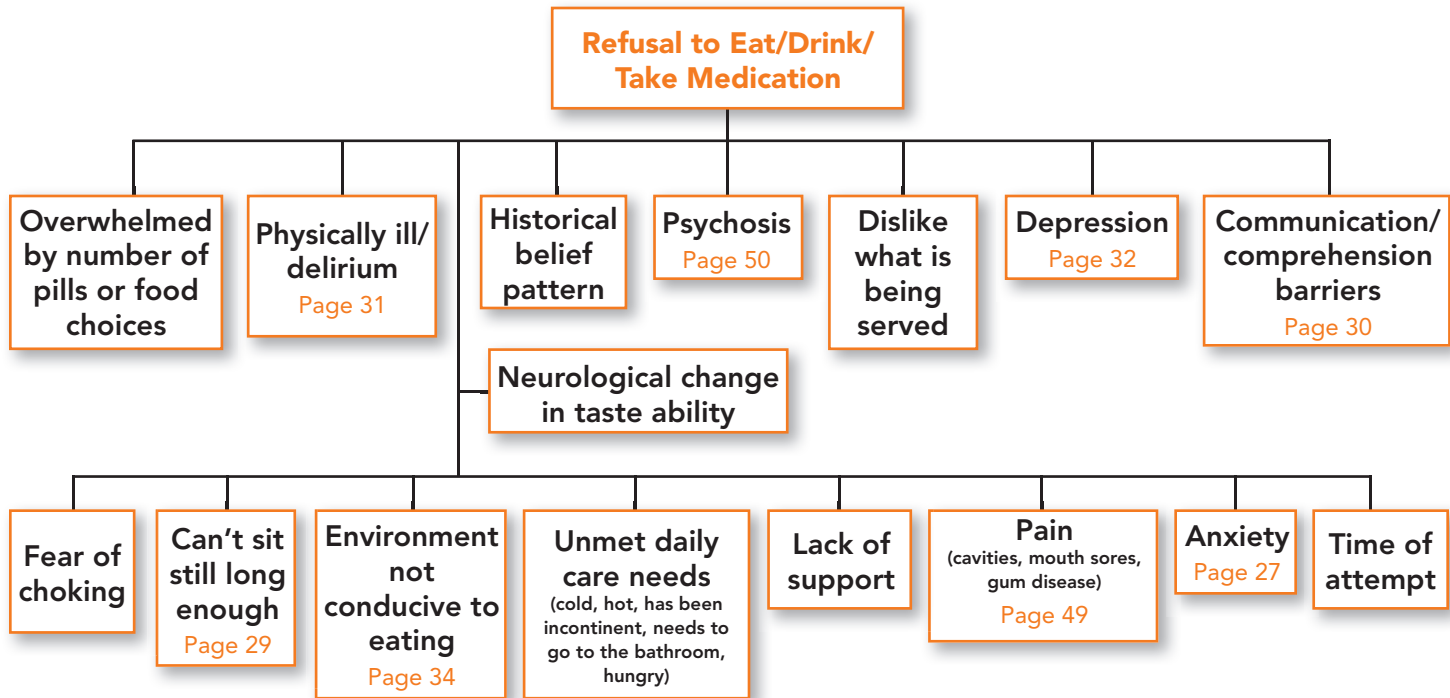
Possible Reasons for Specific Neuropsychiatric Challenges

Disruptive Vocalizations



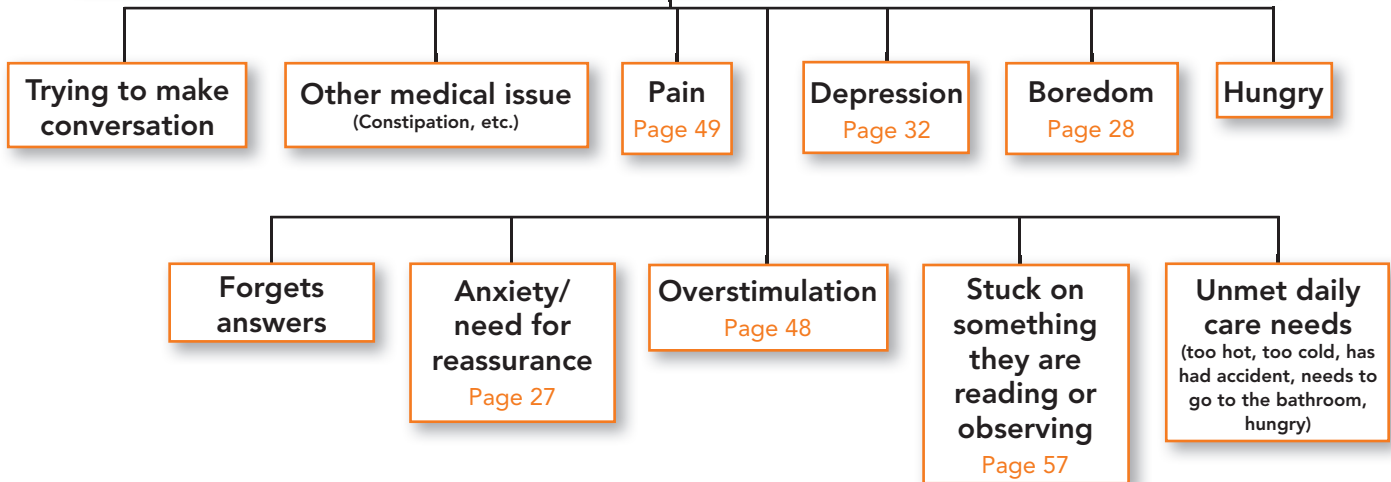


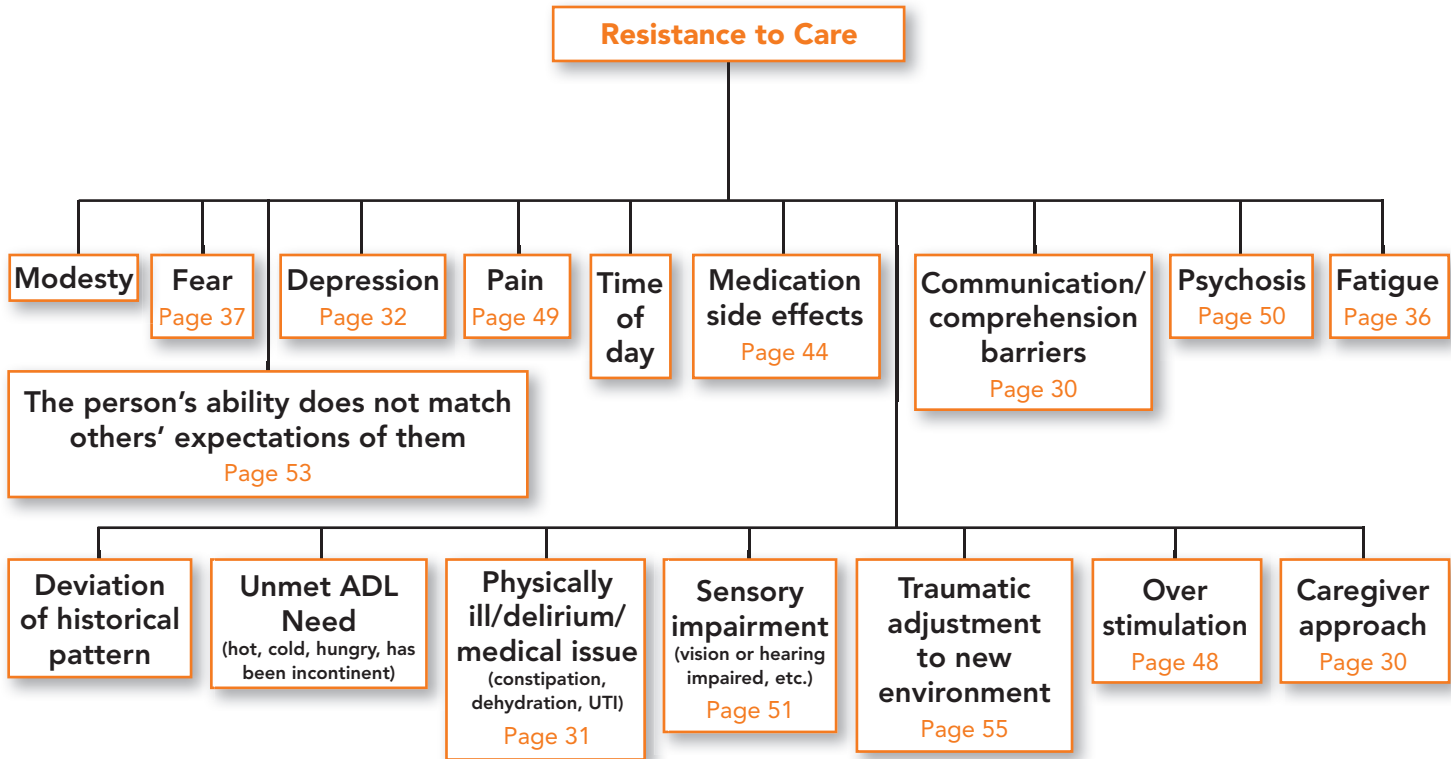


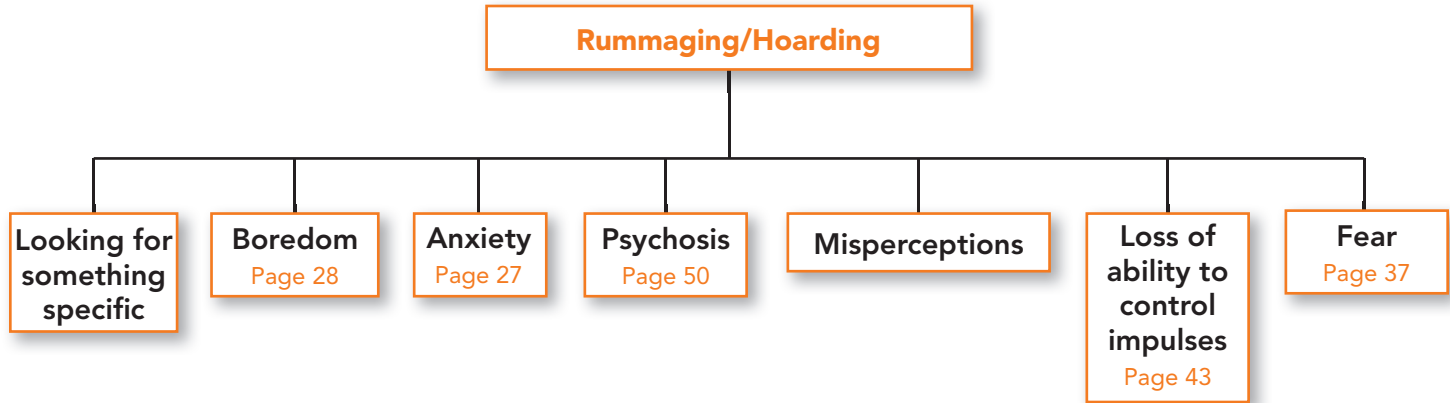


Repetitious Questioning

Due to the prominent nature of short term memory loss in this disease, asking questions multiple times is common and expected. It is important to be attentive to the specific features of the repetition. How many times and for how long are the same issues/questions repeated may add some insight. Facial expressions and tone indicating distress are important features to pay attention to and may indicate other issues.

