

FTD When There Are Kids in the Home: Creating a Village of Support

The stress put on families when a parent is diagnosed with FTD and have children at home is significant. Residential and facility care staff have an opportunity to help the entire family cope by supporting the primary caregiver. Providing information and resources for education, while offering comfort throughout all phases, is essential to ensure the health of the family and to the adjustment and well-being of individual members.

THE CASE OF DAVID S. HISTORY AND DIAGNOSIS

David S., 47, had an established career as a distinguished chemist and college professor. He had earned his doctorate degree from Yale, and was well-respected as a researcher and teacher. His work had been published in many research journals, and he lectured internationally on his research findings. Married to his college sweetheart, Kristin, the couple had two daughters: Laura, 15 and Carrie, 8. He was a devout Catholic, enjoyed movies and remained close to his college friends.

David's father was diagnosed with behavioral variant FTD (bvFTD) and died at age 65. David's mother was his father's primary caregiver, and he and Kristin assisted with his care when possible. David was saddened as his father, also a distinguished researcher, had retired early just as David was starting his own career. His father had displayed compulsive behaviors, such as food binging, and had spent most of the family's savings on ill-advised investments. His father lost his ability to speak, and eventually required nursing home care.

Because David's father's family had a history of dementia, at 43, he chose to be tested for the genes known to cause familial FTD. The results were positive for the C9ORF72 gene. David and Kristin extensively discussed the probability of him developing FTD. He was emphatic that he needed to move to a care facility if his symptoms negatively impacted his wife and daughters as he wished for them to have happy memories of their home and of him.

David gradually began to develop symptoms over the next few years. He missed several lectures and made research errors, things that had never occurred previously. His family and friends noticed changes in his personality. At home, Carrie became annoyed when he began to change the channel regularly away from shows she was watching, and Laura was embarrassed when he made degrading remarks to friends and strangers. He was aloof at times. He binged on foods like pizza, and lost interest in activities they enjoyed as a family. He showed less interest in the girls' activities or their emotions. Carrie was troubled by this and asked Kristin tearfully why Daddy didn't love them anymore.

David retired two years after being diagnosed with bvFTD, at age 47. Kristin returned to work as a teacher, which left him alone during the day. Neighbors would periodically check in with him, and some of his college friends visited monthly for pizza get-togethers. Kristin researched additional FTD resources and participated in an AFTD telephone support group for people caring for a diagnosed partner who have children at home. She also read materials, such as "[What About the Kids](#)," published by AFTD. Laura and Carrie utilized the AFTD Kids and Teens website (www.aftdkidsandteens.org), which gave them a chance to see stories and videos from other children whose parents had FTD. Kristin and her daughters attended individual and family counseling sessions. She and David had agreed to talk with their daughters honestly about his illness in ways each could understand. Kristin answered the questions they asked about his changing behaviors and provided the information they needed without elaborating. She also allowed them to decide what to say to their friends, and when. *(continued)*

FAMILIES WITH YOUNG CHILDREN AND TEENS

FTD frequently occurs in middle age, meaning that there are often children at home. Families with young children and teens are confronted with three fundamental challenges when one parent is diagnosed with FTD:

- learning about FTD and how to plan and provide care for the affected spouse or partner;
- deciding how to address the diagnosis and disease with the children; and
- helping children cope while the parent is both in the midst of their own grief, and facing often overwhelming stress.

Siblings within a family will be at different places developmentally and emotionally. Each will understand the disease and process grief differently as they grow.

..... Some families must also consider the genetic aspects of the disease and that children may be concerned about their own risk of heritability. Adequate emotional and practical support for the primary caregiver, and access to appropriate medical and community supports for the patient, is critical.

"Some families must also consider the genetic aspects of the disease and that children may be concerned about their own risk of heritability."
..... of the children above those of the person diagnosed, which may mean turning to an adult day program or a long-term care facility earlier than in other families without children. Knowledgeable and compassionate residential and facility care staff working with the primary caregiver can help children feel safe, and can promote understanding and healthy ways for them to deal with their emotions. Children and teens can become resilient and confident adults despite—and often as a result of—adversity.



