

## UNDERSTANDING AND MANAGING APATHY TO IMPROVE CARE IN FTD

### INTRODUCTION

**A**pathy is one of the most common symptoms of behavioral variant frontotemporal degeneration (bvFTD). Best understood as a decline in goal-directed behavior, apathy is associated with a variety of undesirable consequences, such as accelerated functional decline and even mortality. Deficits observed in apathetic patients include poor planning, poor motivation and the inability to initiate even the simplest self-care activities. Caring for a person with apathy is particularly challenging due to the physical and emotional demands associated with performing activities on their behalf.

### THE CASE OF LINDA M.

#### BACKGROUND AND EARLY CHANGES

Linda M., age 54, was an account manager for a healthcare technology systems company where she oversaw project budgets and interfaced with clients. She and her husband of 27 years, Kevin, have two adult children. She had several hobbies, including gardening – she tended to her flowers every day.

Kevin began to notice changes in his wife. She had become less productive at home, and less interested in her hobbies. Her flower beds were becoming overrun with weeds. One day, she told Kevin that her company placed her on probation for failing to meet performance goals, yet she didn't seem particularly bothered by this. Concerned, he called her boss. He learned that Linda was regularly late to work, wasn't returning emails from clients and wasn't able to produce budgets for projects. Kevin grew even more concerned, but when he asked her about her performance issues she shrugged and told him not to worry.

Kevin began to wonder if his wife's behavior was due to a mid-life crisis or depression, so he took her to see their family doctor, who administered the Mini-Mental Status Examination. Linda easily answered the doctor's questions. The doctor suggested she might be depressed, even though she denied feeling sad. Nevertheless, she was started on an antidepressant.

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### COMPONENTS OF APATHY

The concept of goal-directed behavior provides a useful model for examining the mechanisms underlying apathy. Three distinct components of goal-directed behavior are initiation, planning, and motivation. Each is supported by a distinct region of the frontal lobe. Apathy may emerge where there is dysfunction of any one of these components; understanding them may help care providers and families to develop interventions tailored to an individual's particular needs.

**Initiation:** The inability to self-generate or activate actions or thoughts. Patients who tend to sit quietly in the same position all day without speaking or talking are said to be in an akinetic mute state. Another related term, abulia, describes a loss of initiative and of spontaneous thought. Both are associated with damage in the brain's anterior cingulate region.

**Planning:** Plans of action are complex in nature, often involving multiple mental steps. Executing a plan is highly dependent on the cognitive processes needed to formulate and carry out multi-step goals. When these processes fail, individuals may experience a loss of ideas and curiosity for new routines. The anatomic basis of executive dysfunction has been linked to dorsolateral portions of the prefrontal cortex.

**Motivation:** Motivation is based partly on the processing of reward information. Apathy may result from a lack of responsiveness to either reward or negative-consequence feedback. Persons with FTD have an early degeneration of the orbitofrontal cortex, an area important for reward processing. Research has shown that individuals with FTD are insensitive to negative consequences, which may underlie their reduced motivation. They may show blunted emotional response to activities and situations that were once motivating.



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## DESIGNING INTERVENTIONS FOR APATHY

Designing approaches based on the specific nature of a person's apathy can increase goal-directed activity. The closer the fit between the reason for inactivity and the intervention, the greater the effectiveness of the intervention.

Individuals with **initiation difficulty** may benefit from Multi-Sensory Stimulation (MSS), a therapeutic approach that provides visual, auditory, tactile and olfactory stimulation, and external sensory cuing. For example, to use MSS to encourage someone to shower, use a verbal cue (e.g. "It's time for your shower"), show the resident a checklist or schedule and/or the bathing area, provide lavender aromatherapy soap, and help him to feel the water before showering. Introduce these one at a time. Playing warm, soft music while minimizing distractions in the bathing environment can also increase initiation.

When **planning difficulties** are prominent, there is benefit to be gained from simplifying activities. Consider providing just one or two choices to limit overwhelming decision-making. Develop and post a daily schedule of individually preferred activities. Include quiet time or rest. If the person diagnosed can use a smartphone, it may help to schedule reminders to perform certain activities. Tailor a person's past interests to their current level of ability; for example, if they enjoyed playing full-court basketball, get them a small hoop. Remember that confusion and frustration contribute to inactivity.

