

Frontotemporal Dementia Part 2 - How FTD Is Managed

This podcast does not provide medical nor legal advice. Please listen to the complete disclosure at the end of the recording. Hello, everyone, and welcome to Everyone Dies, the podcast where we talk about serious illness, dying, death, and bereavement.

I'm Marianne Matzo, I'm a nurse practitioner, and I use my experience from working as a nurse for 44 years to help answer your questions about what happens at the end of life. And I'm Charlie Navarrete, an actor in New York City, asking, what happens if you die without a will? Answer, the laws of the state you live in decide who gets what. Two-thirds of Americans do not have a will.

Plan for the worst, prepare a will. So please relax, get yourself something to eat, loosen the top button of your shirt, and thank you for spending the next hour with Charlie and me as we talk about frontotemporal dementia. In the first half, Charlie talks to us how to live on

beyond the groove, and I have the recipe of the week.

In the second half, I'm going to be continuing our discussion about frontotemporal dementia diagnosis and treatment, which is the type of dementia that's been announced that Bruce Willis has. And in our third half, Charlie has a poem about loss. So a few weeks ago, we were treated to the Tom Cruise cake as our recipe of the week.

So if it works once, it's got to work 20 other times, right, Charlie? It's Tom Cruise, yes. So this week, we have Martina McBride's creamy chicken tortilla soup. And as she says, I do love making soups, and I feel like it's something you can put on the stove and let it simmer all day, and it makes the whole house smell good.

Well, she had me convinced. So yesterday, I made it, and I am telling you, this soup is freaking good. Yeah.

It's like you want to pick up the pan and just drink the soup part. Of course, it has sour cream in it, and heavy cream in it, and oh, God, it was so good. Whipping cream? Shaving cream? Not shaving cream, though, right? No shaving cream.

No shaving cream involved. So check out our recipe of the week. I'm telling you, it's a keeper.

So Charlie, what do you have for us? Well, I think we may have found the perfect place for the cremains of your loved ones, especially music lovers, vinyl. Wait, stay with me here. This is a company... Vinyl? Like the clothes? Like pants? Yeah, like Michelle Pfeiffer in her Catwoman costume in Batman Returns.

Yeah. Vinyl. Exactly.

Exactly. Vinyl. Okay.

I'm glad we cleared that up. There is a company in London that will press a vinyl

record with cremated remains of your loved ones, along with music, stories, or anything else you would want for a soundtrack. They are Env Vinyl, and they help people live from beyond the groove.

These are real vinyl records made using traditional vinyl production techniques, with additional specialist inline processes, not in great PVC blanks. Your audio is mastered and cut to A-side and B-side lacquers from which the metal pressing plates are grown. These pressing plates are used to press the hot vinyl into a record with the audio spiral groove impressed at this stage.

The cremated ash, cremains, is sprinkled on the vinyl before the final press. This results in pops and crackles while the record is being played, and you can hear them every time you listen to the record. You can prepare the album before you die, except for the cremains part, so that after your death, all they have to do is add the cremated remains, and you

have an album that the whole family can treasure.

You can use the album to tell your family and friends your wishes regarding your will, tell them favorite stories that no one asked you about while you were alive, share recipes, or anything else that can be pressed into a record. It takes three to five weeks for them to complete a record for you, and each side is 18 to 20 minutes long. Cost depends on how fancy you want to be, but they will be happy to give you an estimate.

Our show notes have their contact information and a video all about it. So, Marianne, does that appeal to you? Um, not really, because, you know, my theory is, as I've said before, if you're not going to listen to me while I'm alive, why do you care about listening to me when I'm dead? I'm sorry, did you say something? Yes, see? Yeah, okay. So, folks, please go to our webpage for the recipe to Martina McBride's Creamy Chicken

Tortilla Soup and additional resources for this program.

We ask for your support in the form of a tax-deductible contribution so that we can continue to offer you quality programming. Thank you in advance for going to our website to make your donation, as well as following us on Facebook and Instagram. Visit us at www.everyonedies.org. That's every, the number one dies.org. Marianne? Thanks, Charlie.

You know, last week we talked about the diagnosis of frontotemporal dementia and that there were three types that you can see with this disease. Specifically, there's a behavioral type, second there's the communication type, and the third type affects movement. This week I'm going to go over the diagnosis, the management, and what to expect from death from this disease.

