

## Think Like an Occupational Therapist

# THE IMPORTANCE OF INDIVIDUALIZED ACTIVITIES IN FTD CARE

### INTRODUCTION

**F**rontotemporal degeneration (FTD) impairs a person's thinking, behavior, communication and movement. Creative and individualized approaches to activity engagement are essential to helping people with FTD manage challenging symptoms and promote quality of life. Occupational therapists (OTs) contribute critical skills in functional assessment and developing interventions that enhance care planning for people with FTD.

### THE CASE OF DAN

#### HISTORY AND DIAGNOSIS

Dan, 63, met his wife when they were both in high school. After graduation, while they were still dating, he had decided to enroll in the army, forcing them to go their separate ways. Several years later, they met again and married. They settled in a rural area of Ohio and had two sons. He was a family-oriented dad, who enjoyed spending time with his sons and working around the house. He was great with electrical work, plumbing and woodworking, and enjoyed working on cars. Dan worked hard to support his family, having a long career in maintenance for a chemical company. He never missed work and always did a good job. Dan and Rita have been married 36 years, with sons in their late 20s.

Four years ago, changes implemented at work had created problems for Dan. His job duties changed and additional important safety regulations were imposed. Dan didn't understand why he couldn't continue to do things the way he previously had. He didn't adjust, and didn't comply with the new regulations. This resulted in supervisory actions at work; eventually he was "retired" by the company. At home, Rita noticed that Dan had become distant and was very critical of her and their sons. Rita felt at first that he just didn't love her anymore. She knew he was stressed, but grew especially worried about the loss of interest in his home life, and his lack of concern about job performance.

Rita's concerns about Dan's personality changes, coupled with his loss of employment, prompted them to seek a medical evaluation. He was initially evaluated by a local neurologist, who diagnosed Alzheimer's disease and started Dan on an Exelon patch. Dan's wife felt that the medication did nothing and that he was getting worse. She

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### OCCUPATIONAL THERAPY INTERVENTIONS IN FTD

Occupational therapists (OTs) have training and skills that are uniquely suited to assist with many of the symptoms associated with FTD. There are many ways FTD affects a person's ability to engage in activities. For example: apathy may make it hard to initiate an activity; cognitive impairment may affect planning and organizing the steps of a complex task; language changes may make understanding verbal directions difficult; and changes to balance or motor skills may limit physical abilities. Despite cognitive impairment and loss of function, people with FTD can learn new or alternative ways to participate in daily living activities, and caregivers can be empowered with positive interventions.

The aim of occupational therapy interventions is to determine the person's interests, routines and preserved capacities in order to modify activities and environments to promote optimal function and positive engagement. Occupational therapists assess the cognitive and physical skills needed for specific tasks, break complex skills into smaller steps and reestablish routines to fit a person's current abilities. They assess the home and other environments for potential hazards, and make recommendations to ensure safety during activity performance. In addition, OTs recommend and train in the use of durable medical equipment (DME) like a bath chair or raised toilet seat, to make accomplishing tasks easier. OT interventions always include teaching these types of strategies to caregivers. An OT works collaboratively with the family and other rehabilitation specialists, as well as the doctor and direct-care staff to help people with FTD to maintain abilities and remain as engaged in daily activities as possible, to promote positive behavior, health and quality of life.



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expressed her concern to the neurologist, who continued to prescribe Exelon as the treatment of choice. Rita was not satisfied that he had the expertise needed, and her sons agreed. She asked for a referral for a second opinion. Rita sought a clinic where doctors had more experience in young-onset dementias, and she was willing to travel as far as necessary to find it.

Dan was referred to a university medical center clinic a two-hour drive from their home. He was evaluated by a neuropsychiatrist with a special interest in young-onset

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dementias. Based on the results of that evaluation, Dan's diagnosis was changed to FTD. At the time, he was 60 years old. He was weaned off the Exelon patch and treated with an SSRI antidepressant. Rita and Dan also participated in an early FTD clinical drug study at the medical center. She gained support and knowledge from the neurologist, the nursing staff and the social worker during these study visits. The clinic's team encouraged her to attend an FTD caregiver support group 45 minutes from her home. As Dan's disease progressed, Rita found the combination of education and support to be critical to her ability to cope.