Individualized planning is central to interventions when **motivation difficulties** are present. For patients with impaired goal selection, modifications such as enhancing rewards may be useful. For example, individuals with bvFTD often find food rewarding. Therefore, offering a favorite sweet or chewing gum may be a good motivator.

Two interventions—music therapy and physical activity—can be effective strategies for apathy generally. Create a personalized music playlist. Adapt interests in fitness or sports to help the person remain as active as possible.

In addition to understanding the components of apathy, knowing specific strengths and challenges of the various subtypes of FTD disorders will influence how you communicate and engage with the person. Providing structured steps for activities may be important for an individual with primary progressive aphasia (PPA); due to their difficulty understanding everyday speech, they can become easily overwhelmed. Simplifying your communication—speaking at a slowed rate, using shorter sentences, omitting unnecessary words—can also enhance comprehension. People with bvFTD often respond well to following an established routine of structured,

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Over the next couple months, Linda became more withdrawn. Once a very social person, she stopped calling or going out to see her many friends, and Kevin noticed they were no longer coming by their house as often. Their neighbors also noticed her changing behavior; for example, she stopped making friendly conversation with them. Kevin took her back to her doctor, who recommended an increase in her antidepressant dose and suggested that she see a psychiatrist to further manage her depression.

The psychiatrist took a detailed history and then administered cognitive tests, including an assessment of Linda's executive functioning – planning, working memory, verbal fluency, and mental flexibility, among other skills. Kevin noticed she seemed to struggle with this part of the assessment. An MRI revealed prominent atrophy in the frontal lobe of her brain, which corresponded to the difficulties evident in her cognitive tests. Linda was diagnosed with behavioral variant FTD (bvFTD).

## MANAGING APATHY AT HOME

Over the next year, Linda's motivation continued to decline, forcing Kevin to plan and schedule all of her activities. Overwhelmed, he became angry at his wife's non-responsive behavior. At times, he thought she was being intentionally defiant; he often struggled to interpret her behavior as a symptom of her disease.

Kevin turned to AFTD for help. He joined a **support group** with an AFTD-affiliated leader that meets in his area and asked how others were managing the apathy of their loved ones. One caregiver suggested that he develop a curriculum of activities to help Linda to stay engaged. Another predicted those activities would soon become a part of her routine. Kevin took his fellow support group members' advice, making sure to keep the activities straightforward. If they required multiple steps, he broke each step down further, into even more simplified steps, letting Linda cross each step off when completed.

As Linda's FTD progressed over the next few years, her apathy increased. She began to neglect her appearance. She only bathed when prompted. If Kevin didn't intervene, she would watch static on the television all day long. The activities in her curriculum were now becoming too overwhelming for her to complete independently; she required frequent cuing from her husband to perform these tasks. During a doctor's visit, Kevin asked her physician if any medications would encourage Linda to engage more. The doctor mentioned central nervous system stimulants (e.g. methylphenidate), but cautioned against them, because their

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effects in FTD are mixed and may worsen other behaviors. Kevin did not want to take that chance.

He worried about whether he was doing enough to help his wife. Spurred by these feelings of guilt, he began seeing a psychologist to get help coping with his emotions. The psychologist pointed out that he was likely experiencing caregiver strain, and suggested he seek respite by enrolling Linda into a local adult day center.

When Kevin met with the staff at the adult day center, he shared with them AFTD's **Provider Letter**. The letter contains an overview of FTD, helping the staff to understand that even though Linda appeared to be very healthy physically, her apathy was extremely debilitating. The day center's activities director was particularly helpful in creating a program that incorporated Linda's interests and functional ability. For example, her "jobs" included arranging fresh flowers and watering the plants around the building. (For more information on individualized activities in FTD, see the **Summer 2016 issue of *Partners in FTD Care***.)

#### TRANSITIONING TO RESIDENTIAL CARE

Linda eventually developed incontinence. Her personal care, along with her behaviors, became too overwhelming for Kevin to manage at home. She transitioned to a residential dementia-care assisted living community, where the staff were willing to work closely with the couple's FTD specialist. Kevin shared AFTD's Daily Care Snapshot resource, which described Linda's needs and preferences, with the assisted living community's activities director. He noted that she always enjoyed music, and that it remained a source of stimulation for her.

The assisted living community's occupational therapist evaluated Linda's functional ability and developed a care plan to promote her involvement in positive activities. Linda was scheduled to attend the regular music therapy group; additionally, staff established personalized one-on-one activities with her each day. Kevin created a personalized music playlist on her iPod. The staff played upbeat music to help get her started, which was especially helpful in the morning.

