

Changing Our Minds: From Parenting to Caregiving A Mentoring Tool for Alzheimer's Caregivers Training Manual



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Introduction

This project was funded, in part, by a three- year Alzheimer’s Disease Demonstration Grant from the United States Administration on Aging. During Wisconsin’s statewide grant activities to improve quality and access to services for people with Alzheimer’s disease, it was discovered that smaller, community located care environments were very successful. To promote the use of these environments, a project began to support existing caregivers and encourage further development of these settings for people with Alzheimer’s disease.

This tool was developed in response to the need to provide training for people who are owners and caregivers in Adult Family Home settings in Wisconsin (family/caregiver who has 1-4 residents living with them). Many caregivers reported having minimal or no training in Alzheimer’s disease and related dementia, yet had an interest in providing this care.

The hallmark of this tool is to build on the existing skills and dedication of caregivers who work with and live with people who have dementia every day. It is designed to pinpoint the common themes caregivers face in Alzheimer’s care, and help them to shift their current approaches to something more effective. In addition, caregivers learn the underlying mechanisms of the Alzheimer’s disease process, which allows them to problem-solve situations creatively.

As statewide training progressed with this tool, other audiences developed. Care managers, direct care providers, family caregivers and other professionals adapted it to mentor people in all care settings.

- The use of this mentoring tool provides **Alzheimer’s caregivers that have little knowledge of dementia** the ability to think on their feet and experience success, when faced with challenging situations.
- **Care managers and other professionals** find this common sense approach a valuable way to support family and workforce caregivers in day to day situations.
- **Experienced caregivers** discover the powerful things that they are “doing right”, ways to enhance them, and creative new strategies and perspectives that are energizing and insightful.

To use this tool, review the first sections on the brain and effects of Alzheimer’s disease, and then follow the instructions on page five.

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Model for Understanding Alzheimer's Disease and Caregiving

This model assumes that everyone draws their caregiving beliefs and approaches from the things they learned as a child while being parented, which were then reinforced in them as an adult when parenting or guiding children (parenting becomes instinctual). When people come into the caregiving role for an older adult with Alzheimer's disease, certain learned assumptions from the parenting approach will not be effective in the dementia caregiving role. The reason that parenting approaches don't translate from one role to another have to do with the **differences in the brain of the child and the older adult with Alzheimer's disease**, despite similarities between them in their outward behavior.

Parenting skills do not equal Alzheimer's caregiving skills.



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Developing Child

(Learning and growth focused)

In normal brain development the brain's job is to learn new information and store it. Nerve pathways of communication are continuously being formed between the body and the brain, which allow learned information to be accessed and performed quickly. The pathways to memory are made stronger over time through repetition and association. Parents and others in the role of guiding children, guide the child into learning information and mastering skills.

Declining Older Adult with Alzheimer's disease

(Struggle to maintain decreasing function)

In the brain of someone experiencing Alzheimer's disease, scar tissue causes the person to have increasing difficulty learning new information, and mastering new skills in usual ways. Alzheimer's disease causes scar tissue to be deposited on the nerves, which weakens and blocks nerve pathways that used to be strong. As the pathways are blocked, access to information stored in memory is impaired. In addition, new learning cannot occur normally because new pathways cannot be formed easily through the scar tissue.

The strongest memory pathways in the brain are the ones that were created early in life that were reinforced over and over during a lifetime. As the brain deteriorates, people with Alzheimer's disease tend to access these strongly reinforced memories from the past as if they were the present. All of the rich experiences and skills of the person's lifetime from the past are still available, but her ability to function normally in the present diminishes. As Alzheimer's disease progresses, pathways can short circuit with each other, which may cause the person to substitute words and have illogical thought patterns. In addition, parts of the brain die off - which may result in permanent changes to personality, reasoning, emotional control and physical abilities. *The person with Alzheimer's disease is aware that these*

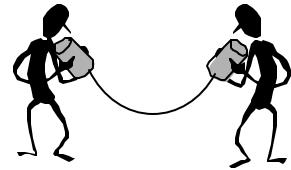
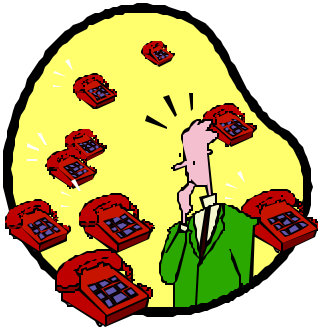
changes are happening during the early stages of the illness, and she struggles to stay independent in the present, while still functioning in the past. The more we can build our foundation of care on the person's rich past interests and abilities, the better things will be.

