

Emotionally Absent: The Loss of Empathy and Connection in FTD

Empathy – emotional warmth and understanding the feelings and needs of others – forms the bonds that create the caring partnerships of marriages, family relations and effective professional caregiving. A relationship fractures when one partner no longer reacts in expected ways. The loss of empathy and loss of relationship in FTD contribute to complex care issues.

The Case of Mimi Jones

Mimi Jones, now 57 years old, was diagnosed with behavioral variant FTD at age 48. Prior to her illness, Mrs. Jones was a homemaker who gave piano lessons in her home to school-aged children. She greatly enjoyed working with these students and was well-liked by them. She and her husband of 30 years have one 25 year-old daughter, Sophia. The story of Mrs. Jones shows the impact of her loss of empathy throughout progression of the disease.

Introduction

Nine years ago Mrs. Jones' relationship with her family began to change. She became less interested in the activities of her husband and daughter, then 16 years old. She stopped having dinner as a family, a routine important to all of them, because she preferred to eat in front of the television. When Sophia asked for her help in buying a gown for her first prom, Mrs. Jones refused, stating she'd rather stay home and watch television. Mr. Jones realized she was no longer giving piano lessons. When asked, Mrs. Jones stated she'd had enough of teaching.

Around this time, Mr. Jones was diagnosed with thyroid cancer necessitating surgery and a three-day hospital stay. Mrs. Jones neither visited nor called while he was hospitalized and didn't ask how he felt when he returned home. When Sophia learned of her father's diagnosis, she began to sob; Mrs. Jones scolded her for "being a baby." Unable to understand the significant change in his wife's feelings for him and Sophia, Mr. Jones begged her to attend family counseling, but she refused, stating she no longer wanted to be burdened with a family. She moved into a furnished apartment in the same city two weeks later, taking one of the two family dogs with her.

Mr. Jones and Sophia began individual counseling to deal with their feelings of confusion, hurt and anger. Their counselors encouraged them to visit Mrs. Jones in her apartment to maintain their relationship. When they arrived, they found dirty dishes around the house and stacks of unopened mail, unpaid bills and magazines piled on couches, tables and floors. But most upsetting was finding the dog lying panting and listless next to an empty water dish. Mrs. Jones said she grew tired of taking the dog outside to urinate, so decided to limit his water intake.

"I know I'm supposed to feel something, but..."

Realizing something was seriously wrong, Mr. Jones persuaded his wife to return home with them. Their family doctor performed a Mini-Mental Status Examination, did a history

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and physical, and ordered laboratory studies. All results were normal. Upon a return visit with the physician to go over the results, Mrs. Jones sat quietly while her husband and daughter sobbed about the changes in her behavior and their life together. When asked what she thought about her family's obvious dismay, Mrs. Jones stated, "I know I'm supposed to feel something when they cry, but I just don't." Concerned about a possible depression, the physician prescribed an antidepressant medication and family counseling. Mrs. Jones agreed to move back home because she liked the television set better.

The family noted no improvement in Mrs. Jones' mood after six months of antidepressant treatment and weekly family counseling sessions. In addition, they noted new symptoms. She ate five candy bars obtained from the neighborhood grocery store every day and insisted on eating three bananas a day; her weight increased by 8 pounds. When taking a walk with her husband one day, Mrs. Jones approached young children in the park, asking them to play with her. Mr. Jones explained to horrified parents his wife was ill and requested an urgent visit with her physician. A brain magnetic resonance imaging (MRI) scan revealed atrophy of both frontal lobes. Mrs. Jones was referred to a neurologist with a diagnosis of FTD.

"Why doesn't she love us anymore?"

Mr. Jones and Sophia contacted AFTD for educational material and referral to a local support group. They addressed the behavioral issues by hiring in-home help to accompany Mrs. Jones on her walks and keep her away from young children. Mrs. Jones continued eating five candy bars daily, but the family substituted bite-sized ones and kept the bag hidden. Bananas left on the counter were divided into three sections so Mrs. Jones ate just one banana daily. Mrs. Jones increas-

ingly spent more time watching television, insisting her meals be given at precise times so she wouldn't miss her programs.

