Care, Support & Treatment of PPA

Many clinicians are involved in the diagnosis and care of individuals living with primary progressive aphasia (PPA) and their families. We refer to this as a care team. The members of one’s care team will vary by individual and over time. Examples of individuals who may be a part of the care team include:

- Neurologist (specialists in brain disorders who make the diagnosis and monitors its symptoms)
- Neuropsychologist (evaluate cognitive abilities through specialized paper and pencil tests)
- Psychiatrist (assist with behavioral and mood symptoms)
- Social worker (help families navigate the difficult decisions related to their diagnosis)
- Speech and language pathologist (provide strategies to maximize communication abilities)
- Physical and occupational therapists (help optimize movement and activities of daily living)

Other professionals may include creative arts therapists, individual/family therapists, elder law and estate planning attorneys, palliative care/hospice, mediation services, companion care, adult day services and nursing services.

Our center offers quality-of-life programs that may be helpful for individuals with PPA and their families. You can also visit our Join a Study page (../../join/index.html) to learn about our research into optimizing care and support.

Treatment (Medications)

Currently, there is no cure to stop the progression of brain diseases that cause PPA. PPA is caused by one of three families of disease: Alzheimer’s disease, FTLD-tau or FTLD-TDP-43. Effective treatments for PPA will likely rely on knowing, at the individual level, which disease is causing PPA. Scientists are actively looking for and testing biomarkers for this purpose.

For those with suspected Alzheimer’s disease pathology, Alzheimer medications may be appropriate. Unfortunately, no medications exist for those with suspected FTLD-tau or FTLD-TDP43 pathology. Other medications may be useful for treating behavioral symptoms such as depression, anxiety and/or agitation, which may occur later in the illness.

Non-Pharmacological Treatment (Non-Drug Interventions)

There are also life-enriching interventions that may be helpful for managing symptoms and maximizing quality of life, including speech-language therapy, support groups, creative arts therapy and individual counseling. Learn more about some interventions below.

Speech & Language Therapy

Speech and language therapy is an important intervention for all individuals with PPA. Speech-language therapists can help identify strategies to maximize communication abilities and quality of life throughout the course of the illness. Because every individual living with PPA is different, strategies may vary from individual to individual. These approaches include impairment-focused, compensatory and environmental modification strategies. Both the diagnosed individual and their communication partners will need to adapt to new methods of communication. Working with a speech-language pathologist can help make this transition. Our center is actively recruiting for a speech-language therapy clinical trial (../../join/active-studies.html).

Social Work Services

In addition to communication-enhancing strategies, people living with PPA and their care partners can benefit from ongoing education, counseling and access to useful resources. Social workers are available in the Neurobehavior and Memory Clinic (https://www.nm.org/conditions-and-care-areas/neurosciences/neurobehavior-and-memory-clinic) to meet with patients and families to develop a personal and customized approach to care.

Social workers will:

- Review the diagnosis and provide the opportunity to ask questions and obtain up to date disease information
- Discuss changing language, behaviors and other diagnosis-related symptoms and offer helpful communication strategies
- Provide counseling regarding changing roles as the disease progresses
- Help you to assure your own self-care and to strengthen your support network
- Provide referrals for individual, couples and/or family counseling
- Connect you to elder law attorneys for estate planning to and to establish powers of attorney for healthcare and finances
- Provide counseling regarding advance directives
- Guide you to specialized support and education groups for newly diagnosed individuals and families, quality-of-life programs for meaningful and purposeful activity and other community programs

Support Groups

Mesulam Center Groups

FTD/PPA Caregiver Group: (../../care-and-support/ftd-ppa-support.html) For families and friends of those diagnosed

The Association for Frontotemporal Degeneration

This association, outside of the center, offers in-person and by-phone support groups, as well as annual caregiver conferences. Call the helpline at
Resources

The Association for Frontotemporal Degeneration (http://www.theaftd.org/) is an organization dedicated to improve quality of life for people affected by FTD/PPA and drive research to a cure.

FTD Disorders Registry (https://www.ftdregistry.org) is an online database to collect information from those affected by all types of frontotemporal degeneration, including PPA.

FTD Talk (https://www.ftdtalk.org/) is a website that provides jargon-free updates about research in PPA and FTD.

More in Primary Progressive Aphasia

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