

The VOICE of FTD

SUMMER 2020

FTD Resources for You!

Information on the disease, specialists, caregiving, research, and more

Whether you have recently received a diagnosis of frontotemporal degeneration (FTD) or have been living with it or caring for a diagnosed loved one for several years, the good news is that resources to learn more about these diseases and to find support are increasing.

“Information is powerful,” stated FTD Disorders Registry Director Dianna Wheaton, Ph.D., CHES. “When someone receives such a diagnosis as FTD, we want to arm them with the necessary information and resources they can use so that they are empowered to cope with the disease. This information provides guidance and enables people to engage in tangible actions.”

A degenerative brain disease, FTD is a common cause of dementia in people under the age of 60. Often striking people in their prime, these disorders are characterized by progressive degeneration of the frontal and/or temporal portions of the brain, the regions responsible for language and behavior. During the course of the disease, FTD patients may lose the ability to behave appropriately, make good judgments, communicate, and carry out daily activities.

“A diagnosis of FTD is a very overwhelming and isolating event,” noted Dr. Wheaton. “One way to combat that

is to have access to resources. The good news is that there are more helpful resources being created to serve people affected by FTD. For this reason, the Registry recently updated and expanded the FTD RESOURCES section on our website.”

Hurdles to Finding Resources

Because FTD is rare, has a younger age onset than other types of dementia, and displays different symptoms than other dementias, there are challenges in dealing with it. Finding resources is one hurdle, noted Sharon S. Denny, MA, senior director of programs for the [Association for Frontotemporal Degeneration](#) (AFTD)

“FTD is such an isolating disease,” Denny said. “Add to that the lack of public awareness and professional awareness means it’s really hard to find information.”

Families often navigate this disease by themselves, she said. They are told that it is progressive and leads to dementia, and they are directed to resources for people with Alzheimer’s disease.

“While there is some general information in the Alzheimer’s world that initially might be helpful, people

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affected by FTD want information that relates to their experiences,” Denny said. “Information can now be found by searching online for FTD or frontotemporal degeneration; the challenge comes in understanding the source of that information and knowing what to do with it.”

Popular Resources

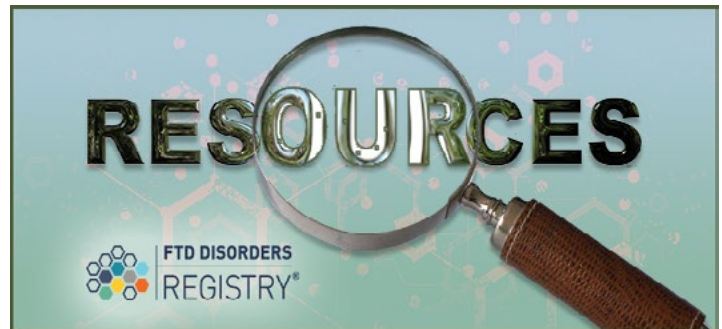
[FTD RESOURCES](#) is a frequently accessed page on the Registry’s website after clicking to join, or the [FIND A STUDY](#) page, Dr. Wheaton said. “The resources we highlight in the expanded section are a combination of materials produced by the FTD Registry as well as resources offered by other organizations, such as the AFTD.”

Denny noted upon their first visit to the [AFTD’s website](#), people tend to click first on “What Is FTD?” to learn about the disease. Second, they want to find a doctor or specialist who understands FTD, and then they return seeking support. While the association’s website has a separate Resources page, there are numerous resources throughout both the WHAT IS FTD? and FIND HELP sections.

Additionally, AFTD operates a Helpline where people can leave a phone message or send an email anytime. They are answered during business hours Monday through Friday. Each year 2,500 people have their questions answered by an association staff person.

“Each person who contacts us talks to a staff person and gets an individualized response to their question,” Denny said.

Another important resource offered by AFTD is its network of support groups across the United States led by more than 100 volunteer leaders. Denny said that



feedback from contact with these communities helps the association understand the needs of the people and spot any new trends, so new resources can be created.

