

Easing the Transition: Residential Long-Term Care and FTD

Transitioning to a new environment is stressful for almost everyone. For people with dementia it is particularly challenging. Relocation Stress Syndrome (RSS) is a nursing diagnosis that acknowledges that elders and people with cognitive impairment may experience heightened confusion, agitation, behavioral issues and physical issues as a result of a change in environment and routine. People living with FTD experience relocation trauma to varying degrees, depending on their symptom presentation.

Most individuals living with FTD who are moving to long-term residential care are in the moderate or advanced stages of their illness. Typically, they have symptoms of both behavioral- and language-variant FTD (<http://www.theaftd.org/understandingftd/disorders>). These symptoms are often more challenging for staff to understand than those of Alzheimer's disease (AD). Additionally the transition from home-based care to facility-based long-term care can be particularly stressful for family members who are emotionally overwhelmed, exhausted, drained and unfamiliar with the culture of the residential care setting. This is especially true for younger families.

While relocation stress is expected, family members and staff alike are often unprepared for the degree of challenges that may arise. Sometimes the resulting behavior challenges are addressed with medications that further complicate the transition. As part of the assessment, it is important to understand the reasons long-term care has been selected, and how the person typically responds to changes in routine. Time spent on planning and coordination can ease the transition for the resident, family and staff, and contribute to a positive experience in residential care.

✂ Case Study: Meet Gerald R., Accomplished Surgeon ✂

Gerald R. is a 56-year-old married orthopedic surgeon. He stepped down from his position as chair of his department at age 52, due to a diagnosis of behavioral variant FTD. Gerald had begun to make poor decisions regarding his departmental budget, lavishly redecorating the faculty offices and trying to seduce residents on his leather sofa. At home he was becoming increasingly hostile towards his wife, Addy, calling her "a load" and "past her prime" because she was unemployed while raising their four sons, now 33, 31, and 29 year old twins. Nothing she could do was right. He routinely threatened her with divorce, but he never pursued one.

He became aggressive at social events, proposing irrational solutions to societal problems and occasionally threatening friends with aggression when they disagreed. He had several spontaneous bowel movements during social engagements and made seductive statements to his friends' wives, all of which ensured that he was excluded from social invitations and activities.

Gerald never seemed to notice this rejection. He had been an avid hunter and had many guns. Previously, the guns were locked in a safe, but after his retirement, he hung rifles in the living room and left handguns lying around.

Addy had to return to work. Gerald seemed content at home with his computer and pacing his Florida neighborhood. While Addy was at work, Gerald purchased a million-dollar cabin on Flathead Lake in Montana, sight unseen. Addy closed

ASK THE EXPERTS: What is Relocation Stress Syndrome?

Relocation Stress Syndrome (RSS) is a nursing diagnosis that describes physiologic and/or psychological disturbance resulting from a move from one environment to another.¹ A move by a person living with FTD from their home to an assisted living facility or nursing home can result in symptoms such as anxiety, confusion, fear, agitation and an increase in behavioral issues. RSS usually starts a few days after admission and lasts several weeks to a month on average. While this reaction to moving is not unexpected, for family members, it can trigger increased guilt, grief, and anger if they are unprepared for this challenging time.

For individuals living with FTD, three factors contribute to challenges that may arise when transitioning to long-term residential care: 1.) relocation stress for the new resident; 2.) the family's exhaustion and emotional stress over placement; and 3.) the staff's limited experience with the disease.

The combination of these factors is a common trigger for increased agitation for the resident. The prescription of mood-controlling medications, often in high doses, may create tension between the staff and the family, and may also actually increase the target behavior in the resident. Agitated behavior, especially from a resident not well known to the staff, may prompt a second and unwanted placement change – to in-patient care. Careful planning with staff and family prior to initial placement in long-term residential care can help ease the adjustment of the person diagnosed with FTD, and contribute to an appropriate and effective long-term care placement.

