

COPING WITH FTD by Cindy Odell

I have the interesting experience of addressing FTD from two different directions. I have been the caregiver for three family members, my grandmother, my mother and my aunt. My grandmother's third child, my uncle, also died from dementia but I was never his caregiver. All four of these family members were diagnosed with "dementia" and it was assumed that it was Alzheimer's, but no biopsy or autopsy was performed on any of them. Not much was known about FTD at that time and, unfortunately, it still is unknown to the majority of people. Knowing what I do now, I firmly believe they each had FTD, not Alzheimer's. My symptoms are mirroring theirs perfectly.

After the death of my mother, and early into my aunt's battle with dementia, when I was in my early 50's, I was also diagnosed with FTD. Since I was in the earlier stages, it helped immensely that I was helping to care for my aunt at the same time because I understood the disease much better since I was dealing with it myself and was able to be much more patient with her.

I am quite fortunate that I can still read and write. Several people have suggested that I consider writing a book. My husband has had a book published, so I know how much stress is involved in the process. I also would rather provide my insights and opinions free of charge. I do not claim to have all the answers, especially since no two cases of FTD are identical.

I am writing on all sorts of problems and common questions about FTD. I do not pretend to be an expert on FTD. I have no medical training. I strongly suggest you discuss any changes or issues with a doctor. What I do have is the advantage of dealing with FTD from both sides. What I have written here is simply my experiences in dealing with FTD as a caregiver and dealing with it myself. I hope that my experiences may help others to cope better when dealing with FTD.

ANGER

Anger can be a huge issue for someone with FTD and maybe even more so for the caregivers. The most important part of this for me to stress is that it is not intentional. When someone with FTD lashes out in anger, I like to say that it is the disease talking, not the person. I know that realizing this does not always make a difference in trying to deal with the anger and lashing out.

It is easy to understand where a lot of the anger comes from. It begins with the anger of having the disease as well as the symptoms that come with it. Then comes all the frustrations. Trying to do things that used to be simple and can no longer be accomplished or with great difficulty is extremely frustrating. This includes even simple tasks that have always been done by rote without seeming to need to think about them. It can be household chores, dressing, writing a check, figuring out correct change in a store, truly anything at all. This frustration can quickly lead to anger, anger at the world, anger with ourselves and anger at anyone who doesn't seem to understand. Of course, this anger will often be directed at the caretaker only because they are the only ones around. The frustration can build throughout the day and the anger can build right along with it.

The most important thing is to maintain safety. The caregiver needs to ensure that they

are in no physical danger first. Secondly, they have to ensure that the one with FTD who is lashing out can do no harm to themselves. If everyone is safe, backing off for a few minutes to allow the one with FTD to calm themselves may take care of the anger. If they are communicative, try to figure out what has set off the anger. You can do a quick check to make sure they do not have something bothering them physically such as wet pants, hunger, thirst or an injury. Perhaps ask what has frustrated them or if you can help them do something. That comes with a risk because if the anger has stemmed from being frustrated by no longer being able to do something, that might make it worse. One time with myself, I lashed out at my husband (fortunately only verbally) when he asked a question while I was trying to loosen my shoelace. I was intensely frustrated because I knew I should be able to do it, but could not figure out which part of the lace to pull on to feed more lace to the top. This frustration led me to one of the nastiest screaming sessions to date.

One of the first things to try is to reduce any distractions that are surrounding them. If possible, take them into a darkened room that is totally quiet. I find that if I can take a "time out," I can calm myself down. If there is no quiet place, just reducing the stimuli may help. Turn off the television if it is on. Take the pets out of the room. Anything to remove additional stimuli that may be contributing to their distress.

For me, it is not unusual for me to retreat to my bed and curl up into a fetal position. I am usually able to calm myself by doing this. During this time, it is important that no one come in my room and just let me calm down.

Sometimes, the anger is worse during the earlier stages and actually improves later on in the progression of the disease. There are medications that doctors can prescribe to help. Some of the medications for depression or mood swings can help. Many have reported that Seroquel has been of help. I have discussed this medication under the section "Medications."

Do not be afraid to ask the doctor about the anger and/or frustrations that are cropping up often. Anger is not the fault of either the one with FTD or of the caregivers and should be openly discussed with the doctor. Together, you can decide how to address the problem.

Many experts or professionals who deal with FTD do not believe that psychotherapy is of any help. I disagree based on my own experience. I have been seeing a psychologist who specializes in dementia for many, many months. At first, I saw her weekly, then slowly increased the time between visits to where we only meet once a month unless I am having a crisis. She helps me develop coping mechanisms. She has helped me find ways to better communicate with my husband, my primary caregiver. This includes ways to let him know when and how something is adversely affecting me. It is also a place to vent without judgment. When anger or frustrations are building, I can ease them myself now by knowing I can talk to her about them the next time I see her. She also encourages me to do things such as going out with friends. I actually made a trip, along with my daughter, to an FTD conference last spring. Without her encouragement and ideas on how to cope with any problems, I would not have been able to go. I learned so much at that conference, it really would have been a shame to miss it.

Like anything else, whether psychotherapy will help is trial and error. It probably works for some and does not for others. I am fortunate that my insurance covers these visits and that they help. It is certainly worth checking into.

APPETITE

Appetite can vary greatly for those with FTD. Many caregivers report that their loved ones eat only one food for days on end. This can range from hamburgers to bagels to ice cream. The amount of appetite can vary as well. Some days they may seem to want to eat everything in sight. Other days, they have to be strongly encouraged to eat anything at all. On days when they will not eat anything, or nothing of good nutritional value, you can try to get them to drink Boost or any other nutritional type drink. Be creative. If your loved one is only eating ice cream, blend ice cream into Boost (Carnation Instant Breakfast or something similar would work as well) and call it a milkshake. If you have to, add sugar (honey or agave), vanilla, spices or salt to foods to increase the flavor as stronger flavors sometimes are the only things tasted, especially sugar and salt. Blend veggies into sauces. For example, if they won't eat oatmeal, try adding some jelly, honey, brown sugar or anything to spice up the flavor. Try not to be aggressive in trying to encourage their eating. Try to avoid having it escalate into a fight. If it goes on for a length of time, I would suggest checking in with the doctor. There are actually medications to stimulate the appetite.

A huge issue for those with FTD is the craving for sweets and carbohydrates. This craving is beyond any food cravings I have ever experienced before in my life. What I try to do is limit the sweets and carbs to things that have even a tiny bit of nutritional value. Instead of candy, I eat a chocolate covered granola bar. There is one that is caramel nut flavor that tastes just like a quality candy bar, others have raisins or peanut butter. Yes, I know that the nutritional value is low, but at least there are some whole grains (oats) involved and a tiny bit of protein. Fruit is a good way to satisfy the sweet craving. I will take canned fruit (the sweet kind) and put it over cottage cheese. Including peanut butter into the snacks at least provides some protein. Trying to totally deny the sweets and carbs is most likely going to be a constant battle. I used to blend peanut butter, honey and a little butter to spread on crackers for my mom. My suggestion is to be creative and sneak in nutritional value if you can.

The caregiver of someone in the end stages complained that his wife would only eat ice cream. I told him, so give her ice cream and ask if she wants cookies or cake with that. It comes to the point that quality of life is more important than following nutritional guidelines.