The staff also recognized that Linda's apathy predisposed her to developing physical health complications. For example, she was vulnerable to decubitus ulcers because she rarely moved while sitting down. To minimize that risk, the staff limited her time in a chair to 60 minutes. To further encourage movement, staff consulted with a physical therapist to develop a range of motion, balance and strengthening exercises. Staff also put her on a toileting schedule to help manage her incontinence; she was prompted to use the bathroom every two hours.

Linda had stopped initiating conversation prior to the move to assisted living. Her verbal communication decreased to one or two words uttered occasionally, making it difficult to assess how much she understood. A speech therapist worked with Kevin to create a communication board depicting common words and pictures (such as toilet) to help with prompting.

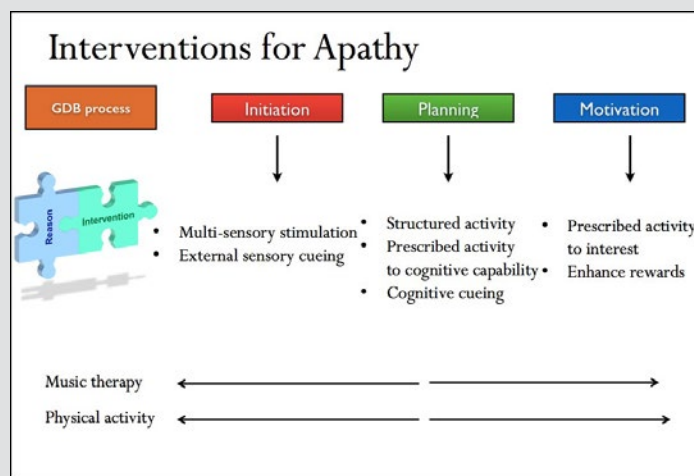
Kevin continued to visit his wife regularly. They enjoyed taking walks outdoors and looking at flowers. Kevin would describe them, encouraging Linda to smell and touch them to engage her senses.

As her illness progressed, Linda responded less to music and verbal or physical prompting. She exhibited increased motor slowing, increasing her dependence on others. At times she resisted staff assistance, which further complicated personal care. She became increasingly predisposed to complications such as urinary tract infections, contractures (stiffness of the muscles and joints) and pressure ulcers. Staff worked to prevent these and other apathy-related complications by using tactile interventions, touch therapy, staff physical therapy, range-of-motion activities, a toileting schedule, and pain management. In time, she developed difficulty eating and had several falls; meanwhile, her physical condition continued to deteriorate. With staff support, Kevin arranged for hospice services to be provided in dementia-care assisted living to ensure Linda's comfort in her last days.

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repetitive activities—sorting papers, coins or cards; folding laundry; doing puzzles.

This chart highlights the different approaches you can take when caring for someone who exhibits specific components of apathy. Note: "GDB process" = Goal-Directed Behavior.



## Questions for discussion:

### What changes in Linda's daily activities first revealed apathy?

She was regularly late for work, did not return emails and her productivity decreased to the point that she was put on probation. She stopped tending to her beloved flower garden and seemed uninterested in hobbies. Once a very social person, she stopped making plans to see friends and did not engage neighbors in friendly conversation when she was out in the yard. When Linda's husband Kevin asked her about these changes, she did not seem concerned and told him not to worry.

### What distinguished her apathy from depression?

Linda's family doctor ascribed her loss of interest in activities and relationships to depression, despite Linda doing well on the Mini-Mental Status Examination and not presenting as sad or concerned about the changes in her life. Antidepressants did not change her symptoms. She struggled throughout a psychiatrist's evaluation of her planning, working memory, verbal fluency, and mental flexibility. Her history and executive-function impairment prompted the psychiatrist to order an MRI to investigate further. Prominent atrophy in Linda's frontal lobe indicated the apathy was due to degenerative disease rather than depression, and the doctor diagnosed FTD.

### How did Linda's husband cope with her growing lack of motivation and activity?

Kevin found himself frequently overwhelmed and angry that he had to plan and arrange all of Linda's activities. He found himself thinking that she was sometimes being purposeful and defiant, even though he understood that her changing behavior was a result of FTD. He attended a **caregiver support group** led by an AFTD-affiliated facilitator where he could talk with others facing similar challenges. Group members suggested structuring her daily activities, and encouraged him to simplify the steps. When his children started to offer advice, Kevin struggled with guilt; he wondered whether he was doing enough for Linda. His doctor suggested he see a psychologist to help cope with his emotions and the stress of caregiving. This helped him continue to manage Linda's care while acknowledging his own need for support and assistance.

