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Meaningful Lives As We Age

Recognizing and Responding to Frontotemporal Degeneration

Applications from The GSA KAER Toolkit for Brain Health
Momentum Discussions Podcast from the Gerontological Society of America

Recorded August 2026

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	Guest: **Esther Kane,** MSN, RN Director, Support & Education Association for Frontotemporal Degeneration

Announcer:
Welcome to the Gerontological Society of America's Momentum Discussion, where we explore groundbreaking topics in the field of aging.

Elana Kieffer Blass:
Welcome to this GSA Momentum Discussion podcast episode titled *Recognizing and Responding to Frontotemporal Degeneration.* We are grateful to Eisai, Genentech, and Lilly for their support of The GSA KAER Toolkit for Brain Health and for today's podcast. My name is Elana Kieffer Blass, and I am the Director of Strategic Alliances at the Gerontological Society of America. I am pleased to serve as the host for today's Momentum Discussion. Today's conversation explores frontotemporal degeneration, or FTD, one form of dementia that is underdiagnosed and is the most common type of dementia for people under the age of 60. We will learn what FTD is, how it differs from other types of dementia, how to identify it in patients, and how to respond thoughtfully after a diagnosis. I am delighted to be joined by Esther Kane, the Director of Support and Education at the Association for Frontotemporal Degeneration (AFTD).

She leads initiatives to promote accurate and timely diagnosis of FTD while advancing education and support resources for individuals and families affected by this disease. Through her work, Esther is dedicated to improving quality of life and strengthening care throughout the FTD community. Esther, welcome, and thank you for joining me today.

Esther Kane:
Thank you so much, Elana and GSA, for having me. I'm really looking forward to this conversation.

Elana Kieffer Blass:
Wonderful. Let's start with a basic question. What is FTD?

Esther Kane:
FTD, or frontotemporal degeneration, as you pointed out, is a group of progressive brain disorders caused by degeneration of the frontal and temporal lobes of the brain. These areas are responsible for behavior, personality, judgment, planning, social awareness, language, communication, and movement, making FTD a very complex and heterogeneous disease to care for.

Elana Kieffer Blass:
How does it differ, and how is it similar to Alzheimer's disease and other related dementias?

Esther Kane:
FTD is one of the main types of dementia we hear about. It makes up about 10 to 15% of all types of dementia that are out there. FTD is different than Alzheimer's disease in many ways. Alzheimer's disease typically presents with memory changes or a little bit later in the age space. In contrast, FTD presents with symptoms that affect communication, personality, and movement. The presentations are very, very different. Yet both diseases occur in the brain. These diseases are progressive, with limited treatments and no cures to stop their progression.

Elana Kieffer Blass:
How does FTD fit among other neurodegenerative diseases?

Esther Kane:
FTD really sits at the crossroads of many neurodegenerative diseases. We have connections with ALS con - ALS symptoms. We have Alzheimer's connections. There are relationships with other forms of mental health and brain diseases. It often mimics many other forms and diseases. We are seeing and working in the ALS, Parkinson's, and Alzheimer's spaces, really trying to raise awareness of FTD and better understand how families are impacted by it.

Elana Kieffer Blass:
The GSA KAER Toolkit for Brain Health is really geared to help primary care teams provide excellent care for their patients as relates to brain health. Thinking from that framework, what are some early clinical red flags that primary clinicians can look out for as possible signs of FTD?

Esther Kane:
Primary care clinicians should consider FTD when a patient, especially someone in midlife or under age 65, shows progressive changes in behavior, personality, judgment, or language. That is new for them, and it's not well explained by stress. Very often, it's misdiagnosed as depression or a midlife crisis or stress that's occurring. We hear this from families repeatedly.

Really paying attention to what the patients are telling you, in the case of how they're explaining their symptoms, how they're explaining how they're feeling, will really help you to be able to assess maybe it's more than just depression. Maybe this is more than just a midlife crisis and get them seen by the specialists they need.

Elana Kieffer Blass:
You said that it's the most common type of dementia for people under the age of 60. Is there typically like a minimum age that it starts at?