While these strategies decreased problematic behaviors, Mr. Jones and Sophia continued to feel angry and hurt by Mrs. Jones' lack of emotional concern for them. They were particularly confused by what she was still able to do: she kept track of the times and channels of her many television programs, she maintained an excellent sense of direction (although she was no longer driving), and she knew the date of Sophia's prom but expressed no interest in her dress. Mrs. Jones was not troubled by their anger and did not believe anything was wrong with her.

Mr. Jones stated, "My head knows this is part of the disease, but my heart...my heart. Why doesn't she love us anymore?" Sophia, now 17 years old, became extremely angry with her mother and spent more time away from home. She was embarrassed and no longer invited friends over. She refused to continue counseling because no one could cure the disease, and she frequently felt her mother was acting this way on purpose. She was arrested for using marijuana in public. When the judge learned of her mother's illness, Sophia was given a suspended sentence with community service and a requirement to return to counseling. Due to Sophia's continued anger and depression when confronted daily with her mother, Mr. Jones placed Mrs. Jones in a Residential Care Facility near their home.

"Me first" behaviors become common

To her husband's surprise, Mrs. Jones willingly accepted this placement once a new television set was installed in her private room. She attended the morning discussion group, but usually returned to her room after a few minutes. When prompted, she related the details of the programs she watched, played

Troubles & Tips

Q: A 49-year-old male resident with FTD moved into our Memory Care Community three weeks ago. Residents complain that he is grabbing food off their plates and visitors say his blank stare has them concerned for the safety of their family members. Staff is frustrated because he does not respond to them in the same way as their other residents. How can we address their concerns and help him be successful in the community?

A team approach involving the other residents, visitors, his family, and staff is essential. The following steps will promote success:

- The first step is to help all involved understand that his flat facial expression and blank stare are due to the disease. The resident is not conveying indifference or anger.
- Have his family share his past interests, personality prior to FTD,

pictures of family and pets, and props highlighting his successes such as, trophies. These will help others understand him on an individual, personal level.

- Implement positive interventions such as: serving meals to him first; inviting him to low stimulus programs of interest; and introducing him with a positive description, i.e., "This is John, he taught history for 20 years and was named teacher of the year."
- Provide training and support for staff so they don't expect validation from him. Explain that unlike Alzheimer's disease, FTD affects the frontal lobe of the brain, the area that enables us to connect emotionally with others. Help staff act from their own empathy to provide for his comfort and care and take pride in extending the type of interpersonal connection that the disease has taken.



bingo without difficulty, and gave correct, but short, responses to questions about the significance of the 4th of July holiday. Mrs. Jones enjoyed playing the piano in the recreation room and other residents appreciated her music. She was able to read sheet music and play requested songs. However some problems arose during the first two weeks.

If another person was already playing the piano when Mrs. Jones entered the room, she stood directly behind, saying, “Get up. Get up.” One day she pushed a man off the bench onto the floor and began playing. When the supervisor asked if she would like someone to push her like that, Mrs. Jones replied, “No, I might get hurt.” Asked to apologize to the man she pushed, she stared and said, “But I’m not sorry. I wanted to play the piano.” To solve this problem, Mrs. Jones watched television in her room until other residents had their turns and then aides accompanied her to the recreation room for her turn. Mrs. Jones also pushed other residents aside when waiting for dinner, including a frail woman using a walker. When asked about the behavior, Mrs. Jones stated the woman moved too slowly and she didn’t care if she got hurt. Mrs. Jones’ primary aide suggested bringing her to the dining room first, before other residents. This solved the “me first” behavior.

Other residents complained Mrs. Jones was impolite and mean because she didn’t smile or say good morning. The staff validated their feelings and encouraged them to share their observations with Mrs. Jones at the morning meeting, but Mrs. Jones did not reply and walked away. Staff then suggested they give Mrs. Jones more time to adjust to her surroundings. While staff felt able to manage the above behaviors, they found Mrs. Jones hard to be around because they couldn’t “connect” with her and establish a relationship. While she appeared more cognitively intact than many of the other residents (ability to play games, describe television programs, read piano music), she did not interact appropriately.

