

# **Understanding, Managing and Changing Challenging Behaviors**

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## Learning Objectives

- Implement strategies designed to significantly improve positive outcomes for those living with brain injury and neurological conditions in all communities.
- Define the term “challenging behavior” and verbalize examples of challenging behaviors.
- Identify both internal and external causes of challenging behaviors.
- Discuss ways that verbal and nonverbal communication affects a person’s behavior.
- Demonstrate effective communication strategies when a consumer is expressing a challenging behavior.
- Develop and discuss strategies to respond to someone experiencing a challenging behavior using a problem-solving method.

## What is Challenging Behavior?

Challenging behavior is defined as "culturally abnormal behavior(s) of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behavior which is likely to seriously limit or deny access to the use of ordinary community facilities". Ordinarily we would expect the person to have shown the pattern of behavior that presents such a challenge to services for a considerable period of time. Severely challenging behavior is not a transient phenomenon. Challenging behavior is most often, though not exclusively exhibited by individuals with dementia or other mental health needs, such as strokes or acquired brain injuries, and individuals with psychosis, although such behaviors can be displayed by any person.

If the person you care for must rely on others for his daily care, he may feel a loss of control over his life. He may feel frustrated or helpless at times. His personality and behavior may change because of the emotional and physical changes he experiences.

A person who has always had a difficult personality may become even more difficult with the stress of an illness or disability. When a person becomes sick or disabled, not only his life but the lives of those around him change dramatically. If you can recognize the reasons a person is difficult and learn methods to cope, it will help you both maintain a healthier relationship and get through the trying times.

### Common types of challenging behavior include:

- self-injurious behavior (such as hitting, head-butting, biting, scratching),
- aggressive behavior (such as hitting others, head-butting, shouting, swearing, screaming, scratching others, spitting, biting, punching, kicking),
- inappropriate sexualized behavior (such as public masturbation or groping),
- behavior directed at property (such as throwing objects and stealing)
- stereotyped behaviors (such as repetitive rocking or echolalia - the uncontrollable and immediate repetition of words spoken by another person ).

### Causes

Challenging behavior may be caused by many kinds of factors, including:

- biological (pain, medication, the need for sensory stimulation)
- social (boredom, seeking social interaction, the need for an element of control, lack of knowledge of community norms, insensitivity of staff and services to the person's wishes and needs)
- environmental (physical aspects such as noise and lighting, or gaining access to preferred objects or activities)
- psychological (feeling excluded, lonely, devalued, labelled, disempowered, living up to people's negative expectations)

Most challenging behaviors (Percentage ranked as 1 <sup>st</sup> Choice)		Biggest caregiving challenges (Percentage ranked as 1 <sup>st</sup> Choice)	
Agitation or Aggression	25%	Dealing with memory loss and impact of the disease on your loved one	25%
Repetitive speech or actions	12%	Handling the stress and emotional toll on self	16%
Wandering or restlessness	10%	Having patience with your loved one	15%
Incontinence or constipation	10%	Handling loved one's mood swings or behavior changes	12%
Late-day confusion	8%	Daily activities (bathing, bathroom, dressing, meals)	11%
Sleeplessness	6%	Keeping loved one positive and motivated	8%
Refusal to eat	5%	Bills, finances, health insurance	4%
Paranoia	5%	Managing and administering medications	3%
Refusal to take medicine	4%	Speaking with loved one's health care providers	2%
Hallucinations	5%	Scheduling appointments and time management	1%
Refusal to bathe	4%		
Choking on food or liquids	4%		

Challenging behavior may also simply be a means of communication. A lot of the time, challenging behavior is learned and brings rewards and it is very often possible to teach people new behaviors to achieve the same aims. Behavior analysts have focused on a developmental model of challenging behavior.

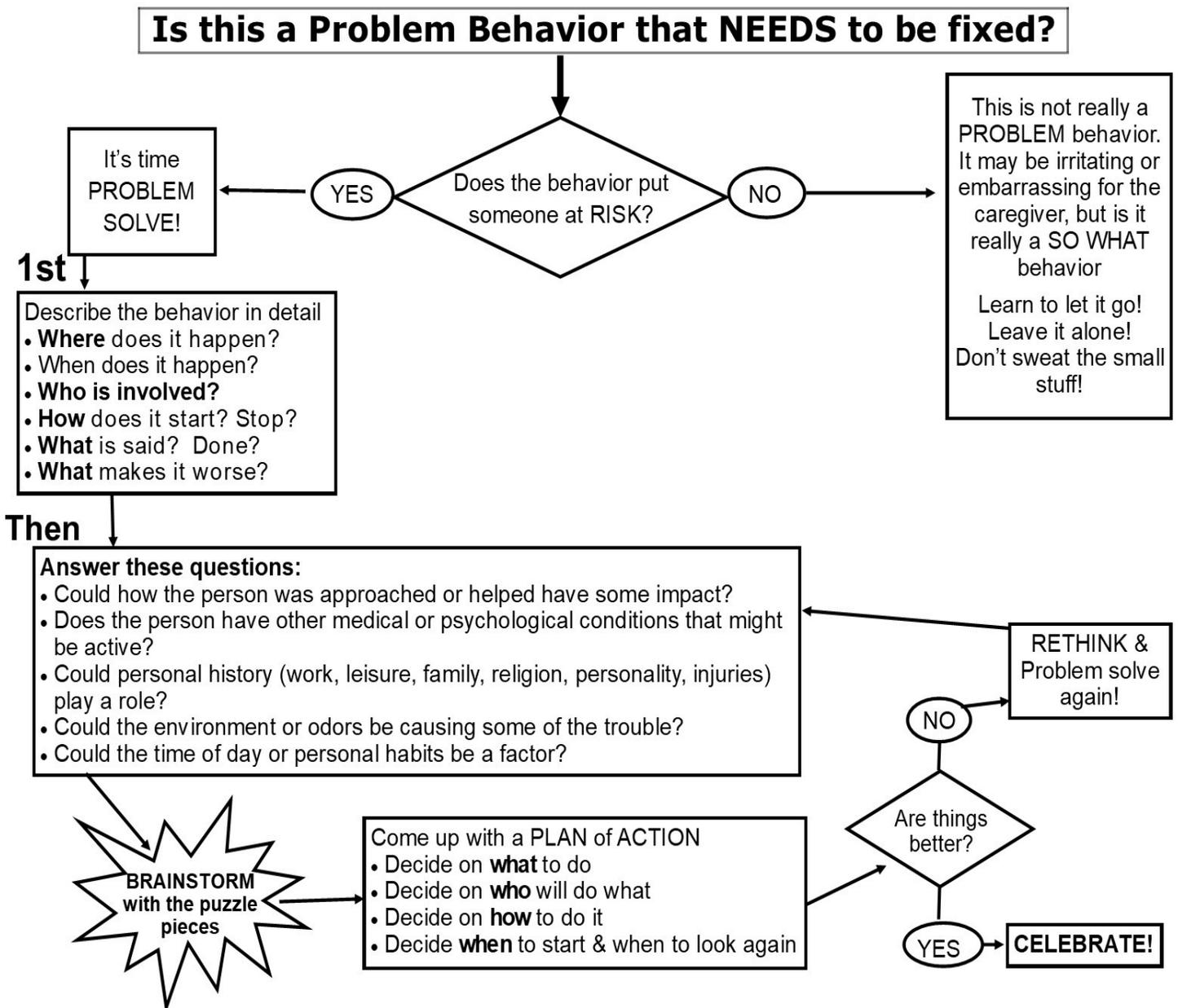
Experience and research suggests that what professionals call "challenging behavior" is often a reaction to the challenging environments that services or others create around people with developmental disabilities,, and a method of communicating dissatisfaction with the failure of services or others to listen for what kind of life makes most sense to the person, especially where services or others create lifestyles and relationships that are centered on what suits them or the service and its staff rather than what suits the person.

Challenging behavior can often be viewed as a 'behavioral equivalent' of a mental health problem. However, research evidence indicates that challenging behaviors and mental health problems are relatively independent conditions.

A common principle in behavior management is looking for the message an individual is communicating through their challenging behavior: "All behavior has meaning". This is a core in the functional analysis process.

Like children, many people with brain injuries communicate through their behavior, especially those who have not acquired language and vocabulary skills to tell the adult what the problem is.

Certain types of challenging behavior can predict contact with police and hospital admission.



## What makes it challenging?

- Frequency
- Context
- Time limitations
- Disruption
- Level of social acceptance
- Dangerous

## Always identify...

- Is it really necessary to intervene
- Can I let it go because it doesn't need my attention?
- Or do I need to step away for my safety?