So, typical symptoms that you see with frontotemporal dementia or FTD, let me just

give you a list. Inappropriate behavior in public, impulsivity, loss of inhibitions, overeating, and in particular, change in food preferences, such as suddenly liking sweet foods and poor table manners, neglect of personal hygiene, repetitive or obsessional behaviors, such as humming, hand rubbing, foot tapping, or complex routines, such as walking exactly the same route repetitively, seeming more selfish, inability to empathize with others, making you seem sort of cold or uncaring, irritability, being tactless or rude, being less or more outgoing than in the past, being lethargic, meaning, you know, kind of sleepy, wanting to lay around, lacking enthusiasm, and depression. And just even listening to that list, you can see how those behaviors would make it very difficult to care for somebody with this disease.

But let's talk more about evaluation. How do you know if you have the disease? Evaluating a person to determine a diagnosis of frontotemporal dementia is pretty difficult. In the beginning of having symptoms, people

may appear to be depressed or they may be misdiagnosed with Alzheimer's disease.

To help diagnose frontotemporal dementia, a healthcare practitioner has a few things that they can assess. And essentially, what they're doing is they want to rule out anything else that it could be that could be treated. So they'll perform a physical exam, ask about symptoms, look at personal and family medical history.

Most changes in behavior or personality caused by FTD may not be obvious at first. These kinds of symptoms, for example, risk-taking, loss of social or sexual inhibitions, or obsessive behavior, can sometimes look more like the person is going through a difficult or emotional challenging time as opposed to a disease. They can order laboratory tests to help rule out other conditions.

And they can order genetic testing. And this can show if the person's condition is caused

by a specific faulty gene. Now, having a genetic test can have a serious impact on a person and their family.

So genetic counseling will always be offered before a test. Because if they find that there is that faulty gene for frontotemporal dementia, then the rest of the family sort of has a choice to say, do I want to be tested? Do I want to find out that this might be in my future? So it's a pretty thorny issue. They will conduct tests to assess memory, thinking, language skills, and physical functioning, and usually order imaging of the brain.

A psychiatric evaluation could help determine if depression or another mental health condition is causing or contributing to the condition. Only genetic tests in familial cases or a brain autopsy, which you only do after a person is dead, can confirm a diagnosis of FTD. So it's either you find that faulty gene or you wait till after death and you do a brain autopsy.

That's the only way to absolutely say this is absolutely FTD. There are studies using biomarkers. And biomarkers are proteins or other substances in the blood or spinal fluid that can measure disease progression so that these can be tracked over time.

So if you see that these biomarker numbers are going up, you can say, well, they're increasing. This is probably what it is. But this is still relatively new.

Currently, there are no cures. There's no treatment to slow it down. There's no way to prevent it.

I was reading on Facebook that something about Bruce Willis being diagnosed with this. And somebody made the comment of, oh, he snorted too much cocaine in his day. It's like, A, I don't know.

How do you know that? And B, no. It has nothing to do with it, at least as far as we know. So I don't want to say you can snort all

the cocaine you want and not get frontotemporal dementia because I don't know if that's even true.

But it's highly unlikely that those kinds of behaviors led to his dementia. So let's not say that. So what you're left with, really, is to manage the symptoms, which can change pretty rapidly.

People don't kind of stay in one stage for very long. But there are what they document seven stages of frontotemporal dementia. So let me tell you about the seven stages.

So we know that frontotemporal dementia starts slowly. It can be very subtle at the very beginning. And it gradually worsens over time.

Unlike other forms of dementia, frontotemporal dementia does not immediately present with memory problems. It does present usually often at a young age, normally affecting people from age 40 to 60.

But you can see onset as early as people in their 20s and as late as people in their 80s.

This can mean that the behavioral and neurological effects of the condition are misdiagnosed or missed altogether in the initial stages. So stage one. Stage one is where you don't see any symptoms.

Early in many diseases, there may not be any symptoms. The disease has not yet progressed far enough to cause any symptoms. And the person would seem as being normal and completely healthy.

But you can have something sort of brewing, something beginning to change. And it's very subtle. Stage two.