### ACTIVITIES AS POSITIVE BEHAVIORAL INTERVENTION

As an individual's FTD progresses, it may become increasingly difficult to engage in activities. Everyday tasks like getting dressed and making a meal; leisure activities like gardening, walking and painting; or other interests such as listening to music and watching a movie can be challenging. People with FTD can also have difficulty thinking of an activity, knowing how to initiate it, following a sequence of actions, recognizing and correcting errors, or just understanding what to do.

Because of these changes, people with FTD often become restless, which can trigger behaviors like agitation, wandering and rummaging. Engaging in activities that are familiar, enjoyable and meaningful can serve as a way to reduce the occurrence or frequency of distressing behaviors. However, activities may need to be modified or changed a little so that the person can have a positive experience. Caregivers may also need to let go of their expectations in the activity being done the "right way." For example, "playing chess" can involve moving the chess pieces on the board without specific intent; "folding laundry" can involve moving the clothes from the dryer to the laundry basket. Helping a person engage in activities can improve their mood.

It may offer the caregiver a little free time or offer the pair the opportunity to enjoy an activity together.

This article drew on information from the book *A Caregiver's Guide to Dementia* by Laura Gitlin and Catherine Verrier Piersol, as well as from the article "Enhancing Caregivers' Understanding of Dementia and Tailoring Activities in Frontotemporal Dementia: Two Case Studies," published in *Disability and Rehabilitation* in 2016.

### THE NEED FOR STRUCTURED ACTIVITIES

Even with the medication, Dan continued to be very active and became increasingly restless. Without the daily routine of work or other activities, he would roam and ride his bike for hours. Rita was concerned that he was less attentive to his surroundings and that a decline in judgment increased the chance that he could get hurt. Rita needed to find activities that he could enjoy in a safe environment.

After visiting several programs, she found an adult day program 35 minutes from home. While the staff did not have experience with people with FTD, the director listened to Rita's perspective on Dan's strengths and needs and agreed to try.

When Rita asked Dan if he wanted to go, he said, "No. That's for old people and I'm not an old man." Rita tried to convince him that it would be helpful; their conversation just escalated to yelling, so Rita stopped. As a last resort, Rita called and spoke with the director again. They decided to arrange for Dan to visit and work as a "volunteer." The director told Rita that this approach had worked with other people.

Dan visited the program and once there, got involved in an activity. Rita stayed with him during his first day. He did not resist

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visiting after that first experience. Rita told the staff that at home, after dinner it was a family routine to clean up your own dishes. The staff capitalized on this routine and ability of Dan's, and asked him to collect dishes after lunch, clean up the tables and wipe them down. These were part of his "volunteer" activities. Dan did well with the activities he took part in on a routine basis. This offered the opportunity for him to feel productive.

Dan was considerably younger than others who attended the program and tended not to participate in many group activities. The staff started to set up activities with him in a quieter area, but it became apparent that he preferred playing solitaire on an Internet-disabled computer.

Dan developed unusual repetitive behaviors at home. For example, once the trash cans were emptied on garbage day, he ran from house to house putting them all away. He also began to compulsively collect aluminum cans from neighbors. He would walk around the neighborhood gathering cans from the street, out of trash cans in the park and from other places he passed. He also brought home some bags of cans that belonged to neighbors, who had planned to recycle them. Over time, he became angry and agitated if Rita or a neighbor tried to stop him.

Dan's habit of roaming and going through trash cans scared several people in his neighborhood. On a number of occasions, Rita found local law enforcement at their home after neighbors called 911. Dan needed constant supervision, which was increasingly difficult. At the suggestion of a member of her support group, Rita asked her primary care physician to refer Dan for home-based occupational therapy to evaluate his daily function to help her manage.