¹ North American Nursing Diagnosis Association (NANDA)

Limiting TV to Ease Transitions

Uncharacteristic increased television watching can be a sign of the apathy and loss of interest in previously enjoyed activities that often accompany FTD onset. As FTD progresses, television may become a factor in other difficult aspects of care management or part of a person's rigid daily routine, e.g., demanding to eat dinner immediately after watching *Jeopardy*. Seeing a specific show may prompt an immediate search for food. In addition, over time, FTD makes it increasingly difficult for people to follow television shows or understand what they see. Furthermore, the extra stimulation of television can be misinterpreted. People living with FTD may respond personally when violence or arguing is depicted onscreen. Although people with FTD lose language, they still respond to emotionally powerful visual images, to facial expressions and to tone of voice. Misinterpreting such stimuli can lead the resident to

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think that what is depicted on screen is real and actually happening to her/him. Some people with FTD develop severe psychotic features that may require sedating medication and/or hospitalization, adding further to relocation stress.

The transition to long-term residential care is often eased if there is no open access to television in the resident's room.

Therefore, consider eliminating television from the room as part of an individualized transition plan. Removing television during transition contributes to predictable environmental routines and increases opportunities for early acceptance of staff. When family cannot imagine the person without access to a TV, a certain program (e.g., *Wheel of Fortune* or the game show network, if such shows do not escalate challenging behaviors) may be identified. Identifying appropriate shows will then require staff to turn the screen off before other shows come on. It may be appropriate to use a DVD for a favorite, less agitating movie, for a program series, or for pre-recorded sports for some down time during the day. After family members and staff observe that the resident has adjusted, a television in the room may be introduced.

their bank accounts and opened new ones in her name. She replaced his credit cards with gift cards after cancelling all of the old accounts. Addy now assumed all responsibility for family finances. Addy thought she had locked up all of the guns in the house, but Gerald located one and threatened her during an angry outburst. She called 911. He was taken to a nearby hospital emergency room where he was kept overnight and treated for a urinary tract infection.

At age 53, Gerald began to refuse to bathe, shave or care for his teeth. He wore only camouflage pants and olive-colored T-shirts. At age 54, he began to have problems communicating, struggling to pronounce words and not understanding some of what was being said.

✂ Seeking the Right Residential Care ✂

At that time, Addy felt she could no longer care for Gerald without considerable help. She and her sons discussed long-term care options. Despite heated disagreement from the two eldest sons, Addy decided to move Gerald to a group home near their home, convinced it was the least restrictive environment possible. Gerald was admitted, but he was discharged within 24 hours because he made sexually aggressive gestures toward younger female staff.

Then Addy found an assisted living facility with a memory care unit. Addy tried to discuss her reasons for the move with Gerald, but he became increasingly agitated. Gerald was admitted to a private room in an area where there were several other male residents. Addy and the staff felt the men might become friends. The first few days things seemed to be going well, but on the third day Gerald found a cardboard box and started to pack his belongings. Despite staff reassurances that this was now his home, Gerald's agitation escalated. The facility contacted their psychiatric consultant, who ordered 1 mg of lorazepam (Ativan®) for agitation every four hours as needed. This did not help and may have made the agitation worse.

On his fourth day in memory care, Gerald grabbed a care aide's arm and tried to drag her to the door, screaming for her to unlock it so that he could leave. When she did not, he broke a window. Addy and her sons responded to the facility call. The facility summoned an ambulance and Gerald was taken to the local ER. The hospital did not admit him as his behaviors had subsided. He was discharged back to his home with Addy, who felt she could manage him better than the facility.

For the next six months Gerald resided at home and became mute. Meanwhile, Addy needed to return to work and was also exhausted from the physical and emotional toll of providing care. Then, Gerald became aggressive, breaking Addy's wrist while she was shaving him. Her sons took Gerald to the ER, and he was admitted to the hospital's psychiatric unit for assessment. Addy and her youngest son applied for and were awarded guardianship.