This is where mild symptoms begin to present themselves. These patients will present with a slight change in social interactions and personalities. These symptoms might be so subtle at this point that a diagnosis is missed.

If symptoms are noticed, they might be explained away as the person being stressed or having a bad day or being grumpy or less kindly than usual. And it's really not until a little later that you look back and say, you know, he was acting this way, you know, a year ago or six months ago. And we just kind of just thought he was having a bad time.

So stage three. Stage three features some cognitive issues marked by a deterioration in social skills, meaning not good social skills, and issues including changes in language use and intellect. These changes, while still relatively subtle, are marked enough to draw the notice and concern of colleagues and family members.

Problems begin to occur at this point with behavioral and working memory and social skills, along with obsessive behaviors, which can include binge eating, overeating carbohydrates or sugars, snatching food from other people. Stage four. In stage four, the person will be having difficulty with regular

social interactions and will struggle with thinking, you know, cognitive kinds of puzzles and intellectual issues.

Their language may worsen. They might start using less words than before and struggling to speak in some instances. If a diagnosis is made at this stage, it's considered early onset diagnosis.

So early onset, and we're in stage four, which means it's been caught early and they might benefit for some treatments that might not work in later stages. And by treatments, we're talking like rehab kinds of things. I'll talk about those in a few minutes.

So I don't want you to think about treatment as, oh, there's a medicine. There's not. Stage five.

By stage five, the midpoint of the disease progression, the patient is clearly in need of medical intervention, often requiring the services of a carer, a nurse, or for some or all

of the time. Social skills are markedly poor. Intellectual and cognitive problems are commonplace.

And language and social skills are in decline. Emotional non-reactivity is another symptom that presents. And the patient may not react appropriately to news that should trigger a strong emotional response, whether happy or sad.

Until now, the disease has been progressing relatively slowly, but now will start to accelerate with degeneration occurring rapidly. In stage six, there's severe cognitive issues, loss of bodily control, including urine or stool incontinence, and a decline in moral judgment. They're all present at this stage.

Poor impulse control is another symptom of frontal temporal dementia. And this means that patients often need to be monitored around the clock to prevent them from behaving in a manner that could be dangerous to themselves or others. Speech

issues can occur with pronunciation problems presenting more and more commonly.

Stage seven, this is the last stage. And this is the hardest stage of any type of dementia for both the patient and the loved one. Patients can become withdrawn, struggle to communicate.

They can be very difficult to handle, refusing to cooperate with carers and becoming very distressed over minor upsets. Help will be needed for almost everything from eating and drinking to dressing and bathing. Eventually, social skills vanish entirely, along with motor and verbal abilities.

For the family and the care partners, understanding the changes in personality and behavior and knowing how to respond can reduce frustration and help provide the best care for the person with FTD. This is not easy. You may feel you don't know the person who

has FTD, the person that you loved and you knew has disappeared.

So some of the strategies for managing that try to make it a little bit easier for you if you're the caregiver is try to accept rather than challenge someone with behavioral symptoms. Arguing or reasoning will not help because they can't control their behaviors or see that they are unusual or upsetting to others. Instead, be as sensitive as possible and understand that it's the illness talking and not your loved one.

And let me tell you, this is really hard to do. You know, like if they're humming constantly or whistling constantly and you're saying, stop that. And they're like, what? What? I'm not doing anything.

And you feel like you're the one who's kind of losing your mind because this is such a difficult situation to be in. So you need to take a time out when you're frustrated. Take deep

breaths, count to 10, leave the room for a few minutes.

We have a couple of podcasts about mindfulness that would be really helpful for you. To deal with apathy, that attitude that they don't care about anything, what you want to do is you want to limit the choices and offer specific choices. Like open-ended questions such as, what do you want to do today? Are more difficult to answer than specific ones such as, do you want to go to the park or for a walk? Limited to two things.

Do you want the blue shirt or the red shirt? Keep it simple because your mental health depends on it and kind of helping keep them calm depends on it. Maintain a regular schedule. Reduce distractions and modify the environment to reduce confusion and improve the person's sleep.

Some people get real aggravated with mirrors. They look in the mirror and they

become frightened. Who is that person? I don't know that person.

So if you have to remove the mirrors, remove them. If they're knocking over your favorite tchotchke, whatever it is, just remove it. Put it away.

