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# Providing Care for a Person With a Frontotemporal Disorder

People living with frontotemporal disorders, sometimes called frontotemporal dementia, can have a range of symptoms, including unusual behaviors, emotional problems, trouble communicating, and difficulty walking. Caring for someone with a frontotemporal disorder (FTD) can be hard, both physically and emotionally. Caregivers may face challenges with managing the medical and day-to-day care, as well as changing family and social relationships, loss of work, poor health, stress, decisions about long-term care, and end-of-life concerns.

## What Is Frontotemporal Dementia? FTD Types, Symptoms, and Diagnosis



## How frontotemporal disorders affect families

People with FTD and their families often must cope with changing relationships, especially as symptoms get worse. Spouses or partners may find themselves not only taking on caregiving responsibilities, but also household

responsibilities that their partner can no longer perform. Children may suffer the gradual loss of a parent at a critical time in their lives. Family members and friends may feel alienated or embarrassed by the person's behavior. Life at home can become very stressful.

## Justin's story

After Justin graduated from college, he went home to live with his parents. It didn't take long for him to notice personality changes in his 50-year-old mother, a successful executive. She became more childlike and had trouble finishing household chores. By the time she was diagnosed with **behavioral variant frontotemporal dementia (bvFTD)**, Justin's relationship with his mother had deteriorated. Learning about the disorder helped Justin understand and accept the changes he was seeing in his mother.

## How FTD can affect work

People living with FTD may have difficulty with basic work skills, such as organizing, planning, and following through on tasks. Activities that were easy before might take much longer or become impossible. People may lose their jobs because they can no longer perform. As a result, the caregiver might need to take a second job to make ends meet, or reduce their hours, or even quit working to provide care and run the household.

An employment attorney can offer information and advice about employee benefits, family leave, and disability if needed. Workers diagnosed with FTD can qualify for Social Security disability benefits through the [“Compassionate Allowances” program](#) (800-772-1213), a program that helps individuals with certain serious conditions access benefits quickly.

## Strategies to help manage FTD symptoms

There is no cure for FTD and no way to slow it down or prevent it. However, there are ways to help manage symptoms, which include changes in behavior, speech, and movement.

- **Managing behavior changes in FTD.** Try to recognize it's the illness “talking” and accept rather than challenge people with behavioral symptoms. Arguing or reasoning with the person will not help; they cannot control their behaviors or even see that they are unusual or upsetting to others.
- **Treating language problems in FTD.** To help with language issues, speak slowly and clearly, use simple sentences, wait for responses, and ask for clarification if you don't understand something. Gesturing, drawing, and using an album with labeled photos of people and objects may help communicate without talking. A speech-language pathologist can determine the best tools and strategies for a particular person.
- **Managing movement problems in FTD.** Several types of FTD cause problems with movement, including difficulty balancing, walking, and swallowing. Medications and physical and occupational therapy may provide modest relief for the movement symptoms of FTD. A doctor who specializes in these disorders can guide treatment.

Learn more about [strategies to manage FTD symptoms](#).

## Be a part of finding better treatments

Do you know someone living with FTD? Researchers are looking for people to participate in a study to track disease progression and advance treatments.

Visit the [ALLFTD study page](#) to learn more.

## FTD caregiver health and support

Caring for someone with FTD presents unique challenges. Many caregivers face declines in their own health while caring for a person with FTD or a related disorder. To stay healthy, [caregivers](#) can:

- Get regular health care.
- Ask family and friends for help with child care, errands, and other tasks.
- Spend time doing enjoyable activities, away from the demands of caregiving. Arrange for [respite care](#) — short-term caregiving services that give the regular caregiver a break — or take the person to an adult day care center, a safe, supervised environment for adults with dementia or other disabilities.
- Join a support group for caregivers of people with FTDs. Such groups can be a valuable resource to share experiences and tips with others who may be in the same situation. Nonprofit organizations and community organizations may provide online or in-person support groups. [Alzheimer's Disease Research Centers](#) may also offer education and support groups.



## Long-term care for people with FTD

For many caregivers, there comes a point when they can no longer take care of the person with FTD without help. The caregiving demands are simply too great, and the person may need around-the-clock care. As the disease progresses, caregivers may need home health care services or to look for a residential care facility, such as a group home, assisted living facility, or [nursing home](#).

[Get more information about long-term care.](#)

## End-of-life care for a person with FTD

People with FTD typically live six to eight years with their condition, sometimes longer, sometimes less. Most people die of problems related to advanced disease. For example, as movement skills decline, the person may have trouble swallowing, leading to aspiration pneumonia, in which food or fluid gets into the lungs and causes infection. People with balance problems may fall and seriously injure themselves.

It is difficult, but important, to plan for the end of life. Legal documents, such as a will, living will, and durable powers of attorney for health care and finances should be created or updated as soon as possible after a diagnosis of FTD or a related disorder. An attorney who specializes in elder law, disabilities, or estate planning can provide legal advice, prepare documents, and make financial arrangements for the person's spouse or partner and dependent children. The [National Academy of Elder Law Attorneys](#) and the [American Bar Association](#) can help families find qualified attorneys. Local bar associations can help identify free legal aid options.

Read more about [end-of-life care](#) and [advance care planning](#).

## For more information about caring for a person with FTD

### **NIA Alzheimer's and related Dementias Education and Referral (ADEAR) Center**

800-438-4380

[adear@nia.nih.gov](mailto:adear@nia.nih.gov)

[www.nia.nih.gov/alzheimers](http://www.nia.nih.gov/alzheimers)

The NIA ADEAR Center offers information and free print publications about Alzheimer's and related dementias for families, caregivers, and health professionals. ADEAR Center staff answer telephone, email, and written requests and make referrals to local and national resources.

### **Alzheimers.gov**

[www.alzheimers.gov](http://www.alzheimers.gov)

Explore the Alzheimers.gov website for information and resources on Alzheimer's and related dementias from across the federal government.

### **Association for Frontotemporal Degeneration**

866-507-7222

[info@theaftd.org](mailto:info@theaftd.org)

[www.theaftd.org](http://www.theaftd.org)

### **Social Security Administration**

800-772-1213

800-325-0778 (TTY)

[www.ssa.gov](http://www.ssa.gov)

### **National Academy of Elder Law Attorneys**

703-942-5711

[naela@naela.org](mailto:naela@naela.org)

[www.naela.org](http://www.naela.org)

### **Eldercare Locator**

800-677-1116

[eldercarelocator@USAgings.org](mailto:eldercarelocator@USAgings.org)

<https://eldercare.acl.gov>

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Content reviewed: October 7, 2021

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