## Examples of Some Behaviors:

- Swearing/cursing
- Threatening
- Aggression/combativeness
- Paranoid thinking, delusions, hallucinations
- Mania
- Repetitive questioning
- Medication non-compliance/refusal to attend appointments

## Consider...

- Is behavior annoying?
- Is behavior risky?
- Is behavior dangerous?

## Behavior response cycle

Challenging behaviors may be viewed as occurring in a cycle: Trigger (what causes the behavior), Behavior (what you see or hear), Consequence (what is a result of the behavior). Analysis of this cycle provides a foundation for using a variety of strategies to minimize the triggers of challenging behavior, teach more appropriate behaviors in response to these triggers, or provide consequences to the challenging behavior that will encourage a more appropriate response. Behavioral strategies such as Applied Behavior Analysis, operant conditioning and positive behavior support use similar approaches to analyzing and responding to challenging behaviors.

## What Conditions Cause Challenging Behaviors?

### Types of Acquired Brain Injury

- Traumatic brain injury
  - Closed head injury: brain is damaged without opening the skull
    - Car accidents
    - Falls
  - Assaults with blunt instruments
    - Sports injuries
  - Penetrating head injury: a sharp object goes through the skull and enters the brain (e.g. gunshot wounds; stab wounds)
- Stroke Hemorrhagic Ischemic
- Anoxia: oxygen to the brain temporarily cut off
- Brain tumors
- Dementia: progressive diseases that usually result in decline over time
- Mental Health

### Changes After ABI / TBI

- |                         |                             |   |
|-------------------------|-----------------------------|---|
| • Orientation           | • Perception of Environment | • Reasoning   |
| • Alertness             | • Expressive language       | • Sequencing  |
| • Focusing Attention    | • Receptive language        | • Multi-tasking   |
| • Speed of Processing   | • Fatigue                   | • Behavioral Control (start, stop, & resisting impulse) |
| • Remembering New Info  | • Executive Skills          | • Emotional Control (inappropriate or intensity change) |
| • Remembering Past Info |                             |   |

### How Long Will Problems Last?

- Traumatic brain injury: fastest recovery in 1st 6 months, with more gradual changes up to 1-3 years
- Stroke: peak of recovery at approximately 6 months
- Anoxia: Peak of recovery at approximately 6 months
- Brain Tumor: variable depending on type of tumor and site
- Mental Illness: Some people may only have one experience (known as an "episode") of mental illness that might only last a few days, weeks or months but others may have long term conditions which do not go away which are managed often with medication.
- Dementia: progressive decline
- Restoration Verses Compensation - Spontaneous restoration of functioning occurs most rapidly and dramatically in the first year following a brain injury. Generally speaking, the greater the time from the injury the more rehabilitation efforts will focus on compensation

## Typical Problems After An Acquired Brain Injury

- Reduced Awareness of Problems
- Reduced attention
- Reduced memory
- Problems with language and social communication
- Problems with initiation
- Problems with organization
- Emotional and behavioral changes

**What Is Reduced Awareness?** Reduced ability to recognize problems caused by damage to the brain

## Challenging Behaviors Related to Mental Illness

Handling the challenging behaviors (symptoms) associated with mental illness is not something caregivers have to deal with alone. Seeking support and information can help guide a constructive response to someone who is exhibiting symptoms or challenging behaviors and reduce the tension for both persons.

## Challenging Behaviors

Some of the more challenging symptoms experienced by persons with mental illness may include the following:

- Delusions: fixed beliefs based on imaginings, which result in suspiciousness or paranoia.
- Hallucinations: hearing voices and seeing images that can be persistent or frightening.
- Mood swings and mood reactions that do not relate to the current situation.
- Difficulty concentrating due to other symptoms.
- Irritability.
- Changes in sleep patterns.
- Important! Some symptoms may be related to other medical conditions. A thorough evaluation may help to determine what is causing each symptom.

## Responding to Challenging Behaviors

The following ways of responding to challenging behaviors are often successful with people with mental illness:

- Speak in a calm, slow voice.
- Give directions one at a time and in a clear manner.
- Explain things in a simple, direct way.
- Avoid sarcasm.
- Avoid statements that could be confusing.
- Do not try to convince the person that their delusions are not real. Instead, display sensitivity to their feelings by saying things such as, "This must feel very frightening to you; how can I be of some help?"
- Lower the stimulation in the surrounding area. Background noise, such as a radio, may be contributing to distractions or hallucinations
- Reduce movement in the surrounding area. Too much movement may distract or distress the person.
- If the person is agitated,
- Stand aside and allow space for them to exit.
- Invite them to go outside if there is not a risk of their running away.
- Provide a safe environment.
- If the person threatens violence,
- Be gentle but firm about setting limits.
- Take the necessary measures to keep them, yourself, and others around them, safe.
- Leave the area, if necessary.
- Do not argue or increase the stress level. Let them know in a calm manner that you will not tolerate anyone in the family getting hurt, including them.
- Contact the local mental health center or the police if you feel there is imminent danger.

## Effects of Medications on Behavior

People who have mental illness and their caregivers must consider the side effects of medications or the interactions of different medications, because they, not the mental illness itself, sometimes cause the behaviors (symptoms) listed below.

Many times, we assume these symptoms are a natural part of the disease and overlook the possibility that they may be caused by medication or another condition. It is important to try to find the cause of each symptom and to explore whether or not it can be prevented, avoided, or reversed by adjusting the medications.

If a specific medication causes an undesirable side effect, you can consult a doctor to explore the possibility of using a different medication. Unfortunately, an ideal solution is not always available. Sometimes an individual may need to decide between dealing with the symptoms of their illness or the side effects of the medication taken to reduce the symptoms.

- Hallucinations.
- Delusions.
- Paranoia.
- Confusion.
- Disorientation.
- Anxiety.
- Shuffling gait.
- Drooling.
- Facial tics.
- Increased/decreased sexuality.
- Incontinence.
- Constipation.

# Challenging Behaviors Related to Dementia

## Challenging Behaviors

The more common behaviors and issues that we observe in people with dementia are:

- Agitation/anger/combativeness.
- Wandering.
- Wanting to go home.
- Shadowing.
- Verbal repetition.
- Changes in sleep patterns.
- Loud yelling/noises.
- Catastrophic reaction.
- Hoarding.
- Driving.

## Responding to Challenging Behaviors

Here are some useful responses for each of the behaviors mentioned above. Remember that they may not work each and every time, and responses may change as the disease progresses. When the action you take is not effective, try a different approach.

## Physical and environmental causes

People with dementia are often unable to tell you what is wrong. Caregivers need to be aware of and look for signs of physical discomfort. When a person exhibits an unwanted behavior, consider the following possible causes before assuming that the mental illness is causing the behavior:

- Physically ill.
- Experiencing pain.
- Needing to use the bathroom.
- Hungry or thirsty.
- Distracted by noise.
- They may also be agitated by the following physical conditions in the surroundings:
  - Bright lights.
  - Not enough light.
  - Loud, bold colors.
  - Room temperature.
- Frightened by how someone approached them or talked to them.
- Experiencing a side effect of a medication.
- Experiencing a medication interaction if they are taking more than one medication.
- Anxious about being in an unfamiliar place.
- Distracted by too much activity in the area.

**People with memory loss may recognize the need to eat or drink or use the toilet, but are unable to locate or ask where or how to satisfy those needs. In frustration, they may then have a sudden change in behavior or functioning level.**

## Angry or agitated behaviors

- Alternate quiet times with more active periods.
- Make sure the person is well rested before starting an activity.
- Reduce the noise level, clutter, or number of people in the area.
- Maintain a consistent routine.
- Remove the person from a stressful situation gently and in a calm manner.
- Use food items or a favorite activity to distract them.
- Use music, photo albums, massage, or readings to calm the person.
- Use a gentle touch, such as holding their hand or hugging to help them feel reassured.
- Make sure they are comfortable, not too hot or too cold, or that their clothing is not binding or tight.

## Wandering

- Allow a person to wander if the environment is safe and secure.
- Place familiar objects, furniture, and pictures in surroundings.
- Help direct the person with clearly marked rooms, using name plaques, pictures, or a decorated door.
- Remove items that trigger desire to go out, such as shoes, coat, purse, keys, etc.
- Try locks on doors that are out of reach or sight. Install slide bolts on top or bottom of outside door.
- Distract with food, activity, or conversation.
- Place night lights throughout the home.
- Consider using a beanbag chair for sitting and resting. They are comfortable yet difficult to get out of without assistance.
- Provide wanderer with some type of identification such as Medic-Alert bracelet, labels sewn into clothing, emergency cards in wallets, purse, or pocket.