It is not uncommon for those with FTD to gain weight. This is true even if there is no craving for sweets. It was explained to me that the brain knows there is something wrong in the body and something is stressing the body. The brain then tells the body to pack on some extra weight to protect itself and feed itself. I experienced this phenomenon 20 or so years ago. I needed to have surgery on my jaw that required it to be wired shut for eight weeks. I kept saying that at least I will lose weight. The surgeon explained that no, I wouldn't, that I would lose about five pounds and then my body would go into starvation mode and believe it needed to slow down my metabolism. He was right. I lost five pounds and that was it. It is amazing how the brain controls the whole body system.

BATHING AND SHOWERING

Because FTD often causes a lot of apathy, it is easy for bathing and other hygiene issues to be ignored. If you don't care about anything, most likely you don't care if you don't smell so fresh either. Bathing and showering can be difficult and uncomfortable so it is more likely to be avoided when possible. There are things that may help.

One of the problems can be lack of security in the tub or shower. They may not even be aware of it but you may notice them moving or standing awkwardly. First of all, the floor surface should be non-slippery, even if you have to use those not so attractive sticky rubber pads. They may look like you have retreated to the 1960's, but because they adhere, it seems to work better than a removable bathmat. If you do not have any safety grab bars on the walls of your shower or bathtub, get some. If the wall surface is such that you can't install permanent ones, there are others available and can be easily found online. There are ones with large suction cups to stick to the wall and there are ones that fit over the sides of your tub. I have seen a very sturdy example of the ones that fit over the sides of the tub that are adjustable to fit any tub with a secure fit. It was around \$30. A small investment versus possible injuries from a fall.

One of the big factors in the reluctance to shower is the fear of the water. It sounds silly, but to someone with dementia, the water is something they can't see but is hitting them and getting in their eyes. Adding a removable shower head to your shower might make it easier to give a shower without the water constantly hitting the face. This, obviously, requires more involvement by the caregiver, or you can mount at shoulder height to hold the removable head.

In the shower, try a shower chair, one with a back as well as a seat for added security and less chance of exhaustion. This doesn't even have to be one specially made for the shower. During chemo treatments years ago, we used a small plastic chair from the patio. As long as it fits, is water resistant and sturdy (not likely to tip over), try it out. That may add enough security to make showering more comfortable. If a bath is preferred, again, make sure you have sturdy grab bars for getting in and out of the tub. It might also help if you had a sturdy, heavy/wooden chair right outside the tub to balance on or sit on to dry off afterward.

When an independent shower is no longer possible, it often works for the caregiver to wash them down, skipping the private areas. Then they can be told it is their turn and suggest they clean those private areas. This is so important to prevent urinary tract infections. For some reason, this worked for my mom, even in the later stages. I think somewhere deep in her brain, she didn't want someone else touching her private areas either.

One thing that I found to help when someone refuses to wash, if they will soak in the tub for a while, buy cheap shampoo and use it as "bubble bath" in the tub. The water will be just soapy enough to soak off most of the dirt on the lower part of the body to save that battle anyway. It will not leave them soapy enough that you have to make an effort to rinse them.

When it comes right down to it, be imaginative and try anything you can think of. Again, I came up with the shampoo in the tub trick by remembering the bubble bath my cousin and I used when we were young. It was called "Soaky" and promised to get you clean by soaking. I can still sing their jingle. "Soaky soaks you clean in oceans full of fun..."

CARE PARTNERS

Notice that I titled this section "care partners" not caregivers or caretakers. Those with FTD must be partners with the one providing care. It will not work well if it is one-sided in either direction. Even with being diagnosed a little over five years ago and experiencing the continuing decline, I cannot decide which is worse... having FTD or caring for

someone who does.

Above all, let go of the guilt. You cannot be a super hero and do it all. If you lose it occasionally and yell back at them, they will survive. If you are having a lot of trouble dealing with the situation, you should discuss it with your doctor. Many care partners need to be on antidepressants on a short-time basis. It might also help to see a therapist if possible. Join a support group. You will learn how others cope and they will listen to you rant when you need to.

Care partners get very tired of hearing "It's not them, it's the disease." This is fairly true, but while it may bring some comfort, I doubt that it helps much in the day-to-day strain of dealing with someone with FTD. After enough angry outbursts, threats, blaming, embarrassing incidents and more, it gets pretty darned difficult to deal with some days.

This constant strain on emotions and drain on energy is exactly why care partners absolutely must get some sort of respite. A weekend off would be wonderful, but if that is not possible, even an afternoon would benefit. This can seem impossible though.

You know all those people who say, "Let us know if there is something we can do" in a placating way. If you are like me, you probably just brush it aside or say "no, we're doing fine." It is time to call on them and say that you remember them offering, and ask if they could come over and spend an afternoon keeping the one with FTD company so that you can get out and get some things done. If they don't want to do that, ask for them to bring you a meal or mow your grass, anything that needs done. Ask family members or friends to come stay for a night or two so you can get away and relax. Asking for help can be very difficult to do, but you never know until you ask. Be specific when you ask. You will quickly find out who your friends are, that's for sure. There are grants available to help cover the expenses for a caregiver respite through AFTD, the Association for Frontotemporal Degeneration.

While they are still able to make decisions, discuss what would be best for long-term care in case the time comes that you cannot keep them at home. My mom made me promise that I would never bring her into my home. She had done that with my grandmother, and she said she didn't want me to end up hating her the way she did with her mother. Rather eye-opening, isn't it? You might also want to meet with an elder care attorney to plan finances for the future before it is too late to do so.

If the time comes that they must be placed into a long-term care facility, whether assisted living or a nursing home, do not fall into the trap of feeling guilty. They will adjust even if it doesn't seem so at first. One suggestion I will make is that after they are placed, stay away for the first few days so that they can become oriented to their new surroundings. After putting my aunt into assisted living, I needed to go out of town for a couple days. On the way home, we stopped to visit. I expected anger or sadness, but she was off playing Bingo!

All you can do is to do your best. You don't have to be perfect and you don't have to be a saint. Stop feeling guilty, you can only do what you are able to... above all, ask for help.

DOCTOR VISITS

Try to schedule appointments at a time the doctor is less likely to be behind schedule. We usually schedule for the first appointment after lunch. The doctor is fresh, fed and

relaxed plus the wait is usually much shorter.

One of the best ideas I have heard is to tape record your doctor visits. Audio recording is adequate and be sure to clear it with the doctor. Though, I must say, if my doctor refused this, I would find a new doctor, but that is just me. This is a great idea, even if the caregiver goes in with the patient. So many things can be discussed that afterward you may not remember everything.

Encourage the doctor to engage both of you. This may sound silly, but if a doctor only looks at the caregiver, the patient may get frustrated and non-cooperative. The same can be said for the caregiver. If the doctor doesn't look to the caregiver to affirm or deny what the patient is saying, that isn't going to work either.

There are doctors who specialize in geriatric health. These doctors may be more familiar with dealing with patients with dementia. Odds are, they deal mostly with Alzheimer's disease, but there are enough similarities to make it work. I also go into any new doctor's office armed with FTD information. It continues to amaze me that so many medical professionals know nothing about FTD.

There are hints to survive the waiting room in the category "Waiting Room."

