



What About the Kids?

**FRONTOTEMPORAL
DEGENERATION:**

*Information
for Parents
with Young
Children
and Teens*



The Association for
Frontotemporal Degeneration
Opening the gateway to help and a cure

Photo on cover: Weston Brown and his mother, Michelle Brown.



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Introduction

You are probably reading this book after learning the devastating news that your spouse has frontotemporal degeneration (FTD). You are terribly worried about your partner and how you will lose the love of your life to this devastating, progressive disease. But naturally, you are very concerned about your kids. How will they handle their parent's illness?

Unlike many other dementias, FTD frequently occurs in middle age, meaning there are often children at home. When any parent faces a serious illness, their young children and teens need support and flexibility as well as lots of love and understanding. Few situations can be as stressful on a family as losing a parent to a degenerative brain disease. FTD is a rare disease with challenging symptoms that can cause considerable impact on the family. As FTD progresses, it creates ever-changing obstacles and unique challenges for families to manage. Meanwhile, children grow and change. Their development heads in the opposite direction as their ill parent's. What your kids can understand about the disease and what it will mean for their lives will evolve over the years.

Children are very perceptive. They will be aware that a family member has changed or is ill. Maintaining an open dialogue with your children will help them cope and create a sense of well-being. Most importantly, taking care of yourself by practicing positive behaviors that decrease your anxiety will set a good example for the kids.

Lynn, a mom:

Take a deep breath.
Find out as much as you can.
Take care of yourself.
Don't forget your own
interests and passions.

As difficult as it may be for you to admit, at some point you will need to prioritize your child's wants and needs above your spouse's. Sometimes, that means turning to an adult day program or a long-term care facility earlier than in other families without children. Do

not measure your choices against others'. Trust yourself to make the right choices for your family.

This booklet's goal is to assist families like yours to navigate successfully FTD's diagnosis, challenges and changes. Furthermore, this booklet aims to reassure you, the well parent. Children and teens can become resilient and confident adults despite—and often as a result of—adversity. Your strength will help your children feel safe and will show them how people who love each other help one another in tough times. No one welcomes the changes that FTD brings. Yet, hidden within the loss is the potential for unexpected positive growth.



Frontotemporal Degeneration and Diagnostic Challenges

As a parent, it is essential to have a basic understanding of frontotemporal degeneration to talk with your children openly and honestly. Your kids' friends will be asking questions, so your children should be knowledgeable and reasonably comfortable talking about the disease. However, understanding FTD can be challenging for anyone. It is a complicated illness, and all of the research—while exciting and hopeful—can be confusing. Misinformation abounds and can cause anxiety.

This booklet aims to assist you to understand how to help your children cope with FTD. However, it is advisable that you also continue to educate yourself about the disease and care management via the helpful websites, books and articles listed in this booklet's appendix.

Already, you understand that FTD is neurodegenerative—meaning it is a progressive brain disease with unusual symptoms. Unlike other illnesses, many of the initial symptoms are changes in behavior, emotions and personality.

Often these symptoms can be very confusing and embarrassing for the adults and kids who love the person with FTD. The situation is often complicated by misdiagnoses that delay a proper explanation.

How the disease presents in the beginning stages varies. Some people have significant behavioral changes, such as disinhibition, apathy and/or verbal and physical aggression. For others, language skills are impaired, making them difficult to understand or difficult for them to understand you. FTD may also affect motor skills, such as walking, balance and taking care of daily personal needs. Many people face a combination of all of these changes. What is predictable is that struggles change over time.



How to Talk to Your Children

You might worry that talking about FTD with your children might scare them. It is important to recognize that most kids are very smart and intuitive. Even preschoolers often sense the changes FTD brings. Your kids are likely to be confused by the symptoms. Your child may experience their ill parent as less tolerant, more short-tempered.

If children are not given factual information, they use their imaginations to fill in knowledge gaps. A child may become very frightened, embarrassed, feel rejected and unloved, and/or feel it is in some way their fault. They can convince themselves it is contagious. However, if their questions are answered in a supportive and loving environment, a lot of anxieties will be eased. By openly discussing FTD, your child gains a more accurate picture of the disease and its causes. Armed with facts, they can resolve many of their imagined fears. If they feel listened to and understood by adults, they will ask more questions as they arise.

It is important to clear the air. By holding family meetings and talks, kids have a chance to discuss their feelings, understand why they feel the way they do and find healthy ways to deal with their emotions.

As a parent, you know your child best and will know how they deal with new and potentially distressing information. Ideally, it is better to introduce information in response to your child's questions. Start with only basic information and gradually build up facts about the illness as they ask for it. Questions often will arise when you least expect them. Think about what your child may ask and prepare answers. If you do not know the answers to their questions, be honest and say so, but be prepared to find out and get back to them.