## Wanting to go home

- Go for a walk or a drive. Getting out even for a short time is helpful. Upon returning home, the person often recognizes it as home.
- Respond to the emotion being expressed, i.e. "Are you feeling scared?" or "I know you are lonely."
- Offer reassurance.
- Look at a photo album with pictures of the person's childhood. Reminiscing about the past may ease tension and anxiety.
- Try redirecting the person's attention with an activity, food, music, a walk, or other exercise.

### **Shadowing (following caregiver around)**

When a person is totally dependent on someone, and that person sometimes cannot be seen, the older adult may then become distressed and panic. The following approaches can help reduce the distress:

- Maintain a consistent routine.
- Involve them in a regular activities program.

Give repetitious chores to perform such as the following:

- Folding towels.
- Winding yarn.
- Dusting.
- Give reassurance.

### **Verbal repetition**

- Do not remind the person that they have asked the same question before, as this may be upsetting to them.
- Respond to the emotion instead of the specific question. The person may simply want reassurance.
- Use brief statements.
- Try a gentle touch when verbal response does not help.
- Use a calm voice when responding to repeated questions.
- Use simple written reminders with people who can still read.
- Do not discuss plans with a person until just before the event if this causes agitation and repeated questions.
- Ignore the behavior. If there is no response or reinforcement, the behavior may stop.
- Redirect their attention to focus on a simple task or activity such as looking at a magazine, picture book, or TV.

### **Changes in sleep patterns**

- Check whether the person is too hot or too cold upon awakening. Internal thermostat may change with dementia.
- Provide adequate lighting during evening hours. Shadows, glares, or poor lighting may contribute to agitation and hallucinations.
- Have the person spend less time in bed. Try getting them up earlier or keeping them up later until tired.
- Make sure the person is getting adequate exercise. Try to take one or two vigorous walks a day.
- Make sure the person is not hungry at night. Try a light snack before bedtime or during the night.
- Avoid bathing or heavy activities late in the afternoon or evening unless a warm bath relaxes a person.
- Allow the person to sleep in an armchair, recliner, or on the couch if refusing to go to bed.
- Give a backrub or massage legs at bedtime or during night wakefulness.

### **Loud verbal noises/yelling**

- Provide adequate meals/snacks to minimize hunger.
- Have a regular toileting schedule to minimize incontinence.
- Make sure there are frequent position changes if bedridden or in a chair.
- Lower stress in the environment. Minimize the noise and avoid overstimulation.
- Approach with soft, soothing voice.
- Call the person by name and identify yourself.
- Explain in short, simple sentences, what you are doing or going to do with them.
- Break tasks into short steps briefly explaining each one.
- Try massage, stroking the person's hands, arms, or head.

### **Catastrophic reaction**

Sometimes a person with dementia may become suddenly angry or physically violent reacting to stress or frustration. This is known as a "catastrophic reaction." Should this occur...

- protect yourself.
- try to remain calm.
- distract the person by talking about something else, offering a favorite food, or suggesting a different activity.
- if they are unable to be controlled or redirected, remove yourself from the room and get help in handling the situation.

### **Caregiver sets the tone**

- Someone's attitude, mood, or approach, when talking to a person with dementia, is very important. A caregiver can lessen distress and set the tone in almost every situation because the individual with dementia takes their cues from the caregiver.
- If the caregiver is abrupt, talking too loudly, or rushing through a task, this will be communicated to the person with memory loss, and he or she may react negatively. A caregiver speaking calmly and reassuringly can reduce anxiety for the older adult with dementia.
- Find out what the person has enjoyed in the past and organize activities that appeal to his or her interests and abilities. Music can reach people when not much else can; it can decrease agitation and improve mood, socialization, and appetite.

## Signs of Reduced Awareness

- Generally does not seem concerned about their limitations, as if nothing is different
- Insists that he/she can do things as well as before the injury or wants to do activities you don't think he/she is capable of
- Complains that the doctor and you "don't know what you're talking about."

Impaired awareness may affect some areas of functioning and not others (e.g., may realize they have memory problems, but not realize that their ability to drive is impaired).

## Strategies for Increasing Awareness

If a person does not understand that they have a problem or cannot recognize one when it's occurring, provide them with cues to help or re-arrange their surroundings to make things easier for them.

- Memory problem- Use checklists of activities; wall calendar/schedule
  - Getting off topic- Develop a signal that will alert them when they're off topic
  - Organization: Use checklists.
- If a person does not understand that they have a problem or cannot recognize one when it's occurring, provide them with cues to help or re-arrange their surroundings to make things easier for them.
- Memory problem- Use checklists of activities; wall calendar/schedule
  - Getting off topic- Develop a signal that will alert them when they're off topic
  - Organization: Use checklists.
- If a person understands they have a problem and recognizes it when it's occurring, but can't anticipate a problem, teach them to use strategies in all situations.
- Carry memory notebook everywhere in case they need to refer to it.
  - Make checklists for all activities.
  - Always watch listeners for non-verbal cues
  - Ask for feedback from listeners
  - Watch your behavior closely

## What You Can Do To Help Your Family Member

- Be patient- Your family member is not ignoring problems on purpose.
- Point out problems when they occur- in a kind and calm way. Do not yell or get angry with them.
- When it is safe, let them make mistakes on their own. Remember to talk things over with them after they make the mistake. Help them think of a way to get around the problem next time.

## Memory

- Memory problems are common following all types of brain injury.
- Most people remember information from their pasts, but may have trouble learning and remembering new information.
- Memory for non-routine things (like medical appointments) may be worse than for routine things (like when a TV show comes on).

### ***For most, Brain Injury is: A loss of Self, A loss of future, and loss of possibilities***

**"I had a job, I had a girl, I had something going mister in this world....."** A 10-year survivor of a TBI quoting a Bruce Springsteen song when describing what he had lost because of his injury

## What Types of Things Might Your Loved One Forget?

### Strategies for Improving Memory

- Allow extra time for your family member to learn new things. Keep in mind they will learn more slowly.
- Forgetting Appointments
  - Repeating questions or the same story over and over
- Forgetting names, especially names of new people
  - Needing to have information repeated
- Losing or misplacing things (e.g., keys, wallet)
  - Forgetting things quickly
- Forgetting to take meds, or forgetting they were taken and taking them again
  - Taking longer to learn new information
- Repeat things that you want them to remember.
- Write all important information down.
- Use a digital watch to keep up with date and day of the week.
- Organize!
  - Keep household items in specific places. For example, have a special place for keys.
  - Make sure everyone in the household returns items to their special places.
  - Label drawers and cabinets.

## Memory & Medication

- Correct medication and dosage time is crucial to your loved one's health.
- Buy a pill box and label each dose with the time and date they should be taken.
- Each dose should go in a different section of the box to avoid confusion.

## Attention

- Attention and memory are closely related.
- Sometimes it seems like your loved one is having trouble with memory when instead they may have a hard time paying attention to what they need to remember.

## Common Attention Problems

- Trouble keeping their mind on one thing.
- Easily distracted by noises that wouldn't have bothered them before.
- Difficulty doing more than one thing at a time (e.g., cooking and answering the phone).
- Difficulty "switching gears" or shifting focus from one thing to another.

## Strategies for Improving Attention

- Keep your home organized and free of clutter to minimize potential distractions.
- Make sure everything is put away except those things they are working with.
- For example, when cooking, only take out items needed for that particular dish.
- Encourage your loved one to work on one thing at a time.
- When you want to talk to your loved one, turn off the TV, radio, etc., and keep other people and distractions to a minimum.
- Encourage them to talk themselves through things that they are doing and ask themselves if they are reaching the goal.
- If your loved one is "stuck" on one idea or task, gently redirect their attention.

## Common Language Problems

### Problems with expression:

- word-finding difficulty
- word substitution errors (e.g., uses "pencil" for "pen")
- slurred speech
- slowed rate of speech
- may speak in short sentences or lose train of thought

### Strategies to Improve Expression

- Allow more time for them to answer or to explain what they want.
- Encourage them to use gestures or signals to help express themselves.
- Encourage them to speak slowly and not worry too much about finding the right word.
- If they can't think of the proper word, encourage them to tell you something about that word (e.g., "that thing with the tires that you use to haul stuff")

### Problems understanding others:

- may not follow directions accurately
- responses may not be related to what you actually said
- may have difficulty following group conversations
- may have trouble "keeping up" with others who speak quickly

### Strategies to Improve Understanding

- Every so often, ask your loved one if he/she understands what you are saying. Ask him/her to repeat the information to you.
- Encourage them to ask for information to be rephrased or repeated. Reassure them we all have to do this sometimes.
- Use gestures and signals to help you communicate with them.
- Try to have only one person at a time speaking to them.
- Encourage them to ask the speaker to "slow down." Reassure them we all have to do this sometimes.

**Communication and Social Interaction:** Even though your loved one uses words and sentences adequately, he/she may still have problems interacting with others because of changes in social communication skills.