✂ Preparing for Long-Term Care Admission ✂

Gerald was ready for admission to a nursing home specializing in the care of people with difficult behaviors. Prior to



looking at nursing homes, Addy and her sons were counselled by the hospital's nurses and a social worker on principles of behavioral care and FTD. All acknowledged that Gerald had a potential for aggression, and they agreed to find a facility with specially-trained staff and a consulting psychiatrist who would oversee Gerald's care. All of them realized that such a facility might not be close to Addy's home. The director of nursing and social worker did a pre-admission home assessment focusing on Gerald's past, his behavioral symptoms and triggers for aggression. Addy and her sons were directed to AFTD caregiver support resources (<http://bit.ly/1PDU8Xz>), a local FTD support group and several on-line FTD caregiver groups for information on care techniques and the experiences of other caregivers.

Addy and the family were encouraged to visit as often as they liked; however, for the first month, they were advised to visit immediately before a meal and plan to stay just 15 minutes. They were encouraged to bring an activity to do with Gerald, such as looking at labeled family and nature photos and playing simple games, and they were encouraged to plan to leave when Gerald began the meal. Based on past behavior, the psychiatrist and Addy agreed that Gerald was to be maintained on a low dose of atypical antipsychotic medication (quetiapine, 25 mg at bedtime) for at least two weeks after admission. The psychiatrist would visit at least weekly until any RSS reaction subsided.

A room was identified in a quieter area of the facility. Addy brought in a bedspread similar to the one at home and Gerald's pillow. His computer was installed without internet access at a desk in his room. Because of the potential for misinterpreting stimuli and developing psychotic features, there

was no television in his room. The telephone was removed because even though Gerald was mute, he continued to dial home obsessively. The staff determined how closely Gerald's usual daily routine could be followed and followed it to the highest degree possible. Realistic goals were set for personal care: bathing once a week by a male CNA using a towel-bath procedure. Addy purchased several identical sets of "camo" for him to wear. These steps encouraged positive interactions with staff.

Staff and family agreed that the first 24-48 hours after admission would be quiet, with meals served at his desk, supervised by a staff member. The director of nursing identified one of his most experienced and laid-back caregivers to spearhead care for the first two weeks. A male caregiver was identified because Gerald seemed to respect men more than women. Gerald was supervised carefully around women, both staff and residents. Close, unobtrusive monitoring by staff was implemented to monitor for elopement potential. Staff and Addy agreed to meet at the end of two weeks to mark any progress or problems.

✪ Planning Pays Off ✪

Gerald adapted without any major problems. Consistent staff were assigned to assist him and trained in non-confrontational approaches. If Gerald did not want to do something, no one tried to force him. The care plan noted the special nature of his needs, including facilitating his obsessions of continuous walking and shredding paper. Although Gerald did not bond or make friends with staff, he allowed them to provide most care. Gerald did not participate in group activities, but seemed content to watch other residents while walking or shredding. He ate his meals in a quiet area of the

Navigating Concerns Raised About Behaviors and HIPAA

An effective transition to facility care requires integration into the community environment of other residents and families. Residents with FTD are often more solitary, interacting less with other residents, and participate in group activities less often than residents living with Alzheimer's disease. Additionally, the person living with FTD may exhibit compulsive behaviors such as pacing or rummaging that—while intrusive or annoying to staff and other residents—help the person with FTD to soothe anxieties.

Behaviors such as repetitive vocalizations, roaming or rummaging can draw concern from other residents and their families. Family members concerned on behalf of another resident may express fear for their loved one's safety, or even demand that the facility move a person not perceived to be appropriate. It is possible to address questions about these behaviors within HIPAA privacy and confidentiality constraints. Some strategies include:

- Administrators suggesting a meeting between the other resident's concerned family members and the health care proxy or POA of the resident with FTD.
- Asking family members of the resident living with FTD to provide a listing of answers to frequently asked questions about FTD behaviors.

