Frontotemporal Dementia Part 1- What Is FTD

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, 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 Navarette, an actor in New York City, reminding you to prepare by making choices. Former President Jimmy Carter, 98 years old, opted for hospice after a string of hospital visits.

Mr. Carter plans to spend his remaining time at home with his family, and he has their support. Make sure you have someone who has your back. So please relax and get yourself something to eat, loosen the string on your sweatpants, and thank you for

spending the next hour with Charlie and me as what? You're not wearing sweatpants? I'm supposed to, wait a minute, you didn't say anything about that I had to be wearing pants, Marianne.

So thanks for joining us as we talk about frontal temporal dementia. Okay, in the first half Charlie talks to us about Aboriginal funeral customs and what is known as sorry business. Sorry business encompasses Aboriginal and Torres Strait Islander approaches to death, dying, and memorialization of past loved ones, as well as the remembrance of traumatic events, such as a systemic removal of Indigenous children from their families.

He also has our recipe of the week. In the second half, I'll be talking about frontal temporal dementia, the type of dementia that Bruce Willis has been diagnosed with. And in our third half, Charlie talks about Australian singer Nick Cave.

You know, Charlie, we have a lot of listeners in Australia, about 10% of our listeners are from Australia. Did you know that? I did not know it was up to 10%. I know, yeah.

Yeah. So I thought we would chat a bit about things Australian, other than Bruce Willis, who is not. Is not Australian, yeah.

And as a shout out to to our listeners in Australia, I will not be talking in an Australian accent, I promise. You're welcome. And you are gonna be so happy he's not.

Yes. So Charlie, what do you got for us? Well, Indigenous Australian people constitute about 3% of Australia's population and have many varied death rituals and funeral practices, dating back thousands of years. Aboriginal communities may share common beliefs, but cultural traditions can vary widely between different communities.

For Aboriginal and Torres Strait Islander people, the time before and following death

are subject to several customary practices. These practices have meanings that are sacred. Aboriginal and Torres Strait Islanders are not a homogenous group and must be recognized as two distinct and diverse cultures.

Furthermore, customary practices vary between and within these two tribal groups. There are over 50 Aboriginal language groups in Queensland and two primary languages in the Torres Strait. Aboriginal people believe in two human souls.

One is associated with a person's autonomy and identity, and the other comes from the dreaming or God. Upon death, the two souls separate. The identity soul becomes a dangerous ghost that stays with the deceased's bodies and belongings, while the dreaming soul returns to the environment.

When Aboriginal people mourn the death of a family member, they follow the Aboriginal death ceremonies or sorry business. From the

moment someone has died, people will say, we've got sorry business in our community. How long that sorry business goes for depends on the family and that community.

It could go on for a week. It could go on for a month. With sub-Aboriginal groups, there is a strong tradition of not speaking the name of a dead person or depicting them in images.

There is a belief that when you show somebody's photograph or a video recording or their voice has been played, you're bringing their spirit back to the present and they don't belong here anymore. It is believed that doing so will disturb their spirit. This is why some Aboriginal families will not have photographs of their loved ones after they die.

They may also use a substitute name, such as Kamanyayi, Quintayayi, or Kunamanara, in order to refer to the person who has died without using their name. Not all communities conform to this tradition, but it is still

commonly observed in the Northern Territory in particular. Many Aboriginal tribal groups share the belief that this life is only part of a longer journey.

When a person dies, the spirit leaves the body. The spirit must be sent along its journey. Otherwise, it will stay and disturb the family.

The smoking ceremony is conducted after a death. The smoking of the deceased person's belongings and residence also assists with encouraging the departure of the spirit. Aboriginal communities have used both burial and cremation to lay their dead to rest.

Now traditionally, some Aboriginal groups buried their loved ones in two stages. First, they would leave them on an elevated platform outside for several months. Then, once only the bones were left, they would take them and paint them with red ochre.

The painted bones could then be buried, placed in a significant location in the natural landscape, or carried with the family as a token of remembrance. However, in modern Australia, people with Aboriginal heritage are more likely to opt for a standard burial or cremation, combined with elements of Aboriginal culture and ceremonies. Be aware that if you are a non-Aboriginal person, you may not be invited to observe or participate in certain ceremonies and rituals, though this differs between communities.

If you are present during a traditional song or dance, it is appropriate to stay respectfully silent unless told otherwise. Our recipe this week is for Anzac biscuits, and these are historically baked on the Anzac Day, which is an acronym for Australian and New Zealand Army Corps. When they celebrate and remember the First World War, the wives, sisters, and mothers prepared these biscuits for their men who went to fight the war.