### Social communication skills include:

- Starting, maintaining and ending conversations
- Selecting and maintaining topic
- Awareness of feedback from others (e.g., can they tell if their listener is interested in maintaining the conversation?)
- Nonverbal communication

## Non-Verbal Communication

- Facial expressions
- Body posture and gestures
- Social distance
- Eye contact
- Physical contact (e.g., touching another's shoulder)
- Pauses, pitch and tone
- May also have difficulty "reading" or "picking up" another's social cues, especially those relatively subtle cues.
- Changes in your loved one's language and social communication skills can lead to problems interacting with family & friends.
- It may seem as if personality has changed.

## Strategies to Improve Social Communication

Develop a signal that will let your family member know when they have gotten off topic.

- For example, you could hold up your index finger.
- Signals may also be used to let them know they are repeating themselves, providing too many details, or asking an inappropriate question.
- If signals don't work, try saying, "We were talking about..." Remember to use kind words and a gentle tone of voice.
- Praise them when they start conversations on their own.
- Encourage them to practice starting and ending conversations with others in their community (e.g., sales clerks, wait staff).
- If they seem to use personal space or contact inappropriately, explain appropriate distances and contact. Remember to use kind words and a gentle tone of voice.
- Encourage your loved one to practice non-verbal communication in the mirror.

## Coping with Initiation and Organization Problems

**What is Decreased Initiation?** Trouble starting activities on their own. Decreased initiation is a result of injury to the parts of the brain that control our ability to make plans and start activities.

Examples of Decreased Initiation

- Do not seem interested in things they liked to do before
- Seem to sit all day doing nothing or staring at the TV
- Need to be reminded to bathe or brush their teeth
- Knows what needs to be done, but doesn't seem to be able to get started

**Decreased initiation is not the same as decreased motivation.** While it may look like a symptom of depression, decreased initiation does not always mean your loved one is depressed. Accept that this problem is a result of the brain injury. Your loved one is not being "lazy." He or she may have little control over this behavior.

## Strategies to Improve Initiation

- Help them make a daily activity schedule
  - Ask them what activities they like to do
  - If they cannot come up with realistic activities, give them a choice of 2 or 3 doable activities
  - Make the activities a part of their daily routine (e.g., take a walk after breakfast)
  - Make checklists to help them start and complete activities
- Physical or cognitive problems may prevent them from resuming activities they enjoyed before their injury. Help them come up with new activities they can do.
- At first, try new activities with them and help them cope with problems they might face (e.g., frustration or fatigue).
- Find something they really like and use it to reward them for being more active (e.g., if they take a walk around the block, they can rent a movie).
- Get them involved in a support group for persons with TBI.
- Get them involved in a church group or volunteer organization.

## Examples of Organization Problems

- Difficulty organizing their time to get things done (e.g., may tell someone they can be at a party at the same time they have another appointment)
- Trouble setting goals, planning the correct steps to reach a goal, or completing the correct steps to reach a goal
- Trouble completing tasks in the correct order (e.g., does not put soap in the washing machine when washing clothes)
- Trouble getting ready for daily appointments, school, or work

## Example of a Checklist

### Getting ready in the morning

- pick out clothes to wear
- lay clothes on bed
- take a shower
- brush teeth
- get dressed
- comb and fix hair
- make and eat breakfast
- take medications
- feed the dog
- get things together
- memory book
- keys
- wallet
- lunch
- leave the house

## Strategies to Improve Organization

- Break activities down into smaller steps.
- Use checklists to help organize daily activities.
- Use checklists to keep track of the steps needed to complete a particular activity. They can check off the steps as they do them.
- Have them use a memory book or calendar to keep track of their daily schedule.
- If they have trouble getting organized to leave the house in the morning, have them get some things ready the night before (e.g., choose clothes, get together anything that may be needed for the outing)

## Coping with Emotional and Behavioral Changes

- Depression
- Anger/Aggression
- Irritability
- Inappropriate or Embarrassing Behavior
- Impulsivity (acts quickly without thinking)

## Symptoms of Depression

- Sad or irritable mood
- Loss of interest in things they used to enjoy
- Difficulty sleeping or sleeps too much
- Little or no energy
- Increased or decreased appetite
- Decreased feelings of self-worth
- Says things like, "I would have been better off if I died in the accident" or has suicidal thoughts or plans
- Most people do not have all of these symptoms. They may have a different combination of symptoms over time.
- Feeling sad is a normal part of dealing with their brain injury and their losses.
- They may become more sad as they become more aware of their problems.
- Depression occurs when these feelings get in the way of their daily functioning.

## Strategies to Manage Depression

- Talk to your family member about their feelings. Let them know that you support them and realize how much the injury has changed things.
- Talk to the doctor about whether counseling or medication would help.
- Get your family member involved in activities that might take their mind off of their sadness.
- Encourage them to exercise regularly.

## Inappropriate or Embarrassing Behavior

Your family member may be more disinhibited because of damage to the parts of the brain that are important for monitoring and controlling our behavior. As a result, your family member may say or do things they would not have done before. For example, before the injury, they may have had rude thoughts about another person. After the injury, they may say those rude things out loud.

## Examples of Inappropriate or Embarrassing Behavior

- Tells strangers about personal matters
- Asks personal questions of others he or she does not know well
- Makes embarrassing sexual comments in public
- Cusses a lot

## Strategies for Managing Embarrassing Behavior

- Calmly let your family member know that this behavior is wrong and bothers other people. Do not yell or lose your temper.
- When in public, use a signal (e.g., hold up hand, shake head) to let them know they are acting inappropriately. Practice this signal before going out. The goal is for them to stop the behavior when you give the signal.
- Reward them for acting appropriately and following the signal. Praise them often.
- If your family member is acting inappropriately and not responding to your signal, stop the activity.
  - *For example*, if you are at the mall, return home immediately. Your family member will learn they can only go out with you if they act appropriately.
- Don't let this behavior run your life.

## Impulsivity

- Impulsivity is acting quickly without thinking ahead.
- Examples of Impulsivity:
  - Says whatever comes to mind
  - Does whatever they want without regard for what may happen
  - Does things that are dangerous (e.g., crosses street without looking for cars)

## Strategies for Managing Impulsivity

- Stop them when they are acting without thinking. Talk calmly about the possible consequences.
- Develop a special signal that will let them know when they are being impulsive
- Reward them for thinking before acting. Let them know how pleased you are.
- Remove car keys, guns, knives and other items that could be used dangerously.

## General Tips

- Remember to praise your loved one for small daily accomplishments.
- When providing feedback, start off with emphasizing something positive that they've done, followed by the feedback, followed by a re-emphasis on the positive (sandwich technique).
- Encourage them to try different strategies for improvement, and be there to help when they try.
- Try to avoid taking their difficulties personally. Put things in the perspective of the injury. However, do not give in to the tendency to blame the injury for all difficulties.
- Avoid reacting with frustration to problems. Take time out when you feel frustrated.

## A compromised brain can lead to compromised behavior, further adding to social isolation and social failure

### Behavioral Statistics

- Approximately 90% of all people who experience severe disability following an acquired brain injury experience some emotional or psychiatric distress
- 40% continue to demonstrate behavioral difficulty five years post injury
- 25% experience behavior dysfunction that interferes with other activities of daily life
- 3%-10% experience severe behavioral dysfunction that may require intensive professional and residential intervention (~3,000-9,000 new people per year)
- "Aggressive behavior is associated with presence of major depression, frontal lobe lesions, poor premorbid social functioning and a history of alcohol and substance abuse" Tateno et.al J of Neuropsychiatry Clin. Neuroscience 2003
- Research conducted by Wood and Lioffi in 2006 reports "it is tentatively suggested that significant impairment in verbal memory and visuospatial abilities against a background of diminished executive-attention functioning is associated with the development of aggression after brain injury, especially when other risk factor such as low premorbid IQ, low socioeconomic status, and male gender are present" J of Neuropsychiatry Clin. Neuroscience
- "Impairments in recognizing the emotional state of others may underlie some of the problems in social relationships that these patients experience.....TBI patients were found to be impaired on emotional recognition compared to the control patients both early after injury and one year later" Ietswaart et. al. Neuropsychologia, 2007
- "Almost all people who experience disability following brain injury are not inherently aggressive or assaultive. However, for some people, when challenges are not properly addressed this can result in..."McMorrow, Jacobs and Hudson; HRSA Webcast July 27, 2006

### Examples of Behavioral Aggression

- Lack of responsiveness to requests
- Property destruction
- Verbal or physical aggression
- Violation of personal or sexual boundaries
- Wandering or flight
- Self harm/self abuse/suicide