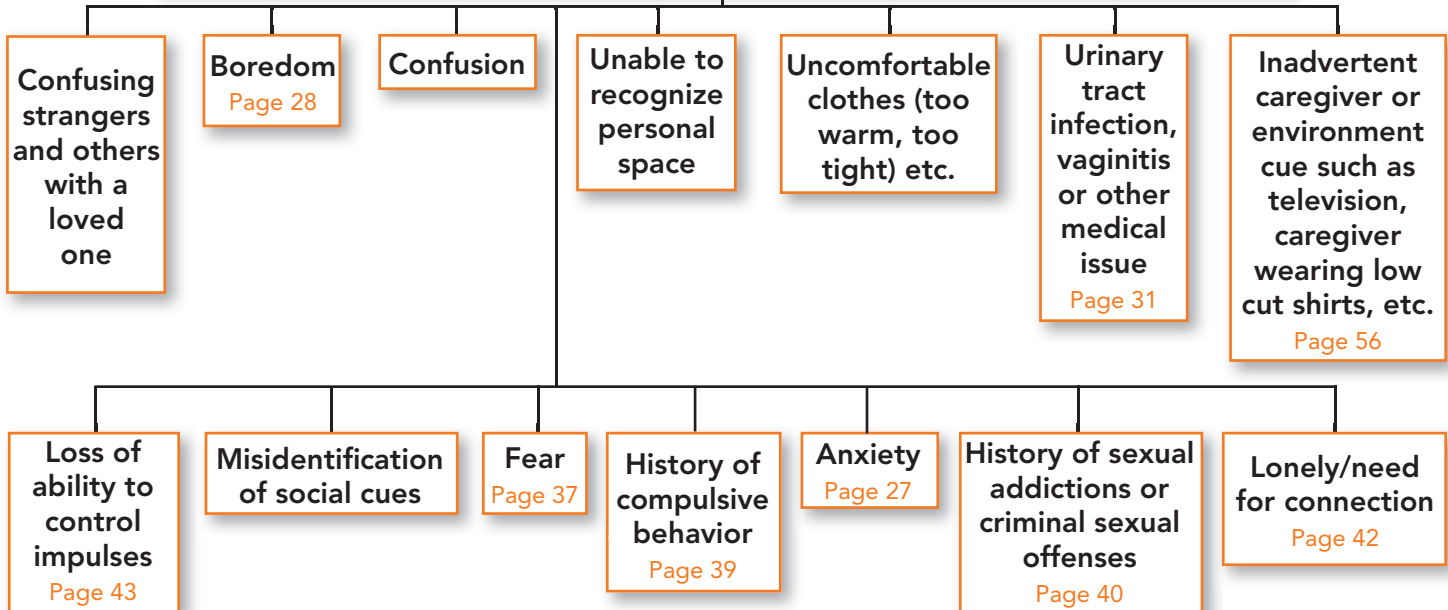


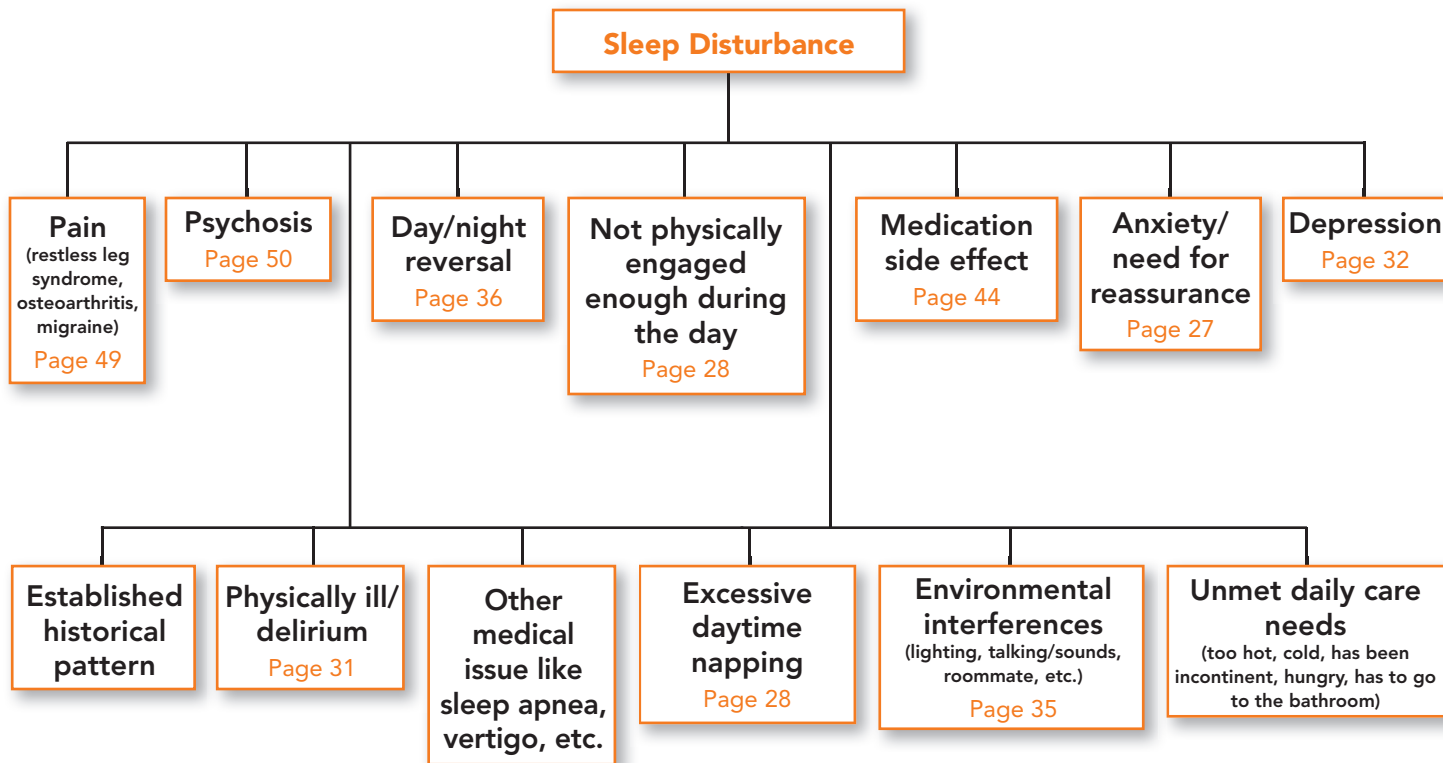




Sexually Inappropriate Behavior

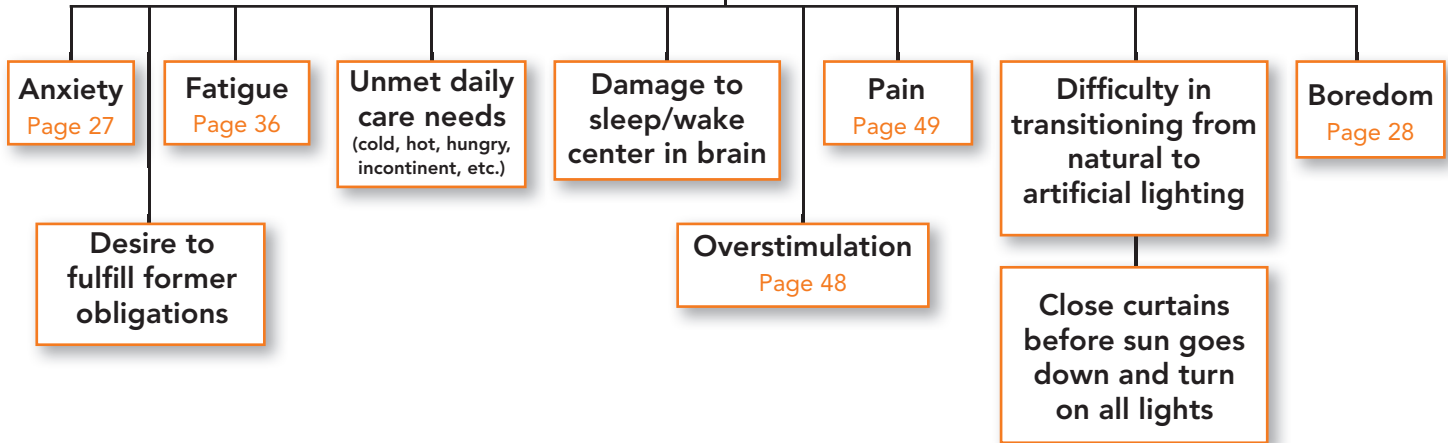
Behavior, seemingly sexual in nature, may or may not have sexual intent. Further, sexual expression in a person with Alzheimer's disease does not necessarily constitute inappropriate behavior. Identify the behavior specifically and consider a range of non-sexual considerations.



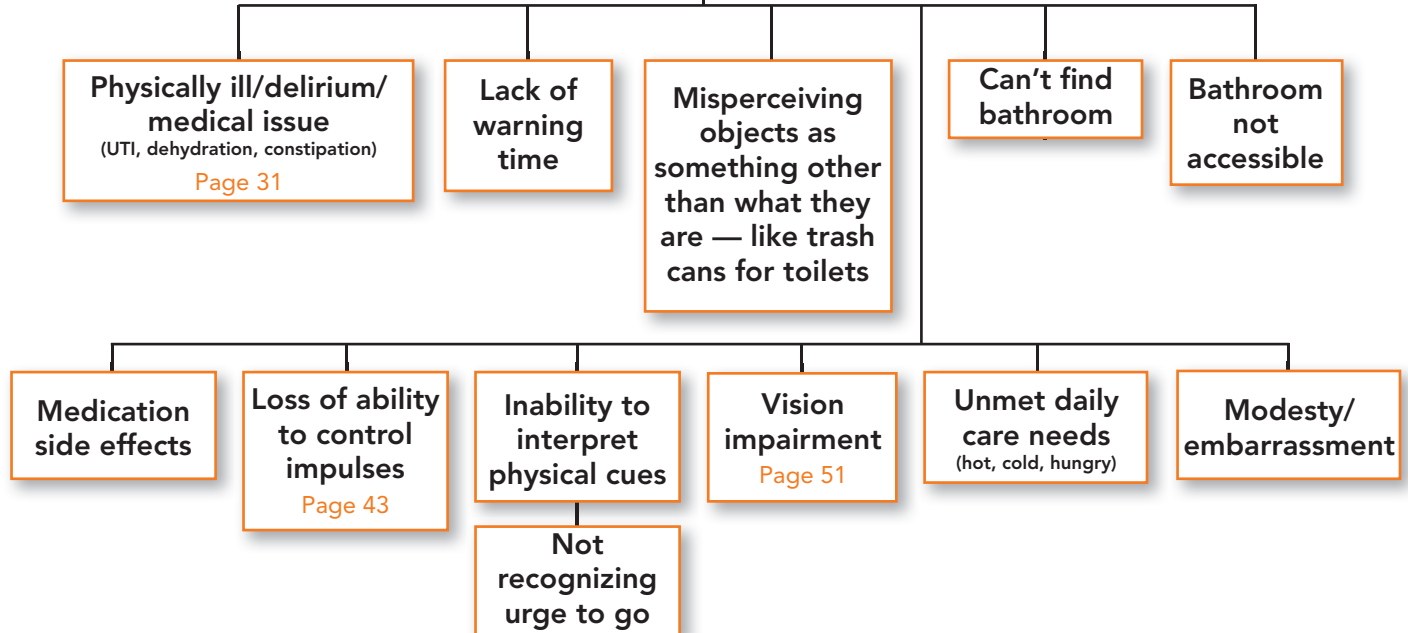


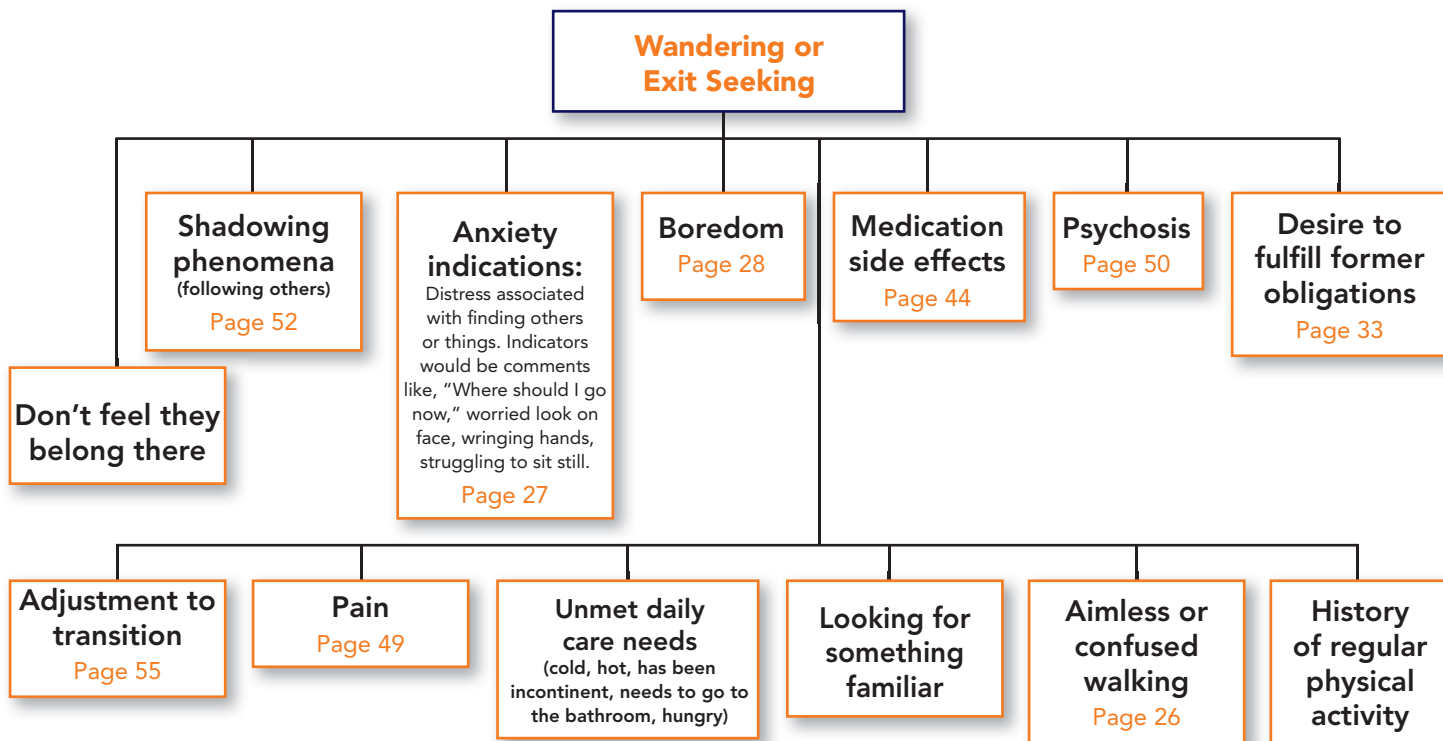
Sundowning

Agitation/restlessness/worsening cognition that occurs at cyclic times of the day.