The biscuits contain oats, coconut, and a secret golden syrup, and would be a welcome contribution to any funeral lunch. That sounds good. Yeah, you gonna bake some? No.

But I'll send you a picture. Of what? Of the biscuits. Where are you going to get them? The picture? Oh, I'm sure I can find one online and send it to you.

I mean, no, I mean, I'll I'll, yeah, I'll I'll Pat it and bake it and stamp it with a P, put it in the oven for No, that's the wrong initial. Well, anyways, let's move on folks. So with all this Information So with all this fruitful information, please go to our webpage for the Anzac Biscuits recipe 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 dot org.

Marianne Thanks, Charlie Bruce Willis's family put out a statement about his diagnosis with frontotemporal dementia So I thought it would be a good time to talk about this disease Dementias come in different types and the one that's most common is Alzheimer's disease The second most common type is frontotemporal dementia, which You could say FTD, you know frontotemporal dementia. So i'll say FTD just to Make this go quicker FTD is different from Alzheimer's disease in many ways specifically it gets worse faster and has a higher death rate FTD has not yet been fully understood in terms of what causes it but genetic factors are believed to be involved FTD happens from damage to the nerve cells of the frontal and temporal lobes of the brain And can extend to the cortex subcortex cerebellum and the brainstem so now for the science portion The frontal lobe is the part of the brain that controls important thinking skills in

humans such as emotional expression problem solving memory language judgment and sexual behaviors It is in essence the control panel of the personality and our ability to communicate So if you put your hands on your eyebrows and took them all the way up to your hairline Assuming where like hairline normally is Up there that area there that's where the frontal lobe is. It's right in the front on the top So the temporal part of this name of this disease the temporal lobes main function are seeing smelling and auditory processing and memory creation It plays important roles in emotional responses and in communication It plays a role in managing emotions processing information about your senses storing and retrieving memories and understanding language and those temporal lobes if you Start at your eyebrows and kind of go back towards your ears that where you're you're that's where you're Those temporal lobes are and there's two of them one on either side So damage results in symptoms of having unusual behaviors emotional problems trouble communicating

difficulty with work or difficulty with walking About 20 percent of people with symptoms of dementia are diagnosed with frontal temporal dementia FTD is the second most common neurodegenerative dementia in people younger than 65 years old 60 percent of people with FTD are 45 to 64 years old genetically approximately one-third of FTDs are familial meaning they're genetic they run in families and typically when you see a A disease that starts very young That will typically have a genetic link So you see how young this disease, you know starting in age 45 That leads you to say hmm Could it be genetic and in fact it is There is no treatment.

There's no cure and survival time after onset of Of the disease is between 3 and 14 years Clinically syndromes of FTD are categorized into three types and this is important because How they progress and the symptoms you see depends on what type you have So the first type is called the behavioral type. The second type is the linguistic variant type Which is diagnosed by what's called primary

progressive aphasia and that Appears to be the type that Bruce Willis has because last year they had Said that he was quitting acting because of aphasia or difficulty talking and the third type is The sportive manifestation type which is FTD with Amitrophic lateral sclerosis or ALS or Lou Gehrig disease and we've done a show or a couple shows about that And atypical Parkinson's disease and we've done some shows about Parkinson's disease so you can look those up If you want to learn more about those particular diseases It's important to understand that people with these disorders cannot control their behaviors They can't control the other symptoms and they lack any awareness of their illness They do not know that what's going on is what's going on So let's talk about those three different types the behavioral variant frontal temporal dementia Is the most common Um kind of FTD it involves changes in personality behavior and judgment People will have symptoms with thinking but their memory stays relatively intact and symptoms can include Problems planning and sequencing

meaning thinking through steps. What comes first? What comes second? So if you ask this person, could you make me a cup of tea? they would be all over the place because Do I get a cup do I get a teabag do I put the water on which do I do first? It's sort of a mess So let's say problems with sequencing They have difficulty prioritizing tasks or activities like which one should I do first, which one should I do second like if they You say I have to open the mail and I have to go to the bathroom And I have to feed the dog They don't know which one to do first and they may end up wetting themselves because they didn't prioritize going to the bathroom They repeat the same activity or say the same word over and over and this is called perseveration So this is a word that you can throw around and impress people So when you're repeating the same activity or saying the same word, it's perseverating on something They tend to act impulsively or saying or doing appropriate things without considering how others perceive their behavior They might you might be out at