### What interventions targeted Linda's difficulty with planning and motivation?

Kevin found that having structured activities helped to address Linda's difficulty with planning and motivation. He created a curriculum, or regular schedule, of pre-planned activities personalized to her interests. He simplified the steps so she could do the activities with minimal frustration; a checklist provided a visual cue for her to follow. She marked off each step as she finished them, and could see what came next. Selecting activities she liked—and breaking them into steps she could do effectively—helped her to stay motivated; encountering frustration caused her to withdraw. As her apathy increased she required frequent verbal and visual cuing from Kevin to bathe or take care of her appearance. Using input from Kevin, the adult day program prescribed activities based on her interests, such as caring for plants and flowers at the program. When Linda moved to assisted living, a personalized playlist of music on an iPod provided auditory stimulation that increased motivation in self-care and other tasks. As her disease progressed and mobility problems limited outdoor walks with Kevin, she responded less to physical and auditory prompting. At this stage, staff engaged her with tactile interventions such as touch therapy.

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## THE MUTUAL BENEFITS OF A STRUCTURED DAY

### ONE CAREGIVER'S APPROACH

Eleanor and Richard had retired early to travel, spend time with their grandchildren and do more volunteering in their community. Those plans took a drastic turn when Richard's behavior became increasingly peculiar. When a neurologist diagnosed Richard with FTD, Eleanor became determined to make the best of each day, for both of them.

First, she read voraciously to learn about FTD, what to expect, and how to care for someone with a progressive brain disorder. She realized that spending time with Richard was more enjoyable when there was a plan, and when Richard could take part in activities he valued. Her approach to caregiving was designed to maximize her husband's abilities, thereby making her experience more positive.

Eleanor's next step was to take stock of the people, places and activities that Richard had valued most throughout his life. Richard had an intellectual side that loved history and debate. His roots in the community ran deep; he was active in his church and gave back through volunteering. By recording what Richard valued most, Eleanor helped to capture who Richard is at his core.

She then identified six initiators of action, those fundamental needs that motivate us and direct our actions: spiritual, emotional, physical, nutritional, intellectual, and social. She worked with Richard to plan daily activities in each of these areas to ensure his quality of life as the FTD progressed. She created a "curriculum" of activities for each day (6:30 a.m. to 10:00 p.m.) for both of them. While the curriculum allowed for some flexibility, Eleanor noticed that Richard's behavior was more consistent when they adhered to the routine.

Eleanor and Richard review the curriculum every two months and make changes. Each morning she lists the activities for the day, rather than planning too far in advance. They volunteer at the nursing home together now because of Richard's increased problems with knowing what to do next. Eleanor fills in the specific skills that have become more difficult for Richard, and looks for new ways to keep him engaged.

Planned structure is very helpful for FTD patients who are apathetic and have trouble with initiation. By eliminating the need to make decisions about what to do, a daily curriculum allows them to remain more engaged. In particular, people with disinhibited behavior tend to benefit from greater activity; boredom tends to exacerbate problem behaviors. Physical activities can also help people with sleep disturbances because they are more naturally tired at night.

Each day offers activities that are meaningful to the person with FTD (and manageable for the caregiver.) It is important to carefully match these activities to their abilities and stage of illness.

### KEY PRINCIPLES OF THE APPROACH:

*The approach is holistic:* By incorporating activities from all six initiators of action—spiritual, emotional, physical, nutritional, intellectual and social—Eleanor has ensured that Richard's life is varied, stimulating and challenging. The specific activities and his ability to participate will change as the disease progresses, but the holistic approach allows him to live with dignity.

*Activities are highly individualized:* The curriculum uses knowledge of Richard's strengths and interests from the past to inform his activities today. Planning activities that connect with valued aspects of his pre-FTD life encourages engagement.

*Activities are matched to changing abilities:* Activities must be adapted to utilize remaining strengths, minimize frustration, and maximize "success." When the goal is to preserve functioning for as long as possible, "success" is defined as continued involvement in one's life, at whatever level they are able.