In Their Own Words

(excerpts from www.aftdkidsandteens.org)

My mom pulled all four of us aside: my brothers, sister and me. She sighed and said gently, “We are going to have to put Dad into a nursing home.” A hush went over us as we sat there silently; each of us looking at one another, waiting for one of us to say something, anything.

“His illness is declining. It’ll be best for him. There will always be someone watching him so we won’t have to worry all the time.” My mom continued with her voice growing weaker and raspier trying to hold back the tears from each word. We quietly got up and departed our own ways with nothing left to hear but the sliding sound of our feet against the hardwood floor.

Every once in a while, I would go visit with my mom or my older brother. I tried not to go with my mom to avoid getting stampeded with questions about how the visits made me feel. With each visit, you would notice something different with him and heard less from him. With each visit, he got easier to find; he’d be in bed with his hands under his pillows or latched together in a tight grip. Occasionally he’d have an accident, which became more frequent by the year. It seemed as if at each visit there was less of him; he was getting more cadaverous with each one.

I learned to cherish every second you have with someone because you never know what can happen. It has made me more responsible for my things and makes me thankful for what I have. Throughout everything, I think the biggest impact was it made me stronger emotionally. I’ve been through a lot, so I know I can take a lot. I couldn’t be what I am today without my dad. He was still a big part of my life even though it wasn’t the way of most fathers. He still helped me develop into who I am and I thank him for that.

– Spencer, age 14

It’s a stupid holiday anyway, Thanksgiving. This is what I think at the moment, probably because I’m not feeling very “thankful” as I walk with Mom to the front door of Parker. Parker is a nursing home, a nursing home full of elderly people who sit in wheelchairs all day. I open the door, and Mom signs us in at the front desk. We walk through the hall and turn past the TV area. That’s when we see Dad walking toward us already wearing his coat. Parker is a nursing home full of elderly people in wheelchairs plus Dad. He’s 58 years old, so I don’t think it would be fair to call him elderly, nor does he need a wheelchair...

It wasn’t a happy Thanksgiving at all, not for me at least. I wasn’t hoping for a happy day. I don’t hope for Dad to get better either. I would never let myself hang on to such a ridiculous idea. All I know is that things are not supposed to happen like this. I shouldn’t be losing my Dad any time soon. He shouldn’t be leaving us before he’s really gone. It’s not fair. There is nothing I can do about that though. All I can do is visit him again and hug him again and spend time with him and walk away when I’m done. Again and again and again. This is all I can do until... well... until I can’t.

– Melanie, age 14

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“Three events in the same month prompted Kristin and David to tour memory care communities for his on-going care.”

MEMORY CARE – MOVE-IN

David was initially able to remain home with oversight from friends and family. Kristin would leave a written routine of activities for him to do around the house. He rarely completed them all, but she felt he was safe. Laura, the older daughter, spent more time away from home, visiting friends at their homes, and joined multiple after-school programs. Her friends rarely visited their house. Carrie was the opposite. She came directly home from school, shadowed her father to make sure, as she explained, that he was “not getting into trouble,” and refused activities that she previously enjoyed. David’s mother spent several afternoons each week at their home and provided care to him and his daughter, Carrie. She also began to make regular dates with each of the girls to do something special away from the house as David’s care and managing the household required more of Kristin’s attention.

Three events in the same month prompted Kristin and David to tour memory care communities for his on-going care. First, Kristin went to the grocery store for 15 minutes, leaving him home with the girls. She had become very careful to discard outdated food in the refrigerator as David’s food binging had increased. In this case, there was outdated food that she had not yet discarded, and he wanted to eat it. When Laura and Carrie tried to stop him, he uncharacteristically threatened them verbally, cursing and saying he would lock them in the garage. By the time Kristin arrived home, David had eaten all the food and thrown empty containers all over the kitchen; the girls were huddled in the bathroom crying.

The second event occurred the following week. David had unexpectedly entered the basement room where Laura and her friends were watching movies, during one of the rare times they visited. He had taken off his pants (underpants were still on), and was tracking feces. Laura yelled for her mother, who quickly helped to usher him back upstairs. Laura was embarrassed and upset, and her friends wanted to leave. Several parents called Kristin to tell her their children were no longer permitted to visit.