You don't need one more thing to worry about. If compulsive eating is an issue, consider supervising eating, limiting food choices, locking cabinets in the refrigerator. I know that's hard to hear, but there is no control.

So you might find that they'll just eat and eat and eat until they're they're sick. Distracting the person with other activities like, I want to eat, I want to eat. It's like, let's go play cards.

Let's go do this. So for people who have the language variant, there are generally two treatment goals. Maintaining language skills and using new tools and other ways to communicate.

Treatment tailored to a person's specific language problem and stages of the FTD language aspect generally works best. Since language ability declines over time, different strategies may be needed as the illness progresses. So the following strategies could help.

Use a communication notebook, you know, an album of photos labeled with names of people and objects, gestures and drawings to communicate without talking. You know, I scuba dive and so when we're underwater, nobody can hear us. So there's a language that's spoken underwater.

You know, like if you put your hand straight up in the middle of your head, you know, there's a shark ahead. There's ways to communicate. And so there might be gestures and other ways that you can figure out to communicate with someone who doesn't have language skills.

You could store a list of words or phrases in a computer or a phone to point to because sometimes they'll be able to read, but they're not able to speak. So if you point to, you know, milk or coffee or whatever, they might be able to tell you what they want. Again, this is what you'll figure out from what is preserved, what's not affected, and what is.

Speak slowly and clearly. Use simple sentences. Wait for responses and ask for clarification if needed.

And that's hard, especially, you know, I'm a northerner. Charlie's a northerner. We'll tend to talk quickly and, you know, you compare that.

I mean, all you have to do is take a vacation down to the south and you say, oh my God, everybody talks so slow down here. You'll notice it. I mean, you will truly notice it.

And you don't think that you talk fast, but you do. So if you're kind of in that mode, you've

got to slow yourself down because the processing speeds in your loved one's brain is affected and slowed. And so you have to slow down.

You can work with a speech-language pathologist who's familiar with FTD to determine the best tools and strategies to use. But pay attention to the fact that speech-language pathologists are trained to treat aphasia caused by strokes, which requires different strategies from those used with FTD. So be sure you ask questions before you book the appointment.

You don't want to get there, pay your co-pay, and find out that this speech-language pathologist isn't going to be able to help you. So be sure to ask the question. Now remember, there's movement disorders with FTD.

There's a second variant. And so with movement disorders, there may be medications, physical and occupational

therapy, that can provide a little bit of relief for the movement symptoms of FTD. So for people with a corticobasal syndrome, and we talked about this last week, but this is where areas of the brain shrink and your nerve cells degenerate and die over time.

The disease affects the area of the brain that processes information and brain structures that control movement. So Parkinson's disease medication might offer some temporary improvement. Physical and occupational therapy may help the person move more easily.

And speech therapy may help them with language symptoms. I say may because it depends on what else, what other kinds of symptoms the person has. So put that out there as a possibility, and then apply it to your individual situation.

So for people with progressive supranuclear palsy, this is an uncommon brain disorder that causes serious problems with walking,

balance, eye movements, and later on, swallowing. The disorder results from the deterioration of cells in areas of the brain that control body movements, coordination, thinking, and other important functions. Now, sometimes Parkinson's disease drugs provide temporary relief for slowness, the stiffness, and the balance problems.

Exercise can keep the joints limber, and weighted walking aids, such as a walker with sandbags over the lower front leg, can help maintain balance. Speech, vision, and swallowing difficulties usually do not respond to any drug treatment. Antidepressants have shown some modest success with kind of helping with mood.

And for people with abnormal eye movements, bifocals or special glasses called prisms can sometimes be prescribed that are helpful. And for the people with FTD with the ALS variant, typically decline pretty quickly over two to three years. During this time, physical therapy can help treat muscle

symptoms, and a walker or wheelchair may be useful.

Speech therapy may help a person speak more clearly at first, but later other ways of communicating, such as a speech synthesizer, can be used. And that's like a computer kind of program that can help with language, help communication. And the ALS symptoms of the disorders ultimately make it impossible to stand, walk, eat, and breathe on one's own.

Regarding medications for symptom management, drugs such as SSRI, antidepressants to help control the symptoms like obsession, overeating, and depression may be helpful. So you can ask your health care practitioner about it. Generally, when I'm treating patients, I'm generally willing to give these kinds of things a try, because if they make it better, that's great.