Rita, a mother:

The father before FTD loved his wife and children far beyond anyone else or anything else. Remember the person before FTD.

A Guide to Developmental Issues

At various developmental stages, children understand and process information differently. If you have more than one child, consider having some separate discussions to address each child and discuss issues at her age-appropriate level. No matter what your child's age, always be honest. Children need to know they can trust you. Even if you decide not to share some details, still keep a policy of honesty. (This issue will be discussed more in a later section.) At ALL ages, children need to know that they can feel safe asking questions and voicing their feelings, concerns and needs.

The following is a guide to typical development and signs of distress for each age group:

Infants and Toddlers:

The youngest children may perceive that adults are sad, angry, or anxious, but have no real understanding of the reasons or significance of emotions. It is important to recognize that children pick up emotional currents that affect them. Children at this age will need comfort, care, soothing and routine. Be aware that they should not be overly exposed to the negative mood states of adult caregivers.

Signs of distress include changes in sleeping and eating patterns, tantrums and withdrawal.

Preschoolers:

Young children can understand some information about illness and usually have experiences to draw upon. Preschool and even early elementary children tend to engage in "magical thinking" related to

events. For instance, a child this age may imagine that FTD can be reversed or changed through enchantment, perhaps like a fairytale character, or simply through special effort. Children this age often possess a healthy narcissism—an emphatic belief in their own importance and power. This is completely normal and may mean that the child believes that if they are very good, the disease will go away. Similarly, the child may believe that the disease was caused by their being “bad.” This is one of the many reasons to communicate with your child to make sure they do not blame themselves.

Children will begin to have questions, such as “Why is Daddy messy?” or “Why is Mommy crying?” They process events and emotions through play and creative activities. They can identify basic emotions such as happy, sad, scared and mad.

Along with the signs mentioned for younger children, children this age may act out aggressively or regress. Regressive behaviors could include a return to thumb-sucking, bed-wetting or clinginess. A child this age may develop new fears and some may seem unrelated to what is happening with the family.

Early Elementary School:

Between ages five and nine, kids begin to comprehend causes and effects. They may begin to grasp that FTD causes symptoms in their parent and be able to identify very vivid observations about how they see this playing out. They also have a more sophisticated understanding of illness and how some illnesses are more serious than others, and that sometimes people die. Children this age may be curious about how the body works and have questions or observations that seem blunt or insensitive to adults. Children are less apt to connect feelings to what is going on. They do not tend to verbally describe emotions but process events and emotions through play.

Signs of distress include aggressive acting out or withdrawal. Children may also have problems socializing with other kids, sleep disturbances, changes in eating habits, regressed behavior or fears, and physical complaints such as stomach aches.



Middle School:

Children between ages 9 and 13 can understand sophisticated concepts regarding illness and the body. They will most likely be able to understand how the disease causes changes in their parent and why. Like elementary-aged children, they may have questions or concerns that seem insensitive to adults. Middle-school-aged children still tend toward a more concrete understanding of what is happening. However, they may be able to verbally identify specific feelings. At this age, children may want and need to talk about what is going on. Adults can suggest a talk to help process events and feelings. Middle school children may show a stronger sense of empathy and have significant concerns about both the well parent and the parent with FTD.

Children at this age are developing stronger peer relationships. They may begin to be concerned about social status and what friends and other people know about what is happening with their ill parent. They may begin to voice concerns about embarrassment or become secretive about the family.

Signs of distress include regression, decline in school performance, withdrawal from friends, acting out, oppositional behavior to norms and rules at school or home, sleeping and eating disturbances, and physical complaints. More severe distress would be self-harming behaviors and suicidal thoughts.

High School:

Teens will be able to understand the facts and concrete information, and they will be able to identify concerns and emotional states. Most teens will grasp the implications of an FTD diagnosis and will consider the “what ifs” and other abstract and intangible issues. A teen may be concerned about what it will mean for them to have a seriously ill parent in terms of their identity, future and peer relationships. They may seek out friends and family for comfort or they may withdraw to deal with their feelings. Teenagers are generally capable of handling much more information and asking more specific and difficult questions. They typically respond more positively to an open dialogue, which includes give and take, but shut down when the conversation feels one-sided or like a lecture. Teenagers often talk more openly with their friends and peers than with their parents.

Signs of distress in teens include changes in habits, social withdrawal, acting out, oppositional behavior at school or at home, and drug or alcohol use. Teens (as well as some younger children) with a history of depression, suicidal behavior and chemical dependency are at particular risk during stressful events.