How the Brain Works: An Overview

Formation of "Nerve Clusters"

Brain research on fetuses in the womb suggests that the brain development starts when nerve cells begin to form into clusters, with each cluster eventually specializing individually in different tasks. One cluster, for example, will specialize in heartbeat functions, another in eyesight etc. Nerve cells in the body form long chains that become gateways of communication connecting the body part to the special cluster in the brain. At first, the nerve pathways signal many clusters at once, much like a telephone connection ringing multiple phones in an apartment building.

Initially the signal from the body causes many clusters to react – or many phones to ring in the brain. Nerve pathways become more "worn in" as clusters that are specific to the signaling body part develop strongly. As this happens, other clusters simply disconnect from the pathway and stop reacting because they are not in use for that pathway. This gets the phone call from say, the eye, to ring only one phone or nerve cluster in the brain - the eye



specialists. This is important to understand because it shows how patterns work in the brain over a person's lifetime. The phrase "**use it or lose it**" describes how skills developed and used over time are retained, while skills not used tend to die off. (For example, just think of how many people can remember their high school algebra equations once they've stopped taking algebra!)

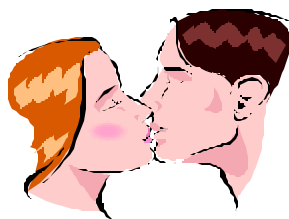
Two Kinds of "Memory"

As a child learns and grows, the nerve pathways that are the most frequently used form stronger and stronger connections in the brain. In this way, all new learning builds on previous pathways. Complex tasks or "skills" are mastered and corresponding specific clusters form for specific skills. These are the skills that are used and remembered throughout our lives. The skills of walking, talking, reading, eating, etc. are filled with sequences of tasks that we don't even consciously think about as we perform them over and over. In fact, the tasks become so routine that the body takes over with what seems to be a kind of automatic "body memory". When we master a set of tasks in this way they literally become part of our brain's "**ingrained memory.**"

The second type of memory that gets stored is a "**holographic memory.**" In this case, we experience an event so intensely that it involves all of our senses – smell, sight, touch, hearing – and a highly emotional out of the ordinary state. In this moment the experience goes immediately into long-term memory, and is stored like a three-dimensional hologram.

When something “triggers” the memory – it could be a smell, emotion, situation, song or something that reminds us of the experience - the essence of the remembered event is recalled vividly (like a hologram) as if we were actually there again.

Holographic memory experiences often recall where we were, whom we were with, what we were wearing and how we were feeling. An example of this would be for us to remember the experience of when we learned of the attacks on the World Trade Center in New York on September 11th, 2001. Other times could be riding a bike for the first time, a first kiss etc.



Holographic memories are unique because they are stored in many clusters all over the brain simultaneously. For this reason, these memories are not as easily damaged by Alzheimer’s disease. It’s important to realize this because **people with Alzheimer’s disease still have access to holographic memories** from their lives – both fond and traumatic, and may still be able to form them. This explains why a person can vividly recall events from the past in detail, yet not be able to remember today’s date or the name of the person he is with. **The key to unlocking the uniquely rich person and skills inside a person with Alzheimer’s disease is to help them access fond holographic memories.** This is why reminiscence is such an effective tool for caregivers.

Research has also shown that vividly imagined events – perhaps from reading a novel or doing a guided visualization – could equally develop holographic memories. This could explain why a person in later stages of Alzheimer’s disease could tell a vivid story of living on a western ranch, when in real life he grew up in a big city! In fact, Olympic athletes often use intense visualization as a tool to perfect their athletic skills and performance before they take to the field.

Damage to the Brain in Alzheimer’s Disease

A person with Alzheimer’s disease experiences damage to the brain in two ways. First, early in the disease process, damage occurs to a tiny structure in the brain called the hippocampus. The hippocampus is responsible for **translating short-term memory** (the first 5 seconds or so of learning) into stored long-term memory. It is this damage that renders the person with Alzheimer’s disease unable to recall new information consistently. This explains why people with Alzheimer’s disease repeat questions they’ve just asked and forget things they have recently experienced. To help a person with Alzheimer’s disease remember something, you have to work around the damaged hippocampus.