*High level of involvement:* Eleanor's involvement with Richard's daily activities is key to the curriculum's effectiveness. Her steady presence helps him to stay engaged and provides continuity across settings and transitions. Other people are also involved, but Eleanor is the constant.

*Consistency and familiarity:* The curriculum is a structured approach to caregiving, providing a routine that engages Richard and reduces Eleanor's stress. Its value lies in its familiarity and predictability; however, the need to adjust the curriculum as Richard's FTD develops is constant.

*Positive attitude:* It can be very difficult to find hope and remain positive in the face of such a devastating illness. Eleanor credits the physician who delivered Richard's diagnosis with setting a positive tone, which she internalized. He did not minimize the eventual outcome, but stressed that much can be done toward insuring dignity and quality of life.

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# TWO VIEWS OF APATHY

## My Perspective as a Person Diagnosed with FTD

The truth is I burn up tremendous amounts of energy to maintain a thin veneer of normalcy. My family knows that my life is not normal, and I am aware to some degree on how changes in behavior, attitude and affect have impacted my family,

When I get organized I can still cook and am not a hazard in the kitchen. There are a few chores and errands I get done most days, but some more complex tasks never get finished. When we go out to eat, I can't decide what to order. Everything looks the same; one choice doesn't override the others.

It would be easier to just watch television. That is the day for many persons with FTD. Every day I take some afternoon quiet time to make sure I get through the day.

I have managed to contribute some time and expertise to a couple of non-profits.

My interest in photography has waned.

On any given day, I don't know what I can or cannot do.

Every morning I wake up with apathy—truly no sense of the motivation that drove a successful family life and career. It is profoundly strange, and it can take two to three hours to get started in the morning. If Marie, my wife, is home, it is much easier. She helps me stay on task, although at times I bristle because my mind is exhausted. She has learned to let me check out for a while.

So much of my time is consumed with, "What am I doing?" or, "What am I supposed to be doing?" The result is I am not present to those I love. I don't think about their needs—or, when I do, I can't respond in a timely way. I know that my spontaneous expressions of tenderness have gone away.

It has been difficult to grasp that the will might be totally organic, and that I have little control of my levels of ambition, interest and motivation.

—By A. Brandt Henderson, PhD, living with behavioral FTD

## My Perspective as an FTD Caregiver

It's terrible when a degenerative disease process affects the frontal lobe of the brain and causes changes in a loved one's emotions, ability to plan and initiate activities. My once accomplished and active husband has become a different self. Through no fault of his own, he no longer takes action to accomplish daily tasks. This leaves me, our friends and our family with a host of emotions, wondering how to deal with this new and changing reality.

When my husband fails to respond to a request, or simply stares blankly, I sometimes feel that he is being willfully defiant. So I stop and try to put myself in his position: I imagine being so tired that my task at hand—whether balancing a checkbook, solving a complex puzzle or reading a technical article—is so taxing I decide to put it off for another day.

When the task seems too large or confusing he may lash out, argue or make excuses that seem like lies. I try to imagine a very stressful situation that I have experienced—driving on an icy road, being blamed for something, or navigating in an unfamiliar environment in a hurry—and realize I have had the same responses.

Even with this understanding, apathy can be a real struggle to deal with. It affects each day and often results in frustration, hurt and anger. I have learned to expect that issues will arise. I try to anticipate what I can and solve problems by adjusting my approach or changing something in the environment. Talking to other FTD caregivers at my support group is always helpful. They provide additional suggestions to try and help me realize that, over time, there will be more adjustments to be made.

—By Sandra Grow, RN, caregiver

*In January 2018, A. Brandt Henderson and his wife Marie joined AFTD Program Director Sharon Denny for a webinar on advancing quality FTD care. Watch the webinar on [YouTube](#)*

## Partners in FTD Care Advisors

The Partners in FTD Care initiative is the result of collaboration among AFTD, content experts and family caregivers. Advisors include: Sandi Grow, RN, caregiver • Lisa Gwyther, LCSW, Duke Family Support Program • Barbara Harty, GNP, UNTHSC • Susan Hirsch, MA, HCR ManorCare • Jill Shapira, PhD, RN

AFTD extends special thanks to this issue's special guest contributor, Lauren Massimo, PhD, CNRP, a post-doctoral fellow at the University of Pennsylvania's Frontotemporal Degeneration Center. Dr. Massimo's research focuses on identifying the cognitive and neural basis for decline in neurodegenerative diseases, including FTD.