Explaining FTD to Your Children

What is FTD?

Most children know what it means to be sick. You can begin with referencing what they know about being sick and go from there. You can also start with asking them what they have observed. Sample statements and questions about explaining FTD:

Remember when you were sick with ____?

Sickness is when something in the body is not working the way it is supposed to.

People with FTD can seem like they have a lot wrong with them. This is because FTD is a sickness that affects the brain.

People with FTD can't always do what they want to do or what they used to do because their brain has the sickness.

Nathaniel, age 9-1/2:

Stay strong.



During the discussion, ask your child what they have observed about their ill parent and validate them. Talk about one or more of the ways that FTD has affected their parent: behavior, language, movement, cognition and emotional symptoms. Ask about any feelings and prompt with basic emotions such as happy, sad, scared and mad. Reflect about your own emotions and suggest what they might have felt (without insisting or expecting lengthy reflecting).

Behavior (How a person acts):

Sometimes Daddy acts differently because of the FTD. Remember the time when...

Language (How a person talks):

FTD can make Mommy have trouble saying things. Have you noticed this?

Movement (How a person moves):

FTD can make walking difficult for Daddy. Did you see this?

Cognition (How a person thinks and plans things):

FTD can make Mommy confused, like she doesn't know what to do next.

Emotions (How a person feels):

FTD can make people feel really strong emotions. Sometimes the FTD

can make Mommy seem like she doesn't care or notice us. It is important to remember that this is the FTD.

For older children or teens, FTD can be described as an illness that affects the brain. It starts in the parts of the brain that control thinking, behavior and language skills. A person's ability to control their actions, make decisions and get along with others may be affected. They may not be able to speak clearly or understand words and sentences. These changes are signs of the disease that the person cannot control. Use examples from your situation that they will recognize.

Children may also ask specific questions about why their parent with FTD does or says certain things.

Our brain works a bit like a computer sending messages to different parts of our body. It controls the way we think, eat, walk and talk so if our brain is not working properly, the messages are not clear and our body cannot work properly.

Sometimes you may think Daddy does not love you anymore because he is not interested in the things you do. The illness can make it difficult for Daddy to show that he still loves us, but he does. If you feel sad or upset any time, you can talk to me about it.

For children who are curious about the mechanics of FTD, you can use a picture book or model of the brain or draw your own pictures to explain what is happening inside their parent's body.

Some children might be concerned about "catching" FTD. Often the underlying reason for a child's questions is fear about what will happen to them and to the well parent. It is important to reassure children that they are safe. In answering questions, you can also ask why they are asking or what concerns them so you can be sure to cover any underlying fears.

Who gets it?

Not very many people get FTD. It is a rare disease.

What causes it?

They don't know what causes it yet. We know that it is nothing anyone did to cause it—not your Dad, not me and not you. It is no one's fault.

Can I catch FTD?

No, you cannot catch FTD. It is not like a cold you can catch from

Tips for talking about FTD with Children and Teens:

- Communicate in a straightforward manner.
- Communicate at a level that is appropriate to a child's age and development level.
- Watch your child's reaction during the discussion.
- Slow down or back up if your child becomes confused or looks upset.
- Provide details if the child asks, but do not force children or teens to hear or manage information.
- Always tell your children the truth.
- Remember—it is always OK to say you don't know.
- It is also OK to let children know you have feelings and that being scared, sad or mad is normal.

other people. We are safe; it is only Mommy that has this. Why do you ask? Are you worried about someone catching it?

There may be tough questions about getting better that are heartbreaking to answer. Many children have only seen people get better from illness and imagine that doctors always cure their patients. Though this may be the hardest thing you have ever done, it is highly recommended that you tell the truth—that their parent will not recover from FTD. Telling the truth is a way of preparing your children and letting them know they can trust you. Later, if they realize you did not tell the truth, it could compound their sense of loss. It is important to find a way to tell the truth and protect their sense of safety. Here are suggestions for handling these questions:

Is there medicine to make Mommy better?

There are some medicines that can help a little bit and Mommy's doctor is going to try to help her feel better. We can help her by making her comfortable.

Will Daddy get better?

FTD is a sickness that does not get better. It is a sickness that gets worse over time. This is very hard, but we will still all be here for each other. We are going to go through this together. No matter what,

I will make sure you are taken care of and get to go to school, play with your friends and do all the things you like to do. No matter what, we will still be a family.

Other difficult discussions may come up around the possibility of death and dying. It is OK to talk about this with children if they ask about it. Many children with no experience with death will not think to ask and do not comprehend the concept. Other children may ask.

Will Mom die? When will she die?