### "Neurobehavioral Challenges" are caused by:

- Pre-injury history
- Post-Injury learning and experiences
- Inability to negotiate "difficult" situations
- Others' not recognizing the basic challenges to an individual with ABI, and
- Not providing proper treatment

## Strategies for Supporting Individuals with Behavioral Problems

### Environmental Triggers for Behavioral Problems

- Too much stimulation
- Rapid pacing
- Lack of predictability and clear structure
- Overwhelming physical and cognitive demands
- Negative social input
- TIP: If you manage the environment, you can prevent many problems

### Guidelines for Behavior Management

- Keep the environment simple. People with brain injuries are easily overstimulated
- Decrease interruptions and distractions and surprises
- Be consistent
- Keep instructions simple, concrete
- If the person has problems processing language, try gesturing or cueing
- Write things down
- Avoids reinforcing misbehavior
- **Redirection works.** When the person is upset, agitated, aggressive, focus attention on some other topic, task, person
- Provide choices
- Give feedback and set goals
- Feedback should be direct, caring, nonjudgmental, but not subtle
- Avoid criticism
- Be calm, cool and friendly during an incident
- This can reduce agitation

- Environmental, AKA Prosthetic external memory strategies and devices
  - Changing or modifying the environment to support and/or compensate for an injury imposed deficit
  - For Example: labeling kitchen cabinets
- Expect the unexpected. People with brain injuries can have great variability from day to day. Mood swings are common. People with ABI are sensitive to changes, disruptions in routine, lack of sleep, alcohol, minor illnesses, fatigue and other stressors

### Keep in Mind

- Progress can be inconsistent and unpredictable
- What works today may not work tomorrow, but may work the following day
- Reduced stamina and fatigue may persist
- Impairment of memory may hinder new learning
- Transitions may be especially difficult

### Prevention, Prevention, Prevention

- Communicate expectations
- Recognize internal and environmental triggers, plan strategies
- Provide clear structure and predictable routines
- Maintain realistic expectations
- Help peers learn to alter interactions to avoid triggers

### Areas of Cognitive Functioning that can be supported by Strategies

- |                   |                               |                   |
|-------------------|-------------------------------|-------------------|
| • Attention       | • Processing speed            | • Self-Perception |
| • Memory          | • Problem solving differences | • Inflexibility   |
| • Decision making | • Persistence                 | • Self Monitoring |
| • Sequencing      | • Organization                | • Initiation      |
| • Judgement       |                               |                   |

### Areas of Interpersonal Functioning that can be supported by Strategies

- |                         |  |
|-------------------------|--|
| • Impulsivity           | • Self esteem                            |
| • Frustration tolerance | • Building and maintaining relationships |
| • Social skills         |  |

**Most of these Strategies address more than one cognitive and or behavioral deficit**

### Managing Sexual Behaviors

- May not be sexual; individual may simply be expressing a personal need. For example, a man pulling down his pants may be needing to go to the bathroom
- However, an individual may also be attempting to meet personal needs by masturbating
- If this occurs in an inappropriate area, then redirect the person using a neutral approach. A private location would be better
- Sexual desires do NOT go away with age!
- Note that some diagnoses can lend themselves to confusion about personal touch. Remember to orient the individual as to the purpose of your presence.

### Medication Non-compliance

Significant issue across all age groups, all diagnoses, all people – most of us have been non-compliant at some point in our lives  
Important not to make assumptions

Identify root cause before jumping into solutions

#### Possible causes of Non-compliance

- Forgetfulness/slips/lapses
- Paranoid ideation/suspiciousness
- Side effects or dislike effects of medication
- Severity of illness
- Lack of knowledge/Misunderstanding instructions/lack of education
- Complexity of regimen
- Lack of support
- Stigma of taking medication
- Concerns about cost

#### Potential Interventions

- Establish routine for taking medications to help reduce resistance and arguments
- Streamline medications, minimize dosing times
- Consider rapidly dissolving tabs for persistent refusals
- Ask pharmacist for help if difficulty swallowing pills
- Monitor for cheeking (pretend to swallow their medications but really hide the pills in their cheek)
- Pill boxes can be a useful memory aid for both the person with dementia and the caregiver

### **Examples of strategies-cheap tricks**

- Red lined index card and red stickers: Addresses visual neglect, attention and concentration
- Reading guide: Addresses a number of visual problems including figure ground deficits, jerky eye movements (nystagmus) and impairment in the ability to smoothly move the eyes
- Non-slip mats ("dycem") holds books, plates, bowls, paper etc. in place if one hand/arm has no or limited functioning
- Use of a journal/calendar
- Create a daily schedule
- Labeling kitchen cabinets
- "To do" lists and shopping lists
- Labeling items
- Learning to break tasks into small manageable steps
- Use of a digital recorder
- Encourage use of rest and low activity periods, naps are to be encouraged!
- Work on accepting feedback or coaching from others, consult and collaborate with trusted individuals
- Work on generalizing strategies to new situations
- Use of a high lighter (RED)
- Alarms (on phone, watch)
- Use of smartphone
- Use of a template for routine tasks, on the job, at home, in the community
- Use of ear plugs to increase attention, screen out distractions (Parente & Herman 1996)
- Partitions/cubicles, at work, quiet space at home
- Model tasks e.g. turning on a computer and accessing email
- Use of pictures, for faces/names, basic information, for step-by-step procedures, e.g. making coffee
- Use of a timer, to track breaks at work, the time minimum technique, allocated time to puzzle over a problem or vent a frustration
- Books on tape, movies, keep the subtitles (for processing content in the case of memory and comprehension problems and increase awareness of nonverbal cues/communication)
- Electronic pill boxes/blister packs with day of the week labels
- Review schedule each day
- Post signs on the wall etc. (use pictures/symbols for low literacy skills)
- Try to "routinize" the day as much as possible

### **Listening Skills**

- An area where reduced cognitive skills can be misinterpreted as poor interpersonal skills
- No one likes a "noisy listener"
- Poor listening skills can be impacted by anxiety (about memory, social skills etc.)
- Relaxation techniques can be helpful (breath in slowly over 7 breaths, hold for 4-7 counts, exhale over 7, repeat as necessary)

### **Enhance Communication**

- Model how to paraphrase during conversations to maximize comprehension
- Instruct how to reduce injury imposed tendency to be impulsive in word and/or action by using breaks and pauses
- Speak in short, simple sentences and phrases

### **Communication....**

- Request that the individual jot down notes regarding discussions that he/she has with others and other important information
- When giving instructions, do it verbally and in writing and when possible, physically model the task
- Minimize confusion/socially unacceptable behavior
- Give useful and specific feedback about a behavior
- Ask the individual for permission to coach him/her

### **Behavior ....**

- Be clear on your expectations of the individual and his/her behavior
- Give feedback immediately using the sandwich technique
- Utilize positive reinforcement/feedback
- Formalize your expectations by negotiating a written agreement, signed by all involved parties
- Refer to the agreement frequently, update as needed

### **Keep in Mind.....**

- Talk slowly, use short sentences
- Eliminate distractions
- Accommodate individual needs and learning styles
- Be flexible
- Write things down, provide directions
- Express ideas concretely

# NAVIGATING CHALLENGING BEHAVIORS IN ADULTS

**What is in your control?** Personal responses; Environment, to some extent; Supports; Your own well-being

**Just so we're clear.....what is NOT in your control?**

**Controllable: Your responses**

- |                                   |  |                                   |   |
|-----------------------------------|--|-----------------------------------|---|
| • You can't control other people. | • You cannot change their past.  | • Remain calm                     | • Get support when needed (and available)             |
| • You cannot change who they are. | • You cannot make them want to do something they really do not want to do. | • Respond, but do not be reactive | • If your approach has not worked, try something else |

## What Can YOU Control? OR NOT!

### CONTROL...

- The environment – setting, sound, sights
- The whole day... how things fit together
- How the helper helps -
- Approach, behaviors, words, actions, & reactions

### NOT CONTROL

- The person & who they have been
- Personality, preferences & history
- The type & level of impairment ... NOW
- Other medical conditions & sensory status

### When behaviors occur:

Consider all factors impacting individual:

- |                    |  |
|--------------------|--|
| • Environment      | • Responses to events  |
| • Timing of events | • Potential physical issues (especially pain) affecting individual |

Can you identify an antecedent?

- An antecedent is something that occurs before a certain behavior.

## Looking for the A-B-C's

The analysis of antecedents and consequences is often referred to as the A-B-C Model of functional assessment:

- A stands for the influential events that take place before a behavior occurs (antecedents)
- B stands for the behavior (appropriate or challenging); and
- C stands for the influential events that take place after a behavior occurs (consequences).