Scheduling meetings between concerned family members and the POA of the resident living with FTD—when the POA is given the opportunity to agree to the meeting in advance—offers flexibility to address concerns and provide education about FTD. Note: The resident who is exhibiting the concerning behaviors is not usually included in these meetings. More information about HIPAA for consumers and providers is available here: <http://www.hhs.gov/ocr/privacy/hipaa/understanding/index.html>



dining room with another male resident. After three weeks, Gerald exhibited no aggressive behaviors or excessive agitation. His quetiapine was reduced to 12.5 mg at bedtime and was stopped two weeks later. The consultant psychiatrist continued to see him monthly for four months and then discharged him with the understanding that Gerald could be seen again if his condition changed.

Initially, Addy visited each morning at the same time. She tried to get him to play simple games with her but he preferred to pace. She kept this routine for several weeks but then tapered her routine to visiting twice each week. She began attending an FTD support group, forming close bonds with the other caregivers. She kept a journal of Gerald's illness and began writing a book to help others.

Questions for Discussion

(Use for staff in-service training or in resident-specific situations.)

How did the family and care team assess the capacity of a long-term care facility to effectively serve Gerald?

The nurses and social worker at the psychiatric hospital provided access to information about FTD, and they counseled Addy and her son to be honest and provide as much information about Gerald's needs as possible in the admission process. Rather than prioritize proximity to home, they prioritized finding a facility that had an experienced psychiatrist, or geriatrician or primary care provider dedicated to the team and experienced staff. The placement team also looked for a physical environment that was both secure and offered room to walk – important factors, especially for someone with challenging behavior issues. The facility was prepared to adapt programming to fit Gerald's particular needs.

Residential facilities may not have experience with how FTD differs from other types of dementia. They should ensure that they have the administrative and clinical resources and staff to manage FTD care in an effective manner. Staff and family education about FTD, targeted approaches to care and discussing mutual expectations are essential.

How did the family, facility, physician, and other therapy staff develop a team approach, even before Gerald moved in? What role should he play?

Gerald was in his 50s when his family sought residential care. Addy was emotionally drained from caring for him at home. She also needed to work to maintain income and health insurance, and she faced family conflict about the need for a move. The in-patient and facility staff understood that Gerald and his family would feel upset by the move, and that individualized support would facilitate a smooth transition.

The staff engaged Gerald and his family in various ways prior to admission. Addy used [AFTD's Daily Care Snapshot form](#) to capture information from their family to discuss with admissions staff. The assessment process included more meetings than is typical with staff, Gerald and his family. A visit by the pre-admission team to family home provided valuable information for staff. Gerald, Addy and their son's pre-admission visits with clinical and direct care staff in the facility contributed to building the care team. They coordinated their efforts to first control the most difficult safety issue, Gerald's potential aggression. They agreed upon a medication regimen and psychiatric visits, as well as small group and individual activities for Gerald once he moved in to the long-term residential home.

Were the interventions implemented at move-in appropriate throughout the course of Gerald's stay?

Steps taken at move-in were planned in advance to reduce Relocation Stress Syndrome symptoms and were based on an assessment of Gerald's and Addy's specific needs. They included consideration of the physical environment, staff assignments, activities, family visiting and medications. Strategies were designed to ease the adjustment to the facility, improving the likelihood of successful transition for Gerald, his family and the staff. Like most residents, Gerald adjusted to the new facility over the course of two to four weeks. Steps that ensured a quiet, calm environment facilitated his transition. Addy was hesitant for him to not have a television during the transition, but with education understood that stimulation from movies or shows could potentially cause delusions or psychotic behavior and contribute to RSS symptoms. She found eliminating television temporarily to be preferable to the alternatives, such as risking a need for sedating medication and/or inpatient care should behaviors escalate. These preventive measures were reassessed by the care team when Gerald appeared to be calm and stable in the new environment. On-going, individual assessment is essential.