We don't know exactly what will happen. We don't know if she will get sicker quickly or take a very long time—many years. Eventually, she will die, but we don't know when. You know, it is OK to talk about your worries around what will happen. Let me know what you are worried about so I can help and you don't have to be alone with your worries.

We often don't think of grief until someone dies, but when it comes to illness, there is also grief and loss. You may already feel the loss of not having the partner or the future you thought you would. Your children's questions and reactions may reflect this as well. These are perfectly normal feelings. Children may immediately think of things that they may not be able to do as a result of their parent's illness. They may have lots of question and concerns about how things will change. "What about going on vacations?" or "What about Daddy coming to my baseball games?" or "Can I still have friends over?" Your answers may be definite or, at this early stage of knowing the FTD diagnosis, you may have very few answers.

This is true of teens as well—they may think far into the future and feel a sense of loss thinking about a parent who can't be there to take pictures on prom night or may not be there when they graduate from college. While it is very difficult to be unable to "fix" these losses for your children, you can acknowledge that their reaction is normal. You can be patient with their expression of feelings around grief and loss and, at times, encourage them to process their feelings with you.

Managing change and the emotions (such as grief and loss) that come with it is the cornerstone of resilience. As you and your family navigate FTD, you will have opportunities to build healthy coping skills. Keep in mind, you cannot do it all at once, nor should you expect to communicate perfectly. However, over time, you can strengthen your communication with your children and help them become fully confident and resilient individuals.



Family Structure and Role Changes

When a parent gets FTD, family life turns upside down. Children grow and change as the FTD parent declines. As both parent and child progress, their reactions to the disease and the family unit change.

Recognizing these changes—and talking about them along the way—is key to helping the children understand what is happening at home.

Even before diagnosis, the resulting changes in the marriage can be a huge stress on the parents—and the kids. Children need to be assured that Mom and Dad still love each other, but their roles will change. The roles of husband and wife will now shift to caregiver and care receiver.

How logistics are handled will change. All transportation and planning shifts to the well parent. As the kids get older, logistics get increasingly more complex. And as the parent with FTD becomes more ill, they are less and less competent to handle these tasks. This creates more demands on the well parent, and it becomes critical for you to ask for help from family members and from parents of your children's friends.

Children can be expected to help at home, but also need to be able to stay engaged with their peers and interests through activities, sports and visiting friends. Other parents are often transporting their kids anyway and are glad to help out. And there are people that want nothing more than to find a way to help your family. Let them.



A Parent Who Cannot Parent

At first, children might be confused that the parenting partnership between Mom and Dad is blown apart. The well parent becomes, in effect, a solo parent with the added burden of their partner perhaps acting like an immature child in an adult body. Children will need to understand that—at best—the ill parent will be limited in what they can do for them.

In fact, the FTD parent may shift from directing play for the children to playing in a fashion “younger” than the children. Even more frightening, the FTD parent now may not understand when play is unsafe or when play is too rough. For instance, it may no longer be safe for Daddy to wrestle with the children. It does not matter if the FTD parent still has good days—things shift quickly.

Instead of being a peacemaker, the FTD parent may become the one to instigate fights. Find creative ways to manage these situations. One common problem surrounds fighting over control of the TV. If possible, find a way to get another TV, specifically for the FTD parent.

Importantly, you cannot rely on the FTD parent to supervise younger children who need constant attention. This is a matter of safety for the children. Do not overestimate how the FTD parent could respond to an emergency situation. Things happen quickly.

- The FTD parent goes from a supportive/nurturing/affectionate adult to someone who may be apathetic to their children and possibly someone who picks on them. Their biggest cheerleader may no longer pay attention to them.
- Children might need to “babysit” or look after the FTD parent. It’s a complicated idea. This could lead to your child to believing that he or she is an adult and no longer needs guidance or discipline from the well parent. This should be addressed early and often. Try saying something such as: “I really appreciate your willingness to watch your Mom. That is a big help. I know it may seem inconsistent, but even though I trust you to be able to watch your Mom for a short time, that doesn’t mean that you are ready to make all the grownup decisions for your life. I still am your parent and will continue to guide you as both your Mom and I have done in the past.”

Emotions No Other Children Have

Even though you, family and friends are giving all the support and love you can, many children who have a parent with FTD feel different from their peers. This can be very isolating. It is easy to believe that none of their pals understand or empathize. Describing their situation at home is difficult, and their friends are often too young to know how to react. It is too much to expect another child will give proper support.

Children can be very observant. They know if someone is avoiding the family and notice people feeling awkward and not expressing concern over the difficult situation at home. They may assume that those people just don’t care. This may fuel their anger, sadness and confusion.