<b>A = Events that occur before the behavior, or antecedents</b>	<b>B = The behavior</b>	<b>C = Events that occur after the behavior, or consequences</b>
<ul style="list-style-type: none"> <li>• Physiological</li> <li>• Social</li> <li>• Psychological</li> <li>• Environmental</li> </ul>	The behavior should be described in <i>measurable</i> and <i>observable</i> terms that <i>everyone understands</i>	<ul style="list-style-type: none"> <li>• Did the behavior result in a reward for the person?</li> <li>• Did the behavior result in escape from a particular situation?</li> <li>• Did the behavior allow the person to avoid something?</li> </ul>

### COLLECTING THE A-B-C'S

To further illustrate the use of this form, read the case below, and then refer to the grid that follows.

James, a nonverbal individual with severe brain injury, had a habit of plopping down in front of the refrigerator when he wanted something to eat. He was in the way when staff tried to cook, and because he would not move, they could not open the refrigerator. He also occasionally hurt himself when he plopped himself down on the floor.

### COLLECTING THE A-B-C'S – AN EXAMPLE

As a result of collecting the data, staff decided that giving James food in front of the refrigerator was encouraging him to repeat the behavior. They also decided that James should be offered food ONLY at the table. Staff decided to teach James to use sign language for "eat" and for "drink". When he used the sign, staff rapidly responded to the sign with a snack or drink, which was given to him at the dining table.

<b>A = Events that occur before the behavior, or antecedents</b>	<b>B = The behavior</b>	<b>C = Events that occur after the behavior, or consequences</b>
<ul style="list-style-type: none"> <li>• James smacks his lips</li> <li>• James sits on the floor only when people are cooking</li> </ul>	James "plops" himself down in front of the refrigerator, often with enough force that he bruises himself. He then refuses to move, sitting in a place that blocks the refrigerator door.	<ul style="list-style-type: none"> <li>• Staff give James bits of food while they cook</li> <li>• James makes happy- sounding noises after getting something to eat</li> </ul>

It took a while to replace the behavior of sitting in front of the refrigerator because James would exhibit both behaviors - plopping down in front of the refrigerator and signing - at the same time. Since the food was offered at the table and not while he was in the floor in front of the refrigerator, he gradually began going to the table and signing for what he wanted.

The analysis of the event showed staff that James' internal response (hunger) was being rewarded by an external action or response by the staff (the socialization with staff as they cook AND getting to eat bits of food).

And there can be negative responses to social situations. For example, Johnny loves to watch TV alone. But when others who live in the home come into the room during his TV time, Johnny begins to bang his head. If the others are asked to leave the room, Johnny quits banging his head.

Sometimes you can figure out the "why" of a behavior based on watching the events that occur right before and right after the behavior. But if it is not obvious or you cannot figure it out after trying to collect data on your own, then it is time to call in a professional!

## Case example

Mr. Crawford would watch the staff giving report at change of shift in the hallway. He would rise from his chair in the group room and attempt to join them. Staff would redirect him to his chair and let him know they would be with him as soon as they were done. After a couple of minutes he would rise again, and attempt to join them. The staff were puzzled by this as he had already been toileted. They would redirect him. He became increasingly agitated as he was redirected. This happened each day at report time. He would become agitated to the point of being aggressive. Sometimes it would culminate in yelling and other times in combativeness.

### Why do you want to know?

- Helpful to know the individual's personal history
- Helpful to identify triggers to prevent behaviors from occurring
- Especially useful to know historical triggers
  - History of physical abuse? Sexual abuse? Combat exposure? Any other trauma? History of restraint/seclusion use
- Equally important to identify coping strategies that work to help stop/minimize behaviors when they occur

### Case example - History

Which of the following facts is most significant for you to know in this case?

- Mr. Crawford was being treated for severe behavioral and psychiatric disturbance related to his dementia
- Mr. Crawford had a recent history of significant aggression and combativeness
- **Mr. Crawford had formerly been a CEO of a very large and successful company**

### Case example - Intervention

Ultimately what we were watching with Mr. Crawford was his interpretation of watching his staff conducting a meeting without his involvement. As he was redirected to move away from the meeting, he communicated his frustration in the only way he could at this time, having limited coping skills.

An intervention that worked well with him was to invite him to participate in making decisions, despite the fact that he could not understand what was being said or speak logically about his thoughts. His emotional response, however, was quite positive and his behaviors improved.

#### Possible Physical Triggers

- Medication side effects
- Symptoms of diagnosis
- Infection
- Pain
- Dehydration
- Hunger/thirst
- Fatigue
- Constipation

#### Possible environmental triggers

- Room temperature
- Lights – too bright/too dark
- Overstimulation
- Understimulation

#### Possible emotional triggers

- Change in routine
- Losses
- Family dynamics
- Depression
- Boredom

#### Controllable: Your responses

- Remain calm
- Respond, but do not be reactive
- Get support when needed (and available)
- If your approach has not worked, try something else

#### Challenging Behaviors: Ground Yourself

- Stop – even if for a few seconds
- Breathe – take a few slow, deep breaths
- Concentrate on your breaths
- Be aware of your own reaction style
- Interventions

## If a situation is extremely dangerous; if it is life threatening to you...

- Escape and get help
- Before taking any action...ask this question:
- Is it really necessary to intervene? Is the behavior truly causing harm or distress to anyone?
- If the answer is “no” then there may be no need to intervene.
- If the answer is “yes,”
- Be prepared to make adaptations
- Be attentive to signals (verbal and non-verbal) given by the individual
- Be willing to try something different if what you've tried isn't working

## Approach

- If entering a room, knock and ask permission to enter.
- Always approach from the front, so the person knows you are there, but once there, stand at a 45 degree angle.
- Smile\* and make eye contact\*
- Do not rush or make sudden movements
- Always identify yourself
- Always explain before doing
- \* **Some caution should be used with patients who are psychotic/paranoid. Minimize use of smiles and direct eye contact.**

## Provide Comfort

- Remain calm and neutral
- Speak slowly
- Be aware of the tone and pitch (low) of your voice.
- Keep your pace of speech slow.
- Make sure you speak loud enough for hearing impaired individuals
- Reduce distractions in the environment that cause distress – e.g., turn down the television, adjust lighting

Consider what you know about the patient and offer items or activities that you know have helped in the past

- Listening to favorite music
- Eating a favorite food
- Looking at family pictures
- Taking a walk
- Talking to granddaughter on phone

## It's all about the other person

- Remember to listen more than you speak
- Let the other person get their emotions out
- Acknowledge their feelings
- Set boundaries/limits if necessary (e.g., I know you are upset, but you cannot throw things at me. What can I do to help you?)
- When doing this, remember to be neutral and caring, not condescending, frustrated or angry.

## Distract and Redirect

- Provide distractions
- Change the conversation to a more pleasant topic
- Encourage use of self-soothing techniques
- Consider intervention from another person
- If nothing is working, take a step back
- Consider other alternatives

## Some specific types of challenging behaviors and/or diagnoses

### Personality challenges

- All of us have personalities
- Some of us are more “colorful” than others
- Most people have many coping skills to help cope with stressful situations
- Some with personality challenges have very limited skills that are more rigid and not always appropriate
- They may respond with anger/hostility, emotional lability, or dependency

### Characteristics we see in such individuals may include the following:

- Unhappiness
- Self-centeredness
- Attention seeking behavior
- Manipulative behavior
- Distorted perceptions of events
- Poor social interactions; lack of empathy

### Such individuals can cause caregivers to feel:

- Unhappy
- Frustrated
- Annoyed, irritated, even angry
- Manipulated
- Targeted

## Personality challenges and You

- You are human; it's okay to have these emotional reactions and then you need to put them in perspective
- It is important to understand the basis of these behaviors and that they cannot be changed easily nor without much effort.
- It may be helpful to consider that their behaviors are coping skills, they are just maladaptive.

## The secret

- It is important to find compassion and then use that compassion as a way to connect with the person.
- Remember to empathize, provide choices, and set limits if necessary
- It's also important not to fall into "splits." Many people with personality challenges tend to see things in "black and white." They see people this way too.