Family and facility care team support each other

The staff discussed their concerns with Mr. Jones after the second week of placement and he requested a team meeting. He explained that he understood their inability to connect emotionally with his wife, as this loss of empathy was a primary symptom of FTD and the most upsetting one he and his daughter experienced. He brought videos and pictures

of their family to give them a sense of Mrs. Jones before her illness. Mr. Jones shared topics staff might discuss with his wife: names and antics of their dogs, the university she attended, favorite television programs, and Sophia. Mr. Jones left a Partners in Care packet from AFTD for staff to review.

The strategies helped the staff talk to Mrs. Jones without expecting a response from her. They agreed to assume Mrs. Jones enjoyed offered activities even though she was unable to express her feelings. Residents learned to model these interactions, and most residents eventually accepted Mrs. Jones’ silent presence.

Mr. Jones remained involved in his wife’s care and felt supported by the staff when they shared their positive interactions with him. He visited 3-5 times a week. After three months, Sophia brought the dogs for a visit. While Mrs. Jones showed little reaction, the dogs were very excited to see her. And then Mrs. Jones told Sophia about her first dog which she received one Christmas when she was five years old. Encouraged by this interaction, Sophia began visiting once a week and Mrs. Jones had Thanksgiving dinner at home with them. Sophia also visited the AFTD’s Kids and Teens website and benefited from the experiences teens shared of having a parent with FTD.

Sophia and Mr. Jones learned to not expect a response from Mrs. Jones, and learned a different way of relating to her. They remained sad and mourned their previous life and altered future. Still the anger, though infrequent, flared up without warning, especially in situations of particular significance such as acknowledging Sophia’s graduation from high school and acceptance into college.

Mrs. Jones’ condition slowly worsened over the years and when her physical needs increased she was transferred to a skilled nursing facility. She suffered several bouts of urinary tract infections; the last one caused generalized sepsis. Mr. Jones initiated hospice services and she expired with her husband and daughter at her side.

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Questions for discussion

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

1) What effect did Mrs. Jones’ loss of empathy have on her family?

The first symptom noted by Mrs. Jones’ family was blunting of her emotions involving loss of empathy. She no longer



showed emotional warmth and was indifferent toward other people, including her loved ones. Mrs. Jones was unable to “put herself in another’s shoes” or even experience feelings she recognized she should have. This discrepancy between cognitive (what I should feel) and emotional (what I do feel) understanding creates confusion for family members who may believe individuals are doing things “on purpose,” particularly when other abilities remain relatively normal.

While Mrs. Jones exhibited other behaviors associated with FTD, (including disinhibited behavior, apathy, dietary changes, and loss of the ability to plan and organize her life) the loss of empathy was most distressing for her husband and daughter.

2) How did Mrs. Jones’ lack of empathy affect staff and residents at the facility?

The lack of empathy and changing social behavior of FTD made it much harder for people to establish a relationship with Mrs. Jones. Individuals with Alzheimer’s disease will smile and make eye contact; in FTD facial expression is often blank. Staff was trained to rethink their expectation of emotional feedback and not look for a response. They tried to make a connection even if it was not returned and modeled these interactions for other residents. When Mrs. Jones pushed another person playing the piano before her, staff adjusted so she watched television in her room until it was her turn. When she pushed people waiting for dinner, staff arranged for her to enter the dining room earlier to avoid these situations.

3) How can staff and family connect with the person affected and ensure quality care?

The loss of empathy and its impact on relationships provides an opportunity for staff and family to collaborate. Encourage families to share the “real” person, what they liked to do together. Accept and validate families’ feelings of loss, anger, or sadness. Reframe the relationship with the person diagnosed; offer empathy without expecting a reciprocal response. Use the person’s history to connect even if the connection is not returned. Share with family the ways staff members interact with the individual and any unexpected moments of connection. Since staff does not share a history with the resident, they may suggest ways to remain “in the moment” and new ways for families to relate to the person when they visit. Encourage the celebration of significant events with ceremonies in the facility: college graduate could wear cap and gown to facility; bride and groom can visit wearing their wedding clothes and share cake with all residents.

Emotionally absent: A wife’s experience

By Sandi Grow

We often use the term “they have no heart” to insinuate a person lacks compassion. The truth is the ability to empathize, to understand and share the feelings of another, is a function of the frontal lobe of the brain. When the frontal lobe of the brain is affected by disease there is a change in emotions.