But, there are things you can do.

- Recognize that everyone in the family is dealing with difficult emotions. Remind them (and yourself) that the stress is brought on by FTD—not the ill parent himself. No one chose for things to be this way.
- Realize sadness is often prevalent, but anger can be too - both in you and your children. It's normal.
- It is very common for children to be embarrassed by their parents, especially during adolescence. Having a parent with FTD multiplies these feelings. Instead of wanting to show off or brag about their parent, your child may want to avoid their mom or dad at all costs. Keep track of situations that cause the most embarrassment and do your best to avoid them. Help children to feel in control over what they say to friends and where they visit with friends.
- Be aware that special occasions like Mother's Day or Father's Day can be awkward. Other children their age are making plans and buying gifts to honor their parent. For your children, their FTD parent is often unaware of the special occasion and even if they are aware, they may not care. It hurts. Make your own game plan.
- Find a "safe" place for your children to go. Children often are most comfortable at home. But when a parent has FTD, home might become the place they least want to be. It may be a place of conflict, or simply too unpredictable (or predictable in a bad way). Expect and plan for these feelings. The safe place could be a friend's house or the home of a relative. Also, consider safe supervised activities that are out of the house, like a basketball camp or Scouts.
- Coach your children on how to share information about the disease with others like friends and teachers. Help them figure out how



to answer specific questions—like letting others know this disease is not contagious.

- When life takes them out of their comfort zone, children may become upset as they try to figure out how to respond to questions about their ill parent. Let your children know it is fine to say, "That is something I just don't feel comfortable discussing right now." In time, your children will become more comfortable sharing information. Help them plan for these situations.
- All children need praise, and no one is better at this than a parent. With only one parent, your kids need you to become an even a bigger cheerleader. Look for every opportunity to praise them.
- If you develop medical issues, it can really frighten your children. Develop a plan of action in case you suddenly get sick. Who will care for your child if you should become ill?
- If you have children of similar age, they can offer tremendous support to each other. However, an only child or children of very different ages may feel very isolated. Help your kids find someone to talk to about this disease.
- The academic and social aspects of school are a critically important part of a child's life. Talk to your children's teachers and principal. After one FTD family shared their situation with the principal, she held a special training day for teachers on how to handle kids who have an ill parent at home or who are grieving.
- Your children know the family is even more dependent on you than before. Stay healthy. Take breaks, get rest, meditate, exercise—whatever you can do to help yourself stay strong. Before you can be an effective caregiver and parent, you need to take care of yourself. Seek support to let out your own emotions. Try finding a small group at your church or a caregiver support group. Or, talk to a counselor or a trusted friend. It is best not to develop a pattern of confiding in your children. Find the confidantes you need. Chances are, you will become closer to your children as you live through this disease.

Paul, a dad:

Make sure that they are informed. Make sure they know that it's not their fault.

And love them, because you have to love them for two.

- At a certain point, don't be surprised if the children want nothing more than the FTD parent to be out of the home. It is simply too difficult for them to be around this parent anymore.
- Once the FTD parent is placed into assisted living or some other environment, kids often do not want to visit them. Along with feeling awkward around the FTD parent, these living environments can bring discomfort to younger and older visitors alike. Do not push your child to go if they do not want to visit.
- Regardless of their age and what they are feeling, children need to feel safe to express their thoughts and feelings about the changing family environment. Make sure your children know they are heard, and give them plenty of hugs and affection as they tell you their feelings.



Children as Caregivers

Children need to know what to expect out of their parents to feel safe. But when a parent has FTD, the parent is often unpredictable and the child doesn't know what to do. It is important for you, as the well parent, to recognize that you are responsible for your child's safety. Set limits on what your child is exposed to and make sure your child is safe. Help your child make good decisions that keep them safe and are also respectful to their parent.

As children and teens develop, they will be able to help—to a point. Older children may feel that they have too much responsibility around the home, especially with chores. Take the time to explain that everyone simply has to pitch in more since the FTD parent no longer does some of the chores and might even create more to be done.

In time, the FTD parent may need help with toileting. This is challenging with same-sex children and even more so with opposite-sex children. It might be too much to ask.

Remember, life will change, and much of this change will be very challenging for everyone. That is unavoidable. But even though FTD itself can be unpredictable, the effect on the family and the reaction of children is often very predictable. And through this difficult experience, each member of the family has an opportunity to grow in many positive ways.

Know Your Limits

You will try your best, and you will make mistakes. Don't expect to be the perfect caregiver or the perfect parent. That is not humanly possible. But you can learn from your mistakes and share your experiences with other caregivers.