Two days later, Carrie came home from school, went to her room, and refused to come out. Kristen followed up several times before Carrie finally shared that she had forgotten a homework assignment, and was afraid she was “getting what daddy has.” She also admitted to being teased and bullied by several classmates who said her dad was “a sicko.” Kristen followed up with the school counselor who was aware of David’s illness.

The family selected a memory care community that had experience providing care to individuals with FTD. The director asked how all of them were coping, and indicated wanting to partner with them in David’s care. Carrie was very quiet and stayed close to Kristin, while Laura held David’s hand. They agreed that a gradual transitional process would be best for all.

During the first two weeks, David visited the memory care community twice for 30 minutes. Over the next two weeks, visits were increased to one hour, and then to four hours, including lunch and physical therapy. (continued on page 3)



(continued) The girls did not accompany him on these visits; this gave them an opportunity to slowly adjust to his physical absence.

Prior to David's permanent move-in, he spent a respite weekend at the community. He was still verbal, and retained the ability to reluctantly agree that his family needed a break from his care. The girls had mixed feelings about the move and what it would be like to visit with their father there. Kristen and David let them decide when and how often they would visit. This gradual process also enabled the director to further educate the staff on FTD, specifically regarding the needs of David and his family.

MEMORY CARE – APPROACHES

David's wife, Kristin, his mother, the director and memory care staff had on-going meetings to discuss his care and his family's needs. The staff tailored their approaches to address David's behaviors and challenges. They monitored meal times closely, due to his taking other resident's food. Managing public incontinency was a personal care and a community issue, as furniture was ruined and cleanliness difficult to maintain. Staff had to reassure new community members and visitors who found David's younger age, "flat" facial expression and occasional profanity frightening. The director was tasked with educating State regulatory surveyors, who continually reviewed resident's assessments and service plans to ensure that memory care services were appropriate.

After David completed the transition to living in the memory care community, Kristin and the girls continued with counseling and support. They visited him regularly. Visits were necessarily shorter during the school year. David's mother took a more active role in visiting him, and transporting the girls to the memory care community. Neighbors also helped with after-school transportation, and

Laura often spent nights at her friend's homes. While Carrie wanted to visit daily, Laura sometimes needed encouragement to visit. Both girls shared that it was hard to see the changes in David. He had been an affectionate father who laughed and smiled easily. Now, his personality and facial expression were described by family, friends and staff as "flat." Kristin shared her guilt and stress with the busy schedule, and received reassurance from her mother-in-law and from staff.

Community visits consisted of family walks in the courtyard, followed by visits in David's room. They sat on the sofa and watched movies, the same as they had done at home. Carrie drew pictures with David, and they hung them in his room. David initially helped Laura with her chemistry homework. When this became too difficult for him, Laura stopped bringing her homework. It eventually became a challenge for David's friends and family to take him out for pizza. He enjoyed these outings, but began to take other people's pizza, overate and would experience public incontinency. They eventually brought a pizza slice to him.

The staff provided a private area for them to eat pizza, and set aside seats in the back of the activity room when they attended Mass. Both girls liked most of the residents, but became fearful when they were occasionally mistaken for a resident's own children or were hugged too tightly. Laura had to be persuaded to visit again after one resident, a retired teacher with Alzheimer's disease, yelled at her for being late for school. Staff observed the visits and intervened when necessary. The director always allotted time to discuss their visits – both challenges and positives. Carrie sang in the school choir, and the activity director enlisted the choir to perform. This was one of few instances over a long stretch during which David's family and staff observed him smiling. (continued on page 4)