DRESSING

I lay out clothes for the next day in the early evening when my brain is still in gear. When the caregiver needs to take over this task, I suggest laying them out side by side, not in one pile, so all can be seen. Tying shoes can be a problem. Slip-on shoes, leaving the shoes pre-tied to be slipped on or Velcro fasteners are good ideas. There are also lace alternatives available that are stretchy permanent laces that are not easy to be undone. A dot on the inside back of all their shirts and pants may help for them to get them on correctly. I must wear compression stockings and they are more comfortable if you keep them to one leg throughout their lifespan. I mark a big R, for right, and L for left, on the soles in permanent black marker. It speeds up putting them on correctly. Try to avoid needing to rush the dressing process and allow plenty of time. If you rush them, it probably will not be done more quickly and will save blowups from both the one with FTD and the caregiver.

It takes me anywhere from 15 to 30 minutes to get dressed, even with my clothes laid out. My brain does not "wake up" until around noon most days. I may be awake and out of bed, but my brain has not yet engaged. I like to be left alone in a quiet room with no distractions and no one to see me get confused. Sometimes, I will pull out several outfits to wear then get angry when I have to hang them back up. By doing it alone, it keeps me from lashing out at anyone else and setting a bad tone for the day.

If self-dressing is no longer possible, still try to dress the person with FTD in a quiet room away from distractions. I used to sing silly songs to my mom like "Now we put our shirt on, shirt on, shirt on..." Silly things like that to keep her attention focused on what we were doing. It is something I used to do for my daughter when she was an infant and interestingly translated into my life as a caregiver.

Keep clothing comfortable. Try to not have the clothing tight or difficult to put on or take off. Pullover shirts are easier than ones that button. Elastic waist pants might be easier to take off and put on, as well as easier to deal with when using the bathroom.

If the person with FTD is refusing to get dressed and if they will be home all day, I don't see anything wrong with staying in pajamas all day once in a while, or in sweats. I have done it myself many days.

DRIVING

This is often a very difficult subject to deal with. Driving is so much a part of us and a huge part of our sense of independence. When do you stop allowing the one with FTD to drive? Those with FTD who live alone seem to be the most reluctant to give up the privilege of driving. When you insist they stop, it can be a huge battle.

I have heard many say that they can still drive because they have not been in any accidents or dented their car. It would be simple if that was the only issue. The other issues are lack of impulse control, reduced vision, sudden anger and the risk to others. Personally, I quit driving after a near miss. I was out, saw a restaurant and decided I would pick up dinner. Lacking impulse control, I immediately pulled into the parking lot, forgetting that there might be cars coming from the other direction. I had a couple very irate drivers screaming and honking at me. That was the last time I drove, realizing that I could have hurt or killed someone.

I had already cut back on my driving and would only drive when my husband was unavailable to drive me. The problem was that I would get lost. I would know where I was, but I had no idea how to get to the next point. One morning, on my way to work, a street was blocked so I had to take the next street. I got halfway up the 2-block distance and stopped in the middle of the street because I had no idea how to get to the office from there. I was just around the corner and the route I was taking was the same route I would leave work every evening. I was devastated, to say the least. My husband started driving me to and from work. I was fired shortly after that anyway.

In many states, you can ask the doctor to notify the DMV regarding a driver you believe to be unsafe. That way you don't have to be the bad guy. In other states, you can send a letter yourself to the DMV identifying an unsafe driver. Many react the same way I did, and stop on their own, but many others go kicking and screaming. Keys must be taken away and hidden well to prevent them from taking the keys and taking off. I wish I had any easy answers on this issue, but I don't. It can get ugly, so be prepared with preventative measures ready to go.

ENERGY

When I was acting as a caregiver, I did not understand how limited the energy stores are in someone with FTD. Now that I have it, I have figured out that every little task takes so much more energy than it did pre-FTD. I have decided that it is because not only do I have to do the physical exertion, but also the increased exertion needed from my brain in order to do those things.

I will use the example of a trip to the grocery store, one of my least favorite activities. The physical energy is depleted by preparing to go, walking around the store, reaching and stretching for the right items, taking everything out to the car and loading it, then coming home to unload everything and put it away in the proper place. The mental energy is depleted at the same time by having to make the list, then when we get to the store I need to find the right items. If what I want isn't there, it is draining to try to think of an alternative. Also draining is the background music, people talking, children crying and

running around. If I run into someone I know, I need to make conversation. Going through the checkout counter is extremely draining. Not being able to handle money transactions was one of my first symptoms and it has gotten worse, not better. A trip to the store ensures that I am exhausted for the rest of the day, my patience will be non-existent and I will be difficult to get along with. It is not unusual for this reaction to continue through to the following day.

For me, one of the most exhausting and frustrating parts of a trip to the grocery store, or any other store, is doing it with my husband. I am certainly unable to do the shopping by myself and he has not been able to learn how to do it by himself. Some tips on how to make it work... The caregiver should stay within sight, leading, not following. That will avoid the one with FTD from continuing on when the caregiver has stopped to look at something. It causes panic when I turn around and he is not there. Don't spend time looking for something after the one with FTD has either found it isn't there, has already found a substitute or decided we don't need it. For me, that is no help at all and it makes me feel that I am not capable of making a decision. After I have decided what to do, I am ready to continue, I don't have enough energy to be able to spend much time for each and every item. Try not to argue. I am already stressed from the sensory overload the store causes me and any arguing will most likely be met with me blowing up. It is probably the best idea for the caregiver to do the shopping alone, if possible.

EXERCISE

The neuropsychiatrist who originally made my diagnosis made me promise to walk the equivalent of two blocks a day. At first that wasn't too difficult. Unfortunately, as my gait got worse it became more so. I started walking on the treadmill but that ended in disaster after I fell off on two occasions. When, without warning, your leg or foot doesn't get the message from the brain that it is supposed to move, it can be downright dangerous on a treadmill.

To compensate for not being able to walk, I do lower leg exercises, I walk around the house more. I walk around our large deck or the driveway. Grocery shopping takes care of the exercise for one of the days.

My mother was the same way. She totally resisted going for a walk even though her neighborhood was flat and had decent sidewalks. I could never understand why, but I certainly do now that I am on the other end. There is no sense of security when I walk. I never know when one of my feet will not move, causing me to stumble and oftentimes causing me to fall.

Walking outdoors can also be dangerous with the lack of impulse control due to FTD. I was almost run down by a dump truck while going out for the mail. I need to cross the street to get to our mailbox and since I knew where I was going, I went. I forgot to look to see if the street was empty.

I was very upset the day I admitted to myself that I needed a walking aid. I started out with an awesome walking stick that my father had made for my grandfather many years ago. It was nice that I had that stick to ease me into the need for a cane. It was easier to accept needing a cane once the walking stick was not enough. The next step beyond the cane is a rolling walker.

The wheeled walkers are usually four-wheeled, have a pocket for your "stuff" and a seat to sit on if you need to rest. Many have reverse brakes. The walker will only roll if you are

holding up the handle. If you let go, the walker stops moving. There are also three-wheeled models that are better for tight places and are a bit easier to maneuver. These, though, do not come with a seat. At the time I am writing this, I am in the selection process for one of these rolling walkers. It should be easier to walk a bit more when I have one to lean on. I came up with this conclusion from leaning on the grocery cart. I walk much better holding onto the cart.

My doctor has informed me that Medicare and most insurances will pay for, or help pay for, these walkers. The paperwork is quite onerous, but she says they are almost always eventually approved.

