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## Planning for the Future with PPA Resources

### Our Contact Information

The Mesulam Center for Cognitive Neurology and Alzheimer's Disease  
at Northwestern University  
(312) 908-9339

300 E. Superior St., Tarry 8 Chicago, IL 60611

<https://www.brain.northwestern.edu/>

The Mesulam Center for Cognitive Neurology and Alzheimer's Disease at Northwestern University Feinberg School of Medicine is committed to providing quality care through our affiliated care sites, conducting research on how the brain coordinates mental functions, transferring the benefits of research to afflicted patients and preparing future scientists and clinicians in our field.

Northwestern Medicine Neurobehavior and Memory Clinic

(312) 695-9627

676 N. Saint Clair St. Suite 945 Chicago, IL 60611

<https://www.nm.org/conditions-and-care-areas/neurosciences/neurobehavior-and-memory-clinic>

The Neurobehavior and Memory Clinic is staffed by behavioral neurologists, neuropsychologists, neuropsychiatrists, geriatricians, and clinical social workers from the Northwestern Medical Group. Our clinic offers a comprehensive array of diagnostic, therapeutic and innovative care that treats the whole patient

## RESOURCES

### LEGAL

The National Academy of Elder Law Attorneys

(703) 942-5711

<https://www.naela.org/>

Registry of lawyers experienced in elder law and special needs. An elder law attorney can assist with legal and financial planning, as well as guardianship.

Family/Elder Mediation

(802) 823-2566

<https://apfmnet.org/find-a-mediator/>

Mediation is a procedure in which the families in conflict meet with a trained impartial third person to discuss their disputes and reach an agreement outside of a court of law.

## FINANCIAL

Social Security Disability (SSA)

(800) 772-1213

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

<https://www.ssa.gov/benefits/disability/apply.html>

<https://www.ssa.gov/compassionateallowances/>

If you are under age 65 and no longer able to work due to PPA, you are eligible for social security disability. PPA is marked for expedited SSD approval.

National Clearing House for Long-Term Care Information

<https://acl.gov/ltc>

(202) 401-4634

State specific information to help plan for future long-term care (LTC) needs.

Genworth Cost of Care Calculator

<https://www.genworth.com/aging-and-you/finances/cost-of-care.html>

Find the median costs of different types of care in your geographic area.

Medicare

(800) 633-4227

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

Medicare is a health insurance program for people over 65 or under 65 with a disability.

Financial Planning Association

(800) 322-4237

<http://www.plannersearch.org/>

Find financial planning professionals to help plan for the cost of future care needs.

The AFTD Caregiver Respite and Travel Grants

<http://www.theaftd.org/life-with-ftd/resources>

Families living with FTD/PPA are eligible for \$500 respite and quality of life grants

## FINDING RESOURCES, RESPITE, IN HOME CARE, LONG TERM CARE

#### Community Resource Finder

<https://www.communityresourcefinder.org/>

This tool allows you to search for all types of local dementia care and support services in a specific location

#### Eldercare Locator

(800) 677-1116

<https://eldercare.acl.gov>

The Eldercare Locator provides information about local agencies that offer day programs, support groups, respite providers, in-home care, case management and other caregiving services.

#### National Association for Home Care & Hospice (NAHC)

(202) 547-7424

<http://www.nahc.org/>

NAHC is a nonprofit organization that represents the nation's 33,000 home care and hospice organizations. Search for home care aides, companion care, homemaker services and nursing services.

#### Medicare Care Comparison Tools

<https://www.medicare.gov/nursinghomecompare/search.html>

<https://www.medicare.gov/homehealthcompare/search.html>

Search for local in-home and nursing home care. Use tools to make comparisons of the services offered.

#### National Association of Senior Move Managers

(877) 606-2766

<https://www.nasmm.org/>

NASMM members specialize in helping older adults and families with de-cluttering, downsizing, and moving.

#### National Hospice and Palliative Care Organization

(703) 837-1500

<https://www.nhpc.org/find-a-care-provider/>

Find a local Palliative or Hospice organization near you.

#### Aging Life Care Association

(520) 881-8008

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

An Aging Life Care Professional/Care Manager helps families plan for and arrange for care as needs change. They provide ongoing assessments, referrals & care.

## FINDING EMOTIONAL SUPPORT

Help Starts Here

<https://www.helpstartshere.org/>

Find a therapist or counselor in your local area.

### Support Groups

Alzheimer's Association

(800) 272-3900

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

[https://www.alz.org/events/event\\_search?etid=2&cid=0](https://www.alz.org/events/event_search?etid=2&cid=0)

The Alzheimer's Association provides disease education, support, care planning and referral to community services for family members who are caring for a person with dementia.