RESOURCES for Parents, Children and Teens

- **AFTD's website, www.theaftd.org.** The site has information and resources for family caregivers to learn about the disease and find support. The *Children and Teens* page addresses the concerns of young families facing FTD.
- **What about the Kids?** This booklet (<http://www.theaftd.org/wp-content/uploads/2009/03/What-About-the-Kids-web-version.pdf>) is a sensitive, practical guide for parents to help their children deal with a parent who has FTD. Available on-line or in print from AFTD.
- **Telephone Support Group.** AFTD sponsors a telephone support group for parents who manage care for a spouse with FTD and have school-age children at home. Contact info@theaftd.org or call 866-507-7221.
- **AFTD Kids and Teens.** This website (www.aftdkidsandteens.org/) provides a place where kids and teens can ask questions, find answers and share experiences with peers who are on this journey. Separate sections are designed for children 4-12, and teens 13+. Children and teens are invited to submit their own poems, short stories, videos diaries and other creative works to the *Kids (Teens) Like Me* section of the website.
- **When Dementia Is in the House.** This website (http://lifeandminds.ca/whendementiaisinthehouse/ts_home.html) was created by Dr. Tiffany Chow and Katherine Nichols, a former caregiver. It offers content for parents and teens that was guided by focus groups with children who have been informal caregivers to a parent with FTD. Available in English, French and Chinese.
- **Frank and Tess – Detectives!** A friendly activity book about FTD, designed by Atomic Orange Productions from co-Authors Tiffany Chow and Gail Elliot. In this case, FTD stands for Frank and Tess, Detectives! They are siblings trying to help their mother who is affected with FTD. The activity book (<http://research.baycrest.org/files/Frank-and-Tess-Detectives-.pdf>) includes coloring and puzzle activities that can also involve the person living with FTD.
- **Talking About Genetics With Children:** <http://www.theaftd.org/understandingftd/genetics/talking-about-genetics-with-children>



(continued) **MEMORY CARE – AFTER CARE**

David had a history of respiratory issues. After a year living in the community, he developed pneumonia. He was admitted to the hospital and passed away from complications of the infection. David's family, friends and community staff shared their grief over his death. Staff members attended the funeral Mass. Many shared that David's death, and the impact of FTD on his family, was one of the most challenging losses they had experienced.

Laura initially expressed guilt over not visiting her father more often, and Carrie withdrew. They would sometimes become upset when they forget something; fearing their family history. On the

first anniversary of David's death, Laura and Carrie sponsored a fundraiser for FTD research. They also made a scrapbook filled with the many happy times they shared as a family.

Today, David's family continues to attend counseling and support groups. His mother visits the staff at the community and volunteers in activities. Kristin occasionally visits the staff as well, sharing memories and receiving support.

Kristin, David's mother, and the girls have preserved happy memories of him, due to his decision for early placement, through counseling sessions, support groups and AFTD resources, and through the care and compassion of the staff for David and his family.

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Questions for Discussion

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

1. What steps did David and Kristin take that assisted with the move-in decision?

Because of the family history of FTD and knowing he carried the genetic mutation, David and Kristin discussed the diagnosis and care options when he could still verbalize his wishes. His experience with his own father's illness prompted David to want their daughters to stay on track with school, friends and having a positive relationship with him as much as possible. He and Kristin had determined that when behaviors intruded too much on the family home life, placement was needed. They toured care communities and were fortunate that one in their area had experience with FTD. They were in agreement with the timing and location of placement. The couple also agreed upon the transitional placement process.

2. What were the challenges experienced by Kristin and the children?

While the children were aware of changes in their father, their individual relationships with him and the differences in their ages influenced what they understood. Kristin had to be careful about how she addressed their questions to be honest without overwhelming or scaring them. There were increasing incidents, such as verbal threats and food binging, which demonstrated that care at home was physically and emotionally no longer an option. Laura spent less time at home and her friends were not permitted to visit. Carrie withdrew, and feared that she was going to get "what daddy has." Kristin needed to return to work, which left David at home alone. The visits to the memory care community were shortened during the school year. This resulted in Kristin feeling stressed and guilty. The girls were frightened of several residents' behaviors. They had to adapt visits and activities as the disease progressed, such as not going out for pizza and him being unable to help Laura with her homework. The change in his personality from affectionate and humorous to "flat" was one of the most difficult changes.