EYESIGHT

FTD can play tricks on your eyes. Double vision is very common. Many eye doctors will suggest prism lenses to bring the two images in line. Unfortunately with FTD, they usually do not help. Prism lenses seem to work best with muscle issues of the eyes. With my double vision, it varies constantly. Sometimes the two images will be overlapping, other times the two images are far apart. There is no way a permanent prism can help.

The double vision can quickly lead to a headache. When in a car, I must consciously focus on something inside the car because, for me, the further away I am looking, the further apart the two images become. I am one of the rare "lucky" ones with FTD in that I can still read and, obviously, write (actually type, my handwriting is horrible and I often cannot figure out how to make the letters). I find the best way to read is on an e-reader or a tablet so that I can adjust the brightness of the pages and adjust the size of the fonts.

It is common for the peripheral vision to disappear as well. This can lead to accidents. I am constantly running into people because I can't see that they are next to me. I am often startled when I turn around and someone is standing there. Since I can only see straight ahead, unless they are talking or making noise, I have no idea they are there. When I am cooking, this can be dangerous when I turn around with a hot pan.

Another common complaint is light flashes. Some with FTD have told me that their doctors have explained that these worsen as more areas of the brain die. I have had retinal issues for longer than I have had FTD, so floaters and light flashes are a common thing in my visual world.

Because of my experience with retinal issues, when first seeing these light flashes, I would strongly recommend a visit to the eye doctor, either a retinal specialist or an ophthalmologist. This would be to rule out problems that can be fixed.

FEEDING

When self-feeding becomes difficult, be inventive. If knife skills are poor, serve meals already on a plate with everything cut up ahead of time. When cutting into bite sizes, think about if they swallowed this whole, would it go down. You can try finger foods that are sometimes easier for them to eat rather than wrestling with utensils. Many with FTD seem to eat very quickly, almost as though they think someone is going to take their food away from them. As long as they are chewing and swallowing, don't fight about how quickly they eat.

There are special eating utensils available for people with any type of dementia or motor system difficulties. Some operate with a gyroscope and turn themselves so that they are always level. I have also heard that red utensils are easier to see and they sometimes help. These are easily found on the internet. If your loved one joins you for family meals, try to keep distractions to a minimum. This would include background noises, such as having the television or radio playing. It might be easier for them to self-feed if that is the only thing they are focusing on, without distractions. Restrict arguments and keep conversations calm and low volume.

When my mom reached the point that I needed to feed her, I tried to make a game of it. We would laugh and I would do the old "here comes the airplane" thing that most of us did with our kids. She would giggle and take the bite. I would also sometimes feed one bite of healthy food, then one bite of sweet food. The sweet food was anything from applesauce to soft fruit or even a bit of pudding or ice cream. I didn't see anything wrong with one bite of dinner, one bite of dessert. It worked, that was all that mattered.

Some with FTD lose some of their sense of taste. I found myself using more spices and herbs to make the food taste better for my mom and aunt. Now, I do the same thing when cooking my own food. I also add onions and garlic to most everything except dessert. I also try to make food that is moister in nature, including stews, foods with sauces or gravy and try to cook food that is tender and easy to chew. The moister foods seem to be easier to swallow for me. That, along with cutting into tiny pieces, also helps when one forgets to chew before swallowing.

FOCUS – ONE THING AT A TIME

There is no way to stress this often enough. One of the first nasty tricks FTD plays is to steal your Executive Functioning. This is the ability to focus on more than one thing at a time. It is also being able to think ahead to the next step. Someone with FTD has a limited attention span and can literally only focus on one thing at a time. When I say one at a time, I don't mean eating dinner is one thing. Taking each bite can be one thing. Figuring out where the salt is one thing. Remembering how to take a drink, using the napkin and the list could go on forever. I like to use the example of baking a cake. Baking a cake used to be one thing to me but to someone with FTD, it quickly can become an overwhelming task. You must remember to preset the oven. You must find the proper pan and follow the directions to prepare it. Then comes collecting the right ingredients and following each and every direction of adding them. It becomes a multitude of things quite quickly and can overwhelm very quickly.

I see a psychologist to help me deal with my issues with FTD. One of the best things she has suggested is to make a copy of the recipe or instructions from the box so that I can check off each step as I do it. I have found this a tremendous help for me in order to continue baking. Baking is something that I have always loved to do and this trick is making me to be able to do it after I had just about given up on trying.

Less background noises and activity around the person with FTD helps their attention span. If they are doing something (watching TV, reading the newspaper, trying to cook, truly anything) do not ask a question and expect an answer. All the focus is on what they are currently doing and by asking a question, you have thrown them into sensory overload and they cannot do either one. They are also likely to get frustrated and lash out.

For me, watching television has changed significantly. I can only focus on a show for

about 30 minutes. The thing that has surprised me is that I often do something with my hands (coloring, etc.) to keep myself from fluttering my hands and just listen to the program. When I hear something important, I will look up at the screen. I have no idea if this is true for others or why it works for me.

I play memory games on my computer and as I progress, they take a lot more focusing. If someone turns on the television or talks to me, it stresses me to the point that I cannot do it any longer. If I am trying to do what house or yard work that I still can, I cannot have anyone talking to me. It isn't so much that it distracts me from what I am doing, forcing me to stop, but that it is sensory overload which stresses me enough I must quit whatever I am doing.

I will repeat a story I used in another category. The other day I was struggling to loosen the laces on my shoes. I just could not figure out which part to pull next. While I was concentrating so hard on what seemed to be a simple task, I was asked a question. I blew up at the questioner. It is sometimes difficult for the caregiver to understand how complicated what seems to be a simple task can be to someone with FTD.

Things like this simple example happen quite often because it is extremely difficult for most people to grasp an understanding of the "one thing at a time" principle and how something that seems like a simple task can, for us, be a multitude of tasks. Unfortunately, it seems to get worse as the disease progresses. I find, more and more, that once I am interrupted or distracted from what I am focusing on, I cannot get back into what I was doing. That in turn angers me. I oftentimes will stop watching a television show or whatever I am doing if someone keeps asking me questions.

FRIENDS

Keeping up with friends, or even family can create a multitude of problems for someone with FTD. We may be reluctant to socialize with some people because we are uncomfortable being with them. We might feel almost ashamed of our condition and don't want our friends or even family members to witness our condition. It may also be a moot point, because it seems FTD scares people enough that they don't come around us anyway. Like the old adage says, "You learn who your friends are." In my experience, I swear they think the disease is contagious. People appear to be uncomfortable that we don't seem to be the same person we used to be. Duh! Yes, we have a terminal disease that steals more of our functioning abilities every day.

One of the cruel things about FTD is that the parts of the mind stay strong. It is not like Alzheimer's disease where the memory is stolen pretty early on in the disease process. We still remember the people who were in our lives before FTD and we still remember the things we used to enjoy doing. We are also still very aware of our surroundings and the reactions of the people around us. We very quickly sense when someone is embarrassed or reluctant to spend time with us. We often pick up on those signals more quickly now than before FTD.

I had a life-long friend who mostly avoids me. I think it started before I was even diagnosed. I was early meeting her for lunch at a mall restaurant, so stopped into a store, found a beautiful shirt, tried it on and bought it. When we were seated in the restaurant, we realized I had put my original shirt back on inside out. She seemed to be extremely embarrassed. Some people just cannot deal with their friend or family member being different than they used to be. For me, I accept that. It still hurts, but I understand and accept it.