The second damage to the brain in Alzheimer’s disease effects the **“ingrained” memories**. As scar tissue begins to develop in the brain, it begins to block parts of the nerve pathways. At first when the nerve signal comes through the pathway, it may be like “call waiting” on a phone line. The signal has to take additional time and go around scar tissue in order to

complete the connection. This can produce what might seem like strange behavior in the person with Alzheimer's disease. For example, the person may stop in the middle of a familiar task, such as brushing teeth, because he can't remember how to squeeze the toothpaste. If help is given in squeezing the toothpaste, the person can go on to complete the task. (Remember, it is important to allow the person to complete the task because he needs to use it or he will lose it!)

As the disease progresses, whole clusters of complex skills learned later in adulthood (such as using a computer, cooking, driving a car, etc.) are lost because pathways to them are less "ingrained" and thus more easily blocked by scar tissue.

Eventually the scarring becomes so bad that it cuts off some of the most ingrained pathways completely. Like getting a busy tone on a phone, the pathway in the brain is blocked. For example, a person with Alzheimer's disease may feel the urge to go to the bathroom, but the brain doesn't remember what it means. This results in incontinence. A way to remember how skills are lost over time is "**first in, last out.**"

The Great Grape Comparison...

To illustrate this point, imagine you are holding a bunch of grapes in one hand and a pair of scissors in the other.



Look at the very **thick set of stems at the top**. These represent the thick set of nerve pathways that have been developed over a lifetime of learning and reinforcement.

The **clusters of grapes just below these thick stems, at the top of the bunch**, represent the clusters of skills that were learned early in life.

Now look at the **grapes at the bottom of the bunch**. The grapes here have a tendency to break off and fall away first because the stems that hold them to the cluster are the thinnest. These bottom clusters of grapes represent the most recently learned skills. They are the least reinforced over a lifetime, and their connections are the thinnest and most easily damaged.

Now use the scissors to cut away the grape clusters at the bottom, and then work your way up sequentially one cluster at a time. This represents the progression of Alzheimer's disease and how skills are lost over time.

The Key – Keep Personhood in Mind

All of us are as unique and complex as our individual fingerprints. Although the Alzheimer's disease process impairs a person's ability to function normally in the present, the unique and complex person that she was is still there to be awakened and enjoyed. The key to doing this is to shift from imposing "our reality," stemming from our subconscious "good parent," to understanding the reality of the person with Alzheimer's disease. In order to do this we must

catch our own habits of “parenting” assumptions, and consciously try new dementia caregiving approaches.

Caregivers constantly ask, “How can I get this person to.....like she used to, instead of ++++ that she is doing now” (fill in the blanks). This signals a red flag that the inner parent is at work! The answer is “How can we enable this person to be able to +++++ safely?” Is there a reason why she might be doing +++++ instead of (a habit from her past childhood or young adult years perhaps)?

Here is an example. A caregiver was perplexed because her mother with Alzheimer’s disease was getting out of bed and urinating on the floor. The mother even did this when she had an absorbent undergarment on - she’d simply pull it down. The daughter wanted to get her mother to urinate on the toilet in the bathroom instead, and wondered how she could get her mother to do this. (Does this sound like a familiar parenting approach?) I asked the daughter what she knew about her mother’s past. Did her mother live in a home without plumbing where people used pots to urinate in at night next to the bed? We came up with a list of things she could try to help her mother urinate in her room safely (as she did as a child) instead of trying, unsuccessfully, to change her mother’s behavior to fit what the conventional (parenting) approach would be. In addition, the daughter agreed to explore possible medical reasons for the behavior (bladder or urinary tract infection, pain, discomfort, confusion etc.).

Another example involves an older man with Alzheimer’s disease that used to be in business and supervise a crew of engineers. For years no one in his family would even attempt to bring in a contractor to work on his house because the man believed he was an expert and the only person who could fix the house properly. When a true safety hazard came up that had to be fixed, we tried a creative experiment. Previous attempts to bring in contractors had resulted in the man having outbursts and chasing the contractors out with his cane. This time we told the man a crew of engineers was coming to fix the house, and he would need to supervise their work. By using the title the man used to go by (“foreman” and “sir”), and asking the man to come and inspect their progress periodically, the crew was able to complete the work and provide a reminiscing activity for the man at the same time. It was a success, eliciting many stories!