The Association for Frontotemporal Degeneration (AFTD)

(866) 507-7222

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

<https://www.theaftd.org/living-with-ftd/aftd-support-groups/>

The AFTD offers phone support, disease information, educational events and connections to resources and support.

### The Mesulam Center Support Groups

<https://www.brain.northwestern.edu/care-and-support/support-groups.html>

#### **For Care Partners of Individuals Living with PPA**

This monthly support group is for family members and care partners of people living with primary progressive aphasia (PPA), and is held on the first Monday of each month from 4:30 to 6 p.m. CT.

If you have not been to the group before and would like to join, please contact Darby Morhardt, PhD, LCSW, [d-morhardt@northwestern.edu](mailto:d-morhardt@northwestern.edu), (312) 908-9432, for a brief telephone screening.

#### **For Care Partners of Individuals Living with FTD**

This monthly support group is for family members and care partners of people living with frontotemporal dementia (FTD), and is held on the third Monday of each month from 4:30 to 6 p.m. CT.

If you have not been to the group before and would like to join, please contact Darby Morhardt, PhD, LCSW, [d-morhardt@northwestern.edu](mailto:d-morhardt@northwestern.edu), (312) 908-9432, for a brief telephone screening.

### **For Care Partners of Individuals Living with Younger-Onset Dementia**

This monthly support group is for family members and care partners of people living with younger-onset (under age 65) dementia, and is held on the second Monday of each month from 4:30 to 6 p.m. CT.

If you have not been to the group before and would like to join, please contact Debbie Dyslin, LCSW, [deborah.dyslin@northwestern.edu](mailto:deborah.dyslin@northwestern.edu), (312) 503-5559, for a brief telephone screening.

## **SAFETY**

### **MedicAlert® Foundation + Alzheimer's Association**

(800) 432-5378

[www.alz.org/SafeReturn](http://www.alz.org/SafeReturn)

A 24-hour nationwide emergency response service for individuals with dementia who may become lost.

### **Dementia and Driving**

Helpful readings on dementia and driving. For a local driving evaluation, request a referral to a Driving Evaluation Site from your physician.

<http://www.alz.org/care/alzheimers-dementia-and-driving.asp>

<https://www.theftd.org/driving-and-ftd/>

<https://www.thehartford.com/resources/mature-market-excellence/dementia-driving>

[https://s0.hfdstatic.com/sites/the\\_hartford/files/cmme-crossroads.pdf](https://s0.hfdstatic.com/sites/the_hartford/files/cmme-crossroads.pdf)

### **Occupational Therapy Evaluation (OT)**

OT Practitioners can do a home safety evaluation and also assist a person with PPA/family in making safety adaptations and modifications in the home.

Request a referral for an in-home OT evaluation from your physician.

### **Physical Therapy (PT)**

PT can help enhance mobility and quality of life by improving strength, balance, endurance, flexibility and posture. Physical therapy can maximize one's ability to get

around at home and community and participate in activities. Request a referral from your physician.

### **Speech Language Therapy (SLT)**

Speech-language therapists can help identify strategies to maximize communication abilities and quality of life throughout the course of the illness. These approaches include impairment-focused, compensatory and environmental modification strategies. Request a referral from your physician.

## **ACTIVE RESEARCH**

By participating in research you are taking an active role in

- Helping others, including future family members who may be at risk for Alzheimer's or a related dementia
- Being a part of the cure; the information we learn will be used to inform strategies for optimizing aging and avoiding disease and disability
- Testing new treatments that might work better than those currently available
- Gaining access to the latest information and resources relevant for aging and dementia

The Mesulam Center for Cognitive Neurology and Alzheimer's Disease at Northwestern University Active Studies

<https://www.brain.northwestern.edu/join/active-studies.html>

Communication Bridge: A person-centered Internet-based intervention for individuals with primary progressive aphasia

(312) 503-4012

<https://www.brain.northwestern.edu/join/details.html?id=STU00206086>

The Communication Bridge study is an internet-based, speech therapy intervention for individuals with Primary Progressive Aphasia and their Communication Partner. The goal of the study is to understand how speech-language therapy affects communication abilities in people living with PPA. All study visits take place over the Internet in your home. We will provide you with a computer for the length of the study. We will connect through a video-chat program on the computer. The study lasts about one year. You will complete 5 evaluations with a certified speech-language therapist, 15 one-hour speech therapy sessions with a certified speech-language therapist, and home exercises on the computer we provide you.

National Institute on Aging Clinical Trials:

(800) 222-2225

<https://www.nia.nih.gov/research/clinical-trials>