On the other hand, you may find a friend that you didn't have before. I had decided that I had to just give up on having any friends when I ran into someone whom I had known a few years ago but just as we were getting to know each other, circumstances caused us to drift apart. She is now my best friend. She has learned about FTD so she can understand what I am dealing with. She supports me and encourages me. She reads about FTD and attended a caregiver seminar. She will take me out to lunch and not be embarrassed if I make a mistake. So don't give up on friendships.

GROOMING

The apathy brought on by FTD may make the person with FTD not care what they look like, if their hair is clean and styled or what their clothing looks like. They may need encouragement and assistance. Try your best to get them to brush their teeth. If this is not possible and you need to clean their teeth, try a child-sized toothbrush or a little toothpaste on a piece of gauze and, if they will let you, clean off their teeth as well as you can. Mouthwash does not always work because the concept of "swish and spit" doesn't always still make sense.

A washing of the face with a soft washcloth does wonders. Rather than moistening the cloth and rubbing soap onto it, try making some soapy water in the sink and wet the washcloth with that. That way, you don't have concentrated spots of the soap on the face cloth to possibly get in the eyes, nose or mouth.

Try to maintain an easy-to-care-for hairstyle, what I have always called a "brush and go" style. It makes things much easier. I found it easier to wash mom's hair in the kitchen sink using the faucet sprayer. Less water went in her eyes than in the shower. You can also use baby shampoo that doesn't sting the eyes if a little gets in there. I don't know if this is common with FTD, but both my mom and aunt had extremely dry hair and scalp. It would look like the worst case of dandruff, but was actually dry scalp. Dandruff shampoo made it much worse. I had to use a good conditioner every time. A leave-in conditioner made life much easier. There are dry shampoos to use if and when hair washing is no longer possible. To me, it seemed like they just soaked up the oil and didn't clean the hair. I had better luck using a wet wash cloth wet with shampoo mixed in with water.

One thing about the hair. Try to remember what they liked and didn't like before FTD. If they parted their hair on a certain side, keep doing that. Just a little change like that can make them feel like something is off. If they found pulling their hair back into a ponytail uncomfortable, try not to do that. I was furious one day when I walked in to visit my mom in the nursing home. I took one look at her and saw her hair pushed back with a big, thick hair band. Mom hated hair bands. She found them very uncomfortable and always said they gave her a headache. By that time, she was pretty much uncommunicative so she wasn't able to let them know nor able to rip it off her head. I could tell though, through her fidgeting that she was uncomfortable. I immediately removed it and refreshed her hair. When I asked the staff about it, I learned that a family member had brought the headbands to her, thinking it would be easier for grooming. She was bed-bound by that time. I cannot imagine lying in bed with this big, thick headband on my head. This also serves as a reminder that if they seem to be uncomfortable or are fidgeting, there may be a physical discomfort occurring.

Also see the section on Bathing and Showering for more information on this subject.

INDEPENDENCE

Most everyone is used to being independent and able to do things on their own. With FTD, it becomes more difficult as the FTD progresses. This can lead to the loss of "self." Not being able to do the things that we used to consider part of us is a feeling of loss, like part of us has died already. For me, it is my baking and my artwork. I have always made delicious, beautiful cookies. Each year, more people ask for me to give them a tray at Christmas. It was not unusual for me to make over 100 dozen in a holiday season.

Making and decorating cakes was also something I did for my family and friends. I can still struggle through making the cake and the frosting, but my decorating abilities have gone by the wayside. I used to paint and was an award-winning ceramist. Not anymore. I cannot begin to explain how painful it is to admit to myself that I cannot do it anymore.

I have learned tricks to still be able to do baking on a much smaller scale. The recommendation of copying the recipe and checking off the ingredients has helped quite a bit. Sometimes, though, that is not enough. I made a recent attempt at making a cookie that I have made since I was about 10 years old. I had to throw out three batches of dough until one was adequate to use and it wasn't perfect either. This caused me a few days of deep depression. Here I was, 63 years old, not being able to do something I was doing as a child.

I love coloring in adult coloring books (it could be children's books if the adult ones are too difficult). I am not creating any great works, but since it is artistic, it helps me. I can sit and do it for hours. I use colored pencils because it is too easy for me to make a mess with markers and even crayons. If I accidentally sit on a colored pencil, I may stab myself in the butt, but I am not going to ruin the sofa.

To me, it is still important that I keep trying. If that means only doing the easy cookies that maybe don't look so beautiful and I am not creating great works of art, I must continue to try doing things on my own to maintain a sense of worth.

My husband has taken over laundry duties, but I still like to be able to help by folding my own clothes. Sounds easy, even to myself, but when I try to fold things, I sometimes can't figure out how I am supposed to do it. Sometimes I end up kind of balling things up and stuffing them in the drawer. That is the reason I only do my own clothes. But being able to do some things on my own is important. It is more important that I help do my own laundry, even just by folding, than it is for my drawers to be neat. It took me a while to realize he was only giving me underwear and pajamas to fold. He did the rest so I don't go around in wrinkled clothes.

Try to find things for them to do. If you are doing laundry, ask them to fold a couple towels. You may have to redo them after they go to bed, but it is still worth doing. You could ask them to dust a room. I would choose a room that doesn't have much clutter, such as a dining room or a bedroom to reduce the chance of breakage. Think of simple things that are a single step and be specific when you tell them so they don't have to figure out how to do it. Don't say, "Clean up this mess." Instead, try something like "Could you please pick up that newspaper and put it in the trash can under the sink" or "Could you come over here and get the bread out of the bag for me?" As the disease progresses, even these seemingly simple things may not be possible. I feel it is important to keep trying to give them a sense of worth, even if you have to make up little chores.

MEDICATIONS

At this time, there are no medications to prevent, cure or postpone FTD. There are medications that are contraindicated for FTD, including the medications for Alzheimer's disease. A list of medications that are NOT recommended for use with patients with FTD is available at: <http://memory.ucsf.edu/ftd/overview/ftd/treatment/multiple/medications-avoid>

There are medications that are useful for treating the symptoms of FTD. Antidepressant medications often help. Many FTD patients suffer from depression and it often increases as the symptoms worsen. There are medications that will help with mood swings and anger. At this time, many with FTD have been prescribed Seroquel. It is an antipsychotic medication that is often used for extreme mood swings. It is also used to treat the depression swings of bipolar disorder and schizophrenia. What interests me about this usage is that FTD is often misdiagnosed as one of these two diseases, among others. I have no personal experience with this drug, but have been told by many people with FTD that it has helped tremendously. I do have experience with taking an anti-depressant and can say that it has helped me immensely. Without it, I don't think anyone would be willing to live with me.

When a new medication is prescribed, it is important to watch for side effects and inform the doctor of these side effects. If it seems to be a serious side effect, contact the doctor right away.

I would suggest that you never be reluctant to discuss any symptoms of FTD with your doctors. Any time something new starts to happen, ask about it. Some of them may be things that are tolerable to people without a neurological disease, but they start to add up quickly when you have FTD. There are so many changes that we have to deal with, as one with FTD and as the caregiver. It makes no sense to not try to eliminate any that can be.

SEX

This is a very difficult subject for me to address, but address it I must. A common symptom of bvFTD is hypersexuality. Just when you are probably in no condition to have a healthy sexual relationship, many days that is all you can think about. It is not unusual for someone with FTD to make totally inappropriate sexual remarks to anyone, even strangers. They may even make unwanted sexual advances toward someone. If you add lack of impulse control to hypersexuality, that is what you get.