Using the Alzheimer’s caregiver approach takes time, patience, research into the person’s past and a willingness to try new things – in addition to a sense of humor! However, the rewards for both the caregiver and the person with Alzheimer’s disease can be abundant. It can allow them both to uncover and enjoy the rich person behind the illness.



Summary of Key Points

- The person with Alzheimer’s disease experiences **difficulty learning new information** normally as the disease progresses, because of damage to the hippocampus – which translates present experiences into memory.
- **Holographic memories**, and **ingrained memories** formed early in life, remain the longest for a person who has Alzheimer’s disease. Caregivers can build on these *to unlock the rich, unique person within*, providing connections to a lifetime of experience.
- Caregivers must help the person with Alzheimer’s disease to continue using skills as long as possible by only giving specific needed cues - **use it or lose it**.
- Skills and memories diminish backwards over time - **first in, last out**.
- All of us have an internal “parent” that has been ingrained through our life experience. Our “parent” is instinctively activated in caregiving situations. Once this is understood, it becomes easier to **change our minds** to think like a dementia caregiver instead of acting from parenting instincts.

Using the Guide that Follows

1. Clearly define the situation, and the behavior that you would like to approach differently.
2. Turn to Part A: Locate the behavior topic. Read to learn about the behavior from the point of view of the child’s brain (your possible assumption) and the older adult’s brain (the new information you need to take into account).
3. Turn to Part B: Caregiving Strategies. Compare the parenting and caregiver approaches to the behavior. Consider how the caregiver strategy combined with knowledge of the person’s past and strengths can help you develop some options to try to influence the situation. (If the actual behavior is not on the grid, read others and consider the brain process behind them that might apply.)
4. Brainstorm a list of options: Remember that people with Alzheimer’s disease have good days and rough days, and the illness progresses sporadically. You may need several ideas – things that work one day may not work the next. Build from the person’s past habits, enjoyment, lifestyle and values. (Be sure to include medical possibilities).
5. Involve all caregivers in this process. Input from everyone defines the situation. Approaches need to be consistent from person to person. Share successes with each other regularly too. Congratulate yourself for being creative, and enjoy the person entrusted to your care!
6. Still stumped? Contact your local Alzheimer’s Association, they can really help!



Part A: Common Behavior Themes

The following is a list of common behavior that is exhibited by both children and older adults with Alzheimer's disease. In each case, the physical characteristics of the brain are examined to see the differences between the two.

1. Confusion

Confusion is an inability to follow and understand what is happening.

Developing Child Characteristics

- The child is seeking to explore and understand the world. Nerve clusters that create memories in the child's brain develop through repetition, association and experience over time.
- Confusion in the child is usually a result of an unfamiliar situation containing a lot of information all at once that is too much for the child to grasp.

Declining Older Adult with Alzheimer's Disease Characteristics

- Alzheimer's disease causes scarring and damage to the nerve pathways in the brain, which prevents memories and tasks from being accessed.
- The older adult may forget steps in a routine task or be unable to recognize something or someone once familiar.
- Because the brain cannot create new pathways for learning, appointments, medication routines, use of unfamiliar items will not be able to be remembered in usual ways.
- Confusion is created when the person knows that they are unable to remember, becomes frustrated and afraid, and the emotional reaction heightens the confused state.

2. Word Finding

Word finding is an inability to remember a word on the first try in conversation.

Developing Child Characteristics

- The child is learning vocabulary and building new nerve pathways of association in the brain.
- Word finding is a way to seek validation and reinforcement of having learned the correct word.

Declining Older Adult with Alzheimer's Disease Characteristics

- In the adult brain, recall time normally slows down due to physical changes in the brain as it ages.
- In Alzheimer's disease, nerve pathways in the brain become *damaged* and familiar words cannot be recalled easily or at all.
- Sometimes the pathways become "short circuited" and one word is substituted for another unknowingly.
- In later stages, people with Alzheimer's disease can also have trouble remembering a sentence from beginning to end because the brain cannot even remember it for a few seconds.

3. Incontinence

Incontinence means an inability to control urination and/or bowel movements.