dinner and they might decide to Unzip their pants and go to the bathroom right in the middle of the lobby of of the restaurant They might Come right out and say Things that you you know, you might be thinking but you know not to let it come out of your mouth, but This they'll say that Um, you might see that they're becoming disinterested in family or activities that they used to care about This is called apathy and this is very common in FTD over time language and movement problems may May occur and the person living with this behavioral type of FTD will need more care and supervision So the second type is primary progressive aphasia And primary progressive aphasia involves changes in the ability to communicate to use language to read write speak and understand what others are saying This includes difficulty using or understanding words, that's the aphasia part And difficulty speaking properly like they might have slurred speech People with ppa primary progressive aphasia may have one or both symptoms and they might become mute or unable to speak Many people with ppa

develop symptoms of dementia Problems with memory reasoning and judgment are not apparent at first, but they can develop over time Some people may experience significant behavioral changes like those seen in the behavioral FTD as the disease progresses Now there are three types of ppa categorized by the kind of language problems that appear first Researchers don't fully understand the biological difference of the different types of ppa But they hope one day to link specific language problems with the changes in the brains that cause them So the first type of ppa is called semantic ppa This is when the person slowly loses the ability to understand single words And sometimes to recognize the faces of familiar people and common objects The second type is agrammatic ppa The person has more and more trouble speaking and may omit words that link nouns and verbs such as to from and the Eventually the person may no longer be able to speak at all.

The person may eventually develop movement symptoms similar to those seen in

corticobasal syndrome Now what's corticobasal syndrome? Corticobasal syndrome may start with movement problems such as stiff muscles on one side of the body involving the arm leg or both People with cbs may develop May describe having a hard time controlling their arm or their leg Some people with cbs have language problems first and may develop movement problems over time Thinking and behavior changes may happen either at the beginning or later in the disease Now the third type of ppa is the logopenic ppa This is the person who has trouble finding the right words during a conversation But can understand words and sentences The person does not have problems with grammar So those are all of the um the the ppas the third type Of frontotemporal dementia is movement disorders two rare neurological movement disorders associated with ftd Are the corticobasal syndrome, which I just talked about and can and progressive Supernuclear palsy which occur when the parts of the brain that control movement are affected The

disorders may also affect thinking and language abilities Now the corticobasal syndrome can be caused by corticobasal breakdown A gradual shrinking and loss of nerve cells in specific parts of the brain This breakdown causes progressive loss of the ability to control movement typically beginning around age 60 the most prominent symptom may be apraxia and this is the inability to use the arms Or hands or to perform a movement despite having normal strength such as difficulty closing buttons or operating small appliances Many symptoms can include muscle rigidity and difficulty swallowing Symptoms may occur first on one side of the body, but eventually both sides are affected Occasionally a person with corticobasal syndrome first has language problems or trouble orienting objects in space and later develops movement symptoms Not everyone who has corticobasal syndrome has problems with memory cognition language or behavior As you can see, this is all very complicated and When you have somebody who's been

diagnosed or is having these symptoms, it's really hard to pull it apart and figure out what's going on So I said that progressive supernuclear palsy is also a type of in this area of FTD Supernuclear palsy causes problems with balance and walking People with this disorder typically move slowly experience unexplained falls loose facial expression have body stiffness especially of the neck and the upper body very much symptoms like parkinson's disease A hallmark sign of this disorder is trouble with eye movements, particularly looking down The symptom may give the face a fixed stare problems with behavior Memory problem solving and judgment can also develop Other movement related types of FTD include frontal dementia frontal temporal dementia with parkinsonism And frontal temporal dementia with ALS Frontal temporal dementia with parkinsonism can be an inherited disease caused by what the genetic Variant of the tau I'm not going to go into that because it's really complicated but Just know that it's a genetic variant Symptoms include

movement problems like those of parkinson's disease such as slowed movements stiffness balance problems And changes in behavior or or language FTD with ALS Can also be called FTD with motor neuron disease is a combination of behavioral FTD and ALS The latter in ALS as i've said is known as Lou Gehrig's disease In addition to the behavioral and or language changes seen in the behavioral FTD People with FTD ALS experience the progressive muscle weakness seen in ALS fine jerks and wiggling in muscles Symptoms of either disease may appear first with other symptoms developing over time Changes in certain genes have been found in some people with FTD ALS Though most cases are not hereditary So You might not have to listen to this a couple of times to kind of get the gist of it But it's a what i've given you is a very detailed explanation Of what you might see with this disease But how do you know if someone you know has it Well next week we're going to do a part two which talks about symptom management And what the end of life looks

like with this disease Charlie, do you have any questions about this disease? Um, no, but only only because i'm trying to take everything in there's there's so many There's so many layers there's so many possibilities and you know to your point what you were saying it's not that You know a doctor can look you would say oh yeah you have a cold here Have chicken noodle soup take a couple of days off and that's it Yeah, it takes a while to diagnose what's going on it's I had no idea it was that complicated Yeah, it's really complicated and that's why When bruce willis a year, I mean it was a year ago They said he was quitting acting because he was has troubles with speech. It's taken from then Until now and we'll talk next week why it took so long, but essentially You know spoiler alert Uh for next week is that you have to kind of see what happens? Because there is no Specific test so you have to see what happens, right? Yeah, exactly. Yeah.