The OT assessed Dan's cognitive ability, motor skills and functional performance as well as his daily routines, interests and the home environment. Rita provided assistance, and they were able to identify triggers for Dan's repetitive behavior and design strategies to be used at home. Rita worked with the day program to arrange for Dan to attend on Wednesday, when trash was collected, in order to avoid a visual trigger (see the side article on page 5 for an example of a home care plan). Over time, Dan required more assistance and the compulsive behaviors increased. In fall 2015, Rita sought out 24-hour structure and support through a residential care facility.

#### WORKING WITH AN OCCUPATIONAL THERAPIST AND THERAPEUTIC RECREATION SPECIALIST

Rita searched a large area around her rural neighborhood and decided on a skilled nursing facility not far from their home, so

that she could visit often. The facility staff had no experience with FTD, but they were willing to learn. She brought in literature, but they preferred using the computer to research information. Rita referred them to AFTD's website [www.theaftd.org](http://www.theaftd.org) and to the Partners in FTD Care newsletter.

When he first moved into the residential community, Dan was wakeful for three days and spent most of that time wandering the hallways. The medical director referred Dan for occupational therapy. The OT completed an evaluation and met with Rita and her sons to develop a care plan that included Dan's self-care routine and activity engagement. The OT learned about his occupations, interests, longstanding skill working with his hands and his family life. She worked with the staff to set up the morning self-care routine to optimize Dan's participation and safety. The OT appreciated the benefits of Dan playing solitaire and helped to get him access to a computer so that he could continue playing. She explored activities with nuts and bolts and developed pipes that he could fit together and take apart. The staff allowed Dan to use his "can-crushing device" that came from home and enlisted the staff to provide any empty soda cans. Sometimes Dan would take a bag to go around the unit collecting cans to later crush them.

Therapeutic recreation staff invited Dan to attend other programming, and would arrange a chair in the back of the room so that he could exit easily when he wished. They set up the computer and other activities for him to do on his own and provided encouragement or initiated the activity with him when needed. Staff redirected Dan to the activities as a positive intervention when he exhibited disinhibited behaviors. The care team coordinated closely with Dan's psychiatrist and Rita to adjust medications as symptoms and behaviors changed.

As Dan's disease progressed, the OT staff continued to assess his capacity level and needs. Based on what they observed, they would provide suggestions for personal care due to increasing issues with incontinence. Working with the nursing staff, they designed a toileting schedule. When Rita was visiting, she would follow the same schedule. Rita and the staff learned not to ask Dan if he had to use the toilet; rather they just directed him to use it. They also assessed his activities and suggested changes to the activity plan to fit his level of ability.

He liked dice and now would just sometimes arrange them in a specific order over and over again. Dan had watched various TV shows and videos between activities and in the evening, but some films with shooting and violence became upsetting to him. As a result, Dan's TV watching was limited to old shows or taped sporting events.

Rita realized that many of the strategies she had learned to use at home also worked in the facility. She felt that moving Dan to the residential



## Questions:

care community ensured a safe environment and the supervision needed for his best quality of life, and for her peace of mind. The facility offered secure indoor and outdoor areas where he could pace when restless. The skills and background of an attentive OT and activity staff ensured that activities and care were matched to his interests and needs.

Rita took him out of the facility on occasion for a visit at home. He would immediately get a bag and try to leave to collect cans. Rita decided it was better to take him out for ice cream or a haircut instead of going home, to avoid triggering his prior behavior. She was grateful that he returned without question to the facility and walked right in. Rita appreciated that her input and participation were valued by the care team. That collaborative relationship allowed her to remain active in Dan's care without feeling constant anxiety for his safety.

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### How did advocacy by Rita, Dan's wife, contribute to his care in the adult day program and residential facility?

Rita recognized the need to provide a safe environment for Dan, and that she needed support and help. She requested a referral for home-based OT and later shared strategies that she had used at home with Dan for the staff at the day program and at the residential care facility. She provided educational material for staff and recognized that the rural staff preferred online resources. Rita shared Dan's occupational history, interests and recent behaviors so that staff could tailor individual activities. She participated in treatment team meetings and used the interventions consistently with Dan when she visited. Rita appreciated that her input was valued and that she could continue to contribute to Dan's care.