And if they don't make a change, it's not going to hurt them. And we can take them off

of it after a long enough trial and maxing out the dosage of the medication. But talk with your health care practitioner about that.

Antipsychotics may be given to address challenging and inappropriate behaviors. Psychological treatments such as cognitive stimulation and behavioral therapy can help maintain memory function for as long as possible and address anxiety. Rehabilitative practices such as occupational therapy, physiotherapy, and speech therapy may help the brain to learn new ways to do things.

That's the amazing thing about the brain is that there's sort of redundancies built into our brains. So sometimes other parts of the brain can kind of pick up a little bit of the slack to make things a little bit easier. But ultimately, the person will lose some or all of their speech and require full-time care.

So we know that there's a limited time for progression of this disease. It can be as long as 14 years, but for most people, it's not that

long. The average life expectancy of a person diagnosed with frontal temporal dementia is eight years.

Approximately 50% of deaths are a result of pneumonia following from complications associated with inability of the person to move or care for themselves, meaning that at some point, the person is going to be bedridden, not be able to walk, not be able to move around. And your lungs need to be able to kind of be challenged to get up, walk around, move, and really kind of open up and air out, if you will. And if they're laying in bed all the time, they can't do that.

And so the primary cause of death is pneumonia from that. There might also be an increased risk for infections and fall-related injuries. Again, as much as you can protect the person from falling, there's still going to be falls.

And as frontal temporal dementia progresses, as frontal temporal dementia progressively

worsens, a person may engage in dangerous behaviors or be unable to care for him or herself and result in falls or result in other things that can result in their death. Any questions about that, Charlie? No, it's just, I'm trying to take this all in. That's, wow.

Well, I liked what you said about, you know, when you go scuba diving that you, obviously, you know, you're not talking with each other, but you have to find a way to communicate. And those actions are simple and direct. I mean, so that paints a very clear picture of what to do, you know, how to act, you know, what to say, how to talk to someone with this.

And just to keep it, like you said, to keep it simple and not, you know, overwhelm the person. And really, you wind up overwhelming yourself because you're trying to make them understand and they just can't. And I think that's one of the hardest things for caregivers to really grasp is that if your loved

one could grasp it and understand what was going on, they would.

They're not deliberately doing it. And so it's hard when your brain is working perfectly well to even comprehend what it is to not have your brain working. And so, and of course, the person themselves can't tell you because they don't even realize that anything's different.

So you feel like you're in a constant version of gaslight where you know, somebody's telling you nothing's wrong, nothing's wrong. And you're like, yes, there is. There's these problems and you just can't see them.

And as much as you can try to explain it to him, it's, they're not going to make, it's not going to make a difference. So just stop, you know, and that's hard. That's hard to just stop and accept this is what this is.

And it's heartbreaking and it's difficult and this is a very tough disease. So if you need to

listen to this part two a couple times in order to get the full gist of it, do that. We have a lot of resources and I hope it was helpful for people.

Yeah. Thank you for explaining all this. And let's, let's close out with a poem.

This is a poem by Donna Ashworth Words. It's called, You Don't Just Lose Someone Once. You don't just lose someone once, you lose them over and over, sometimes many times a day, when the loss momentarily forgotten creeps up and attacks you from behind.

Fresh waves of grief as a realization hits home, they are gone. Again. You don't just lose someone once, you lose them every time you open your eyes to a new dawn.

And as you awaken, so does your memory. So does the jolting bolt of lightning that rips into your heart. They are gone.

Again. Losing someone is a journey, not a one-off. There is no end to the loss.

There is only a learned skill on how this day will float when it washes over. Be kind to those who are sailing the stormy sea. They have a journey ahead of them and a daily shock to the system each time they realize they are gone.

Again. You don't just lose someone once, you lose them every day for a lifetime. Please stay tuned for the continuing saga of Everyone Dies and thank you for listening.

This is Charlie Navarrete and from Bollywood actress Krishna Bhatt. Frontotemporal dementia, complicating every goddamn thing. So true.

And I'm Marianne Matzo and we'll see you next week as we are celebrating Ash Wednesday. Remember, we are dust and unto dust you shall return. And every day is a gift.

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