

Planning for Legal, Financial, and Health Insurance Issues



Because FTD progressively affects one's thinking and decision-making abilities, it is important to address legal, financial, and insurance considerations as quickly as possible so that the person diagnosed can make their wishes known and participate in planning.

Legal Protections

Consulting an attorney can help people diagnosed and their families understand their rights and protections under U.S. law.



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- **Americans with Disabilities Act (ADA)** - offers protections for people with disabilities, including the right for reasonable workplace accommodations. FTD is recognized as a disability under the ADA.
- **Employee Retirement Income Security Act (ERISA)** - focuses on regulating and protecting employee retirement and health benefit plans, ensuring their proper management and accessibility to employees when they retire.
- **Family Medical Leave Act (FMLA)** - allows eligible employees who are FTD caregivers to take up to 12 weeks of unpaid leave in a 12-month period to care for an immediate family member with a serious health condition, such as FTD.
- **Genetic Information Nondiscrimination Act (GINA)** - protects individuals from having their genetic information used to justify the denial or limitation of services.
- **Consolidated Omnibus Budget Reconciliation Act (COBRA)** - requires employees who lose coverage under their employer's group health plan to remain covered for up to 18 months, although they must pay the premium themselves, plus an administrative fee.

Legal Decision-Making Powers

People living with FTD should designate someone who will ensure their wishes are respected regarding financial and healthcare decisions, including end-of-life care. It is important to discuss these options with an attorney as soon as possible after diagnosis so that the individual with FTD can participate in the process.

- **Power of Attorney (POA)** - a legal document that authorizes another person to make medical and/or financial decisions on your behalf; it can be as simple or as detailed as you like, although its scope may be limited based on your state. POA is only enforceable if signed by an individual who is deemed legally competent at the time. Make sure that your POA is classified as durable (meaning it applies even after the individual becomes unable to make decisions) or springing (meaning it takes effect once the individual loses their decision-making ability). Otherwise, POA can be terminated when the person becomes incapacitated.
- **Advance Directive or Living Will** - legal documents that state an individual's wishes for medical treatment and services instead of appointing someone else to actively make decisions for them as in a POA. You can set up both a POA and a living will, but the rules governing them – for example, which one takes precedence – vary by state. In some states, they can be combined in a single document.
- **Guardianships and Conservatorships** - a legal arrangement in which a family law judge appoints a third party to make decisions for an individual who is deemed unable to manage their own affairs. Laws and proceedings can vary based on your state. The latter individual has no legal rights under this arrangement. This is an extreme step often involving contentious and expensive legal proceedings, and should only be considered after all other options have been explored.

Financial Assistance

People diagnosed with FTD who live in the U.S. may be entitled to a variety of state and federal benefits. Consult an attorney and financial planner to help you understand and apply for these programs, or if your benefits are denied and you want to file an appeal.

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Financial Assistance (*continued*)

- **Social Security Disability Insurance (SSDI)** - provides financial assistance depending on one's work history. People with FTD who have not reached retirement age should apply, and certain family members may also qualify. Everyone who qualifies will be automatically enrolled in Medicare after 24 months.
- **Supplemental Security Income (SSI)** - provides financial assistance to those with limited or no income or assets who either live with a disability or are 65 or older. Eligibility varies by state. Unlike SSDI, SSI is not contingent on work history.
- **Compassionate Allowances (CAL)** - expedites the application process for disability benefits for people with a terminal disease, such as FTD. CAL does not affect the type or amount of benefits received.

Health Insurance Coverage

Many people diagnosed with FTD lose their employer-sponsored health insurance yet are too young to qualify for Medicare. Alternative health insurance options include:

- **Medicare** - the federal healthcare program for U.S. citizens over 65, or for adults with a disability who have received SSDI for 24 months. All citizens are automatically enrolled in Medicare after turning 65, but you must apply to a Medicare program to receive benefits. Medicare does not cover the cost of long-term residential or custodial care. Visit [medicare.gov](https://www.medicare.gov) to learn more.
- **Medicare Supplemental Insurance (Medigap)** - many individuals choose to purchase a **Medigap policy** from a private insurance company to cover care not included in Medicare. These policies may also cover Medicare premiums, co-payments, and other costs.
- **Medicaid** - a joint federal and state program providing health coverage for individuals and families below a certain income level. Eligibility, benefits, and available programs vary by state and are based on income and asset limits. Unlike Medicare, Medicaid includes programs that cover the cost of long-term residential care. An attorney can help navigate the Medicaid application process, including questions involving dual eligibility for Medicare and Medicaid.
- **Other Health Coverage Options** - For those who are ineligible for both Medicaid and Medicare, health insurance options may include coverage through a spouse's employer, COBRA (Consolidated Omnibus Budget Reconciliation Act), or a previous employer. You can also purchase a policy through the state health insurance marketplace: visit [healthcare.gov](https://www.healthcare.gov) to learn more.
- **Veterans Affairs (VA) Benefits** - All military veterans are eligible for healthcare through the U.S. Department of Veterans Affairs; the programs and services available depend on type of active duty and service (during wartime or in armed combat). For more information, contact your nearest VA office.
- **ALS VA Benefits** - The VA classifies some health conditions as service-related if they can be shown to be a result of active duty; these qualify for more comprehensive services. Starting in 2008, the VA presumes diagnoses of ALS to be service-related.
- **Long-Term Care Insurance** - can help pay for services to assist with daily living but it needs to be in place before health issues occur and therefore cannot be purchased after an FTD diagnosis.

Finding an Attorney/Financial Consultant

To find an attorney who is right for your family, use networks like the National Academy of Elder Law Attorneys or your local bar association. Be sure they practice in your state, as laws can differ throughout the U.S. You can also ask for suggestions from other care partners to find an attorney who is familiar with the needs of families with FTD. There are different types of legal/financial professionals that you can consult: **Elder Law Attorney, Employment Law Attorney, ERISA Attorney, Disability Attorney, Financial Planner.**

The Association for Frontotemporal Degeneration

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