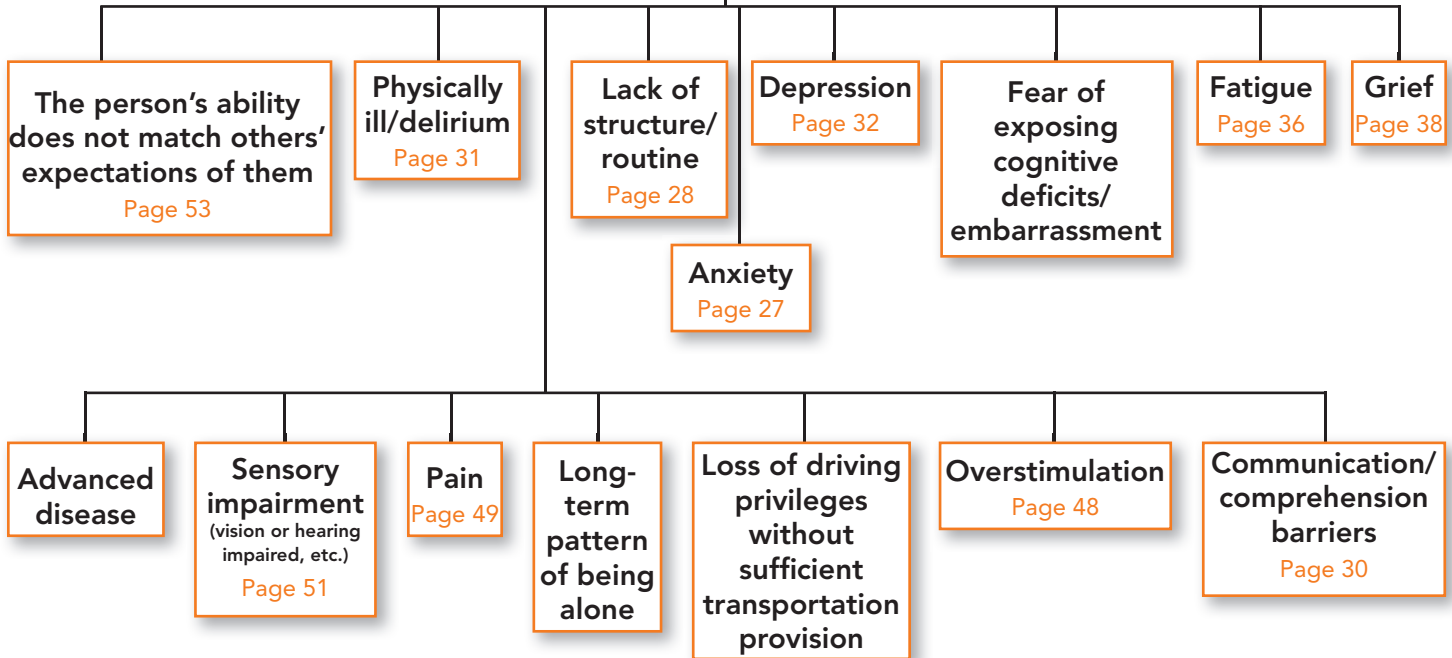


Urinating/Defecating in Places Other Than the Bathroom





Social Withdrawal from Others and Activities

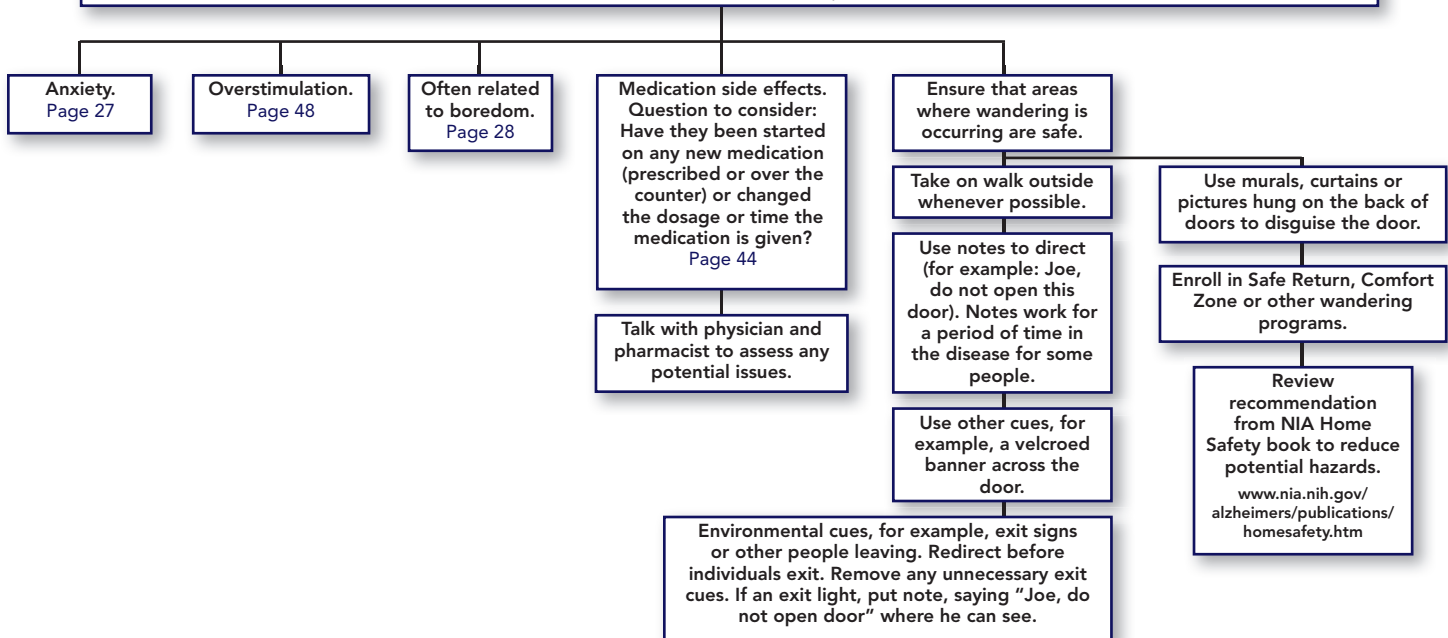


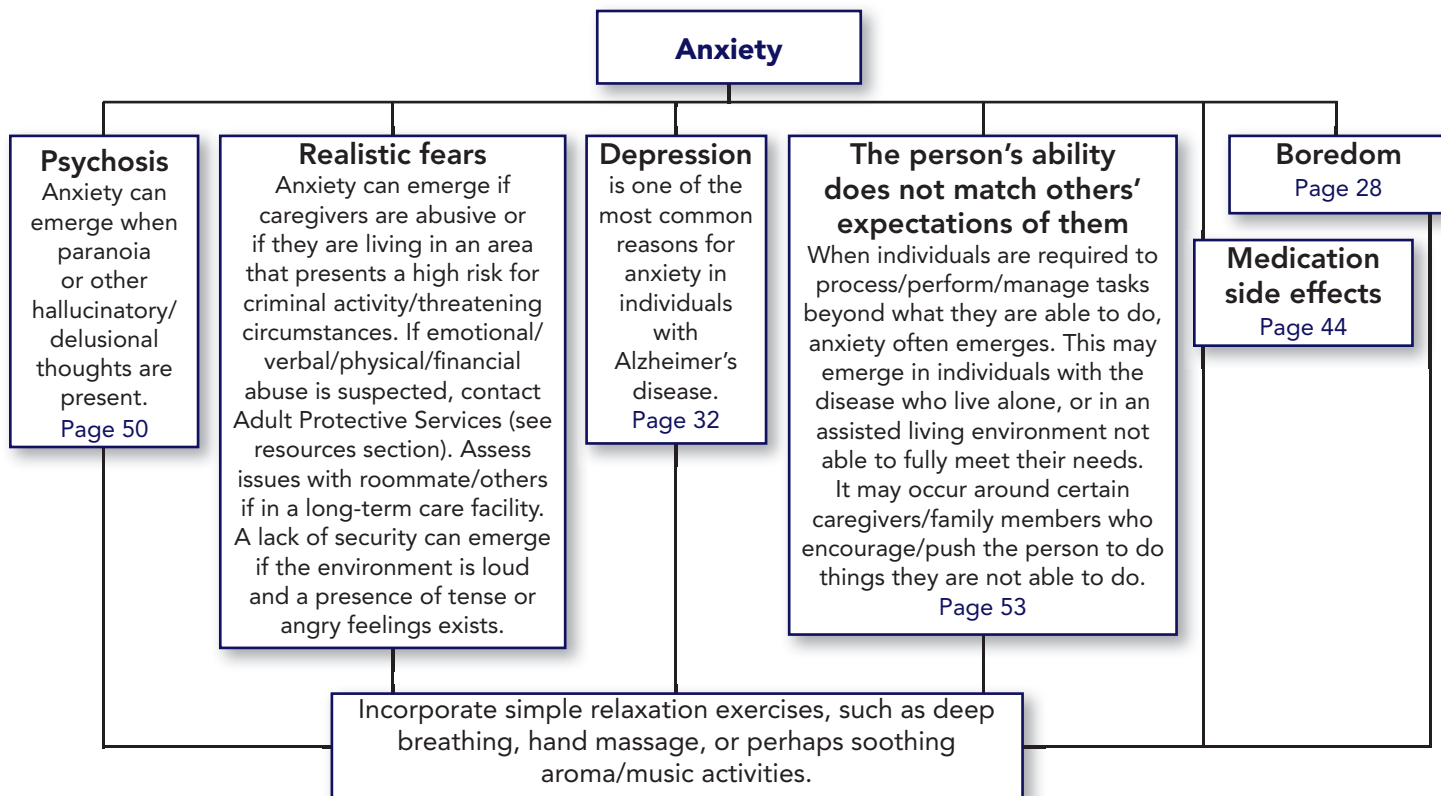
Section III

Interventions

Aimless or Confused Wandering

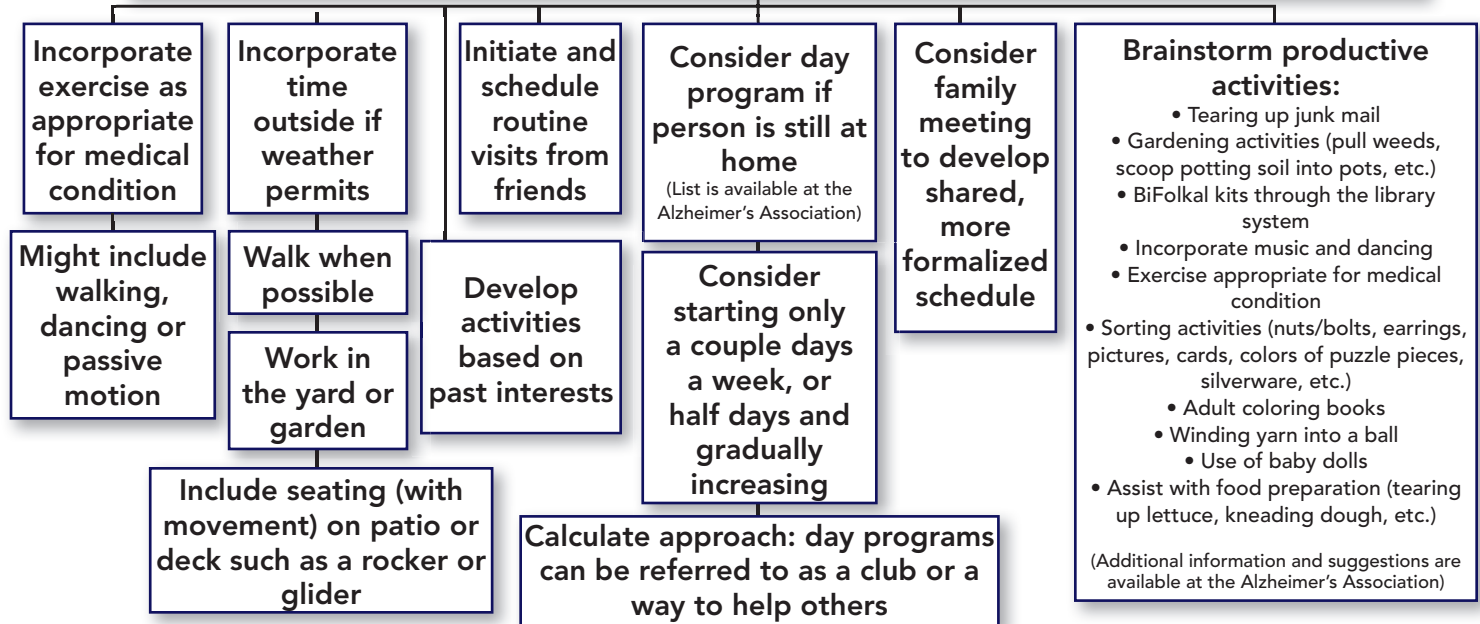
It is generally considered to be a positive for individuals to remain walking through much of the disease. It reduces fall risk, can reduce anxiety, can improve sleep, and represents productive activity. Walking around can provoke some challenges if the person is at home or in an environment that may present elopement risk, however. Aimless walking means that it is not because of psychosis, a search to fulfill previous responsibilities such as searching for mom, or other defined clear explanation.