3. What successful approaches did David and his family implement?

They attended counseling sessions and support groups. David's mother assisted with the care of David and the girls. Neighbors also assisted with transportation. Resources, such as the [AFTD website](#) and other AFTD reading materials, provided information and support. On-going meetings and conversations with the director and staff were helpful. After David passed, Kristin and his mother continued to visit the memory care community. The girls held a fundraiser and made a scrapbook.

4. What successful approaches did the staff implement?

During the gradual transition process, the staff became familiar with David's needs. They were further educated on FTD. During David's stay, the staff regularly met with his family to discuss his needs and revise his plan of care. The activity director developed programs that focused on David's interests and could include his children. The community provided a private place for him to eat with his family, and a chair at the back of the activity room for them to attend Mass. They were attentive to David and his family and the interactions with other residents. At the end of each visit, they discussed challenges, needs and positives. Kristin and the staff created a partnership of caring for him based on open communication, genuine concern and clarification on FTD. After David passed away, the staff attended his funeral, and continued on-going contact with his family.

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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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Creating a Village of Support

Question: The staff of our specialized memory care assisted living community expressed concern about how to best support a new resident with FTD who has school-aged children. What is the staff role with the family, given the complex dynamics and different needs of each person?

People facing FTD have a heavier burden of care than in other dementias, due to the younger age of onset, the presence of behavioral symptoms and a lack of awareness and understanding of the disease. When there are young children or teens in the home, the level of support needed is particularly high. “It takes a village,” as they say. Residential and facility staff can play an important role to the family that seeks care for a parent diagnosed with FTD.

In a survey of young adults who as children or teens lived with a diagnosed parent, they described the following as most difficult to manage: 1) behavior symptoms, 2) loss of established relationship, 3) thinking and communication symptoms, and 4) caregiving responsibilities ([AFTD Task Force on Families Final Report 2011](#)). Special care is needed for children to succeed in school and navigate social adjustment with peers as they try to understand the disease at age-appropriate levels and cope with stress at home.

The facility director can establish a collaborative approach to care with the spouse and those family members or close friends the primary caregiver may identify. A gradual admission process that allows staff to get to know the resident and the family contributes to setting expectations and building trust. A gradual admission process also allows additional time for staff training in FTD. Staff that understand the symptoms and impact of FTD and how the family is coping can facilitate a positive experience in the residential community. Knowledge is needed of additional counseling options, social services available through schools, and other resources, so that these can be suggested where appropriate for a younger family.

Children are smart. They have an intuitive sense when things are wrong. Assist the parent in fostering open dialogue at an age appropriate level. It helps to let children guide or make decisions around how they want to visit in the facility, when and for how long. Similarly, children should decide if they will and how they will speak to friends about their parent’s illness. Children need to know it is safe to ask questions and voice their feelings, concerns and needs. The parent, family and memory care staff should be honest with children, even if they do not provide detailed responses. Coordination should be clear to ensure that information provided to the children is consistent and guided by the family.

Staff and the well-parent can think creatively about visiting at the facility. Visualize the experience through the eyes of a teen or younger child. Each perspective will be different depending on the child’s age. Arrange a private space for children to visit with their parent and encourage engaging in simple, familiar activities whenever possible. The activity director may be able to incorporate school groups, or groups of children in activities or performances at the memory care facility. The care team may benefit from knowing how often the parent plans to bring the children, and from making sure that there is a mechanism in place to determine how the visits are going and evaluate the response of the resident.

The emotional availability of the well-parent can be limited if he or she is working, caring for the spouse/partner with FTD and managing all household tasks. If one has not already been identified, the director may encourage the parent(s) to consider selecting another trusted adult to whom each child can turn as surrogate parent for additional time and individual attention. Over time, the children may come to know memory care staff as additional trusted adults with whom they can speak about their ill parent, and from whom they can receive support.

Staff knowledge about FTD and relevant resources is especially important should children ask about the diagnosis and wonder if it runs in their family. While it is natural that children worry about their own potential risk, the parent may not be prepared for these questions. The care team can support the parent and point her or him to guidance from AFTD on how to respond in an accurate and age appropriate way (see **Resources** on page 3).

Special care is needed for children to succeed in school and navigate social adjustment with peers as they try to understand the disease at age-appropriate levels...