It may trigger an increased or overwhelming desire for sex. Someone who never looked at pornographic websites or publications may start to do so or even get addicted to it. They may constantly ask to have sex with you or want to try new things.

Hypersexuality may be one of the earliest symptoms of FTD manifesting itself, so early that a diagnosis has not yet been made. This may cause you to think they are unhappy in your marriage or relationship. I hate to say it, but some have actually begun affairs. Singles will spend an inordinate amount of time trying to meet a new sexual partner.

Do not be afraid or embarrassed to talk to your physician about this issue. There are medications that may help. Also, by realizing that this is a symptom of FTD and not just them being a jerk, it may help you to deal with it in a safe and sane manner. If you see a

psychologist, this would be a good subject to address there.

SHOPPING TRIPS

Shopping can be exhausting. I used to try to talk my mom into going out shopping just to get her out of the house. I could not understand why she resisted so much. Now that I am the one with FTD, I totally understand. It requires so much energy and can cause endless frustrations. Mental energy is depleted just as quickly as the physical energy. The crowds, finding your way around the store (and why do they always rearrange things?), finding what you are looking for, the background music, children crying, people talking and more can quickly become overwhelming.

I do have some suggestions to cope with shopping trips. First of all, don't attempt it if the person with FTD, or the caregiver, is already having a stressful day. That is a recipe for disaster. You should have a pretty good idea of what time of day they are most capable and when the stores are less crowded and try to go at that time. I suggest only visiting one or, at the most, two stores in one day. I totally avoid malls as they are too overwhelming and quickly produce sensory overload before even entering a store. Stand-alone stores and strip malls where you can directly enter the store are much better for me. If I am making an afternoon of it and want to stop for lunch as well, I must only visit one store. Keep the amount of time in the store as brief as possible. Browsing, just for the sake of browsing, is probably not a good idea. Some people with FTD, who loved to shop before FTD, actually come to hate it. Take someone like me, who never really liked to shop anyway, and it is literally painful.

A good idea is to set up a spot in the store for you to meet up if you should get separated. Another good idea is to reinforce the idea that asking for help can be a good thing. Once in a while, while shopping, my independent streak will come crashing in. I have, several times, insisted on going to a department on my own. I have been known to stop six or eight people to ask for directions to the department I was seeking. It doesn't embarrass me because I figure the person doesn't know that I already asked six other people! Then, I repeated the questioning process until I got back to where we were to meet. This works for me, but only you, as the caregiver, can decide if it is worth taking the chance. One day when shopping with my sister, I did go to a different department. We had decided to meet up at the shoe department since it is right in the middle of the store and had chairs to sit on. It had been quite a while, so my sister asked them to page me. "Will Cindy please meet her sister in the shoe department?" She didn't use my last name so I wouldn't be embarrassed and specified where to meet her in case I had forgotten. Funny thing is, I had been sitting in the shoe department for at least 30 minutes. She didn't realize there were two sides to the department!

I have found that many stores, including department stores and discount stores, have a small stash of carts and usually one or two wheelchairs for the shoppers. Those carts serve as a walker for me. I will allow someone to push me in a wheelchair, but I will not use the motorized ones available in a lot of grocery stores. I can't drive a car so there is no way I can safely drive one of those either. I remember how much my mom enjoyed me pushing her around in a wheelchair when I would convince her to go to the grocery store with me. It was a new experience and a new sensation so I wasn't sure how it would go, but it worked if it was a quick trip.

Unfortunately, the closer you get to the end stages, the less successful any of these strategies will be.

SLEEPING

Sleeping can definitely become an issue. Many people with FTD struggle with nightmares. The first thing I always ask, when someone asks me about nightmares, is if the doctor has prescribed any of the Alzheimer's medications (Aricept, Namenda, galantamine, etc.). Many FTD researchers strongly believe that these medications are contraindicated for FTD. They are two distinctly different diseases and what works for Alzheimer's disease does not necessarily work for all dementias. The Alzheimer's meds can increase night terrors into horribly frightening nightmares. Often, upon awakening, the terror from the nightmare is difficult to get past. The fear can linger for hours. I experienced that myself and it was a serious problem with my mother while I was caring for her. In the section titled "Medications," there is a link to a website that lists the medications that are contraindicated for FTD.

Many with FTD do experience quite vivid and graphic dreams, but, in my experience, nothing like the ones while on the Alzheimer's meds. Physicians often can prescribe medications to help with sleep issues.

Another issue with sleeping is the number of hours of sleep needed. It is quite common for someone with FTD to require 12 or more hours of sleep each day. It was explained to me that it is not only your body that gets worn out and needs rest, but also your brain. With FTD, the amount of rest needed can be long hours. Also, if the one with FTD is experiencing vivid dreams, it may affect the quality of sleep which makes more sleep necessary. When someone questions why I spend so much time in bed, what I hear is that they think I am being lazy. I have actually had a couple people tell me that if I didn't sleep so much, my brain would improve. If only it worked that way!

Suggestions of things that might help someone with FTD get good sleep are pretty straightforward. Comfortable mattress, pillows and bedding, loose-fitting sleepwear, a cool room. Sometimes, playing white noise in the room will help with sleeping. Some have reported that a weighted blanket helps them rest better. Conversely, some do not like being confined with heavy covers. Unfortunately the one with FTD may not realize what is making them uncomfortable, so it becomes trial and error to find what works best.

SOCIAL GATHERINGS

Socializing can be a huge obstacle and an intimidating event. Usually with just a couple people, it will be fine, especially if those people know the limitations caused by FTD. Add in more than a few people and it can quickly become overwhelming. The need for handling just one thing at a time becomes hugely problematic. If more than one person is talking at a time, if voices are loud, if there is background noise even if it is just music or if there are just too many people present, it can quickly become overwhelming and lead to sensory overload. Sensory overload can cause a variety of reactions: total shutdown, screaming, running away, anger, crying and a total meltdown. It can be far from a pretty scene and quickly ruin any event. This is just as true if all the people are close friends or family members. Those with FTD do much better one-on-one or in small groups. More people can quickly lead to sensory overload, as well as conflicting noises, too many people touching them or demanding they join a conversation. On the opposite end, it can cause the person with FTD to withdraw from the group and make those present think they are being antisocial.

There are some things you can do to help. Make sure there is a quiet place that the one

with FTD can retreat to if things get too intense or frustrating. Try to let people know ahead of time about sensory overload. It might help if only one person approaches them at a time, keeps their voice low and avoids touching, depending on the reaction received. One thing that can help is to move them to a quiet corner. Any time I enter a room, I try to locate myself in a corner where people can only come up to me from one direction and where an exit is in sight in case it gets to be too much and I need to walk away for a few minutes to regroup. I find that if someone can approach me from behind it is too much of a stressor. Since FTD can steal your peripheral vision, people approaching can startle you. It startles me to the point that I become frightened and/or overwhelmed. Also, limit the length of time you stay or limit how long you allow others to stay if the event is in your home.

I have heard from others with FTD and have experienced myself the well intentioned reassurances such as "It will be okay, it will only be family or friends that you know." Family reunions are often like that. People seem to think that if all those attending are family members that you know, that everything will be just fine. I heard a care partner say to someone with FTD, "Oh, it won't be any problem, there will only be 30 or so people there and they will all be family!" In that case, give me a place to hide! Two or three people I can handle, more than that and I won't be able to. To be among that many people is just too much for me and probably too much for anyone with FTD.