Yeah, that's what you were saying. Yeah yeah, and so they they took the time they

watched what was going on they Must have seen progression And it starts to follow the course of what you expect with that disease. Then you can say well, this is what we think it is Okay, thanks marianne You're welcome But for our listeners you might want to listen to it a couple times because I know it's a lot of information And we have a lot of really good resources in the show notes for you That'll help with understanding this disease Next nick cave Nick is from warwick nebile a rural area of victoria australia He is a singer songwriter poet lyricist author screenwriter composer and occasional actor He is known for his baritone voice and for fronting the rock band nick cave and the bad seeds cave's music is characterized by emotional intensity a wide variety of influences and lyrical obsessions with death religion love and violence in 2015 Nick cave and his family experienced the biggest tragedy of their lives On july 14th of that year cave's teenage son arthur accidentally fell off a cliff in brighton and died of head injuries As part of his healing process cave set up the red hand files

A site where anyone can ask him anything with zero filters in moderation between the artist and the world A woman named cynthia wrote to the musician and asked him how he deals with the death of his son arthur This is how cave replied This is a very beautiful question and I am grateful that you have asked it It seems to me that if we love we grieve that's the deal.

That's the fact Grief and love are forever intertwined Grief is a terrible reminder of the depths of our love and like love grief is non-negotiable There is a vastness to grief that overwhelms our minuscule selves We are tiny trembling clusters of atoms subsumed with grief's awesome presence It occupies the core of our being and extends through our fingers to the limits of the universe Within that whirling gyre all manner of madness exists Ghosts and spirits and dream visitations and everything else that we in our anguish will into existence These are precious gifts that are as valid and as real as we need them to be They are the spirit guides that lead

us out of the darkness I feel the presence of my son all around But he may not be there I hear him. Talk to me parent me Guide me though. He may not be there He visits suzy in her sleep regularly speaks to her comforts her But he may not be there Dead grief trails bright phantoms in his wake These spirits are ideas essentially They are our stunted imaginations reawakening after the calamity Like ideas these spirits speak of possibility Follow your ideas Because on the other side of the idea is change and growth and redemption Create your spirits call to them will them alive Speak to them It is their impossible and ghostly hands that draws back to the world from which we were jettisoned better now and unimaginably changed with love Oh, that is just beautiful charlie it really is just You know, I mean like you said it's it's it's unfiltered and that's you know with yeah, just Like you said, you know ask ask me anything you want and I will tell you no filters no barriers and I Put the link to that.

Um In the show notes. So if anybody wants to write to him you can Please stay tuned for the continuing saga of everyone dies and thank you for listening This is charlie navarette as marianne pointed out Frontotemporal dementia is a disease which is not quite the same as dementia Which is a general term that describes the symptoms of a large number of different brain diseases including alzheimer's With that in mind Here's a poem with thoughts on dementia You know your first name But not your surname You know where you feel safe But don't know your address You recognize your husband, but not your children You eat the food you are given But don't know what you like to eat You know when you are uncomfortable But don't know when you want to go to the toilet You watch the tv But have no idea what program you have just watched You smile when you are showing a baby But have no idea. He's your great-grandson You drink tea, but don't know if you take sugar You are alive But you are not living And i'm marianne matzo and we'll see you next week Remember one day

we will all have sorry business to do And every day is a gift This podcast does not provide medical advice All discussion on this podcast such as treatments dosages outcomes charts patient profiles advice messages and any other discussion are for informational purposes only And are not a substitute for professional medical advice or treatment Always seek the advice of your primary care practitioner or other qualified health providers with any questions that you may have regarding your health Never disregard professional medical advice or delay in seeking it because of something you have heard from this podcast If you think you may have a medical emergency call your doctor or 911 immediately Everyone dies does not recommend or endorse any specific tests Practitioners products procedures opinions or other information that may be mentioned in this podcast Reliance on any information provided in this podcast by persons appearing on this podcast at the invitation of everyone dies Or by other members is solely at your own risk