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## APATHY

Apathy in FTD can be present at all stages of the disease, affecting a range of everyday activities, including social engagement, household tasks and self-care. The person with FTD may know what they want to do, but have trouble carrying it out due to impairment in initiation, planning and motivation – all functions supported by the frontal lobe. Apathy is among the most challenging symptoms for family and professional caregivers to manage. Effective interventions are individually tailored, rely on environmental strategies, and are delivered with understanding and patience.

### SUPPORT POSITIVE APPROACHES

- Reframe apathy as brain-based rather than the result of stubbornness or defiance. Learning about disease-related brain changes helps to maintain the caregiver's empathic connection to the person and reduce frustration and anger.
- Develop individualized activities based on needs and interests that motivate and direct the person: spiritual, emotional, physical, nutritional, intellectual, and social. Follow the schedule consistently and adapt the level of difficulty of activities as abilities change.
- Check your emotions continually and try to maintain a positive tone. People with FTD may have difficulty understanding speech but understand tone of voice and non-verbal communication. Anger and annoyance impede engagement and task performance.
- Practice patience. People with FTD require time to process information and respond to interventions.
- Plan extra time for activities. Rushing impairs performance and adds to frustration for the individual and caregiver.
- Allocate adequate staff time for care activities, as it may take longer to provide appropriate, successful care to someone with FTD.
- Draw the person's attention away from thinking about what needs to be done. Confusion and frustration contribute to inactivity.
- Remember, you cannot change the person with FTD. Concentrate on modifying the environment and the intervention.
- Provide emotional support for family caregivers struggling to engage a loved one. Many feel anger over apathetic behavior, or feel they "aren't doing enough" for the person with FTD, which adds to caregiver stress.

### INITIATION

- Use external cuing to help a person start an activity.
- Keep it simple. Remember that understanding spoken language is difficult for people with FTD.
- Post reminders or set alarms on a smartphone for someone with early executive function challenges. Sync the reminders to a wearable watch if remembering to look at the phone is hard.
- Present cues through multiple senses including visual, auditory, tactile and olfactory. Reliance on verbal cuing alone will be less effective as the disease progresses; you may have to take more direct action (e.g. put a rake or broom in the person's hand).
- Start an activity side by side with the person (e.g. putting dishes away, folding laundry, viewing family photos) and let them continue on their own.
- Introduce multi-sensory stimulation one sense at a time. If used together they may overwhelm the person's senses and confuse or distract them.

- To encourage someone to shower, use a verbal cue (e.g. “It’s time for your shower”), show the resident a checklist or schedule and/or the bathing area, provide lavender aromatherapy soap, and help him to feel the water before showering. Play soft music to create a calm, relaxing environment.
- Create a consistent routine. Do things the same way at the same time of day. Automatic behaviors are easier than those requiring complex thinking.
- Expect repeated, regular cuing to be needed. A person with FTD cannot learn to cue themselves.

## PLANNING

- Develop and post a structured curriculum of individually preferred activities. Include regular rests or quiet time, because the demands of goal-directed activities are fatiguing.
- Modify past interests to reflect the current level of ability, e.g. if they enjoyed playing basketball, provide a small basketball hoop.
- Break down complex tasks into smaller steps.
- Encourage less cognitively demanding activities, e.g. word searches instead of crossword puzzles.
- Use larger items geared toward young children as motor skills decline, e.g. toys for toddlers.
- Arrange a rehab therapy consultation (speech, occupational and physical therapies) for assistance structuring and adapting activities.
- Consider providing just one or two choices to limit overwhelming decision-making.
- Encourage repetitive activities—sorting papers, coins or cards; folding laundry; doing puzzles—as these are consistent with some behavioral symptoms.
- Plan personal care at their “best time of day.”
- Provide the opportunity to stop an activity as needed.
- Create a personalized music playlist.

## MOTIVATION

- Turn off the television or radio to reduce competing stimuli.
- Provide praise and positive verbal feedback.
- Assume the benefit of the activity. A bored expression or lack of response does not mean they are not participating or enjoying the experience.
- Offer a favorite sweet or chewing gum as a motivator.
- Use amplified lighting in a room or on a specific object to draw attention to it if goal-selection is impaired.
- Laminate photos for residential or day program staff to shuffle through with a resident to see them in a more personal way.
- Create a checklist that the individual can complete. This may provide a sense of accomplishment.