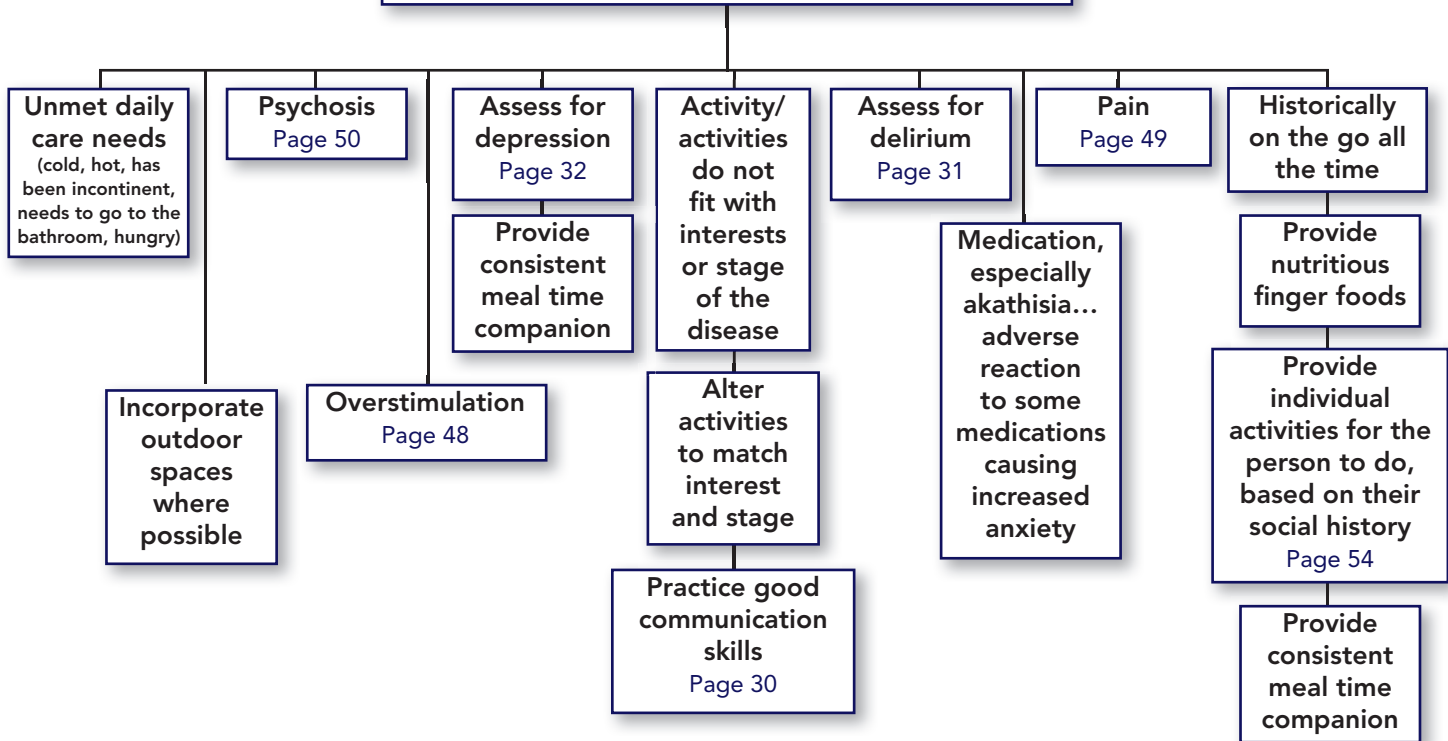


Boredom

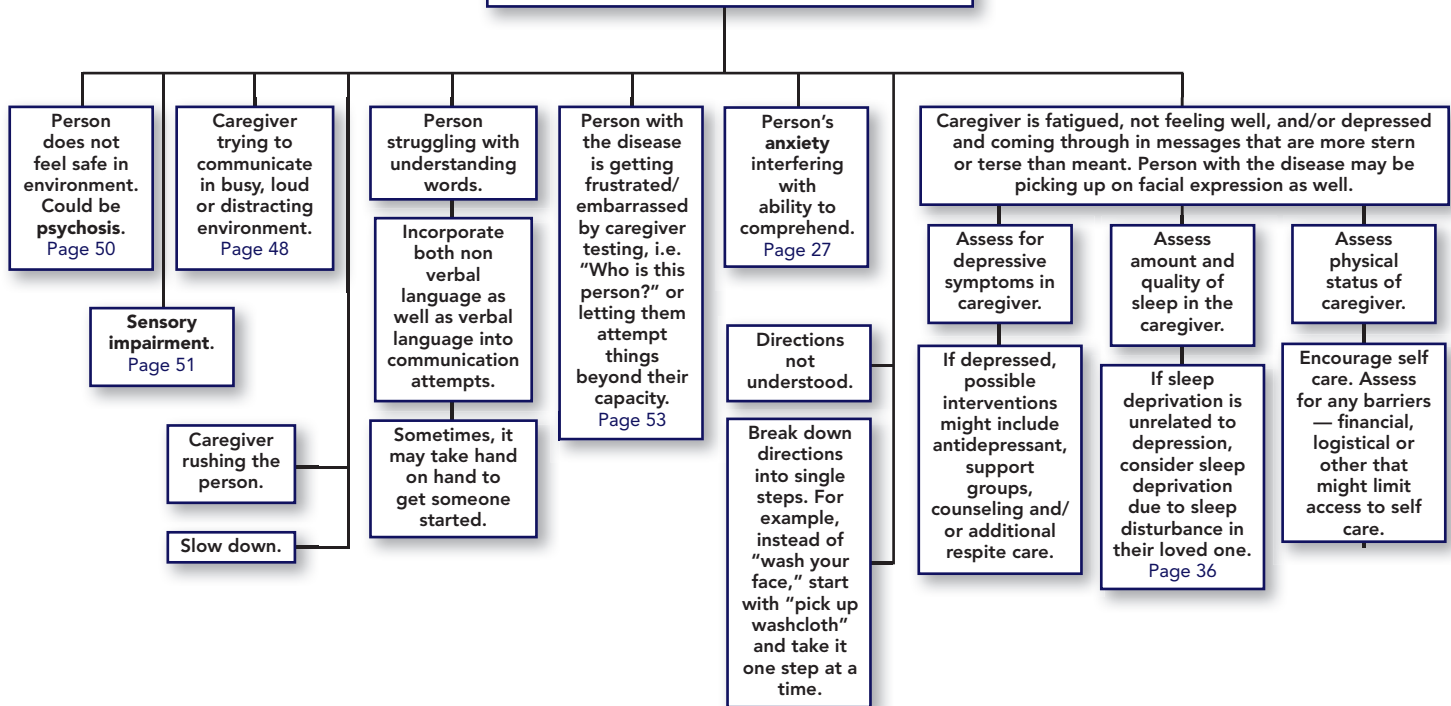
The level of desired and needed activity is individually defined. There are individuals with the disease who are content with limited activity and those that require a full day of activity to support good quality of life. Do not rule out boredom as a reason for behavior and mood challenges just because activities are provided or that they are as busy as you would want to be. Consider prior lifestyles and behavior/mood responses when the person is involved in activities.



Can't Sit Long Enough to Eat/Engage in Activity



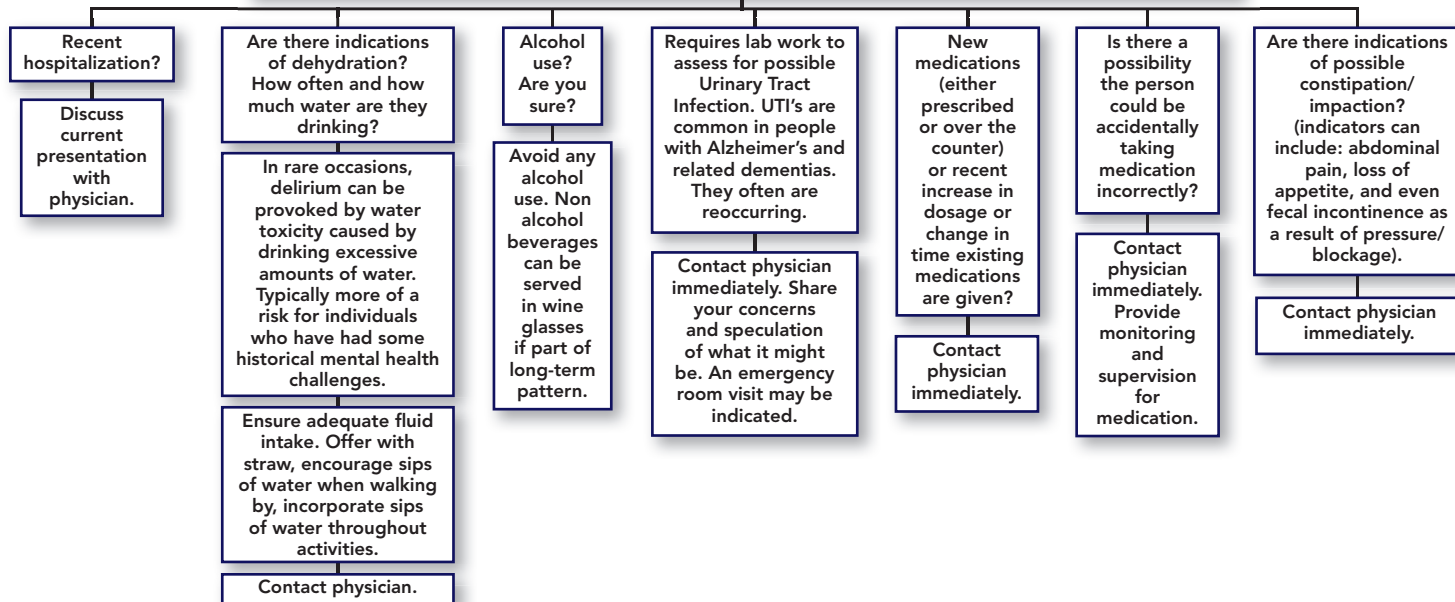
Communication/Comprehension Barriers



Delirium

Indicators of possible delirium include: acute state of increased confusion, inattention, sudden increases in agitation, sudden emergence of psychosis, changes in sleep patterns, acute onset — hours to a couple of days and has fluctuating level of consciousness over the course of the day. Delirium is always caused by something physical and 25 percent can be fatal if underlying cause is not found. Delirium is considered a medical emergency.

Make sure the physician, physician's nurse and/or hospital personnel understand the person's baseline, timing of changes and all information that might be connected with the sudden change.



Depression

Most common symptom in this population is ANXIETY, including excessive worry, ruminating. Other symptoms might include sleep disturbance, changes in appetite, irritability, physical or verbal aggression, withdrawal, loss of interest in previously enjoyed activities, self deprecating comments, expressing wishes of wanting to die, suicidal threats or gestures. A significant percentage of those individuals presenting with combative behavior are primarily depressed.

Consider antidepressant or alteration in dosage of existing antidepressant. Watch for trends in symptom relief and adjust dosage accordingly.

Ensure there is no access to weapons, not only to prevent self injury, but also to prevent risk to others if agitation, hostility and/or if paranoia is part of the manifested depressive symptoms.

May require geriatric psychiatric hospitalization if combative and posing risk to others or if symptoms interfere in care and provoke refusal of medications.

Structured activity that is pleasant and meaningful

Often historical ways they spent their time are less available. Alternate activities should be added. That may include hosting visitors for tea, addition of new hobbies such as watercolor painting, or may include participation in an adult day program.

Reduction of environmental stressors

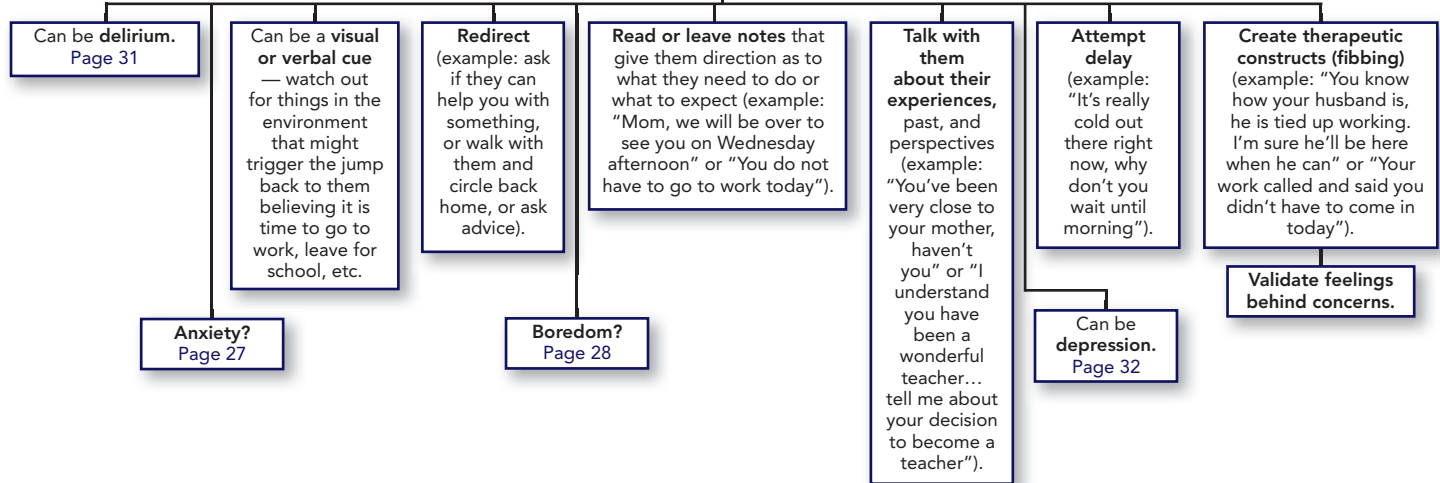
such as exposure to family conflict, high stimuli, negative approaches to communication.