FTD When There Are Kids in the Home

People facing FTD disorders have a heavier burden of care than with other types of dementia. When there are young children or teens in the home, the level of support needed is particularly high. A village of support should be constructed to ensure the health of the family and the adjustment and well-being of individual members.

Access Accurate Information

- Arm yourself with accurate information about FTD to share with the primary caregiver and children as appropriate. Education specific to FTD symptoms and progression is important.
- Help children understand that unusual behaviors and trouble communicating effectively are common symptoms of FTD. Educate them to see that there are many different ways they can still show their love for the person.
- Familiarize yourself with how children handle loss and grief at different developmental stages so that you fully understand their needs and can guide interventions more effectively. Engage children through activities rather than big discussions.
- Expect questions about the risk of inheriting FTD. Help the well-parent to better understand the issues and family history so he or she can answer simply and honestly.

<http://www.theaftd.org/understandingftd/genetics/talking-about-genetics-with-children>

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Facilitate Use of Support

- Hold regular meetings with staff and family to coordinate care and keep everyone informed.
- Listen. Tune in to what the caregiver and children think and feel about the situation. Patience and time spent listening often facilitate a child's sharing of thoughts and feelings.
- Help the caregiver to tell family and friends about the diagnosis and seek needed assistance. Being open with family, friends, neighbors and schools about the disease eases the stress.
- Assist the well-parent to structure time for themselves, maintain important relationships and express feelings in positive ways. Modeling good self-care is important for the children.
- Make sure each child has a "special," trusted person they can talk to in addition to the well-parent. This may be a family member, clergy person, bereavement counselor, school personnel member or anyone with whom the family and child have a trusting relationship.
- Encourage children to stay involved with school and social activities. Suggest that the family ask for help with transportation and other logistics, or consider an online calendar for scheduling.
- Identify and access a full range of formal and informal support resources that the resident and family may need.



FTD When There Are Kids in the Home *continued*

Respond to the Children's Needs

- Facilitate open, age-appropriate dialogue to enable children to understand the symptoms and progression of FTD. Give explanations gently and over time if needed. Encourage questions as they arise.
- Be honest. Provide clear, concrete and truthful answers to questions at the child's level of understanding.
- Make sure young children understand that the illness is a medical condition that they did not bring on with their thoughts or actions, and that they cannot "catch" it like a cold.
- Set the stage for discussions. Many children are more open to talking in the midst of comfortable activities than in direct sit-down sessions.
- Try to maintain as normal a routine for children as possible. They need structure to feel secure during stressful times.
- Prior to a visit, describe what the child can expect to experience at a hospital, hospice or nursing home – including how the person who is ill will look and act.
- Watch the child's reaction during discussion or while visiting at the facility. Experts tell us that more than 90% of communication is non-verbal.
- Provide healthy outlets for energy release and expression with creative and physical activities. Feelings of abandonment, helplessness, despair, anxiety, apathy, anger, guilt and fear are common in a family with serious illness. Headaches, stomachaches and behavioral problems may be caused by anxiety and repressed feelings.
- Help children decide what to tell their friends and when about the parent's illness. Let them decide if and how often they want to visit in the residential care facility. This can provide children with some control over their situation.
- Encourage kids to pick favorite photos or memories and help with a memory book that they can go through at the facility or at home, to remember the fun things. There are websites that can help to easily create digital books.
- If a family activity is "not the same as it used to be," suggest new activities or a change in location. For example, if the preferred activity had been going to a sports event or the movies, get the event or movie on TV or video at home in a controlled situation and call it "movie night." Avoid buffet-style dining if eating is a problem.
- Respect each child's "limits" for visiting and helping with the parent's care. Some enjoy helping with activities – such as meals or exercise – and others are not as comfortable.
- Coordinate with family and residential staff to be aware of interactions between children and other residents. Take steps to reduce unwanted contact, and coach children in how to respond when and if they are confronted.
- Acknowledge and appreciate the good things children are doing in their lives. They can feel overlooked when a parent requires significant time and attention. Focus on their strengths and accomplishments to build healthy coping.

Provide clear, concrete and truthful answers to questions at the child's level of understanding.