## Agitation/Aggression

### General Behaviors

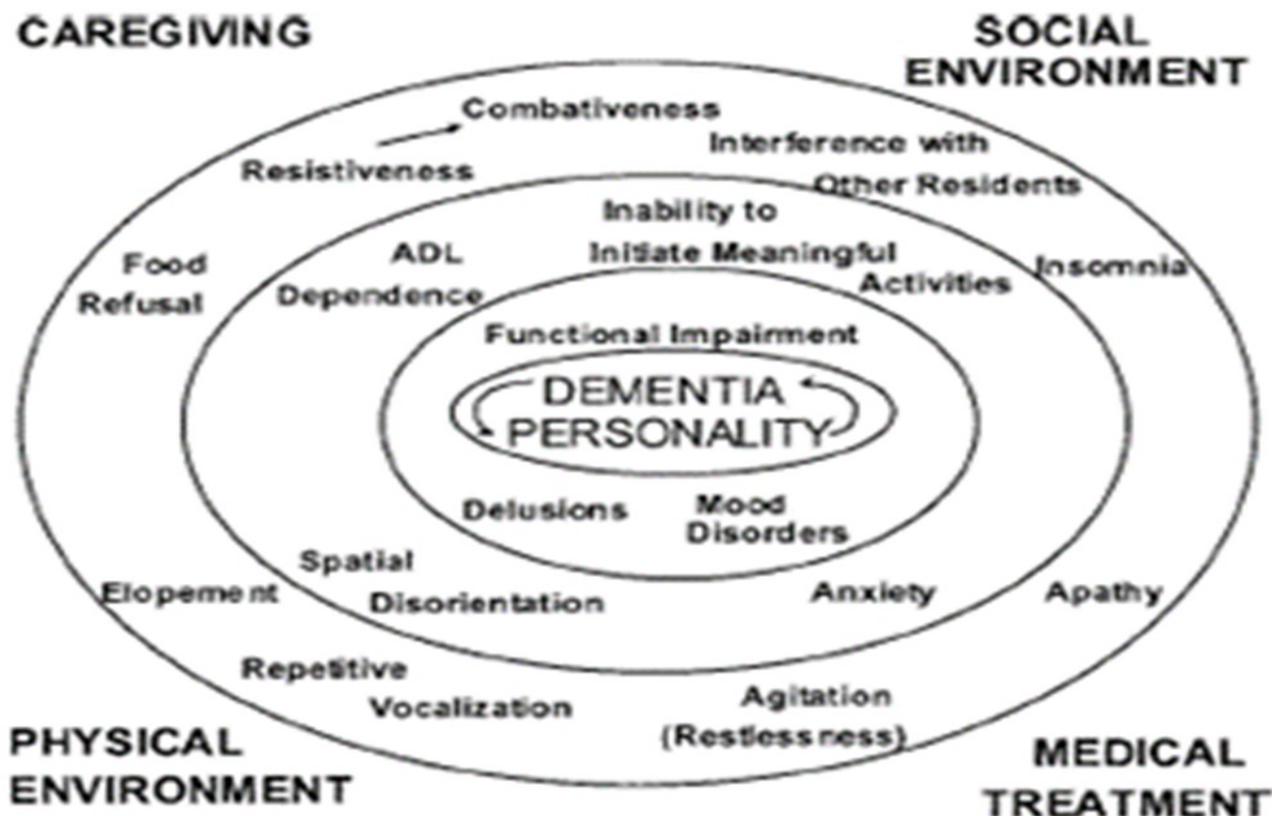
- Attempting to stand unassisted when requiring support
- Disruptive vocalizations
- Not following redirection'
- Obscene or profane language
- Psychomotor restlessness
- Repetitive complaints
- Repetitive demands
- Sexual advances
- Verbal statements considered as insulting
- Wandering
- Yelling

### Acts of Physical Aggression

- Biting
- Cutting
- Grabbing
- Hair-pulling
- Hitting Kicking
- Pinching
- Punching
- Pushing
- Scratching
- Stabbing
- Throwing objects

- Behavior should not just be considered as "confusion" or "agitation"
- As is true for most people, our behavior is a form of communication
- In dementia patients it often represents an unmet need
- As already stated, caregivers cannot change the behavior of others, however, they can change their own behavior and the working environment

## Comprehensive Model



## Comprehensive model of psychiatric symptoms of progressive degenerative dementias

- Functional impairment is the inability to initiate meaningful activities, ADL dependence, spatial disorientation, anxiety
- Lack of meaningful activities may cause agitation, repetitive vocalization, insomnia, apathy
- Thus: **Providing meaningful activities at the level the person can manage might be the first step for managing behaviors**
- This can significantly decrease medication use
- You can follow a similar path by treating depression
- Hallucinations are more common in Lewy Body Dementia; delusions common in both
- These can lead to spatial disorientation, anxiety, and ADL dependence
- This can lead to resistiveness to care or combativeness
- Other peripheral symptoms caused by hallucinations and delusions are: food refusal, elopement, interference with other residents, repetitive vocalizations
- **These can respond well to medication**
- Behavioral symptoms of dementia are influenced by four environmental factors

**Social environment** includes looking at special care settings (e.g., dementia care unit) where individuals are with similar types of individuals

**Physical environment** includes settings that help decrease risk of wandering/elopement

**Medical environment** considerations involve consideration of medication interventions and whether or not they need to be done

**Caregiving** approaches are most important for the resistiveness to combativeness continuum

Dementia patient may not understand need for care

As caregiver persists...dementia patient resists

**Solution:** Avoid escalation through delay, distraction, substitution (e.g., bed bath instead of shower)

## Upset? In pain? Agitated?

- Most aggression is in response to caregiving activities
- Individual believes care does not need to happen or doesn't understand caregiver's motivation (delusional)
- Individual is defending self
- "Agitation can be defined as those behaviors that communicate to others that the person with dementia is experiencing an unpleasant state of excitement and are observable without subjective interpretation, are not strictly behaviors that are invoked by caregiving activities, are unrelated to known physical needs of the patient that can be remedied, and are without known motivational intent." Volicer & Hurley, 2003

## Aggression and Bathing

- **Bathing can be painful for older adults due to**
- Pain from musculoskeletal conditions (e.g., arthritis)
- Fatigue and weakness
- Fear and misunderstanding related to cognitive issues, psychiatric symptoms, and/or previous negative experiences
- Anxiety related to fears of being naked with others, being in a chair lift, fear of falling, PTSD
- General discomfort from cold air
- Feeling rushed by caregivers

## Improving the Shower or Tub Experience

- Switch bathing to a different or familiar time of the day.
- Separate hair washing from body washing if either is distressing or overwhelming to the person being bathed
- Cover the person being bathed with a dry towel when using a hand-held shower to prevent the person from being wet, naked, and cold; simply lift up the towel to wash

## The Towel Bath

A bed bath is often a good choice for persons who are frail, non-ambulatory, considerably overweight, experience pain on transfer, or are fearful of lifts. It is possible to wash people adequately in the bed and it is often much less stressful. It is usually done with a basin of water, soap and washcloths, and rinsing off the soap. A variation on this method is the towel bath. Here, a person is covered with a large, warm, moist towel containing a no-rinse soap solution, and is washed and massaged through the towel.

### **The Recliner Bath**

Several home health aides have reported giving very successful baths when the person is resting in the recliner chair in the living room. They used a basin of water, preferably with a no-rinse soap, and padded each body part being washed with a towel and incontinence pad if available. This worked particularly well for persons extremely fatigued by chronic or terminal illnesses. If the visits are being covered under Medicare, it is important for the aide to “count” this as a bath for reimbursement purposes. Remember, the goal of a bath or shower is to get someone clean and help them feel refreshed. This can be done and needs to be done in many ways.

### **The Toilet or Commode Bath**

This method was useful for an easily agitated nursing home resident. Mrs. Harrington greatly disliked being moved or touched and fought through our attempts to carefully shower her or bathe her in bed. She was often incontinent of stool during her AM shower or bath. So the caregiver, Marie, first placed her on the toilet, allowed her private time to have a bowel movement and washed and dressed her upper torso while she sat on the toilet in her bathroom. Then the Marie washed her legs, and lastly had her stand with assistance and washed her peri area and bottom just prior to transferring her to her wheelchair, ready for the day. Her thin hair was washed also at the bathroom sink using wet washcloths to wet and rinse her hair.

### **The Singing Bath**

For another most complex person, we did the singing, sitting, in- room bath. Miss Florence was infamous for refusing her shower and for fighting when she was forced to shower. Estelle, the nursing assistant who worked with her, discovered that she liked to sing and her favorite tunes were “Jesus Loves Me” and “Happy Birthday”. If Estelle waited until she felt Miss Florence was in a good mood, sang with her, did part of bath while she was lying in bed and part as she began to get up out of bed (following Miss Florence’s lead), she was able to wash her entire body. Her hair was done using an in-bed basin on another day. Interestingly, the family reported that Miss Florence had been refusing to get in the shower or tub for ten years prior to coming into the care facility.

