Understanding, Managing and Changing Challenging Behaviors

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Learning Objectives

- Identify common behavioral problems after TBI.
- Identify a model for
  - Understanding the cause of behavioral problems
  - Guiding treatment of behavioral problems - with emphasis on anger and aggressive behavior.
- Identify non-pharmacological treatment approaches for managing anger and aggressive behavior in persons with TBI.
- Discuss the nature and treatment of other behavioral problems -- through your input and questions.

What Conditions Cause Challenging Behaviors?

Types of 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)

Types of Brain Injury

Stroke

- **Hemorrhagic**
- **Ischemic**

Anoxia: oxygen to the brain temporarily cut off

Brain tumors

Mental Health

Dementia: progressive diseases that usually result in decline over time

For most,
Brain Injury is:

-A loss of Self

-A loss of future

-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

Changes After ABI / TBI

Orientation

Alertness

Focusing Attention

Speed of Processing

Remembering New Info

Remembering Past Info

Perception of Environment

Expressive language

Receptive language

- **Fatigue**
- **Executive Skills**
- **Reasoning**
- **Sequencing**
- **Multi-tasking**
- **Behavioral Control**

  (start, stop, & resisting impulse)
- **Emotional Control**

  (inappropriate or intensity change)

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

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.

Most challenging behaviors (Percentage ranked as 1st Choice)	
Agitation or Aggression	25%
Repetitive speech or actions	12%
Wandering or restlessness	10%
Incontinence or constipation	10%
Late-day confusion	8%
Sleeplessness	6%
Refusal to eat	5%
Paranoia	5%
Refusal to take medicine	4%
Hallucinations	5%
Refusal to bathe	4%
Choking on food or liquids	4%

Biggest caregiving challenges (Percentage ranked as 1st Choice)	
Dealing with memory loss and impact of the disease on your loved one	25%
Handling the stress and emotional toll on self	16%
Having patience with your loved one	15%
Handling loved one's mood swings or behavior changes	12%
Daily activities (bathing, bathroom, dressing, meals)	11%
Keeping loved one positive and motivated	8%
Bills, finances, health insurance	4%
Managing and administering medications	3%
Speaking with loved one's health care providers	2%
Scheduling appointments and time management	1%

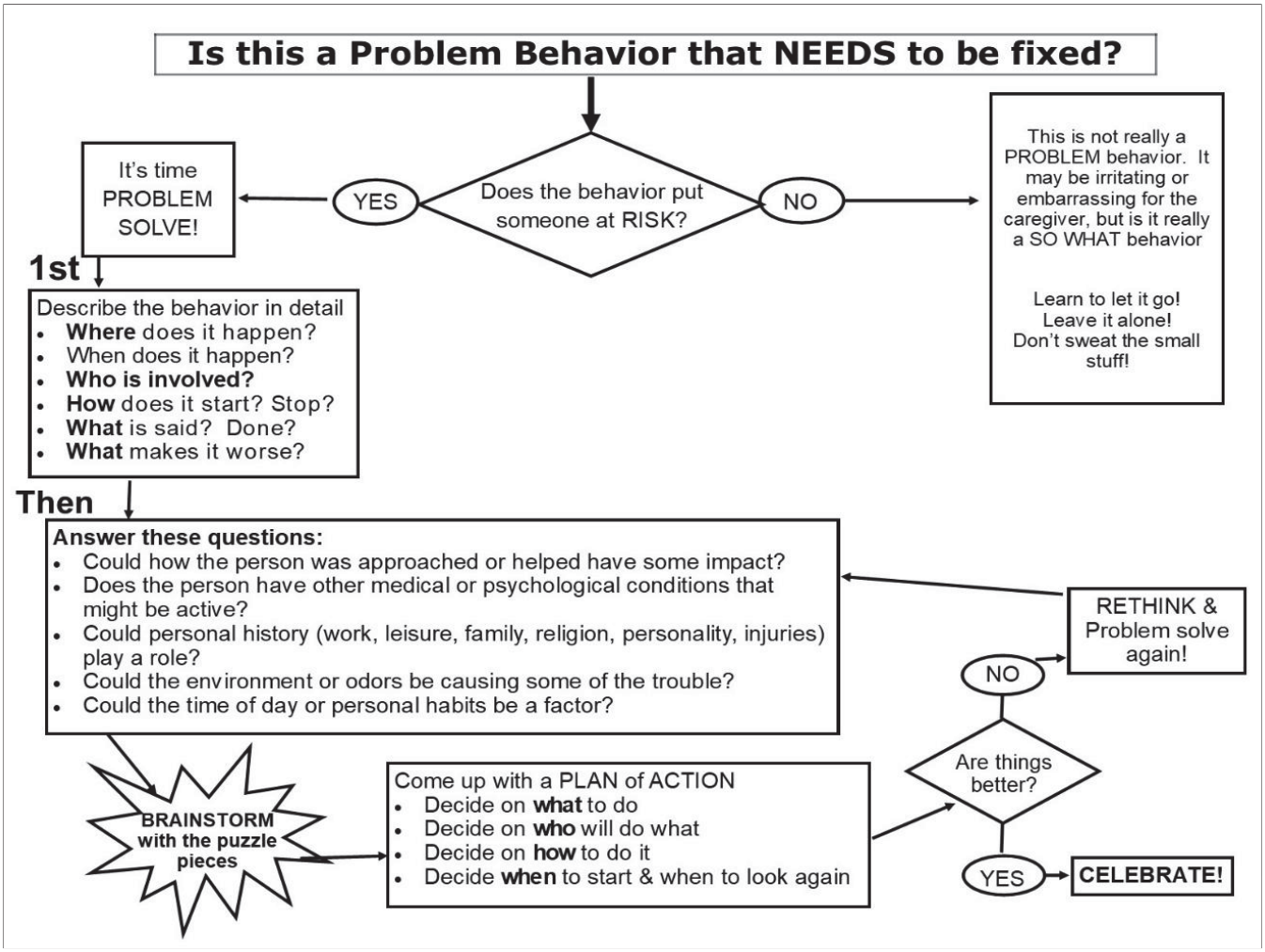
Common types of challenging behavior include:

- **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)**



What makes it challenging?

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

Examples of Some Behaviors:

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

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?

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.

Understanding the Cause of Anger – Aggression Following TBI

Anger Concepts

Common human emotion

Signals a need for change

Expression is what counts!

Texture of Anger

Types of Expression

- Verbal (yelling, swearing, content harmful to others, pressured speech, increased volume)
- Physical (striking out at people, animals or objects, threatening gestures)

Intensity (Continuum)

Frequency

Duration

Factors Related to Anger: Biological Factors

- Location of brain damage
- Neurotransmitter changes
- Medications
- Substance Use
  - Alcohol
  - Recreational - Street Drugs
- Illness
- Fatigue

Regions of Brain Associated with Anger/Aggression

- Limbic System
  - Amygdala, Hippocampus Formation, Septum
- Hypothalamus
- Frontal Lobe

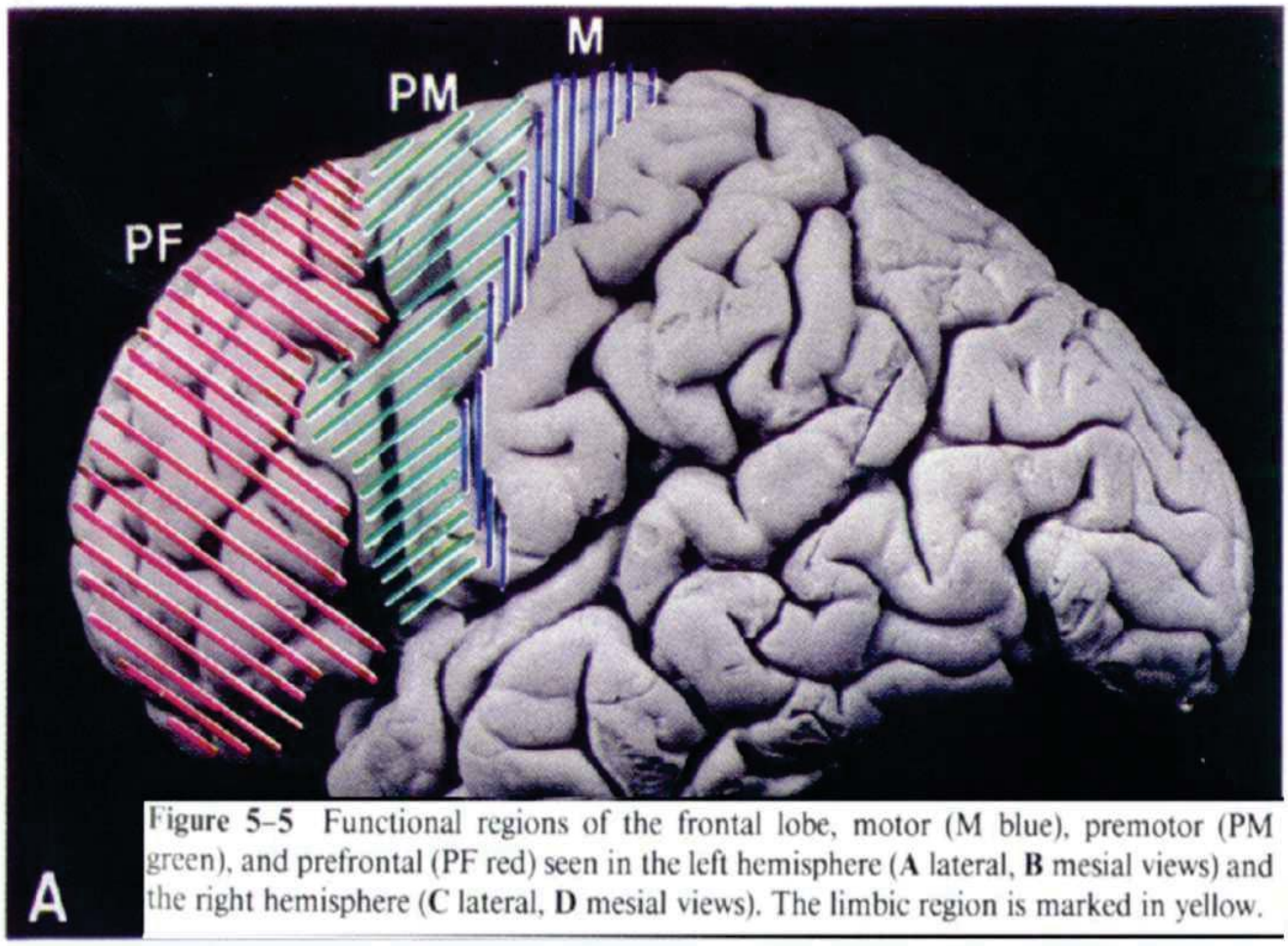


Figure 5–5 Functional regions of the frontal lobe, motor (M blue), premotor (PM green), and prefrontal (PF red) seen in the left hemisphere (**A** lateral, **B** mesial views) and the right hemisphere (**C** lateral, **D** mesial views). The limbic region is marked in yellow.

Prefrontal Cortex

Monitors, supervises, guides, directs, and focuses behavior

Receives and sends messages from various regions throughout the brain, including those associated with our emotional functioning (e.g., limbic system)

Involved in executive functioning – judgment, impulse control, thinking flexibly, problem solving, planning, organization, critical thinking

Prefrontal Cortex Regions and Behavioral Control

Dorsal Lateral

- Attention Span, Sustain Attention, Short-term Memory, Mental Processing Speed, Initiation

Inferior Orbital

- Behavior and impulse control, mood control, social skills

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**

Areas of Cognitive Functioning that can be supported by Strategies