Engage in therapeutic conversation:

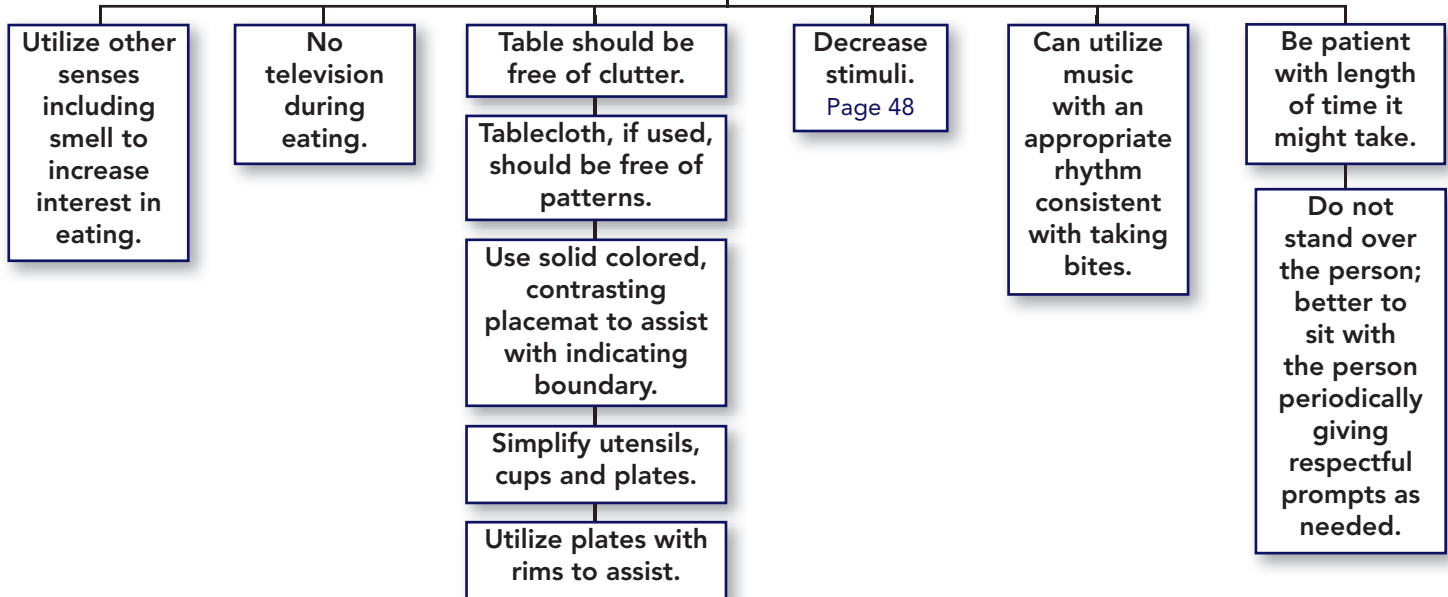
- Listen to feelings embedded in their words and conversations
- Affirm both their current strengths, as well as the past contributions they have made
- Provide reassurance

Desire to Fulfill Former Obligations

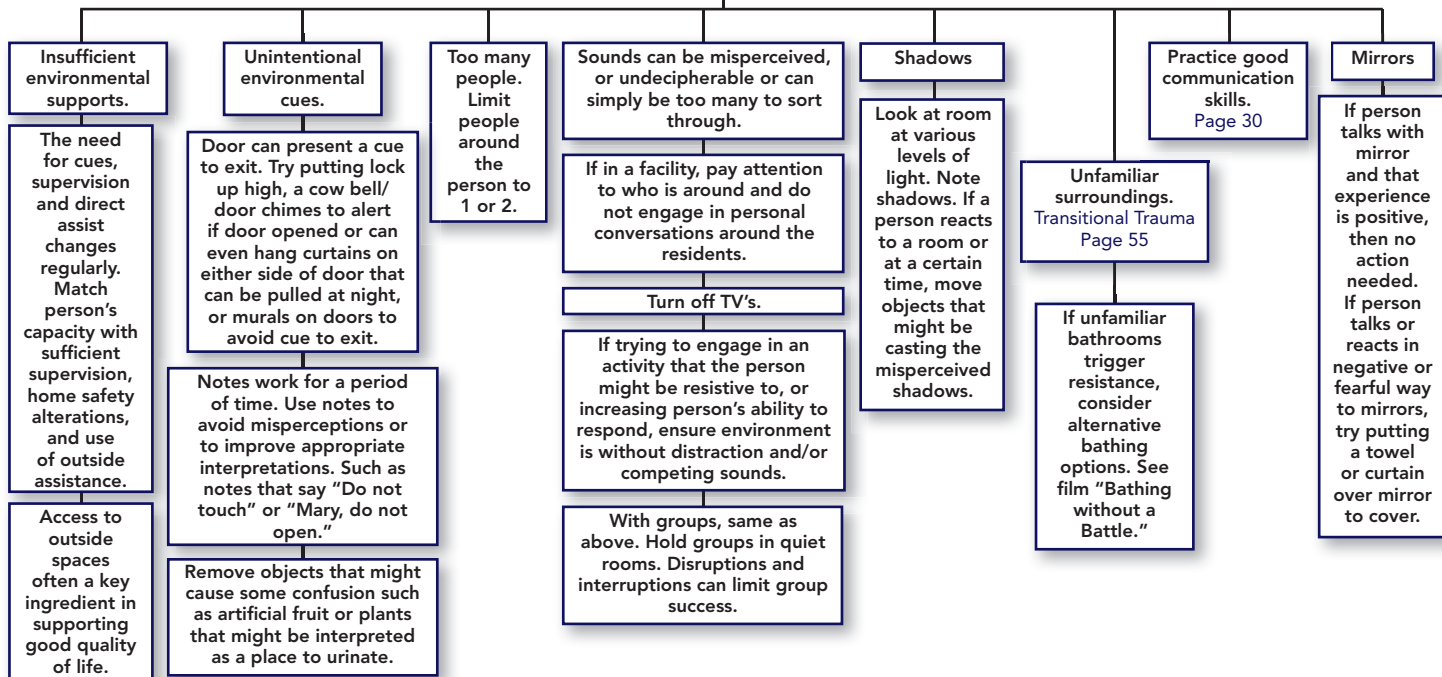
(Wanting to go home or to work or to pick up kids or other demands that reflect back to an earlier time in their lives)