### How did effective activity planning help Dan transition to the day and residential care programs and use them effectively?

In each case, the care team coordinated closely with Dan's family and drew from his personal history and interests to develop a highly individualized plan. They adapted their usual programming creatively to fit Dan's needs, and identified opportunities to engage in meaningful tasks that allowed for the need to be productive, while also providing an element of repetition consistent with the activity. Doing puzzles, folding towels and sorting equipment or tools are examples of activities that have naturally occurring repetition. Such positive engagement in activities offered an effective way to minimize Dan's challenging and potentially disruptive behavior without increased use of medication. They adjusted the complexity of activities as his illness progressed to reduce crises and ease transitions.

## RESOURCES

- *A Caregiver's Guide to Dementia: Using activities and other strategies to prevent, reduce and manage behavior symptoms*, Laura Gitlin and Catherine Verrier Piersol, 2014.
- *Behavioral Interventions for Enhancing Life Participation in behavioral variant FTD and Primary Progressive Aphasia*. Kathleen Kortte and Emily Rogalski, *Int. Rev. Psychiatry*. 2013 April 25(2): 237-245.
- *Enhancing caregivers' understanding of dementia and tailoring activities in frontotemporal dementia: two case studies*. Claire M. O'Connor, et al. *Disability and Rehabilitation*. 2016; 38(7): 704-714.
- *What if it's Not Alzheimer's: A caregiver's guide to dementia*, (3rd edition) edited by Gary Radin and Lisa Radin, 2014.

## 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, Bryan Alzheimer's Disease Research Center at Duke • Barbara Harty, GNP, UNTHSC • Susan Hirsch, MA, HCR ManorCare • Jill Shapira, PhD, RN • Rebekah Wilson, MSW, Choices in Senior Care

AFTD extends special thanks to this issue's special guest contributor, Catherine Verrier Piersol, PhD, OTR/L, FAOTA, Associate Professor, Department of Occupational Therapy and Director, Jefferson Elder Care at the Jefferson School of Health Professions, Thomas Jefferson University.

And We are grateful to Cathleen Johnson, MS, OTRL, FMiota and the staff of Arden Courts Memory Care Communities for their additional contributions to this issue.

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# TROUBLES & TIPS

**Q: We serve a 53-year-old woman with behavioral variant FTD in our memory care community. Her family is urging the doctor to prescribe occupational therapy. How can rehabilitation therapy benefit someone with progressive cognitive disease?**

**A:** Many physicians and community providers see the goal of rehabilitative therapies such as OT to be to restore lost skills. This traditional understanding misses the importance of skilled care to prevent or slow further deterioration of skills in progressive cognitive diseases such as FTD. When the person cannot relearn a skill, there are many strategies that tap procedural memory to improve performance.

An OT works with the individual and with family and professional caregivers to develop a plan, so that the person living with FTD can move away from requiring total assistance with self-care tasks, to needing minimum assistance or supervision. Cognition does not improve, but by simplifying tasks—teaching caregivers to set activities up beforehand and rebuilding routines—the individual may increase engagement and develop more endurance.

Under Medicare, occupational and other skilled therapists can justify improving performance by ecological approaches rather than rehabilitation. In January 2013, Medicare clarified that coverage of skilled therapy "...does not turn on the presence or absence of a beneficiary's potential for improvement from the therapy, but rather on the beneficiary's need for skilled care."

Individuals can access OT services in a full range of care settings. Home health agencies and skilled nursing facilities can be reimbursed for occupational therapy services by Medicare Part A; long-term care facilities and personal care facilities by Medicare Part A and B; and therapy practices that offer home-based outpatient services by Medicare Part B. Private consultation is available to those with resources.

## AFTD SUPPORT GROUP LEADER AFFILIATION MODEL PRESENTED IN MUNICH

AFTD was a proud sponsor of the 10th International Conference on Frontotemporal Dementias in Munich, held 8/31 - 9/2. The conference saw more than 750 attendees from across the FTD research community. Past recipients of AFTD research funding presented prominently. Sharon S. Denny, AFTD's Program Director, presented a poster on AFTD's affiliation model for support group leaders.