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

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.

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

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.

Strategy: using clock or timer

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.

What Is Reduced Awareness?

Reduced ability to recognize problems caused by damage to the brain

- Reduced awareness is a neurological problem resulting directly from damage to the brain.

Reduced Awareness Does Not Equal Denial

- Denial is a psychological reaction to a problem- aimed at defending self-esteem; implies that the person is at least partially aware of the problem

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.

Strategies for Increasing Awareness

- 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

Memory

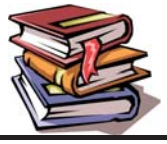
- Memory problems are common following all types of brain injury.
- Most people remember information from their pasts, but may have trouble learning and remembering new information.
- Memory for non-routine things (like medical appointments) may be worse than for routine things (like when a TV show comes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

What Types of Things They Might Forget?

Common Memory Problems

Forgetting Appointments	
Forgetting names, especially names of new people	
Losing or misplacing things (e.g., keys, wallet)	
Forgetting to take meds, or forgetting they were taken and taking them again	

Common Memory Problems

Repeating questions or the same story over and over	
Needing to have information repeated	
Forgetting things quickly	
Taking longer to learn new information	

Strategies for Improving Memory

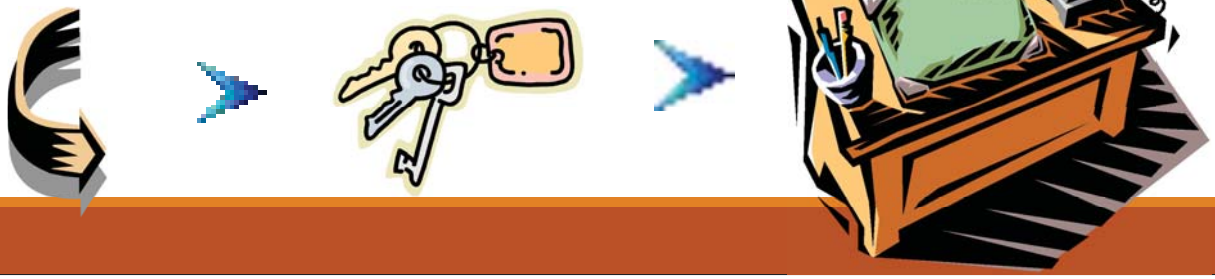
- Help by suggesting that the family member make a memory book
  - Possible sections include: calendar; to-do lists; address book; information about their injury (e.g., dates, hospitalizations); daily journal
  - Help add important dates, appointment times, checklists
  - Cue them to carry this book with them everywhere and to refer to it regularly