Developing Child Characteristics

- The child is learning how to master his body. This takes a complex set of nerve pathways to be connected in the brain and between the brain and the body, resulting in control over involuntary muscles.
- Over time, the pathways are established and mastery occurs.

Declining Older Adult with Alzheimer's Disease Characteristics

- Nerve connections in the older adult's brain, and between the body and the brain, are deteriorating.
- Signals that the brain normally remembered are poorly perceived or not perceived at all. Incontinence occurs because the brain and the muscles cannot work together anymore.

4. Repetitive Behavior (Themes)

Repetitive behavior is an action or activity that is repeated over-and-over again.

Developing Child Characteristics

- Nerve pathways in the brain become connected for quick access to information by repeating tasks over and over.
- The child instinctually is driven to achieve "mastery" of tasks for efficiency and survival.

Declining Older Adult with Alzheimer's Disease Characteristics

- The brain has deteriorated so much that only the well-worn nerve pathways created for survival are working easily.
- Brain activity tends to focus and get "stuck" in these pathways that are both familiar and functioning. The effect is like a repeating recording of the same thought pattern over and over. Reminders can trigger memories of past, usually emotionally charged, experiences.
- The older adult cannot "voluntarily" switch to another nerve pathway or thought pattern.

5. Wandering

Wandering occurs when the person walks away from whomever is supervising them, and usually becomes lost.

Developing Child Characteristics

- The child is instinctually driven to explore and understand the environment.
- Exploration creates experience and learning, and solves the curiosity children have to figure out the world and how it works. Learning ensures the child's survival.

Declining Older Adult with Alzheimer's Disease Characteristics

- The older adult is instinctually driven to expend energy, especially when agitated.
- Movement is calming and the person is seeking familiar objects or places to cling to. The activity is similar to "automatic pilot". Often the "brain" is seeking something to do. Walking is a familiar, repetitive task. Fear arises when the brain fails to recognize the environment as familiar, then panic and agitation can take over.

6. Sleep/Wake Cycle Disturbance

Disturbances in sleeping and being awake mean the person is awake at night and/or sleeping during the day and not at night.

Developing Child Characteristics

- The child is building new brain cells and body structures, resulting in a need for large amounts of rest combined with large amounts of food.
- When the child becomes tired while in an over stimulating environment, adrenaline hormones are released. This results in the child being wide-awake.

Declining Older Adult with Alzheimer's Disease Characteristics

- An older adult has less need for sleep.
- As the portion of the brain regulating sleep/wake cycles becomes more and more damaged the person is unable to tell day from night.
- The brain becomes unable to self-regulate sleep patterns.
- Older adults with Alzheimer's disease can also be easily over stimulated when they can't make sense of situations where too many things are happening around them all at once. This releases adrenaline, and can also trigger emotional distress which releases further adrenaline.
- Person tends to sleep for small amounts of time when tired.
- Large amounts of sleep can result from boredom with environment, illness or an inability to initiate engagement in what is going on, resulting in a low and constant amount of stimulation between day and night, with little contrast in the brain.
- In environments where the person with Alzheimer's disease is engaged in physically, cognitively and emotionally stimulating activity during the awake hours, the brain has an easier time slowing the pace for rest as a contrast at night due to biochemical changes occurring during activity.

7. Need for Reassurance

The need for reassurance means that the person is asking for clarification, or for their safety needs to be met, through their behavior towards others.

Developing Child Characteristics

- The child seeks reassurance to reinforce what is being learned, and to confirm safety and security in times of stress.
- Often the child needs to be "reoriented" to what is real, to calm a very active imagination or fear.

Declining Older Adult with Alzheimer's disease Characteristics

- As the brain deteriorates, the person with Alzheimer's disease loses the ability to recognize things that are familiar, and things that are current.
- This leads to fear, agitation and a desire to be "home" in a familiar safe place.
- The older adult's perception of the environment can't be altered – when the brain doesn't recognize it, the person thinks they are in a strange place. This can lead to a need for constant reassurance that confirms the person is safe.

8. Constant Questioning

Constant questioning is when a person is asking the same question, or streams of related questions, over-and-over. This can continue even once the questions are answered. It is a form of repetitive behavior.

Developing Child Characteristics

- The child is “learning” by building associations between things.
- Often an episode of constant questioning is an effort to understand how things are associated with each other. These questions tend to come in strings of related information (e.g., the “why?” questions).