Behavioral variant FTD (bvFTD) affects the frontal lobe and is characterized by early and progressive changes in personality, emotional blunting and/or loss of empathy. The person typically does not recognize the changes in his or her behaviors, and lacks capacity to express concern for the effects these behaviors have on others.

It is hard to understand how my husband diagnosed with FTD – once caring and fun – is no longer able to share life’s excitements and disappointments. He can no longer comfort me when I face a health challenge, experience the loss of a friend or relative, or even when I’m just having a “bad day”. He is not able to truly celebrate life’s accomplishments – graduations, births, weddings, or winning an award. His “smile” is replaced with a blank look or stare.

A huge part of the grief I feel comes from him being physically present but emotionally absent. My husband of 42 years was diagnosed with FTD at the age of 54. At first the changes were subtle and puzzling. I lost him a little at a time as his behaviors became more bizarre and challenging.

I know we would have been proud and to share the joy of our son graduating with his master’s degree, but my husband was not able to understand. I miss the person that discussed current events and shared opinions, helped to make life’s decisions, shared vacations, parties, movies and a loving hug at the end of the day.

I must remember this is not the person he was. I keep snapshots of him with the family before the disease in his care facility room. I am thrilled when a caregiver takes time to thumb through the pages and get to know the person Karl was. It helps when staff shares their compassion and understanding with the family by recognizing that he cannot control his responses. He needs redirection and creative approaches.

Knowledge of the disease helps us understand “why” my husband does not respond as expected or hoped, but it does not take away our feeling of sadness or grief as we lose him to this progressive disease. When others share their empathy while caring for him, it helps.



The Loss of Empathy and Connection in FTD

Loss of emotional warmth and indifference toward other people, including loved ones, is common when disease affects the brain's frontal lobes in FTD. Uncharacteristically insensitive comments to others, self-centeredness in actions, and flat, emotionless facial expression are common. Other behavioral symptoms, while challenging, can be addressed with specific strategies. Approaches to empathy loss must focus on the family and persons involved in care.

Educate all caregivers about loss of social behaviors

- Recognize that loss of empathy and the inability to connect emotionally are primary symptoms of FTD.
- Acknowledge the hurt, sadness and anger that occur in a relationship when one partner no longer reacts in expected ways. Loss of empathy is often the most distressing symptom for spouse/ partner and family.
- Encourage the frequent use of counseling and support to process emotions, such as AFTD educational materials and FTD support groups.
- Teach others involved in care about FTD. Individuals with Alzheimer's disease will smile and make eye contact; people with FTD do not. It is much harder to establish a relationship without social behaviors.
- Help new staff, residents and visitors learn that flat facial expression and a blank stare are effects of the disease and do not convey indifference or anger.

Help caregivers discover new ways to relate to person

- Develop a new way of relating to the person without expecting a response in return. Act from your own empathy, empowered by feeling good about what you can do.
- Share pictures, videos, and room props like awards and sports memorabilia of the person and his/her family to help everyone understand and to keep positive memories alive.
- Identify topics that care providers might discuss with the person: names and antics of pets, the university she attended, favorite television programs, and family memories.
- Go through the actions of meaningful interaction i.e.: speak in an engaging way, invite the person's input, do previously enjoyed activities, celebrate birthdays, and special occasions.
- Encourage family to remain involved in care and speak frequently with staff to share and appreciate the positive interactions each has with the person. Assume the person enjoys the activities based on their interests and preferences.
- Reassure family and professional caregivers that they are doing something good for the person and for themselves; maintaining the person's individual identity enhances the quality of care.

Help caregivers redefine expectations, connections and relationships

- Recognize how lack of empathy affects interactions with other residents; pushing to get to dining room, cheating at bingo, etc. Use positive, not punishing, behavior approaches.
- Share ways staff members interact with individual. Since staff does not share a history with the resident, they may suggest new ways for families to relate to the person when they visit.
- Recognize unexpected moments of insight or connection with the person and share them with family and staff.
- Help the family recognize when their loss of emotional connection interferes with care decisions.
- Redefine the relationship continuously as the disease progresses. Keep your side of the connection open regardless of what the other person is doing.