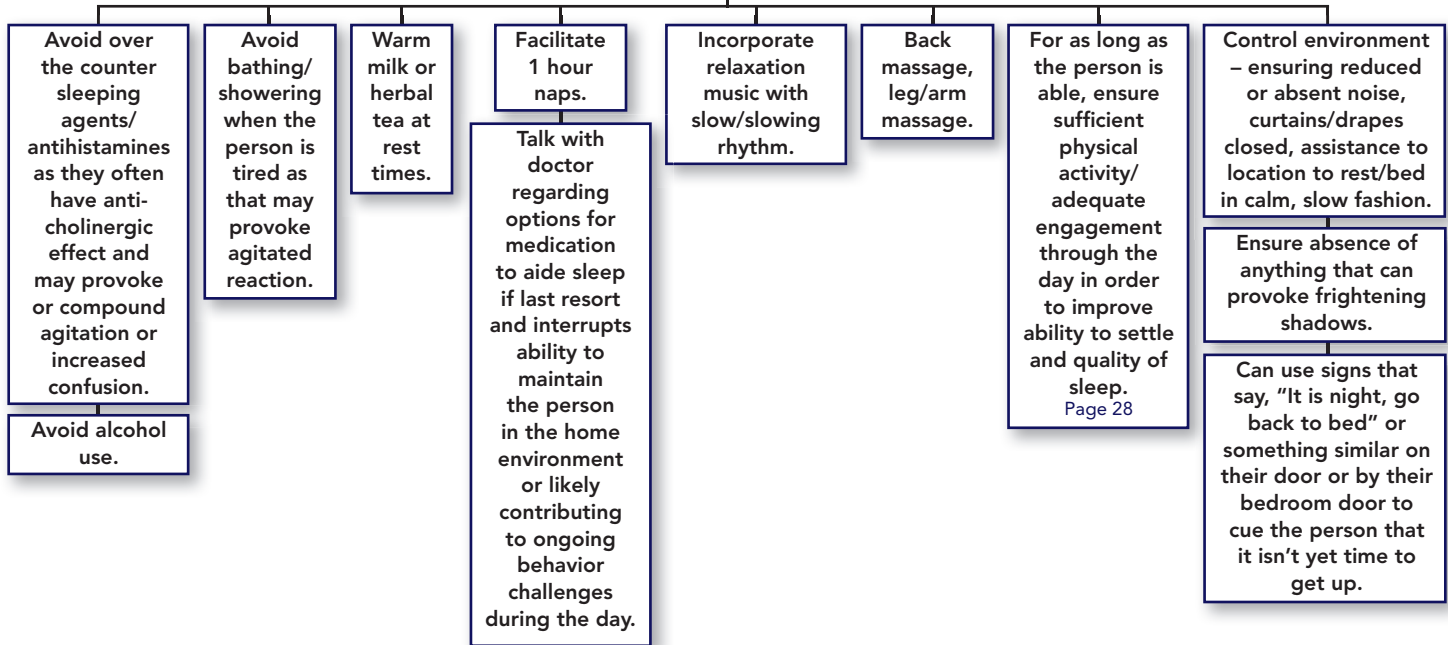
Environment Not Conducive to Eating

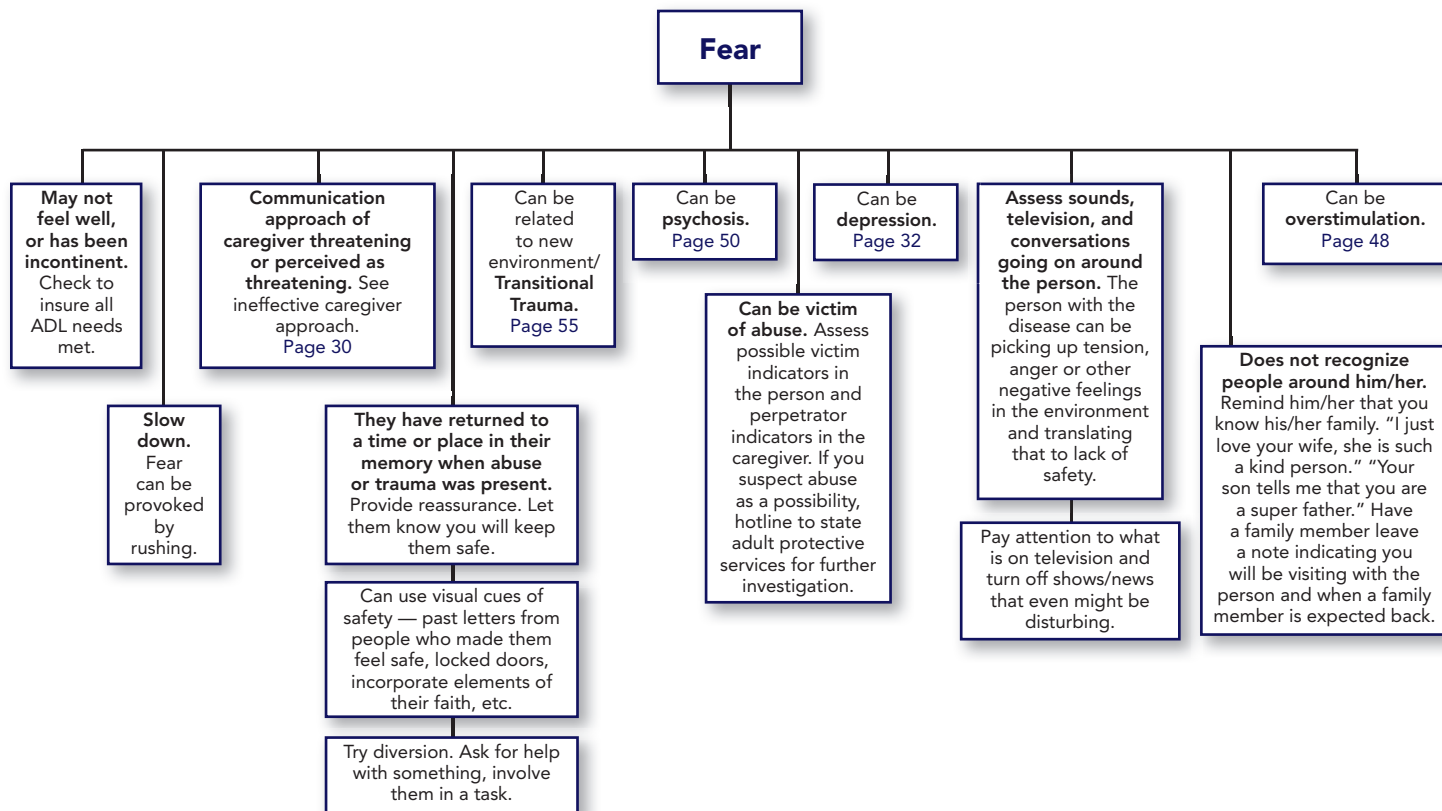


Environmental Contributions

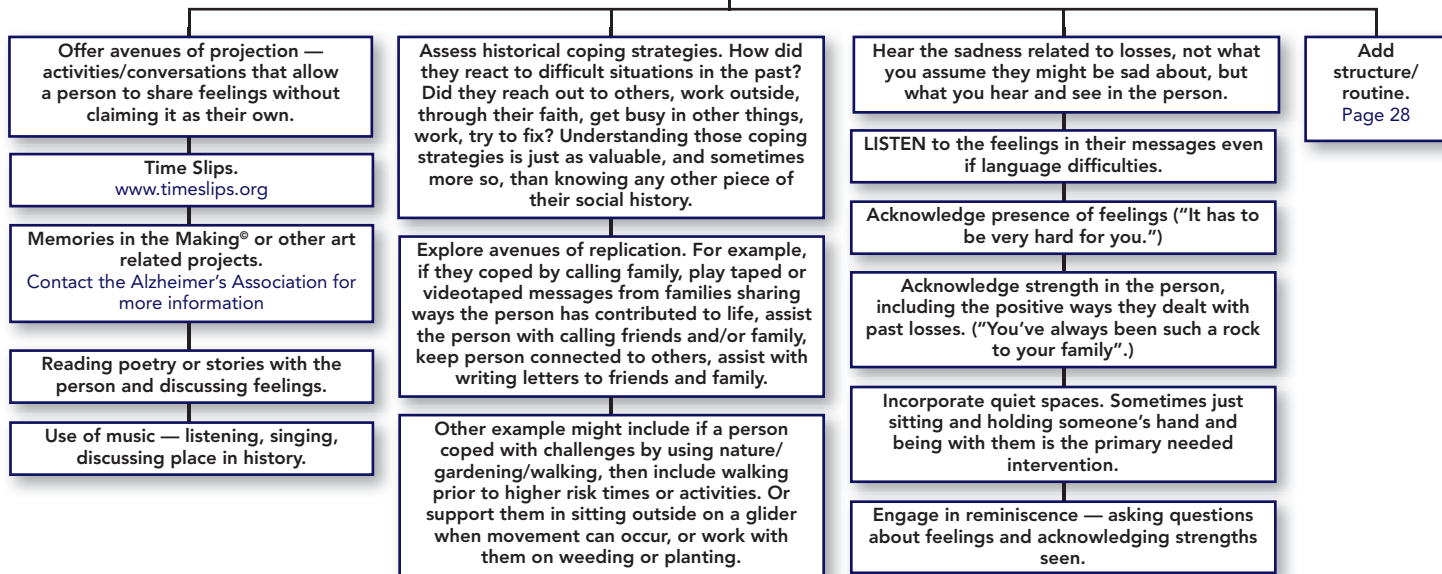


Fatigue and Day-Night Reversal





Grief



Consider use of antidepressant if sadness consistent over period of time and unremitted by non-pharmacological interventions.

History of Compulsive Behavior

Compulsive behavior refers to those excessive behaviors that are driven, not by productive purpose or want, but by a strong feeling. The root of obsessive compulsive behavior is anxiety.

Incorporate those antidepressants used in obsessive compulsive disorder.

Pay attention to potential anti-cholinergic effect.

Kindly attempt diversion.

Seek opportunities for him/her to be in control.

Provide reassurance.

Know all that is possible about compulsive patterns.

Explore and list all psychotropic medication history including dosages, what worked, any negative side effects, and why/when medications stopped or changed.

Integrate geriatric psychiatrist early on, ensuring he/she has full mental health history.

History of Sexual Addictions or Criminal Sexual Offenses

Reduce stimulation in the environment.
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Provide daily physical activity such as walking/exercise as long as possible.

Incorporate geriatric psychiatrist early on. May require integration of mood stabilizers and/or anti-psychotics.

Explore all that is known about behavior, pattern, consequences as well as any other mental health symptom/presentation. Assess potential danger. Avoid cues if possible.

Be cautious of interpreting all behavior as a form of sexual aggression. Getting into bed with someone can be confusion. Disrobing can be due to urinary tract or other infections, pain, just being uncomfortable in some way. Make sure you are fully assessing.

If history of child molestation, make sure the person is not left alone with children.

Reverse jumpsuits can be used to prevent disrobing, or public exposure/masturbation. Should only be used for specific lengths of time with return regular trials in regular clothes. Severely impacts continence so should not be utilized for those who are still independent in toileting and for whom such clothing options would result in loss of this independence.

Keep person engaged in structure/routine.
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Lack of Appropriate Physical Affection

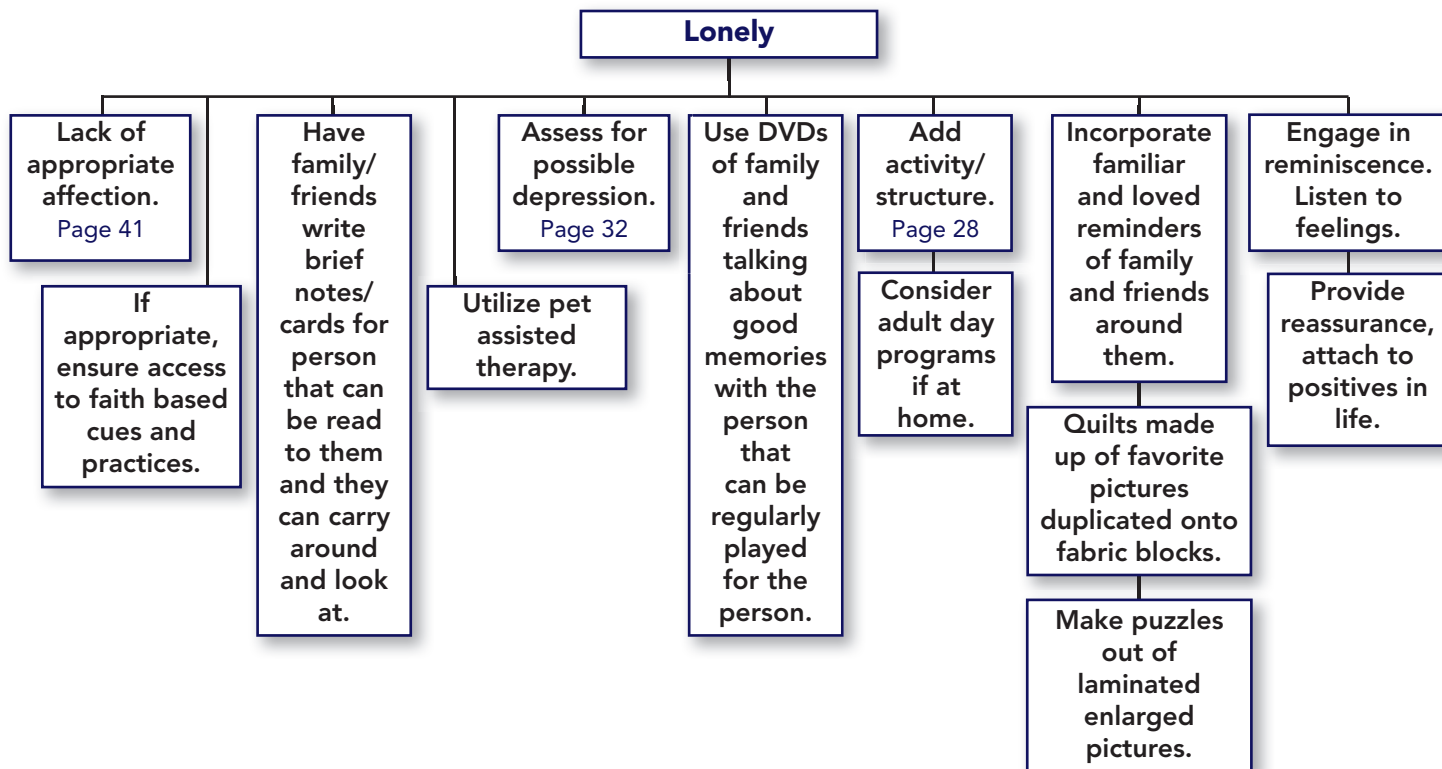
Pat or briefly rub back while the person is engaged in a meal.

Try massaging hands while utilizing hand lotion.

Hold the person's hands — which supports appropriate physical affection while limiting accessibility in using hands for inappropriate touch.

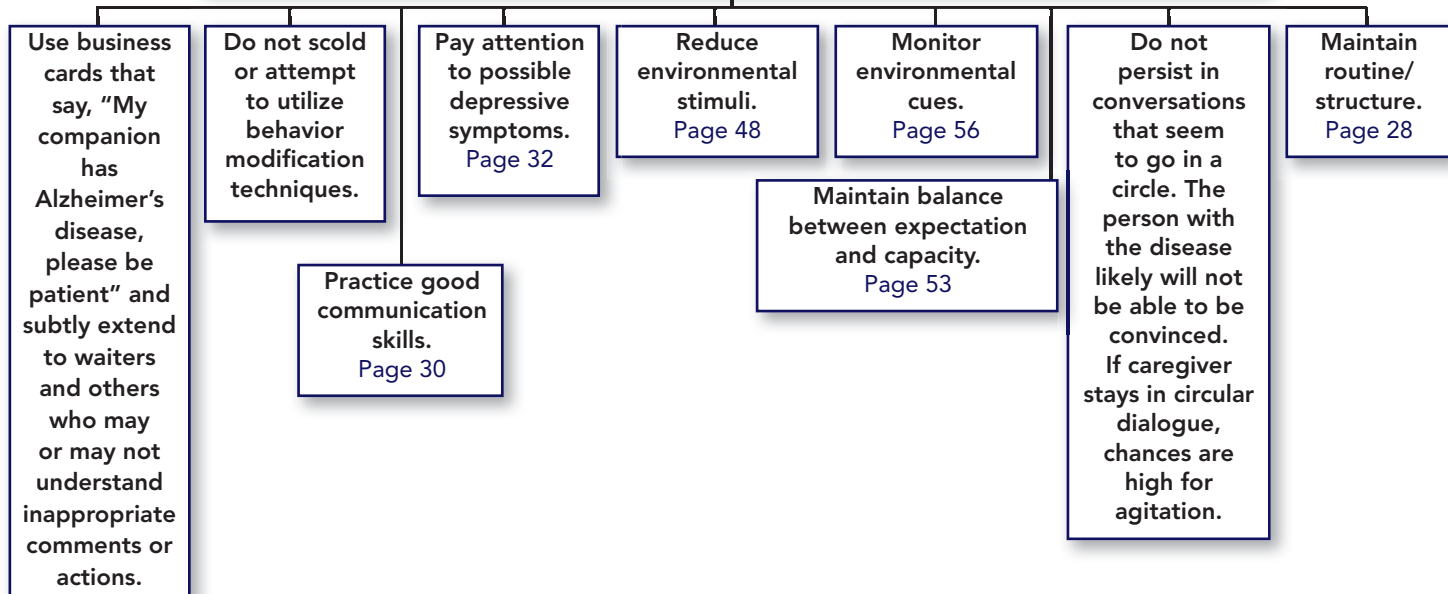
From a time perspective, separate appropriate affection from those times when assistance is being provided for bathing, toileting or dressing.

If inappropriate touching or consistent inappropriate sexually oriented conversation continues over the course of time and unaltered by non pharmacological efforts, consider geriatric psychiatric consult.



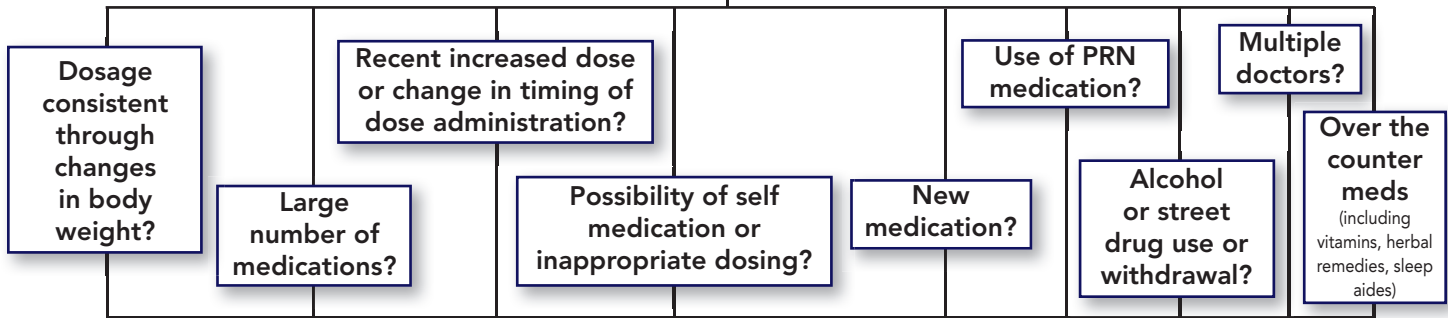
Loss of Ability to Control Impulses

The frontal lobes of the brain are significantly impacted in Alzheimer's disease as well as other dementias. The frontal lobes serve as our filter between thought and action. When this part of the brain is damaged, then reactions to thoughts as well as environmental cues and frustrations can be immediate.



Medication Side Effects

Recent falls, sudden increase in confusion, increased anxiety, increased agitation, excessive sleep/seems sedated, increased unsteadiness on their feet, a change in their level of function, decreased sleep.



Next Steps:

Consult with physician and pharmacist.