Through this model, leaders receive training and support from AFTD Support Services Manager Bridget Moran, MPH, and can access knowledge and resources regarding medical advances, research, support and advocacy. More than 55 support group leaders, representing 50 FTD-specific support groups across the U.S., have now formally affiliated with AFTD. For more information on this model, email [BMoran@theaftd.org](mailto:BMoran@theaftd.org).

## USING OT STRATEGIES AT HOME

A closer look at Dan and Rita's use of occupational therapy strategies at home shows the potential to improve the family's quality of life and help the person with FTD to remain at home longer. An OT worked with Dan and Rita to understand and determine the triggers for Dan's repetitive behaviors. Rita said that as soon as Dan heard the trash truck every Wednesday morning around 9 a.m., he would stand at the living room window waiting, then go outside as soon as the truck left the neighborhood. If Rita tried to stop him, he would get angry. Together, the OT and Rita developed strategies to reduce this behavior. One suggestion was to have Dan go to the adult day program on Wednesdays, and make sure they left the home by 8:30 a.m. In addition, for the days he would not go to the program, an activity was used to occupy his time.

The OT worked with Rita to implement the following strategies: On Wednesdays between 8:30 and 8:45 in the morning, Rita would say to Dan: "Let's go to the TV room." She would have the computer set up in advance with a game of solitaire. Once there, Dan would sometimes sit down and start playing.

If he didn't immediately sit down, Rita would say, "Look at the solitaire game on the computer" to provide a verbal cue. Rita also made sure to have music that Dan liked playing in the background. Rita would stay in the room doing another activity and providing encouraging statements, like "you're great at solitaire."

The OT discussed other activities Rita could set up for Dan, including crushing cans. Engaging in an activity at home out of the earshot or sight of the trash truck kept Dan engaged and reduced the likelihood that he would roam the neighborhood looking for empty cans.

With the help of the OT, Rita turned the can gathering and crushing activity into a positive. After some discussion she had realized that she needed to tell her neighbors that Dan had FTD, and she then let them know that Dan was collecting cans. She found out that the neighbors were very willing to leave their empty cans in Dan and Rita's garage. Rita would leave the can crusher device next to the pile of cans, so that any time Dan walked by he would crush some cans, which he enjoyed. There were so many cans over time that it kept Dan busy and he no longer walked the neighborhood. Explaining everything to her neighbors meant that they understood, and Rita felt better.

The occupational therapist also set up the bathroom and bedroom to facilitate Dan's ability to perform his daily routine. By teaching Rita how to modify the environment (remove unnecessary objects/materials, make sure the light is bright, limit distractions), how to simplify the activity (put supplies out in advance, label the drawers of the dresser) and how to best communicate (use short one-step directions, and avoid correcting Dan if he did something wrong), Dan's functional performance improved and Rita felt empowered to manage his care. When it became necessary for Dan to move to long-term care, Rita encouraged re-engagement of occupational therapy to ease the transition.



## ACTIVITIES AND SELF-CARE ROUTINES IN FTD

There are many ways that FTD may affect a person's ability to manage in self-care and other daily activities. While it can be more challenging to engage individuals with FTD in these activities, there are effective approaches.

