



The Association for
Frontotemporal Degeneration
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People can live for many years with FTD. Maintaining the highest possible quality of life will likely require engagement with a broadly comprehensive medical team: a primary care physician, neurologist, psychiatrist or geriatrician, and other specialists, in addition to a case manager, community services, family and friends. No one can manage FTD without help.

A range of medical providers address different aspects of the FTD journey. You will likely encounter:

- **Primary Care Physicians (PCPs).** Many FTD patients rely on their PCP for ongoing care during the course of the illness. Your PCP may refer you to a specialist or arrange a comprehensive diagnostic evaluation at a medical center. Additionally, your PCP will be critical for maintaining routine physical exams and for providing care for health issues unrelated or indirectly related to FTD.
- **Internists.** Many adults designate an internist as their primary care physician. Internists can be particularly helpful if there are multiple health issues involved besides FTD, such as diabetes or hypertension.
- **Geriatricians.** Geriatricians may be best able to manage complications related to FTD in individuals with health concerns related to old age. Additionally, a geriatrician may be more experienced with the medications and treatments used to manage these symptoms. Many older adults designate a geriatrician as their primary care doctor.
- **Psychiatrists.** Many people may consult with a psychiatrist in the process of seeking a diagnosis for the early changes in thinking or behavior associated with FTD. Because they are knowledgeable in the medications used to treat anxiety, depression, agitation or aggressive behaviors, psychiatrists can be helpful in managing similar symptoms in FTD.
- **Neurologists.** The principal reason to consult a neurologist is for a diagnosis. A neurologist is probably involved in every diagnosis of FTD that is made, whether directly or as a consultant. The second most common reason to consult a neurologist is to clarify the causes of new

symptoms or behaviors as the disease progresses. Behavioral neurologists and neuropsychologists are also able to evaluate cognitive and behavior changes in people with FTD.

- **Palliative Care Physicians.** A palliative care physician will likely not be engaged until the FTD progresses to its end stage, and the person diagnosed enters a hospice program. Hospice medical directors are often palliative care physicians.
- **Nurse Practitioners/Advanced Practice Nurses.** Nurse practitioners are very important in FTD care. They may hold executive level positions as clinic directors or act as a primary care provider for patients. Nurse practitioners may also conduct and administer research programs either independently or in association with a medical doctor. In some states they may prescribe medications, but regulations governing that authority vary.
- **Certified Genetic Counselors (CGCs).** CGCs provide information and support to individuals and families when there is a multi-generational history of dementia or an increased risk of an inheritable form of FTD. A CGC can review a family's medical history and analyze inheritance patterns, offer advice on potential inheritable risk factors, and offer guidance on options including the possibility of genetic testing. CGCs are often part of the teams at specialized clinical or research programs in hospitals or medical centers.
- **Physical, Occupational, and Speech Therapists.** FTD often affects movement and/or speech, making the services provided by these three types of therapists critical. By working with a therapist, people with FTD can learn how to adapt to their changing abilities and preserve their independence as long as possible. Speech therapists are particularly important, as they can advise people with FTD on ways to avoid the risks associated with dysphagia, such as choking.
- **Case Managers/Geriatric Case Managers.** Case manager is a generic title for anyone (usually a social worker) who helps caregivers and patients navigate the often confusing process of finding, accessing and paying for health care services or using and understanding insurance benefits. Social workers who pass a national exam are licensed and able to bill some services to insurance providers. Some case workers may specialize in particular populations or services. For example, a geriatric care manager specializes in health care and other services for seniors such as finding an appropriate residential care facility.

Continued at <http://www.theaftd.org/living-with-ftd/coordinating-care/>