Not all of the resources that AFTD offers are on its website. Some are sent to people who contact the Helpline in response to their specific concerns. “The website is a good front door, but not exhaustive,” she noted.

COVID-19 Influence on Resources

Because of the coronavirus pandemic, AFTD has adjusted some of the content it offers, primarily the delivery method, Denny said. In particular, after the annual Education Conference was canceled, webinars were created to present some of the planned subject matter. In addition, AFTD set up secure conference call lines for support groups so people could stay connected by phone.

The need for resources is magnified by the stay-at-home orders and recommended prevention practices, Denny said. Particularly challenging is following the guidelines for good hygiene practices, that in some cases are really hard for people with FTD, especially people with behavioral FTD.


“The changing circumstances of living with this pandemic are going to require a better response long term,” she said.

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EXPANDED RESOURCES SECTION

You do not have to face FTD alone. In order to better serve the FTD community, the Registry has updated and expanded the FTD RESOURCES section to help you find the information and support you need throughout your FTD journey.

This new section is organized by topic, offering assistance for those living with a form of FTD, their families, and caregivers, whether they are looking for a specialist, wanting to participate in research, considering whether to make a brain donation, or seeking support. Browse the sections below to access resources to help you learn and cope with FTD.

About FTD

Learn more about the neurodegenerative disease that is called FTD. These resources are written in patient-friendly language with FTD-diagnosed persons and their caregivers, family members, and friends in mind.

[Visit the ABOUT FTD page](#)

Finding a Specialist

Finding medical professionals who are familiar with the diagnosis and management of these rare conditions can be challenging. This page lists resources that can help you locate a specialist devoted to understanding FTD and providing state-of-the-art care.

[Visit the FINDING A SPECIALIST page](#)

Living with FTD

People living with FTD, including diagnosed individuals and their loved ones, can face unique challenges when navigating their daily lives. These resources provide information on managing symptoms, handling day-to-day challenges, planning for the future, and more.

[Visit the LIVING WITH FTD page](#)

Caregiving

Caring for an individual affected by FTD can be extremely rewarding yet comes with its unique challenges. These resources are designed to help caregivers tend to their own well-being, connect with others who understand, identify local resources available to facilitate their role, and navigate complex care challenges.

[Visit the CAREGIVING page](#)

Finding Support

Nonprofit advocacy organizations can be a valuable source of support. Many offer opportunities for people who are impacted by these conditions to connect with each other through support groups, family education days, or educational conferences. They also provide helpful resources, including educational materials, financial assistance, and sources for special medical equipment. Read more about advocacy organizations that provide condition-specific support for people impacted by FTD.

[Visit the FINDING SUPPORT page](#)

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Participating in Research

People impacted by FTD who choose to participate in research help the scientific community advance the understanding of FTD disorders and move faster toward finding treatments and cures. FTD-diagnosed people, their loved ones, and caregivers may be eligible to participate in many different types of research studies, including clinical trials, observational studies, and brain donation. Read general information about the different types of medical research, questions to consider when deciding whether to volunteer for research, and information regarding the regulations in place to protect research volunteers.

To learn more about specific opportunities to enroll in FTD clinical trials, please visit our [FIND A STUDY](#) page.

[Visit the **PARTICIPATING IN RESEARCH** page](#)

Brain Donation

Brain donation helps researchers better understand the underlying causes of FTD with the goal of finding treatments and a cure for these devastating diseases. It is also the only way to provide a definitive diagnosis. For those considering this option, these resources provide information on the general process, costs, role of the family, and other key factors to consider while making this important decision.

[Visit the **BRAIN DONATION** page](#)

FTD Registry FAQ

The FTD Disorders Registry has compiled a list of Frequently Asked Questions (FAQ) about the Registry that you can [read online or print as a handout](#). For technical information about creating, managing, and updating your Registry account or troubleshooting any issues that may arise, please contact us at manager@FTDregistry.org.

[Visit the **FTD REGISTRY FAQ** page](#)

**Join the Registry.
Tell Your Story.
Advance the Science.**


“Together, we can make a difference!”



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