



Legal and Financial Planning

Legal and financial matters should be addressed as quickly as possible following an FTD diagnosis. This allows the person diagnosed to be more collaboratively involved in the decision-making process. As the disease progresses, the person diagnosed will be less able to articulate their choices and preferences, so it is critical to get their input early on to ensure that their wishes are met later.

All legal and financial planning should take into account the possibility that the caregiver could predecease the person diagnosed. Where possible, powers of attorney, wills, guardianships, trusts and other documents should identify the person or entity to succeed the caregiver in the event of the caregiver's death.

Legal and financial planning can be very complicated, with rules and regulations differing by state. This page provides a broad overview. To fully understand the issues specific to your state, you should discuss them with a trained professional.

Legal Planning

Depending on your circumstance, it may be helpful to hire an attorney familiar with elder law. The website of the National Academy of Elder Law Attorneys can help you find one.

Power of Attorney

A power of attorney is a document that legally grants someone the authority to make decisions and act on behalf of another person. A power of attorney can be a relatively straightforward document, assigning decision-making authority

to a single individual, or a long and more comprehensive one, delegating the management of specific affairs to different individuals. A power of attorney can also be conditional: a springing power of attorney, for example, becomes effective upon the occurrence of a specified event, such as incapacity. (Its opposite is a durable power of attorney, which becomes effective the moment it is signed and continues indefinitely.)

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Used in this context, the term mental capacity is defined as the ability to understand the details and consequences of executing a power of attorney. (How mental capacity is determined varies by state.) At a certain point, FTD will take away a person's mental capacity, so it is critical to discuss power of attorney as quickly as possible. As long as a person diagnosed is judged to have mental capacity, they can assign – or revoke.

Copies of a power of attorney document should be distributed appropriately to ensure that the necessary individuals and entities are aware of how decision-making authority is delegated. It is a good idea to keep with extra copies immediately at hand in case of confusion or disputes.

Health Care Decisions

As the disease progresses, family members are increasingly asked to make health care decisions on behalf of their loved ones with FTD. Here are some ways to preempt confusion about who can make which decisions:

- A living will can specify the types of treatments, procedures, and pain management that a terminally ill or vegetative patient does or does not wish to receive.
- A health care proxy (or health care power of attorney) designates a person to make health care decisions for the patient, and is not limited to end-of-life situations.
- An advance directive is typically a document encompassing elements of both a living will and a health care proxy.

Guardianship / Conservatorship

In general, a court of law can establish guardianship when a person:

- is not able to manage their affairs or make their own decisions
- has not executed a power of attorney, and is no longer mentally capable of doing so
- may cause or experience serious harm if left on their own

[Americans with Disabilities Act](#) – Forbids employers with at least 15 employees from discriminating against person with disabilities who can still perform the essential functions of their job with reasonable accommodations.

[Family and Medical Leave Act](#) – Lets people caring for a spouse, parent or child with FTD take up to 12 weeks of unpaid, job-protected leave per year without losing their health insurance coverage.

[Consolidated Omnibus Reconciliation Act](#) – 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.

Paying for Health Care

FTD's early average age of onset can be profoundly destabilizing, impacting one's employment, finances and health insurance. The following resources can provide some assistance.

Medicare: Medicare coverage is limited to certain types of care services that are deemed to be medically necessary; it generally will not cover the range of continuing home health supports or assisted living facilities that are often necessary for families caring for someone with FTD. Under specific circumstances, Medicare will approve and pay for PET scans to differentiate Alzheimer's from FTD.

Social Security Disability Insurance (SSDI): SSDI is the federal benefits program for people who are unable to work due to a permanent physical or mental impairment. More information, including the forms necessary to apply, are located on the Social Security Administration's [website](#). But since the

application process can be complicated — especially if you are under 65 — a disability lawyer or eldercare attorney in your state is the best person to turn to for advice.

Social Security Compassionate Allowances: Historically, people with FTD tend to have a difficult time getting SSDI approved by the Social Security Administration. A much faster way to receive benefits is by going through the [Compassionate Allowances](#) (CAL) program. Since 2011, all of the [FTD disorders](#) are included on the list of CAL conditions. We advise applicants contacting a Social Security caseworker to be extremely clear that they want their application reviewed under the CAL program.

Supplemental Security Income (SSI): If you do not qualify for SSDI, it is still worth checking with the Social Security Administration to see whether you qualify for some level of SSI. Work history is not part of the SSI eligibility requirements. SSI may also include access to benefits and services through Medicaid, and may be able to be supplemented with SSDI.

Medicaid: Medicaid coverage is broader than Medicare, covering additional services such as long-term care and supportive living facilities, but finding providers who accept Medicaid can be difficult. Eligibility to receive Medicaid is typically measured by considering your monthly income along with the total value of your assets; people seeking Medicaid may be spend down these assets to become eligible. Because each state administers its own Medicaid plan, with its own requirements and regulations, contacting an elder law attorney who has Medicaid experience in your state can be helpful.

Medicare Supplemental Insurance (Medigap): Because Medicare often does not cover important types of care, many individuals choose to purchase [Medigap policies](#) from private insurance companies. These policies may cover types of care not covered by Medicare, and may cover Medicare premiums, co-payments, and other costs.

Long-Term Care Insurance: [Long-term care insurance](#) can be a good investment for individuals who do not qualify for Medicaid (or do not wish to spend down their assets in order to qualify).

Continued at <http://www.theftd.org/living-with-ftd/legal-financial-planning/>