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 • Geri Hall, PhD, ARNP, Banner Alzheimer Institute • 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

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Troubles & Tips

Our dementia care community usually defers visits by family members for two weeks after move-in, so staff can get to know the new resident. The family of a 51-year-old woman with FTD is vehemently opposed to this. How do we know the best way to facilitate a smooth transition?

Admitting a person with FTD to long-term care is traumatic for the person and family. For the new resident, there are huge changes – in the people around them, the daily routine, the sights and sounds of the new environment and the perceived loss of family. Many people with dementia fear abandonment, especially with the regression caused by the disease.

For caregivers the change can be equally difficult. Fueled by stories in the media and descriptions of worst-case scenarios from acquaintances, they may fear neglect or mistreatment of their loved one. Media and well-meaning individuals continue to express that “home is always the best place for a person with dementia,” producing family guilt, anger and often a sense of failure. These factors can affect interactions with staff and make it stressful to get to know a new resident, especially if family members are demanding or threatening. In response to these challenges, some facilities do seek to lessen the impact of relocation stress by limiting family visits until after a specified period, usually 2 to 4 weeks beyond move-in. Yet, this is often met with increased anxiety and anger by families, and is a controversial topic among care professionals—one that each facility should address by its own criteria, and where possible, on an individual basis.

When making a decision about visitation during this transitional period, consider the resident and the family members’ individual needs.

The table below lists some justifications that have been cited by long-term-care staff for allowing and not allowing family visits for a defined period after admission. When making a decision about visitation during this transitional period, consider the resident and the family members’ individual needs. Some caregivers may be able to visit without issues, whereas others may need respite from caregiving at time of admission. If a caregiver is extremely distressed, suggest a period without visits; however, be sure the caregiver has someone they can call daily for an update on their loved one’s condition and adjustment. Always remember that the caregiver is as much of a consumer of services as the resident. Provide empathy and clear communication, and engage family members as active members of the care team.

Reasons for Encouraging Visits	Reasons for Discouraging Visits (for some residents, and for a defined period)
<ul style="list-style-type: none"> • The Resident’s Bill of Rights states that a person may not be denied visitors. • The resident may perceive a lack of visitors as being abandoned. • The family can provide valuable information to individualize care. • Family members can begin to develop relationships with staff. • Family members can learn the routine practices of the facility, e.g., activities, rest periods and interactions of other residents. • Family members can begin to understand the limitations of facility care, e.g., not being able to prevent all falls. • Family members develop realistic expectations for care, as well as constructive ways to manage concerns. • Decreased family guilt and anger. 	<ul style="list-style-type: none"> • The new resident needs time to get adjusted to new surroundings. • Family members visiting for an extended period of time may prevent the new resident from participating in activities and community mealtimes. • Family members who come and go may cause increased anguish from repeated separations. • Family caregivers can experience extreme grief if the new resident clings to them when they try to leave at the end of a visit. • Family members coming and going may also encourage exit-seeking behavior. • Staff need uninterrupted time to develop relationships with the new resident. • Upset relatives may increase staff stress.



Relocation Stress Syndrome

Relocation Stress Syndrome (RSS) is a nursing diagnosis characterized by confusion, agitation, behavioral and physical issues that result from a change in environment. In FTD, symptoms and behaviors are often not well understood, and the family is emotionally and physically exhausted from caregiving at the time of the move. Careful planning and coordination are especially important prior to move-in, to ease the transition to long-term residential care.