It's said that it takes a village to raise a child. It also takes a village to care for a family with a parent that has FTD. Call on extended family and friends for help and support, especially those who live nearby. Your "care team" needs to know as much as possible about the disease, how it affects your



loved one and your family. Be honest. You can count on these people to love and support your family.

This is no time for independence. You might feel like you have to reciprocate for rides given to the children, but do your best to resist the urge to always reciprocate or to “do your part” of the carpool. People will understand.

Often, people ask how they can help. Be ready with answers. Make a list of needs—taking your son for a haircut, bringing your daughter to a birthday party. When people offer to help, give them a few choices.

Find a Mentor for Your Child

Be aware that you are the main caregiver, and that means you simply will not be as available to support and nurture your children as you had planned.

Your children may miss many things about their parent with FTD. Many times it is really nice for a mom to be able to talk to her daughter or a dad to be able to talk to his son—especially during puberty and adolescence. But these talks are not something an FTD parent can do effectively. Reach out to a trusted man/woman, possibly a relative, to nurture and support the child whose same-sex parent has FTD. It might take time to nurture that relationship, but this person could mentor the child. It is most helpful if this person lives nearby and can spend intentional time with the child.

Children also miss a close relationship with a parent of the opposite sex. Girls really need affection from their dads, and boys need that same affection from their moms. Find trusted adults who can show appropriate affection to your children. And be more intentional yourself about showing affection to your children.

Catherine, a mother:

You can't second-guess yourself or your teenagers with this terrible, unpredictable disease. You can do the best you can in your own way.



Find Outlets for Your Children

Many children respond positively to counseling. You may need to go with your child to help get them started. Planned sessions with your children can be valuable around new issues or transitions. The use of professional **counseling** might ebb and flow as children develop. It can be challenging to find a counselor who knows about FTD. You can help by having a folder of information on the disease and resources to give the counselor to encourage them to learn.



All children need a way to work off anger and frustration in their lives, so **physical activity** is probably more important than ever for your children. Sports offer a chance to focus on and control a portion of their lives. You may need to seek out—or at least be in support of—additional sports for the sake of your children. Clearly, another obligation to drive your child is not what you are after. As you plan activities, make sure you ask for transportation help. Perhaps check

in with the parents of your children's friends and ask if your child can catch a ride with them.

As another outlet, do not forget about the **creative arts** such as painting, drawing, photography, music and dance, which allow for the expression of feelings not easily put into words. Encourage your children to pursue their interests and find a comfortable way to express their feelings.

Take a break with the children from the FTD parent—anything from a brief outing to the park to a vacation. Every person—as well as the family as a whole—will benefit. (Appropriate plans for care must be made for the FTD parent, of course.)

There will come an uncomfortable time when your spouse will be too ill to leave alone at home but not ill enough to be placed in long-term care. When there is a young child at home, this in-between time can be even more complicated, especially if family finances dictate that you, the well parent, need to work.



Doug and Julie

Julie found that their babysitter who cared for her four-year-old was not qualified or interested in caring for her spouse with FTD. This meant using a combination of support people:

- She started her son in full-day preschool at age four. Although she had not planned for this, her son was very happy there. He was out of the house in a loving, wonderful Montessori atmosphere where he focused on friends and learning.
- She enrolled her husband in an adult day program. She hired the driver that the center used for carpooling to transport her husband so she could get to work on time.
- Friends would pitch in on weekends, taking the FTD parent to their house, to a barbeque, to a park or just on a walk.
- If Julie had to travel for work, her family would come in town to stay with both her son and husband. This also helped them see and understand the pressures she faced.
- Twice a week, a teacher at the preschool (with experience in dementia care) would spend three hours at their house to help with both her husband and son while Julie would get a haircut or go grocery shopping on her own.

Julie found that these solutions worked for only about a year. As her husband declined, more difficult behaviors emerged, and often one caregiver could not handle both a kindergartener and her husband.

So, they readjusted.

- When she traveled for work, her husband would stay with one family member, her son another.
- The teacher/babysitter became overwhelmed with the two of them. She still would come to their house twice a week, but Julie would stay, too.

Two years after the diagnosis, Julie's husband's behavior became more challenging. The stresses of caregiving, solo parenting and working took its toll on Julie's own health. Long-term care was the only option to insure her son and husband were both in safe, caring, nurturing environments and she was strong enough to handle their family's situation. In retrospect, Julie believes she probably waited too long to make this move.

Moving day was one of the most gut-wrenching parts of the entire process. Her son went to Kindergarten that morning, fully informed that his dad would be moving. Therapists had suggested keeping him to his routine, keeping his focus elsewhere while Julie and their college friend moved her husband into his new home.