Esther Kane:
We have worked with families who have been diagnosed at 23, 24. Individuals up to 80 or 90. It most commonly starts with individuals between the ages of 45 and 60, which is partly why it's so often misdiagnosed. It's the age. We're not thinking of dementia at 50. We're thinking of some other occurrence; something else is happening. But the reality is that many individuals start to have cognitive changes at a much younger age. The earlier we can pick this up, the better we can support families as they navigate the disease.

Elana Kieffer Blass:
Are there other reasons why you think it's commonly misdiagnosed?

Esther Kane:
It's not well known. For many of you out there, you might be like, "I've never heard of FTD." Or if I have heard of FTD, I don't really understand it or understand how this might impact families. Because of that, many clinicians don't think FTD when the patient comes in. It's much more likely that they might be having depression. We're not always thinking this is a neurocognitive disorder that's happening in this 60-year-old person who's coming to my office or a 55-year-old person who's coming to my office. That leads to many misdiagnoses. On top of that, it mimics many other diseases. As I said before, it can start with ALS and transition into FTD/ALS. It can start with Parkinson's type symptoms or atypical Parkinsonian symptoms. They think they have Parkinson's disease, but they're not responding to treatment.

The symptoms are a little bit different. They might have a form of FTD called progressive supranuclear palsy or corticobasal degeneration. These mimicries of other diseases really complicate the diagnostic process and make it hard for the clinicians to be able to think, “Is this a neurodegenerative disease?” Medical school clinicians are taught that if it's galloping and it looks like a horse, it's probably a horse; it's probably not a zebra. But FTD is a zebra; what ends up happening is that we really need to think about these rare conditions and these zebras sometimes in the diagnostic process.

Elana Kieffer Blass:
Do you have numbers on what percentage of the population has this? You say it's commonly misdiagnosed and just not well known. I wonder if there's a connection between that and it also just being a somewhat uncommon disease.

Esther Kane:
What ends up happening in an FTD diagnosis is we say right now that there are about 50 to 60,000 people in the US who have an FTD diagnosis. But we say that it's highly misdiagnosed.
You're hitting the nail right in the head there, right, when we're talking about this, because many people do not have access to a specialist. They need to get an accurate FTD diagnosis.

A lot of people just get told they have dementia. They're not really given more information as to the type of dementia that it might be. They don't seek further diagnostic evaluation, or they can't participate in it, which is needed to reach a clear diagnosis in diseases like FTD, where we really do not have an easy biomarker test. We're all talking about biomarker dementia right now, with the pTau tests that have come out and how they're really advancing earlier, accurate Alzheimer's diagnosis.

In FTD, we don't have that yet. The diagnosis is really based on brain imaging, which is important. A neuropsychological assessment, a good neurological and health history. They take all that information together to reach an accurate diagnosis. But because of that, it really requires specialists who understand what they're looking at and can give a good differential diagnosis.

Elana Kieffer Blass:
We've talked about primary care teams, and I'm sure some neurologists specialize in FTD. Do you at AFTD work with mental health practitioners? Because you mentioned that sometimes it can be seen as a midlife crisis or depression. I'm just curious whether you provide any training for mental health providers to recognize signs of FTD.

Esther Kane:
We provide extensive training and education for health providers in general (nurses, social workers, mental health providers, psychiatrists, geriatric psychiatrists, and primary care physicians). AFTD has offered an entire education program for health care providers. We have a webpage directly designed for them. We do free CME programming, really looking at different aspects of the diagnostic process, as well as we have a resource called Partners in FTD Care, which is really designed to give you, in your inbox, an e-newsletter every two months that talks a little bit about FTD and provides a little bit of a snapshot of education about the disease so that health providers can be more equipped to be able to manage it. We're targeting everyone because it's so heterogeneous and because People can encounter so many different types of clinicians.

We really want all clinicians to be aware that FTD might be a possibility, especially in the space of dementia. Ensuring patients reach the right specialist early.

Elana Kieffer Blass:
Absolutely. You mentioned a diagnosis. What would a thoughtful diagnosis workup include?