Assessing Fit

- Use multiple pre-admission visits with residents, family members, and administrative, clinical and direct-care staff to develop rapport and assess fit. Visits should occur both at the resident's home and at the facility.
- Ensure that facility staff members are educated about how FTD symptoms, behaviors and management approaches differ from other dementias.
- Ensure that facility staff members are educated about the emotional and physical toll experienced by family caregivers, due to the particularly high burden of care in FTD.
- Inform family members about the different levels of facility care (e.g., group home, assisted living and skilled nursing) and about the ways that regulations affect how care is delivered.
- Prioritize training staff to develop understanding about the symptoms associated with behavior- and language-variant FTD, and ensure the availability of an experienced consulting psychiatrist, geriatrician or primary care provider.
- Counsel family members in FTD disease information and principles of behavioral care; connect them to AFTD through the organization's [HelpLine](#) or [website](#).
- Counsel family to be honest about the person's behavior, and to ask about and assess the facility's particular experience providing care for persons with FTD.
- Educate clinical and direct-care staff regarding the importance of adjusting their approach, as well as adjusting the care program to meet the individual needs.
- If aggression has been a concern, consider the prescription of low-dose atypical antipsychotic medication for the first few weeks after admission. Planned temporary use may avoid the need for higher doses in response to behaviors triggered by relocation.

Careful planning and coordination are especially important prior to move-in, to ease the transition to long-term residential care.

Environment

- Ensure that the facility has adequate, safe inside and outside areas for residents to walk.
- Identify a room in a quieter area of the facility, and furnish it with a few familiar personal items from home, e.g., bedspread, pillow, labeled photographs or a computer (with Internet access blocking as needed).
- Consider avoiding television access in the room for the first 2 to 4 weeks to reduce the potential for misinterpreting stimuli, especially onscreen violence and anger that may exacerbate feelings of threat.
- Establish and post in the room a schedule reflecting the resident's existing daily routine as much as possible. Include: personal care, meals and activities. (*continued on next page*)

Relocation Stress Syndrome (continued...)

Environment, *continued*

- Use information from the resident's family and his/her personal history to inform the selection of caregiving staff, e.g., a need for male vs. female staff in personal care.
- Ensure the opportunity for one to two preferred activities that can be adapted to the new setting, e.g., continuous walking.
- Offer the resident a chair at the back of the programming room and near an exit, which will enable them to enter and exit the room easily.
- Provide increased unobtrusive monitoring by staff during the transition, to facilitate supervision to monitor for risk of elopement.
- Address the concerns of other residents and families early, directly and within compliance of HIPAA confidentiality requirements. FTD behaviors (e.g., vocalizations, rummaging and roaming) can be intrusive to other residents and their family members. Arrange a meeting with the concerned family, staff and the person living with FTD's POA, who can describe the behaviors.

Visiting

- Treat each resident and family member as an individual. Some family members may be able to visit without issues, whereas others may need respite from caregiving at the time of admission.
- Develop a specific plan for visitation during the transition period. Frequent, brief visits with a clearly defined end may be best, e.g., immediately before a meal, limited to 15 minutes.
- Suggest a period without visits if a caregiver is extremely distressed, however, make sure that the caregiver has someone they can call daily for an update on their loved one's condition and adjustment to long-term residential care at the facility.
- Give the caregiver opportunities to make suggestions and additions, such as bringing in a favorite food or providing information on the resident's specific interests or needs, in order to help the caregiver feel included within the care team.
- Debrief caregivers after their first few weeks' visits about what they observed and any fears or concerns. Ask about how the rest of the family is adapting.
- Involve family members in the on-going assessment process to continue to develop their connections with staff, to evaluate the resident's transition, and to adjust the visiting and care plan as needed.
- Help family members to plan engaging visits that will facilitate the transition for the resident and family members; specifically address how to incorporate young children and teens who may choose to visit a parent.
- Encourage family members to participate in a family support group and to find "caregiver buddies" among other resident families.
- Encourage family questions.
- Foster continued recognition among staff of the fact that caregivers report this is the worst time of their lives.
- Always remember that the caregiver is as much of a consumer of services as the resident. Respond with empathy and foster open communication whenever possible.