Track timing of behavior/issues.

Make sure both have a list of medications, date they were started, changed, stopped, and why. Date any dosage adjustments occurred, date of discontinuation of any medications within the last 6 months as well as observations/tracking of behavior issues.

Be prepared to ask questions.

Misidentifying Recipient of Flirtatious or Inappropriate Sexual Overture

Believe person they are targeting their affection and/or overtures toward is a person such as a mate whereby such behavior might have been appropriate

Assess for delirium.
Page 31

Assess for variables that might be appropriate affection if directed to another resident in long-term care.

Considerations are:
Is affection mutual?
Is each party able to say no to touch and physically able to move?
Have both families been educated regarding ongoing emotional and physical needs?

Respectfully introduce self and role upon greeting.

Divert into more serious topic or reminiscence about the person he/she perceives.
"Tell me about how you met your wife."

May be bored. Keep individual engaged.
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Not Feeling Secure

May be that expectations and capacity do not equal one another including the possibility of residing in inappropriate level of care.
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Gracefully ensure the person knows who is in the environment. For example, if visiting a daughter, "We are lucky to find our busy daughter Mary at home today!" so name and relationship is conveyed but in a dignified way.

Direct conversation into those areas where the person felt confident.

Quiet/slow the environment or direct the person to area where they feel more comfortable.

It may be seen in increased anxiety or expressing desire to go home.

Calculate where you take the person — visit with people 1 or 2 at a time, plan outside trips at times of the day that tend to be the person's best time, go to restaurants or other social outings at off times or times with less stimuli in the environment.

Assess what is on television. Often, television shows become more anxiety provoking than helpful.

May be related to communication issues.
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Don't talk about the person in front of them especially if comments are negative or worrisome.

Provide a routine for the person.
Page 28

Consider antidepressant if the person demonstrates ongoing rumination, excessive reaction to anything new or different, or consistent hypervigilance/uneasiness about the environment AFTER medical contributions such as Urinary Tract infections ruled out and non pharmacological interventions fail.

Overwhelmed by Choices

Overwhelmed by clothing/dressing choices.

Give two choices, with dignified cues for one, if the person struggles with the choice. "Do you want to wear the red shirt or the blue shirt? I have always thought you look so pretty in the blue shirt."

Lay out the person's clothes in the order they will put them on.

Hand things to the person one at a time.

Simplify closet.

If the person picks the same thing all the time, have duplicates of these favorite pieces.

Allow sufficient time.

Break down tasks.

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Overwhelmed/reacting to too many pills.

Talk with doctor about which medication is essential.

Talk with pharmacist re: taste of medication/ which ones can be safely crushed in food such as mint ice cream (which can cover taste of medication) or apple sauce.

Talk with doctor re: spreading timing of medications through the day to avoid too many pills given at the same time.

Divert into enjoyable conversations as you give the medication.

Overwhelmed by food choices.

When in a restaurant, supply clues that the person can utilize, such as, "I'm wondering if you are going to have your favorite pork chop" or "Let me see if I can guess what you are going to have — the pork chop, am I right?"

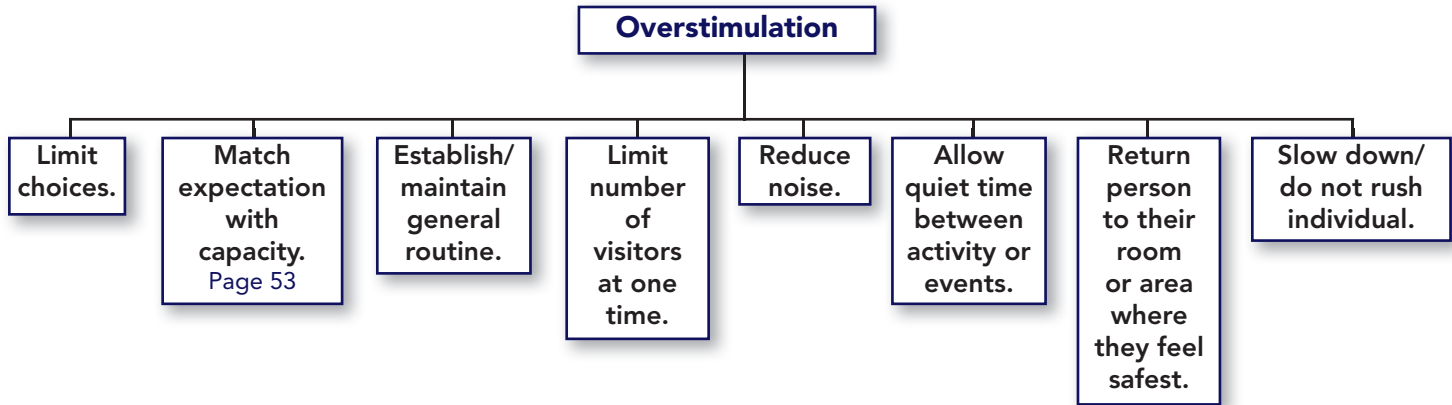
For some people, as disease progresses, food choices should be given one item at a time.

Provide one utensil, such as a fork, and make sure all food served can be eaten with that one utensil to avoid confusion about changing utensils.

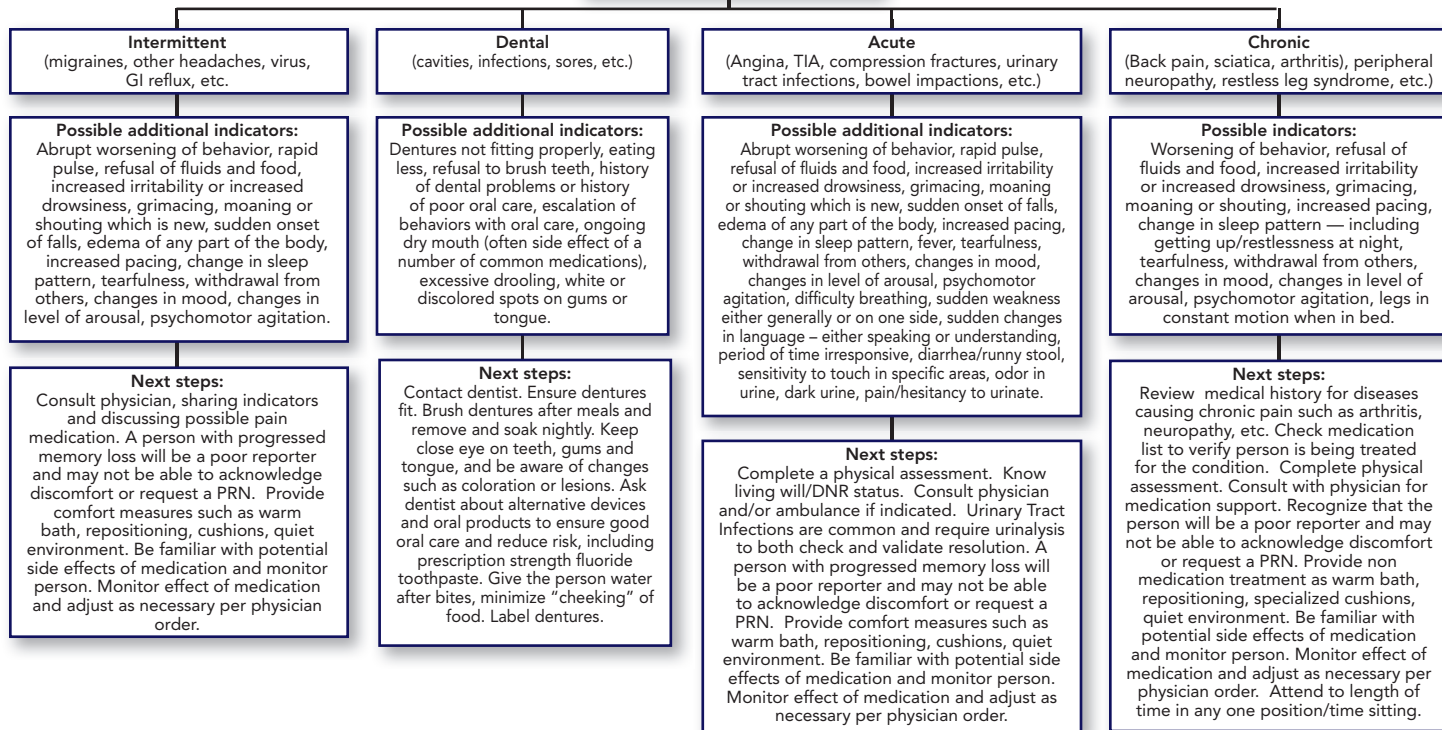
If tablecloths are used, make sure they are absent of pattern and have contrast to plate/food.

Eat with the person to extend visual cue.

Try putting your hand on theirs just to get them started.



Pain



Psychosis

(Beliefs not based in reality or seeing/hearing/smelling/feeling something or someone no one else sees/hears/smells/feels)

Does the delusion (false belief) or hallucination provoke:
Distress for the person on a regular/continuing basis and cannot be reassured or diverted?
Interrupt ability to be cared for on a regular/continuing basis and cannot be reassured or diverted?
If no, go to communication. Page 30

Has the person
retreated in
their mind to a
traumatic time in
their life?

Reassure them
they are safe and
you will be there
for them.

Rule out Urinary
Tract Infection
or other acute
medical condition.

May require
psychotropic
support. Contact
neurologist,
geriatrician
or geriatric
psychiatrist.

Assess the
environment. Is
she/he seeing
shadows or
shapes of things
that are being
misperceived
and provoking
distress?

Look at the
room in a
way that they
might. Remove
potentially
distressing
objects if
possible. If
not, try to
camouflage.

May be a separate
visual problem.
Sensory
Impairment Page
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Are they
watching
television
shows/news
that are
disturbing or
conveying
negative
emotion?

Be conscious
of the
television
shows that
are on.
Perhaps put
on a DVD
of an old
time variety
or music
program.

Are there **family
disagreements** occurring
in the presence of the
person?

Arguments/family conflict
should not be played out
in front of the person with
the disease. Nor should
they be used as pawns
in such disagreements.
It is common for families
to see things differently
— encourage family
meetings away from the
individual with the disease
to discuss issues with care,
support and their grief.

Hotline case to APS if
emotional abuse, financial
exploitation or any
other type of abuse is
suspected.

Fear?
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The person's
ability does
not match
others'
expectations
of them.
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Depression?
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Has the
person ever
experienced
psychosis
before?

Assess for
prior mental
health
changes.

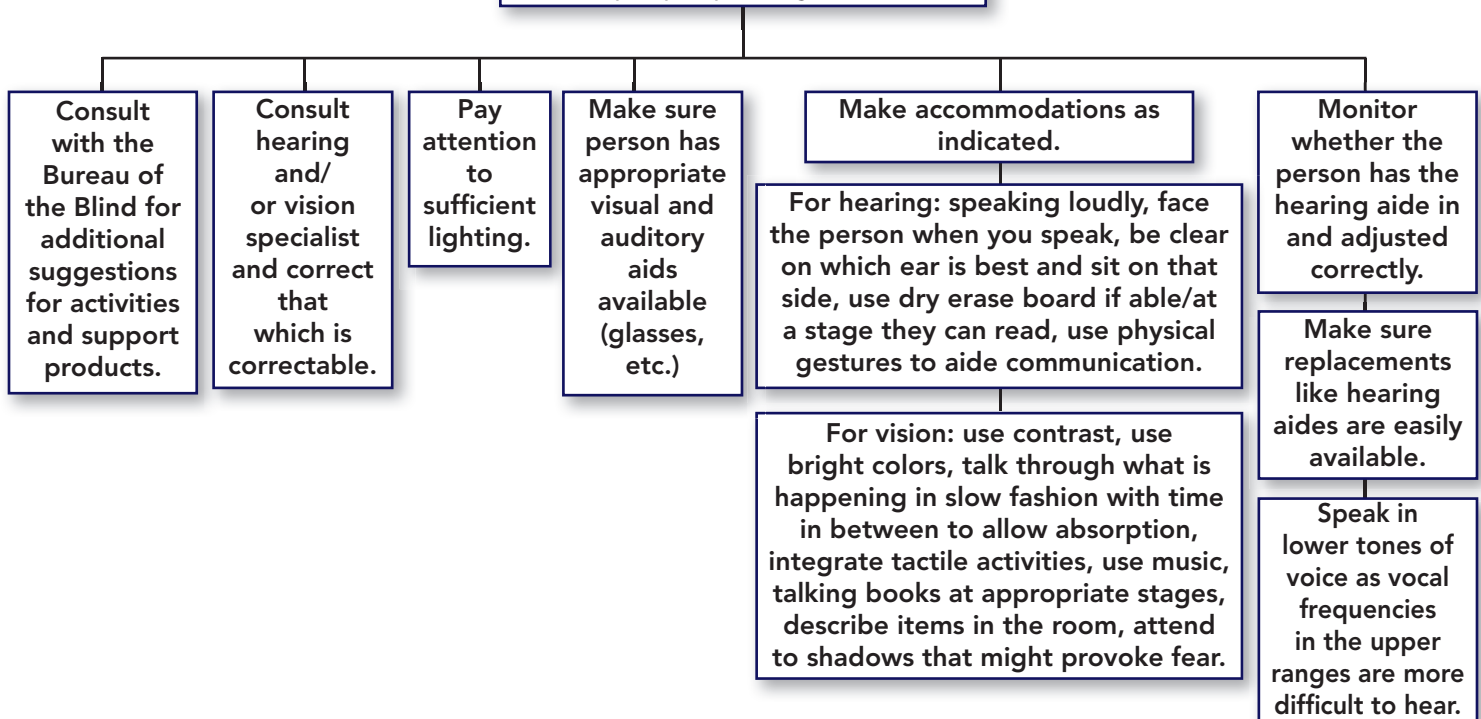
Delirium?
Page 31

Is anyone
threatening
the person
physically or
verbally?