Strategies for Improving Memory

- Allow extra time for your family member to learn new things. Keep in mind they will learn more slowly.
- 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.

Strategies for Improving Memory

- 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. 

Strategies for Improving Attention

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

<u>Problems with expression:</u>

- 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")

Common Language Problems

<u>Problems understanding others</u>:

- 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:

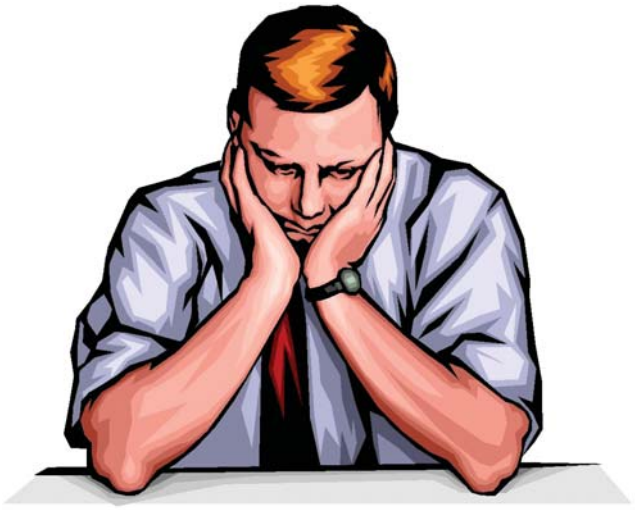
- Starting, maintaining and ending conversations
- Selecting and maintaining topic
- Awareness of feedback from others (e.g., can they tell if their listener is interested in maintaining the conversation?)
- Nonverbal communication

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.

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**

Strategies to Improve Initiation

- **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).**

Strategies to Improve Initiation

- **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**

Examples of Organization Problems

- **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**

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.**

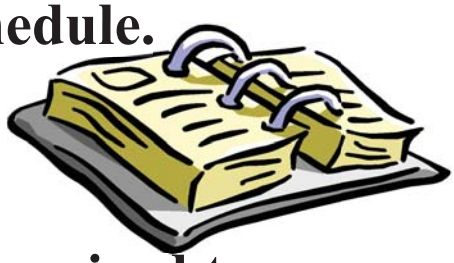
Example of a Checklist

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

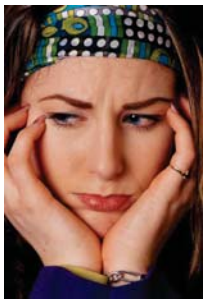
- **Have them use a memory book or calendar to keep track of their daily schedule.**

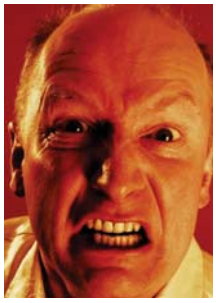


- **If they have trouble getting organized to leave the house in the morning, have them get some things ready the night before (e.g., choose clothes, get together anything that may be needed for the outing)**

Coping with Emotional and Behavioral Changes

Common Emotional and Behavioral Changes



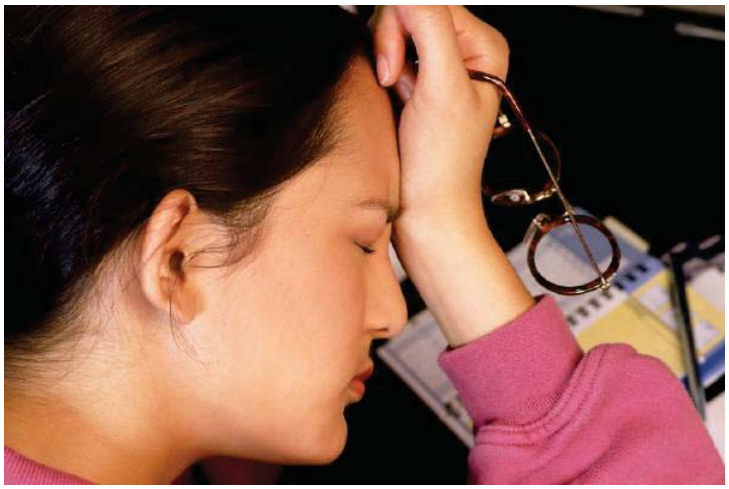


- **Depression**
- **Inappropriate or Embarrassing Behavior**
- **Impulsivity (acts quickly without thinking)**
- **Anger/Aggression**
- **Irritability**