### **The Seven Day Bath**

A family reported good luck in keeping their father, Mr. Simmons, clean by dividing the body into seven parts and washing one each day. He disliked bathing or washing but could tolerate short episodes better than longer, more overwhelming ones

### **The Under-the-Clothes Bath**

Grace disliked the shower or tub, but did well when encouraged verbally and physically to wash herself in her room. However, one day her caregiver, Margaret, arrived to find that Grace had been up all night, which was unusual because she preferred to stay in bed most of the morning. She had rough, agitated night and had a body odor associated with perspiration and urination. A urinary tract infection was suspected and later confirmed and treated. It was the usual day for Grace to get her in-bed bath. Margaret considered just postponing it, but thought she would try to freshen her up and help her feel better. She washed what she could while Grace was sitting in the wheelchair, gently talking to her about her favorite subjects. She continued this approach and reached into her dress to wash her underarms and breast areas and then the genital area. When Grace started to become angry or upset, she stopped. It wasn’t a complete bath, but the priority areas were cleaned and Margaret avoided a big battle at a time when Grace would be easily distressed.

### **The Shared Shower**

Mr. Trask was recently admitted to a care facility. Any attempts by staff to get him to shower or bathe met with fierce resistance. Instead of forcing him to bathe, the facility called his wife to find out how she had bathed him at home. She said that she had showered with him and that it had been enjoyable for them both. The wife was invited to come in and shower with her husband at the facility, with the staff assuring privacy and a pleasant environment. She was glad to be involved in his care and to be able to continue this part of their relationship.

# 12 top tips in caring for a person with dementia

## 1 Remember the person

- Their likes and dislikes
- Provide photos, pictures and mementos to help remember
- Talk about special occasions

## 2 Smile!

The person will notice

- Your emotional state
- Your body language
- Tone of voice

## 3 Slow down

- Provide care in a relaxed manner
- It's ok for the person to do things for themselves
- Keep it simple

## 4 Help with orientation

- If they forget, remind them who you are
- Remind of daily routine
- Use cues – words, signs, pictures

## 5 Communicate clearly

- One point at a time
- Make sure glasses and hearing aides are clean and working
- Take time to understand

## 6 Step back

When the person is angry

- Keep yourself safe – have a safety plan
- Work out why the behaviour happened
- Try again later

## 7 Keep it quiet

- Stop and listen
- Reduce conflicting noises – TV, radio, children
- Avoid overstimulation – crowds, shopping centres

## 8 Don't argue

- Go with the flow
- Acknowledge and respect what the person is saying and doing
- Telling them they are wrong may have a negative effect

## 9 Engage and encourage

- Get the person started with a meaningful activity
- Set activities up to succeed
- Thank them for assisting you and themselves

## 10 Distract

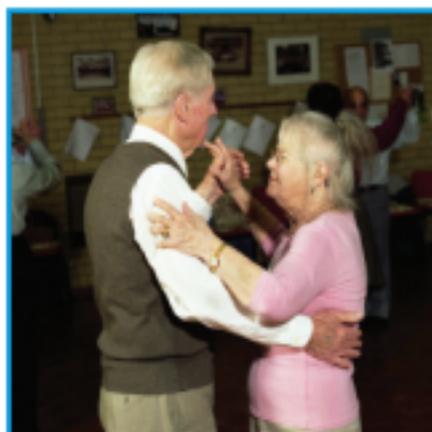
- Talk/yarn about their life
- Give them something to do
- Provide a relaxed environment

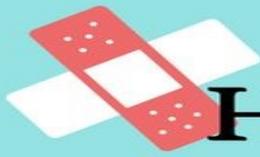
## 11 Talk with others

- Develop support network
- Talk about what has worked and what hasn't
- Record what you did – journal or diary

## 12 Be aware of sudden changes

- Look for a reason – pain, dehydration, infection, constipation
- See GP





# 8 TIPS TO HELP AVOID CAREGIVER BURNOUT



Caregiver burnout is a very real state that can affect anyone providing care for a loved one. Here are 8 helpful tips for Caregivers.

## 1 SET REASONABLE GOALS

Set monthly goals such as scheduling and paying bills. Weekly goals such as laundry days and Daily goals such as washing dishes. But don't stress if something doesn't get done right away. Be sure that goals are reasonable and are not overwhelming.

## 2 KNOW YOUR LIMITS

Know when to STOP! Know when to simply SLOW DOWN! Know that it is OK to not always meet every goal! Know your own limits!



## 3 UNDERSTAND WHAT YOU'RE DEALING WITH

Understand what your caregiver duties are. Learn about your loved one's condition. Try to understand and empathize with their emotions. Understanding what you're dealing with may help you set your own limits and reasonable goals!



## 4 LEARN TO ACCEPT YOUR FEELINGS

It's OK to feel guilt, anger, irritability, stress and resentment. Negative feelings are part of caregiving. Understanding these feelings and learning to accept them may help in finding coping mechanisms.

## 5 REACH OUT AND TRUST SOMEONE

Though, not always easy, it is important to reach out and learn to trust someone. Fostering relationships outside of the caregiver-caretaker relationship may help prevent isolation and could serve as a great way to help cope with stress.



## 6 FIND A SUPPORT GROUP

Find a support to meet other caregivers in similar situations. While having friends and other close relationships is great; they may not understand the challenges of being caregiver. Check out local support groups or online communities; i.e. Facebook Groups or Blogs.

## 7 STAY HEALTHY AND POSITIVE

Aim for walks after dinner, Pilates or Yoga sessions. Join a gym and participate in group workout sessions.



## 8 BE REALISTIC

Be realistic in every aspect of caregiving. You may know your loved one has memory problems; is it feasible to expect them to remember every chore?

# Unfair Hearing Test

## Answer Sheet

	<b>A</b>	<b>B</b>	<b>C</b>
<b>1</b>			
<b>2</b>			
<b>3</b>			
<b>4</b>			
<b>5</b>			
<b>6</b>			
<b>7</b>			
<b>8</b>			
<b>9</b>			
<b>10</b>			

Column A illustrates what words would sound like to a person with a moderate, sensorineural, High frequency hearing loss (TBI)

Column B illustrates what words would sound like to a person with conductive hearing loss (wax in ears, congestion from cold, middle ear infection)

Column C illustrates what words would sound like to a person wearing a hearing aid that is fitted and programmed to meet their hearing needs.

# Guide to Brain Anatomy and Function



## Frontal Lobe

**Function:** Integral to personality, involved in tracking, sense of self, arousal, voluntary motor activity, and awareness of environment. Responsible for executive functioning and judgements, problem solving, emotional response and stability, speaking/ language, and memory for habit

### Symptoms of Impairment

- Changes in personality and social behavior
- Loss of spontaneity in interacting with others
- Sequencing (difficulty planning and completing complex tasks in correct order)
- Perseveration (repeating same actions & comments over without conscious awareness of having done so)
- Loss of flexibility in thinking (mental rigidity)
- Distractibility
- Mood swings
- Diminished abstract reasoning
- Difficulty with problem solving
- Language difficulties & word finding)
- Loss of simple movement of various body parts

## Brain Stem

**Function:** Plays role in heart rate, swallowing, reflexes to sight and sound, sweating, blood pressure, digestion, temperature, levels of alertness, ability to sleep, and balance

### Symptoms of Impairment

- Decreased vital capacity in breathing
- Swallowing food & water
- Difficulty with organization/perception of environment
- Problems with balance and movement
- Dizziness and nausea
- Sleeping difficulties

## Parietal Lobes

**Function:** Involved in visual perception, tactile (touch) perception, knowing right from left, body orientation, integration of sensory information that allows for understanding of concepts, and goal-directed voluntary movements

### Symptoms of Impairment

- Difficulties naming objects
- Difficulties writing words
- Inability to attend to more than one object at a time
- Inability to focus visual attention
- Problems with reading
- Poor hand-eye coordination
- Confusion left-right orientation
- Difficulty performing math calculations
- Difficulty drawing
- Poor visual perception
- Lack of awareness of certain body parts and/or surrounding space

## Occipital Lobe

**Function:** Visual and color perception system

### Symptoms of Impairment

- Impaired Vision
- Loss of color

## Cerebellum

**Function:** Involved in coordination and control of voluntary movement, balance and muscle tone

### Symptoms of Impairment

- Tremors
- Involuntary movement of the eye, usually from side to side (Nystagmus)
- Lack of coordination of the muscles, especially in the extremities (Ataxia)
- Weak muscles (Hypotonia)
- Inability to judge distance and when to stop (Dysmetria)
- Inability to perform rapid altering movements
- Slurred speech (ataxic dysarthria)

## Temporal Lobes

**Function:** Play key role in intellect, understanding language, behavior, as well as auditory perception (hearing), long-term memory and some visual perception

### Symptoms of Impairment

- Difficulty remembering names and faces
- Difficulty understanding spoken words
- Difficulty with identification of, and verbalization about objects
- Difficulty with concentration
- Short-term memory loss
- Interferences with long-term memory
- Aggressive behavior
- Change in sexual interest
- Persistent talking (right lobe damage)
- Difficulty locating objects in environment
- Inability to categorize objects
- Self-centered, lack of empathy
- Seizure disorders, aura and strange reveries (appearing to be lost in thought)