Besides the risk of sensory overload that could trigger a major meltdown, cause me to scream at someone to get me out of there or to get these people away from me, I would not be able to communicate. I would stutter and not be able to have any kind of normal conversation. I would become stressed to the point that I might forget who people are or say inappropriate things.

So, limit the number of people, the background noise, the touching, the approaching from behind, children or animals running around and being loud. These things, along with any other things you can think of that triggers bad responses from your loved one, will increase the chance that the occasion will be successful.

I did attend a family reunion a couple years ago. I sat off by myself and let the other family members come over to me to visit. We only stayed a couple hours, but even with limiting the stress, when I was leaving I had more difficulty walking than I had ever had up to that point. My sensory overload was so bad that my brain wasn't even able to tell my feet to move even using my cane. My husband actually had to walk right up against me, walking in step with me and pushing my feet to trigger my brain to move that foot. I have no idea how he thought of that, but I'm thankful that he did. Fortunately, I laugh when I realize everyone who saw me probably thought I was drunk when all I had to drink was water!

SPEECH

I am limited in experience with speech issues, especially aphasia. None of my family had any form of aphasia with their FTD and I don't have aphasia yet either. My advice on this is to find Facebook support groups on the subject. I know there are numerous aids available to help those with aphasia communicate more and I am sure you could get information on those in the support groups. They could tell you which ones work best and where to get them.

I can address other speech problems though. My main speech issue is that when I start to talk, I will get stuck on the first word of a sentence and keep repeating the first syllable.

“When are we going?” will come out as “wh, wh, wh, wh, wh...” Most often I will give up and stop talking, waving my hand in an erasing motion, and walk away. Other times it will come out something like “Whhhhhhen going?” As you can imagine, this is extremely frustrating, probably to the caregiver as well. It is definitely worse when I am frustrated, upset or tired. Then not being able to talk frustrates me more and often leads to an emotional breakdown. Other times, I will get the first word out, but it has taken so much effort that I forget what I was going to say. This situation is one of the very few that will cause me to break down in tears.

It also helps if the person I am speaking to, especially my caregiver, touches my hand and tells me to just relax for a minute. I can usually calm down and the words will come out. It makes things worse if someone tries to finish my sentences, guessing what I intended to say. That adds to the frustration and often causes me to stop talking at all.

Because being able to read and write is so important to me, I do word games on my computer. They can be finding words in a puzzle, making lists of words that start with a certain syllable, things like that. While my ability in these games is regressing, I still do them every day. It is believed that learning new things can help slow dementia, I figure it is worth a shot. It is certainly not a cure-all and probably will not be effective for everyone. Even if I am fooling myself into thinking it helps, at least it occupies some time.

SUNDOWNING

Sundowning is a term you hear often when discussing dementia issues, in FTD and Alzheimer's disease. It often manifests itself as late-day confusion, causing agitation and discomfort. There are things you can try to reduce these symptoms. Try keeping to a schedule as much as possible. Once daylight starts to fade, turn on lights. A small lamp is not going to be sufficient. I use a full spectrum light or light box in addition to turning on lights. These are often used for people who suffer from seasonal affective disorder which causes issues during the seasons with shorter days. I have one in my family room that I leave on all day, especially in winter. Sometimes it helps to switch meal schedules to a heavy meal at noontime and a lighter supper. Try to reduce napping and increase activity if at all possible.

Perhaps the biggest issue with limiting sundowning effects is limiting stress. A loud television, more than one person talking at a time, dogs barking, kids playing outside, all can all be over-stimulating. More than one stimulus of any kind at a time can be too much. Watching the news or programs on television may be too stimulating late in the day. For some, trying to read is too much.

The best thing you can do is to track what triggers the sundowning and try to eliminate those triggers. Sometimes an earlier bedtime can help by avoiding some of the stressors. Combine this with lighter meals at dinner time so they are not trying to sleep on a full stomach. It's all about trial and error.

Sometimes, it becomes necessary for a prescription medication to be prescribed. Do not hesitate to discuss this or any changes with the doctor. For those of you who live in a state that has legal medical marijuana, many people with FTD have had success with using that, especially for the sundowning. Trying a white noise machine may also provide some comfort.

SUPPORT GROUPS

Support groups can be invaluable. There are support groups for caregivers as well as for those with the disease. There are live support groups and online groups. These are places where you can feel safe talking about the issues you are dealing with. It is also a great place to gain information and suggestions for coping. It is, most often anyway, a nonjudgmental place where you can get a hug or hear a joke when you need it.

There are days and weeks that I could not get through without the support of the online support groups where I participate. The one that helps me most is the one that is restricted to those with a confirmed diagnosis of FTD. No caregivers are allowed in.

Live support groups dedicated to FTD are pretty rare. They are more common in larger metropolitan areas and near major medical centers. Where there are none available, I know of several people who participate in dementia support groups that are geared more toward Alzheimer's disease. The frustrations are similar in both and if nothing else, they give a place to vent frustrations.

Online support groups on Facebook can be wonderful. Modern technology is just amazing sometimes. Most are private, closed groups that require you to request membership into the group. There are also some online groups that utilize video chats. The good ones maintain your privacy at all times so that you can feel free to discuss just about anything. It is somewhere that you can write a message about something you are experiencing or struggling with and get several suggestions on what might help. Sometimes the virtual hugs you get are just as good as the ones in person.

SWALLOWING

Swallowing can become a feeding issue, especially during the later stages of FTD. Many doctors will recommend seeing a speech therapist to address the swallowing issues. Unfortunately, there are often issues with Medicare when trying to get the visits approved or paid for. I do not have any personal experience with speech therapists, so I cannot really give advice about whether it is effective or not.

When swallowing issues first appear, there can be difficulty during feeding. There are some tactics I have found successful. Cut the food into small pieces. Try to keep the sizes small enough that if they are swallowed without chewing, they will get down. Try to avoid dry foods. If I am served a sandwich, I take as much of the bread off as I possibly can. I will also add things to moisten it, such as mayonnaise, tomatoes, pickles, etc. For some reason, people with FTD tend to eat very fast. Try to slow down the pace, no new bites until you are sure the last one has been swallowed all the way. Drink liquids before and during meals to keep the throat moistened. Don't serve large things, like an apple. Instead, try apple sauce or cooked apples. Raw apples, especially with the peels, were one of the first things to give me swallowing problems. Interestingly enough, while I personally find that it helps me to drink more and eat moister foods, for some, it can work the opposite way as well. It becomes trial and error.

There are no tried and true ways to deal with swallowing. All you can do is pay attention to what is happening, and try to find a way to work around it. Unfortunately, it can be ugly and uncomfortable to deal with. Oftentimes, when they cannot swallow, it will lead to spitting things out which bothers a lot of people to see.

In later stages of FTD, swallowing of even liquids can become difficult. There is a product called *Thick It* that can be used to thicken liquids so they can be swallowed.

In the end stages, when swallowing is no longer possible, many health care professionals will recommend a feeding tube be inserted. This is something that you might want to address in a living will. I have it in mine that I do not want a feeding tube at all.

TRAVEL

Most everyone knows this, but just in case, in most states, you can qualify for a Handicap placard with a neurological disease, it doesn't have to be an obvious physical disability. You can also qualify for one even if they no longer can drive. As long as they are in the car, it can be used.