### USING ACTIVITIES FOR POSITIVE BEHAVIORAL MANAGEMENT

- Include the family in creating an individual activity plan, and invite the person with FTD to programs, such as special events, spiritual programs and movies.
- Consult with an occupational therapist (OT) to complete a functional assessment and identify strategies to promote activity engagement as interests and abilities change.
- Create an individual plan: when to engage in a particular activity, how to set it up, how to simplify steps to complete it and how to monitor it safely.
- Identify individual activities based on personal interests and experience. Modify activities to meet the person's abilities. Look for activities that challenge the intellect but are not so difficult as to cause frustration or discouragement.
- Provide a chair for the resident at the back of the programming room, where they can enter and exit freely and easily during community activities.
- Facilitate a small game with others and adapt rules for flexible play. Games may be difficult for the person with FTD to figure out and there may be loss of understanding of social rules.
- Begin an activity with the person and stay with them until they are engaged. A person with FTD cannot always initiate an activity, but once started, she or he may continue independently.
- Find a "job" that allows the person to contribute. Repetitive "work" such as dusting, sweeping, folding papers, watering flowers or clipping coupons may be easiest.
- Look creatively at how to adapt and build on what works. Symptoms and abilities change regularly. If music is a favorite but the MP3 player gets lost, attach it to a firm headset that is easier to keep track of.
- Adjust expectations for word searches that were a breeze before. Remember, the rules don't matter; they may find the word "pl" on one line and "ane" on another. It is not cheating; it is a creative way to find the answers. In later stages, she or he may not be able to find the word, but could go on a "letter" search—find all the "B's."
- Channel compulsive behaviors into activities. For example, sorting objects: a deck of cards can be sorted into suits; colored objects or pegs by color or shape; or matching dominoes.
- Provide daily encouragement, smiles, reassurance at signs of stress. A trusting relationship with staff is important as people with FTD often feel more comfortable talking with staff than older residents with Alzheimer's disease or other dementias.
- Consider music programs that are age appropriate and those with rhythmic activities that may engage people with FTD and offer a sense of mastery. Namaste programs that offer sensory relaxation such as a warm blanket, hand massage with eye contact, soft music, lavender scent, range of motion exercises and finger sandwiches/beverages for calming a busy resident.

**CREATE AN INDIVIDUAL PLAN: COVER WHEN TO ENGAGE IN A PARTICULAR ACTIVITY, HOW TO SET IT UP, HOW TO SIMPLIFY STEPS TO COMPLETE IT AND HOW TO MONITOR IT SAFELY.**

## ACTIVITIES AND SELF-CARE ROUTINES IN FTD

### SELF-CARE AND ADL ROUTINES

- Engage in physical activity to restore and maintain the physical skills, strength, range of motion and coordination needed for personal and self-care.
- Consider adaptive equipment like large eating utensils, stabilization devices, or bathtub seats—or adaptive clothing for younger individuals—to help people with FTD engage successfully in self-feeding, dressing and bathing/grooming, as well as leisure activities.
- Follow the person's usual routine and schedule, based on when they are most agreeable, rather than the facility's schedule. Break up tasks if needed: e.g., bathe arms on Monday, legs on Tuesday, etc., to reduce time. A posted schedule may be helpful.
- Offer constant encouragement; maintain a calm voice and smile as individuals with FTD understand positive emotional expressions better than negative ones.
- Relax the standard of performance, rather than rushing or arguing that something is being done too slowly or incorrectly. What is most important is that the person is engaged in the activity and feeling positive.
- Set out supplies in advance, e.g. place clothes on the bed and in the order each item will be put on.
- Remove objects that are not needed for the self-care activity, e.g. only have a toothbrush and toothpaste on the bathroom counter; remove lotions, deodorant, cleaning liquids, etc.
- Remove sharp objects and poisonous liquids or other potential safety hazards from sight. Secure them in a locked area.
- Provide one-step, simple directions and allow enough time for the person to process what you are saying.
- When engaged in an activity, minimize distractions such as noise and provide enough lighting. If the group dining setting is overwhelming, provide a private area.
- Use contrasting colors that are easy to see; e.g. dark placemat on the table with a white plate.
- Perform activities in familiar environments with familiar objects; e.g. brush teeth and shave in the bathroom, rather than the bedroom.
- Arrange staff in-service trainings by occupational therapists to include hands-on demonstrations of exercise, setting up an activity and intervention techniques.

See previous issues of Partners in FTD Care for additional tips to support positive daily activities:

**WINTER 2015 FOR TIPS ON CHANGES IN EATING BEHAVIOR**

**SUMMER 2014 FOR TIPS ON MANAGING INAPPROPRIATE SEXUAL BEHAVIOR AND PERSONAL CARE**

**SPRING 2014 FOR TIPS ON MANAGING AGGRESSIVE BEHAVIOR**

**WINTER 2014 FOR TIPS ON MANAGING INCONTINENCE**