The first visit for their son was very difficult but things changed quickly after that. That first year, they timed visits to the center's ice cream social day. Often Julie would try to bring her son just after a "first" occurred—a first tooth being lost, for instance. The assisted-living center had wonderful grounds and their son showed off riding his bike to his father. Sometimes they could still play Frisbee or manage a game of family baseball.

That's not to say the visits were all a delight. Sometimes they went well, but often there were tears, moodiness, and overwhelming heartache from the FTD parent, their child—and Julie, too. As much as she knew it was the right thing to do, it remained difficult to see her spouse and her child miss each other.

Over time, the disease progressed and the FTD parent lost many physical abilities. He moved from assisted living to a full-service nursing home. The changes overwhelmed their son, who no longer wanted to visit. It just seemed too scary. A child psychologist told Julie to let her son decide when he wanted to go. Each time Julie visited his father, she asked her son if he wanted to go. Occasionally, he would join her but over the next five years, the visits became fewer and further between. This gave him control of this often out-of-control situation.

Julie focused on helping her son remember his father, creating a "biography" of sorts of his dad. He needed this in order to let his father go. They started a memory box, and filled it with his father's things—glasses, a work ID, a passport, a wallet, cuff links—things that might seem unimportant, stuff easy to throw away. But the tin box full of these items became known at their house as her son's "treasure."

As his father became more ill, Julie would pull the box down. Sometimes she would lead the conversation and tell her son about memories involving each one. Sometimes her son would ask her about these things. It helped prompt conversations that were too difficult to start cold. Six years after his father died, her 6-foot-tall, 16-year-old goes into the box himself on occasion. She recently learned he has been carrying his father's old work ID in his wallet.

When it became clear that Julie's husband would only have days and possibly hours left, her son came to say goodbye. He needed a great deal of encouragement to go, but it became clear to him that this was necessary and important. He talked to his dad to catch him up. The next morning, he asked to go again. For what would be the last time, his father opened his eyes, which followed their son around the room for more than an hour. It was the most beautiful love scene she had ever witnessed. The next afternoon, they lost Doug.



Talking about Genetics - Information for Families with FTD

Everything about this disease is scary and difficult, but when children are involved you also have the added concern about potential hereditary risk. This is one of the first concerns that everyone has. In the majority of families, this fear is unfounded.

Thankfully, most cases of FTD are considered sporadic—meaning it is a disorder that develops in that person by chance rather than being inherited. When FTD is diagnosed in a person with no family history of FTD or dementia (or in which there is incomplete family history), it is often an isolated (sporadic) case, which appears to pose no significant elevated risk to family members. In a minority of persons with FTD (approximately 15%), a family history suggests a hereditary condition with an autosomal dominant pattern of inheritance. This means there is a clear pattern of FTD-type diagnoses being passed from grandparent to parent to child, with virtually every person with FTD having an affected parent and each child of an affected person having a 50% chance to inherit the disorder. In between are a percentage of cases (approximately 30%) where there may be signs of other neurodegenerative disorders in the extended family that may indicate an increased risk of inheriting disease, but it can be difficult to determine or assess the level of this risk.

Approximately 15% of FTD cases are inherited

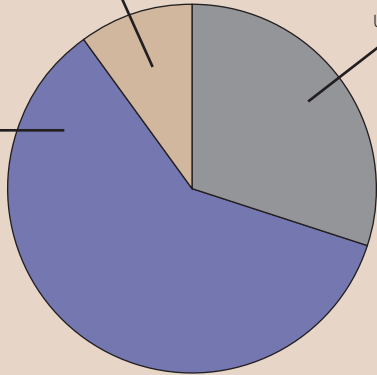
(Autosomal dominant)
Each child or sibling has a 50% chance of inheriting the gene and developing FTD.

20–40% of FTD cases are familial

(May be inherited.)
Family members are at increased, though undetermined, risk.

50–70% of FTD cases are sporadic

(Not inherited.) Family members have general population risk (or there is insufficient family history to determine risk).



How Do I Know the Risk?

Medical researchers are uncovering more about the genetics of neurodegenerative diseases all the time. However, we are still far from a perfect understanding of the genetics of FTD.

The way to determine which sector of the graph your family falls into is to talk to a genetic counselor. This is their area of professional expertise, and they will have the most current information available. They will take a careful family history, review available medical records and arrive at an assessment of risk that conveys the likelihood that FTD is hereditary in this family.

FTD is an adult-onset disorder. Any potential risk to your children is not in the near term. Because of this, and because there is currently no treatment available that would delay onset, genetic testing of a child is not appropriate. Any testing must wait until the child is mature enough to understand these issues and make their own decision about whether or not they want the information genetic testing could provide.