Hotline the
case to Adult
Protective
Services.

Sensory Impairment

(most common hearing and vision, differentiated from perceptual processing errors)



Shadowing
(the person with the disease following another person)

Notes/Signs work for a window of time for some individuals. Caregiver can try a sign that says "Harold, stay here" or "Do not open" on doors.

Ensure person is engaged either in conversation or activity when individuals are exiting. For example if a family visits a facility and the person tries to leave with them, advise them to time their visits so the person can be engaged in a meal or activity before they attempt to leave.

Can be Anxiety
Page 27
Pay attention to affect. If they appear frightened, anxious every time caregiver leaves their sight, then it may very well be anxiety which can be associated with depression.

Ensure doors are secured when people leave/exit. In facilities, that might mean a sign.

Utilize seat alarms with voice recordings. These offer reminders to stay seated utilizing the recordings of family voices rather than fear provoking alarms and other loud noises.

The Person's Ability Does Not Match Others' Expectations of Them

Do not test individuals.

Pay attention to areas that appear too difficult and reduce responsibility in that area.

May be at a level of care that provides too limited support. If living alone, consider increased in-home help or dementia specific assisted living. If in assisted living, assess areas of possible insecurity and consider possibility of move to skilled facility.

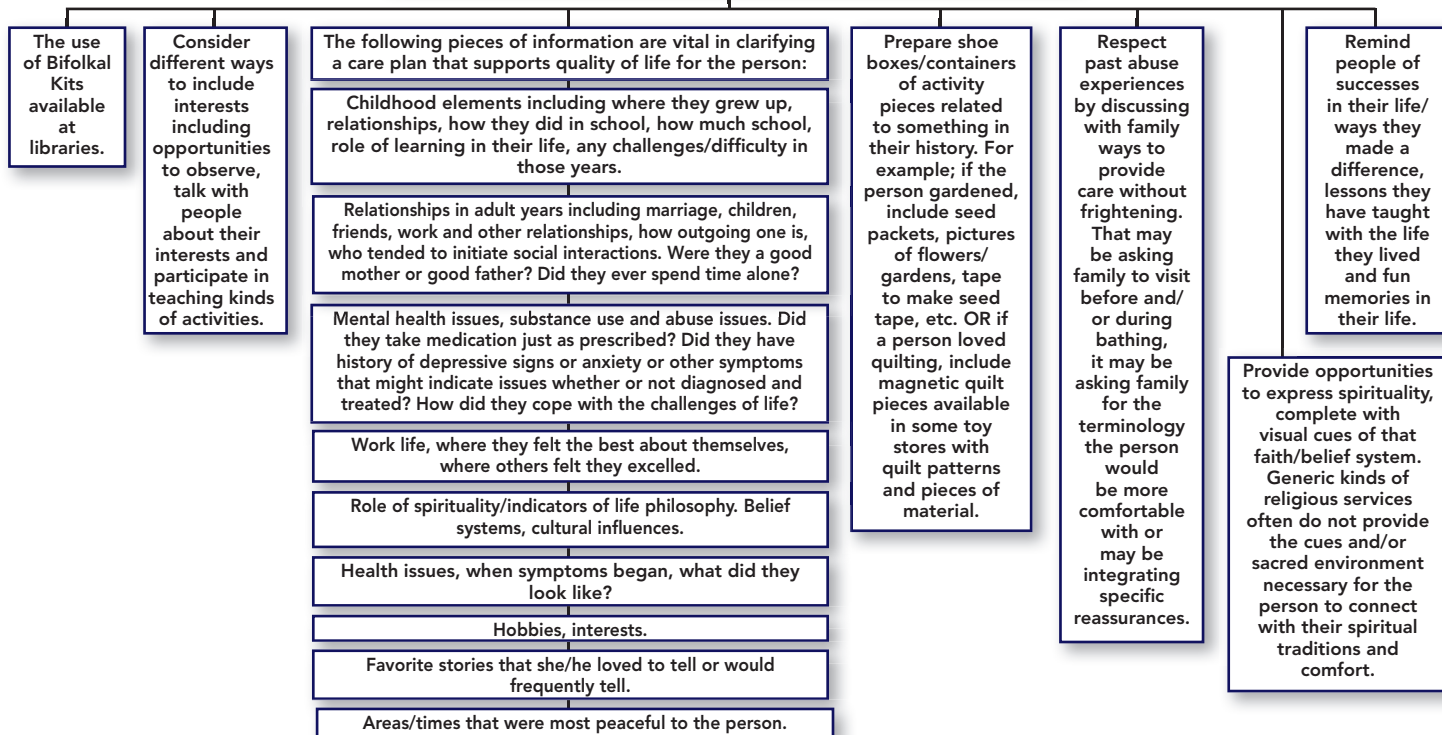
If person left unsupported, especially at night, it can be that their fears get integrated into delusional thoughts that convey their sense of being unsafe.

Break down tasks.
Communication
Page 30

Integrate notes and other external cues for person to rely on.

Allow person to perform tasks they are capable of.

The Person's History Not Integrated Into Care



Traumatic Adjustment to a New Environment

(Increased agitation occurring following environmental changes)

If in hospital

Find ways to identify person as high risk for wandering, delirium and other issues for which a person with the disease is high risk. Possible places for identification: chart, utilizing specific colors for hospital ID band and naming specific protocols.

Consider completing additional history with information re: day-to-day schedules, functional/behavioral patterns, as well as elements of life and history that can provide reassurance.

Frequently reassure.

Facilitate sleep: back massage, warm milk or herbal tea at bedtime; relaxation music/tapes; noise-reduction measures; avoid awakening the person unless vital.

Foster familiarity: encourage family/friends to stay at bedside; bring familiar objects from home; maintain consistency of caregivers; minimize relocations.

Incorporate hospital volunteers, if available, to assist with sitting/interacting with the patient.

Educate family.

Consider psychotropics as last resort.

If in a long-term care facility

Assign management staff member to a new resident and family for the first 2 weeks of individual's entry into the facility. Responsibilities for this assignment would be extra 1:1 time, supporting the resident in adjusting to new routine and to observe for ongoing needs and interventions to include in care plan.

Instruct family to visit regularly and frequently, but to time visits so the resident is engaged in an activity or meal at point of their departure.

Assess historical coping strategies and explore ways to adapt in current setting.

Provide routine and structure.

Know history and information re: day to day schedules, functional/behavioral patterns as well as elements of life and history that can provide reassurance.

Consider incorporation of antidepressant and/or other psychotropic if sufficient trial of antidepressants and titration is unsuccessful.

If move to a family member's home

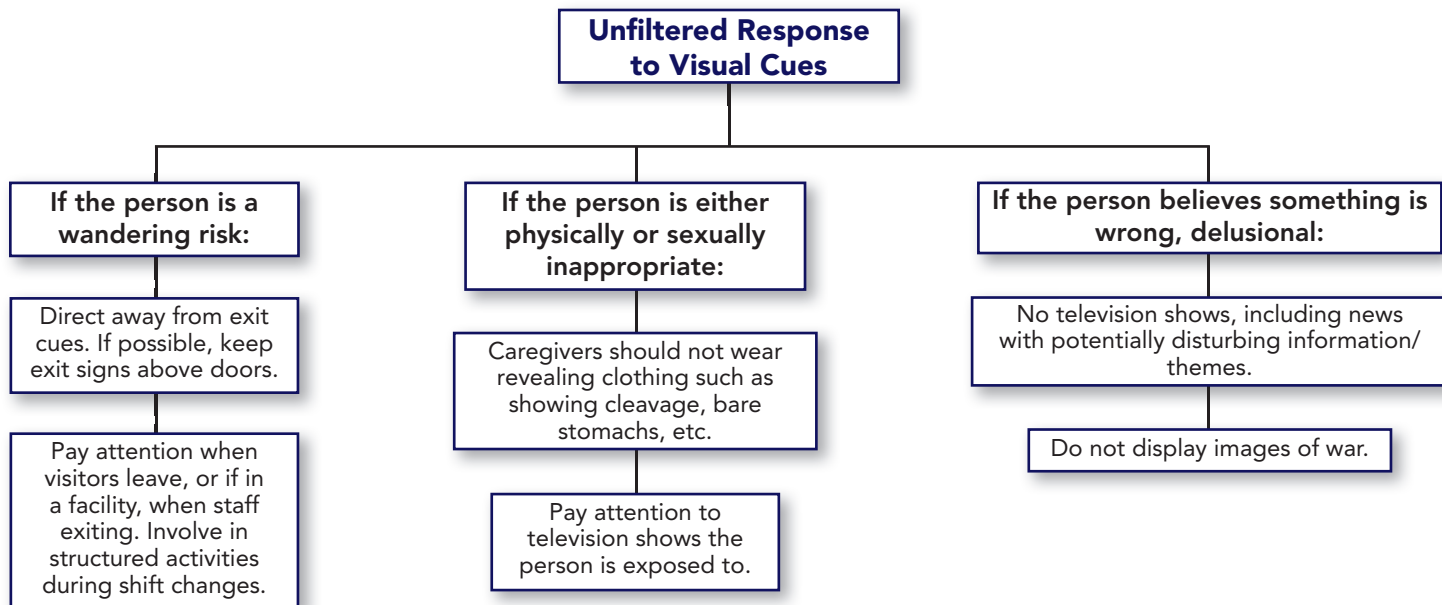
Try to maintain elements of prior day to day structure.

Encourage visitors, but one at a time.

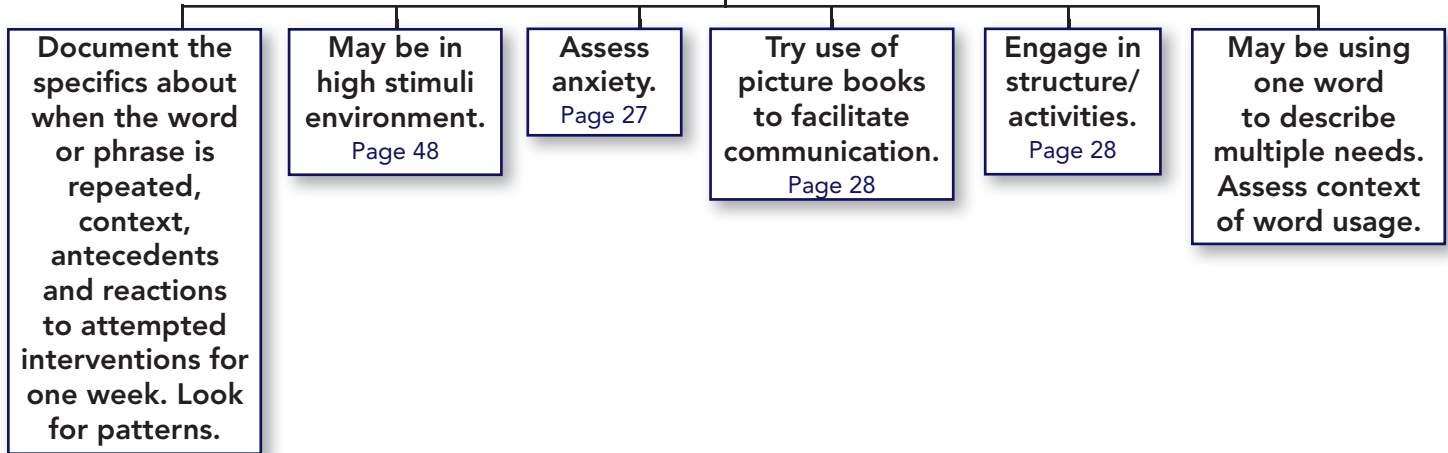
Provide frequent supportive and reassuring comments.

Consider incorporation of antidepressant and/or other psychotropic if sufficient trial of antidepressants and titration is unsuccessful.

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Verbally Stuck on One Word or Phrase



Section IV

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Section V

Alzheimer's Association Information

The Alzheimer's Association is the leading, global voluntary health organization in Alzheimer's care and support, and the largest private, nonprofit funder of Alzheimer's research. Our vision is a world without Alzheimer's, and since our founding in 1980, we have moved toward this goal by advancing research and providing support, information and education to those affected by Alzheimer's and related dementias.

There are many chapters of the Alzheimer's Association throughout the United States. The Heart of America Chapter serves 66 counties including 29 in Missouri and 37 in Kansas. The Chapter offers a variety of services including support groups, family consultations both in the home and in each of the five regional offices, a 24-hour information and support line, early stage programs, educational materials and programs as well as advocacy efforts for all those who are directly impacted by Alzheimer's disease and related dementias. The Chapter also has dementia crisis support coordinators who participate in the quest to figure out the elements of neuropsychiatric challenges, problem solve possible interventions and to support the individual, family and the professionals working through these difficult elements of the disease.

For more information contact:

1.800.272.3900 or 913.831.3888

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