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**

<u>Most people do not have all of these symptoms.</u> 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 the individual 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 them involved in activities that might take their mind off of their sadness.**
- **Encourage them to exercise regularly.**

Inappropriate or Embarrassing Behavior

The individual 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 they 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 the individual 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.**

Strategies for Managing Embarrassing Behavior

- **If the indivual is acting inappropriately and not responding to your signal, stop the activity.**
  - **For example, if you are at the mall, return home immediately. They 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 the individual 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.**

General Tips

- **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

Research findings regarding Behavior Problems after TBI

"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

"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**

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

Guidelines for Behavior Management

- **Keep instructions simple, concrete**
- **If the person has problems processing language, try gesturing or cueing**
- **Write things down**
- **Give feedback and set goals**
- **Feedback should be direct, caring, nonjudgmental, but not subtle**
- **Avoid criticism**

Guidelines for Behavior Management

Be calm, cool and friendly during an incident

This can reduce agitation

Avoids reinforcing misbehavior

Guidelines for Behavior Management

Redirection works. When the person is upset, agitated, aggressive, focus attention on some other topic, task, person

Provide choices

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 Interpersonal Functioning that can be supported by Strategies

Impulsivity

Frustration tolerance

Social skills

Self esteem

Building and maintaining relationships

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

Strategies

Use of smartphone/hand held device

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

Strategies cont.….

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)

Strategies cont.….

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)

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?

You know the answer…

- **You can't control other people.**
- **You cannot change who they are.**
- **You cannot change their past.**
- **You cannot make them want to do something they really do not want to do.**

So, what to do?

Give up

Do the same things and tough it out

Or…

So, what to do?

Take control by giving up control

Identify what is in your control and work on those areas

Identify what is not in your control and how to best intervene for safety (first) and well-being

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**
- **Timing of events**
- **Responses to 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 – that triggers the behavior (antecedents)

• B stands for the behavior (appropriate or challenging); and

• C stands for the influential events that take place after a behavior occurs (consequences).

Antecedents - Questions

Where does the behavior happen?

With whom does it occur?

When does the behavior happen?

What activity is the behavior occurring during?

What are others doing when the behavior begins?

A = Events that occur *before* the behavior, or *antecedents*	**B = The behavior**	**C = Events that occur *after* the behavior, or *consequences***
• Physiological • Social • Psychological • Environmental	The behavior should be described in *measurable* and *observable* terms that *everyone understands*	• Did the behavior result in a reward for the person? • Did the behavior result in escape from a particular situation? • Did the behavior allow the person to avoid something?

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.

A = Events that occur *before* the behavior, or *antecedents*	B = The behavior	C = Events that occur *after* the behavior, or *consequences*
• James smacks his lips • James sits on the floor only when people are cooking	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.	• Staff give James bits of food while they cook • James makes happy-sounding noises after getting something to eat

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

Interventions

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.

Interventions

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

Provide Comfort

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

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

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

Personality challenges

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

Personality challenges

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

Agitation/Aggression

- 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

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

Aggression and Bathing

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

Aggression and Bathing

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.

Aggression and Bathing

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.

Aggression and Bathing

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.

Aggression and Bathing

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.

Aggression and Bathing

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.

Aggression and Bathing

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.

Aggression and Bathing

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.

Let's review…takeaways

Caregiving is hard work even when the care receiver is "easy."

Most caregivers do a great job and have the skills within them to respond to challenging behaviors

In order to do this, caregivers need to first take care of themselves. The oxygen mask needs to be on you first!

Let's review…takeaways

- "Problem" or "Challenging" behaviors always need to be defined before addressed
- A behavior may be perceived by one person as challenging, but may only be a behavior
- Behavior change cannot be imposed on others
- Individuals can change themselves or they can influence their environment
- Changes in environment and personal responses can then have a ripple effect on the behaviors of others

Let's review…takeaways

Many "behaviors" have their roots, ultimately, in something that can be identified early in a process and addressed

This requires exploring the behaviors thoroughly, looking at trends, and identifying root causes

When only the expressed behaviors are treated, then only the surface symptoms are addressed and not the underlying cause