There are things you can do in the near term that will add to the information available for the future. Talk with your clinician about any research studies for which your spouse or partner might be eligible; make arrangements for tissue donation or autopsy to confirm the

disease pathology and keep copies of the medical records so you'll have relevant information at hand when and if your family is ready to see a genetic counselor.

Discussing Genetics with Your Child Today

When should you talk with your child about genetics or the risk of inherited disease? Take your cues from the child and wait until they initiate it. Listen carefully to understand what they are really asking; do not project your own questions or concerns. Gauge the depth of your response to match the child's understanding and need.



Very young children typically will be concerned about what is happening to their parent now, not what will happen to themselves when they are older. When a child asks, "Am I going to get what Daddy has?" it does not require a dissertation on genetics. Find out if your child is really asking if FTD is catching like a cold or the flu. You can honestly reassure your young child that neither they nor you can "catch" the disease.

As children get older and they encounter some basic concepts of genetics in school or perhaps experience a friend or family member with an inherited condition, you will need to answer more substantively. The response will depend on what the family history looks like and what children have seen.

For high school children, ask: "What have you learned in school about genetics?" Explain that many families carry genetic links to different diseases. For some, it could be heart disease or cancer, for others it may be brain diseases. Tell your child that knowing a disease is in the family can be scary but it also allows the family to better understand what is happening and deal with it. For diseases that are treatable, knowing that the disease is in the family encourages a more healthful lifestyle.

For an older child who might observe several members of the family with dementia or if a pattern of inherited FTD has been established, the “Will I get it?” question needs a full answer. Still, first answer the question with more questions: “What makes you wonder about that?” or “What have you noticed about Mom and Uncle Jimmy that raised that question?” If it becomes obvious that they are worried about inheriting the family disease, a simple but honest answer is called for.

Older children will know that if a grandparent and aunt/uncle have the same thing as Daddy, it is being inherited. It is important to stress that any risk to them is still only 50%. Their parent may be taking part in research to work with the many scientists and doctors around the world who are developing treatments not available today. Progress is advancing quickly in FTD research, which offers real reason for hope.

At some point, older children will be ready to read the same information as the parent. Refer to the resources section at the end of this booklet for some of these materials. If you feel you cannot give a more complicated answer, turn to your doctor or genetic counselor for help. Speaking directly and asking questions of the treating physician can be an important way to empower the teen and receive information from another perspective.

Conclusion

The overall approach that your family adopts to the disease is the most important message you can send your children. Children will see in your words and actions that changes in the diagnosed parent are recognized as symptoms of the disease, and that the parent is still loved and respected. The example of self-care and use of support that you provide is a model for your children. They may not do the same things, but they will benefit from your positive example of coping. A parent who is knowledgeable about the disease and aware of or involved in research efforts will reflect the hope that medical advances offer. Taken together, your efforts to communicate and adapt over time will ensure a loving foundation from which children can flourish.

Resources

Frontotemporal Degeneration and Children

The Association for Frontotemporal Degeneration (AFTD)

Radnor, PA
1-866-507-7222 (toll-free)
or 267-514-7221
www.theaftd.org

AFTD is a non-profit organization whose mission is to advocate for people who live and work with all forms of frontotemporal degeneration. Visit pages on the website:

- Caregiving Challenges/Children and Teens – For resources for families with children, and for children and teens themselves
- What is FTD?/Genetics – For more in-depth information on genetics including information on families with inherited FTD
- Support and Resources/Resources – For a listing of books, DVDs and related educational resources
- Research – To understand the science and learn about participating in research

National Institute on Aging

Alzheimer's Disease Education and Referral (ADEAR) Center
Silver Spring, MD
1-800-438-4380 (toll free)
www.nia.nih.gov/frontotemporal

Information and publications on dementia and caregiving for families, caregivers and professionals.

When Dementia is in the House

<http://www.lifeandminds.ca/whendementiaisinthehouse/>

A website launched in fall 2011 that offers content for parents and teens in families facing dementia, including frontotemporal dementia.

Just for Kids and Teens

http://www.alz.org/living_with_alzheimers_just_for_kids_and_teens.asp#introduction

Information and activities from the Alzheimer's Association for children and teens of someone with Alzheimer's disease.

Children and Bereavement

The Centering Corporation

www.centering.org

Online grief and loss bookstore for the bereaved as well as professionals

The Dougy Center

Portland, OR
866-775-5683 (toll free) 503-775-5683
www.dougy.org

Community bereavement center founded in 1982. National resource for children's bereavement center locations across the country.

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The Association for
Frontotemporal Degeneration
Opening the gateway to help and a cure

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