Esther Kane:
A thoughtful diagnostic workup will include brain imaging, either an MRI or an FDG PET scan. We also want to make sure that there's a neuropsychological assessment. Are we really assessing the domains that are changing in the brain, the cognitive changes? At the same time, we're really going to have to make a good differential diagnosis. When clinicians start this process, they're looking to see whether something else is causing these changes. Is it sleep apnea? Are there other blood work changes, or other body systems affecting cognition? You need to rule out all those things during the diagnostic process to ensure we get an accurate diagnosis. As well as that, we often bring in speech-language pathologists to assess when language changes are occurring and what's happening here.

What are the language changes that are occurring? A good speech-language pathologist can really diagnose the patient by just hearing the language changes occurring and what's happening in that space. It's usually very multidisciplinary. It's usually done by some experts who really understand the disease and what they're working with.

Elana Kieffer Blass:
After a diagnosis, what are some immediate care planning priorities that providers should be addressing?

Esther Kane:
For so many families, they are just given a diagnosis, and they're given nothing else. The families feel extremely isolated and alone. They're told they have a neurodegenerative disease, that they're 60 years old, and that they have a limited lifespan with a lot of changes going on. They're not really given much support or information; we've been advocating and raising awareness that families need more. We need to send them to patient advocacy organizations working in those disease spaces and connect them with support groups and others who have lived with the disease. Really get them engaged with the research. Some clinical trials are happening in the FTD space. Early diagnosis is important. Even an FTD versus some other diagnosis within the dementia space, FTD is about 20% of the time caused.

It's genetic. Genes cause it; a large part of our population has FTD that has been running in their families from generation to generation. The families need tools, education, and support. They need to be connected with the research. That all comes from really connecting them with the community that understands the disease they work in. On top of that, we really want to connect them with the dementia community in their local area. Are there guide programs? Are there neuro-palliative care programs? Are there things that we can connect them with right away to help them manage the disease and walk through what to expect? Very often, families will report back to us how frustrated they are when clinicians don't understand FTD or assume that FTD is just like dementia.

They go into the office, and they're talking to the health provider no matter what they are, and the health provider is approaching it like it's Alzheimer's dementia. The family's like, "This is not what I'm dealing with. These aren't my problems. These aren't the symptoms I have. This isn't- this is affecting me differently." The more health providers can educate themselves about FTD, the better families are served. I can't tell you how happy families are. When the clinicians can say, "I understand. I understand what you're dealing with. I understand the approach. I may not have all the answers, but let's figure this out together." It changes their whole lives, for health providers to be informed, and for them to refer people after diagnosis to support and resources so they can navigate the disease.

Elana Kieffer Blass:
Relatedly, and you covered some of this, but how specifically can clinicians support families who want to engage in FTD research specifically?

Esther Kane:
AFTD has partnered with the FTD Disorders Registry, which is a nonprofit that aims to engage the community with what's available to them in the research community. It's also a registry data platform. People can access the registry data, enter their information, and have it used to advance research. The best place to stay up to date on the current research in FTD is to go to the FTD Disorders Registry.

Elana Kieffer Blass:
As we're wrapping up, you've given us a lot to think about and watch for. What is one key takeaway that you want clinicians to walk away with? What is one key takeaway that you want family members to walk away with?

Esther Kane:
If you can do anything for the FTD community, take some time and learn about it. Understand it. Invest in educating yourself so you can support the patients who come your way. For the families, to know that you're not alone, AFTD is here. We have a vast array of support groups, including a helpline staffed by trained social workers who can provide support and information. You can reach out to the helpline at info@theaftd.org or call us at 866-507-7222.

Elana Kieffer Blass:
Esther, I really want to thank you so much for sharing your insight and knowledge, and, obviously, your clear passion for understanding this disease and for supporting patients, their families, and their care teams throughout the process. I know how important it is to educate providers and the public about FTD. Speaking on this podcast today is one way to do exactly that. Thank you for that. To our listeners, thank you for joining us for this episode of The GSA Momentum Discussions Podcast. Thank you all.

Esther Kane:
Thank you.

Announcer:
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