Traveling in a car for long distances can be a challenge. Bring snacks and bottled water. If noise canceling headphones work for your loved one, this is a good opportunity to utilize them. Limit cell phone usage by anyone in the vehicle as it can be another distraction that can lead up to sensory overload which can be pretty unpleasant trapped inside a car. Try to make frequent rest stops for bathroom breaks as well as walking a bit. Sometimes, those with FTD do not communicate or even understand what is making them uncomfortable. Something as simple as shoes feeling tight due to feet swelling from sitting too long can cause distress and add to the overload.

If it is going to be a long trip, don't be afraid to ask the doctor for medication to help make the trip more comfortable. Sedatives are not usually good with FTD and some are on the contraindicated list, but they are sometimes useful on a short-term basis. Oh, and I am saying for the one with FTD, not for the driver!

Air travel can sometimes be a challenge as well. Checking your baggage may help rather than trying to carry everything on. Having your hands full of bags and trying to keep track of everyone can be difficult. Most airports offer attendants with wheelchairs. You can request them as soon as you enter the airport or exit the plane if you have not arranged for them ahead of time. They are free of charge, but tips are greatly appreciated and will go a long way toward the attendant going above and beyond.

You hear horror stories about the TSA. There is one great service that they offer, however. You can call the TSA before your trip. They will take all the information and will arrange for an agent to meet you at either the airport entrance or the entrance to the TSA checkpoint. This varies from airport to airport. Often the actual agent who will meet you calls you ahead of time, then has you call them when you arrive so they can meet up with you. They get you to the front of the line at the checkpoint and can walk you through if necessary. I had an agent stand right by me at the checkpoint station and tell me each step of the way what I needed to do. This was things like, to put my feet on the footprints of the scanner and to put my hands up in the air. He also helped me get my baggage scanned, telling me what to get out and show them. One even helped me put my shoes back on after they were scanned. This is all a free service, it is called TSA Cares. No tips for the agent, just for the wheelchair attendant.

As I said, a tip to the attendant can go a long way (though not to the TSA agent). We had one take us through TSA with the agent, then take us to a restaurant for breakfast, leave us there, then picked us up at a decided time and took us to our gate.

Most hotels offer handicapped rooms. Often, they have a clearer traffic pattern to make it safer, and larger and more accessible bathrooms with additional safety features in the shower. If staying in a hotel, try to take some familiar items with you. If you are traveling by car and space allows, bring their own pillow to help them be comfortable. I have a silk scarf that I like to hold onto when I start getting stressed or when I am trying to sleep. Things like this are easy to stuff into a suitcase. You might want to pack night lights, especially for in the bathroom. Try to keep things quiet and calm in the room if the room is being shared. Bring snacks and bottled water or juice to the room. Dehydration can be a problem on an airplane, in cars and in hotel rooms.

If you are staying with friends or a family member, there are things you can do ahead of time. Explain to them what to expect from the person with FTD. Ask if there is a quiet place in their home where they can go if they start to become overwhelmed. Explain that simpler is better, not too many people, no loud music, etc. Offer to make concessions. If there are children in the home or anyone who would be put off by the feeding difficulties, if there are any, offer to eat separately or in a different room (such as eating in kitchen while others are eating in dining room). Try to keep a balance between the comfort of the one with FTD along with the comfort of your hosts.

WANDERING

Sneaking out of the house and wandering the neighborhood is a huge problem with some. Sometimes it happens because they are frustrated and confused, no longer feeling comfortable in their own home to the point they don't think this is their home. So they go out searching for "home," where they always felt comfortable. If your loved one is a wanderer, I strongly suggest you get ID on them. You can get a medical alert bracelet stating that they have dementia and list a contact number. If they won't wear that, there are ID tags that you can attach to shoelaces. If necessary, write your phone number inside the collars of all their shirts.

A friend of mine put child-proof door hooks high on their storm doors to keep her dad from inside. You could try deadbolts, but make sure all the keys are out of reach. Keep all car keys out of their reach as well as they may not remember they no longer drive.

Call your police department and give them your address and phone number, along with a description of your loved one. Many departments keep a list of those likely to wander off.

I have heard of people hiding the shoes of their loved one to keep them from going outside. I don't think this is a viable solution because they might just go out barefooted which brings on its own dangers.

All my suggestions are from others' experiences. I was fortunate that none of my family members were wanderers and I am not (yet) either. Of course, Grandma did sit in her second story bedroom window and scream at anyone she could see, begging them to come get her and take her home. It ripped my heart out, but fortunately mom's neighbors were aware of the situation. I only remember two occasions when people not from the neighborhood called the police because they thought she was being held prisoner or being abused.

WAITING ROOMS

Doctors' waiting rooms are just as difficult for someone with FTD as they are for children. It is boring to sit there for any length of time. Just the fact that it is an unfamiliar place can be enough to upset. Again, add in other people, children, talking, televisions or background music and it can quickly become a stressful situation. Handing them a magazine to look at can just be another stressor, not something to keep them occupied. If possible, bring something to keep their hands busy. I have some simple games on my Nook eReader that I play while waiting. Some with FTD find holding something to be soothing. There is nothing wrong with them holding onto a stuffed animal or a piece of fabric they find soothing. I have a silk scarf I hold when I am stressed or when I am trying to go to sleep. Something similar might help.

Another thing we often forget about is that holding hands can be soothing to a lot of people. Just that light reassuring touch and reminder that you are there for them can go a long way. Of course, there are just as many who don't want to be touched. As with most everything, it comes down to trial and error and imagination. Try anything and see if it works.

Many people with FTD use noise-canceling headphones. Bose headphones are on the expensive side but seem to be the ones that work best and are the most comfortable. You can use them with music or without, which just blocks outside noises. They can prevent sensory overload, especially in unfamiliar places or in a crowd.

One more bit of advice about waiting rooms. I learned this when I was going through cancer treatments. Waiting rooms are often germ incubators. Try to limit touching things. Those magazines lying in a waiting room? Stop and think about the last three people reading them. How healthy were they and did they wash their hands? No way to know. Most waiting rooms now offer hand sanitizer or you can carry it with you. Anyone with any chronic illness usually has a compromised immune system and should avoid any transferable germs as much as possible. Bring your own magazine if you want something to read. Also remember door knobs are a breeding ground for germs and viruses.

These are certainly not all the subjects that arise while dealing with FTD. I have tried to include the ones that I have seen asked over and over. There are publications available online that can answer your questions in a more formal way, by people with medical and/or research credentials. I have multiple stacks of online publications that I have printed out and often refer back to. One of the publications, by the National Institutes of Health, is one that I often recommend. It is the one I usually take with me when seeing a new doctor for the first time. I have had some doctors who actually keep it and the next time I visit I will be able to tell they read it. I have had others look at it for a few seconds and hand it back to me. The link to this publication is:

<https://www.nia.nih.gov/alzheimers/publication/frontotemporal-disorders/types-frontotemporal-disorders>

Another great source for information is the Association for Frontotemporal Degeneration. Their website is: www.theaftd.org

I realize I have taken a light-hearted approach to a lot of the issues here. Please do not take offense. I do realize how serious FTD and all its ramifications are. I just am one who tries to keep a smile on my face and looks for the positive side in all things, even when they are hard to find. Okay, sometimes impossible to find.