Declining Older Adult with Alzheimer’s disease Characteristics

- When the brain deteriorates, the older adult with Alzheimer’s disease loses the ability to store anything in short-term memory – even for a few seconds.
- The adult can ask a question and forget both the answer, and that the question was asked, almost immediately.
- The questions are usually connected to something that is emotionally charged for the person – so the emotional “need” is still unsatisfied because the person cannot connect the need with the forgotten information.
- These questions can also be part of “repetitive behavior” – see above.

9. Assistance with Complex Tasks Like Dressing/Bathing

Complex tasks always involve sequences of steps of the activity, chained together, to reach the final result. In the brain, the activities tend to become linked together in a rhythm when they become a daily or regular routine task.

Developing Child Characteristics

- The child is learning to master these tasks.
- In the brain the nerves that coordinate the large muscle movements and small muscle movements are developing and strengthening nerve pathways.
- In addition, the child’s brain is storing the memory of the sequences that all of the activities go in to complete the task.
- Assistance helps the child to learn the rhythm through example.

Declining Older Adult with Alzheimer’s Disease Characteristics

- The older adult with Alzheimer’s disease is losing the nerve pathways in the brain that connect sequences of activities together.
- Often the sequences are only partially remembered, interrupting the rhythm of the task.
- This leads to the older adult only being able to partially complete the string of activities, or steps, which add up to the complex task like getting dressed or bathing independently.
- By offering only a prompt of the next step, the learned rhythm can be recalled and the person can complete the task they have mastered many years before.

10. Outbursts

Outbursts refer to occasions where the person has a strong emotional reaction to an event. This can be anger, grief, loud laughter, etc. The most common is anger.

Developing Child Characteristics

- Children, especially when very young, are dependent on others to meet their needs and provide safety.
- The child doesn't always know how to communicate needs beyond emotional expression.
- Often emotional outbursts are a signal for someone to pay attention to her needs.
- As the child becomes older, the emotions become ways to connect with others, set boundaries, and exercise personal will.

Declining Older Adult with Alzheimer's Disease Characteristics

- Parts of the brain that control emotions are some of the first to be damaged in Alzheimer's disease, as the disease progresses to the frontal lobe of the brain.
- The older adult loses his ability to remember what was socially acceptable.
- Emotional associations are the strongest nerve pathways in the brain. They are the first means of communication, and the last to be damaged as Alzheimer's disease sets in.
- Things that are stored in "holographic" long-term memory always have an intense emotional component. For this reason emotions are the most familiar way of communicating, and the easiest way to communicate, for the person with dementia.
- Just as infants and young children are dependent on others to fill their needs, so are people with dementia. Outbursts often occur as a means of communication that can't be expressed any other way, especially if the person has trouble communicating with words.
- Often the older adult with Alzheimer's disease cannot make sense of the events going on around her, particularly if the setting seems unfamiliar, or pain/discomfort is experienced.
- The brain tends to compensate for diminished capacities. When one way of perceiving something is limited, the other ways become more sensitive, so a person with dementia is more sensitive to the emotions of others around her than their words (a survival instinct).
- In dementia, the older adult cues into sensing emotions of people around her to make sense of things, because she can't reason them out. When people around her are emotionally frustrated or tense, this can lead to emotional "mirroring" of those people.
- In another example, a person with Alzheimer's disease can become frustrated because she can't complete a task she used to do, so she responds in emotional frustration.

If the behavior situation or situation you want to influence is not here, **consider the underlying brain processes for the older adult that could apply.** From there, brainstorm possible reasons why the situation could be occurring. Could they be related to the person's past routines, interests, or strengths? Could it be an old habit – or could you try to trigger the person's old habit to re-establish a familiar pattern for him? Is the behavior related to an emotional issue from the person's past (an old "hologram")? Also, consider ways you might be communicating unconsciously through body language, voice tone, etc. Are you frustrated, expecting a person with Alzheimer's disease to respond to your efforts as though he was a child who is able to re-learn or "know better?" Remember that parenting instincts are ingrained in all of our memories! Reframe the situation to see how to build on that person's current associations, skills, strengths and tendencies. Also, consider physical or medical reasons for behavior. These things must be assessed and treated accordingly. (See appendix).