

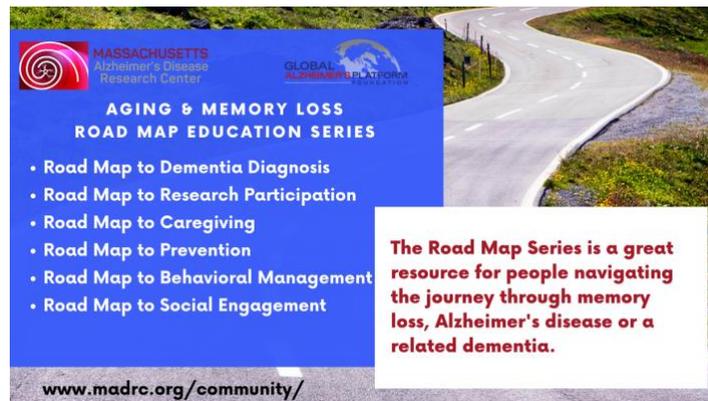
Clinician Partner Newsletter (April 2022) - Updates for our collaborators

Road Map Series

The Massachusetts Alzheimer's Disease Research Center (MADRC) Outreach team has been hard at work creating additional resources for patients and families. Recently we expanded access to our Aging & Memory Loss – Road Map Education series guidebooks by translating them into Spanish. Both the English and the Spanish versions can be found on our website here: madrc.org/community/

These informative booklets help people living with dementia and their families/caregivers get answers to questions about prevention, diagnosis, caregiving, research participation, managing symptoms of the disease and staying cognitively engaged.

These booklets compliment professional presentations given on each of these topics. Links to these video sessions can be found on MADRC's YouTube Channel: [@ADRCMASS](https://www.youtube.com/@ADRCMASS)



MASSACHUSETTS Alzheimer's Disease Research Center GLOBAL ALZHEIMER PLATFORM

AGING & MEMORY LOSS ROAD MAP EDUCATION SERIES

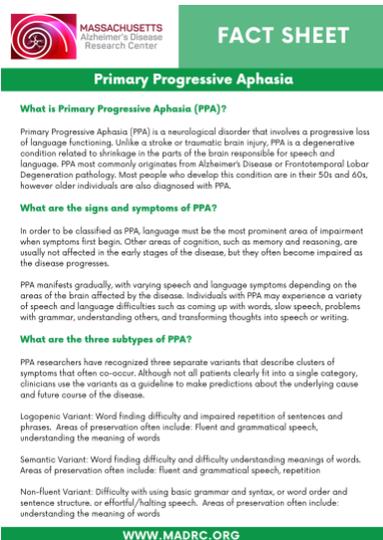
- Road Map to Dementia Diagnosis
- Road Map to Research Participation
- Road Map to Caregiving
- Road Map to Prevention
- Road Map to Behavioral Management
- Road Map to Social Engagement

The Road Map Series is a great resource for people navigating the journey through memory loss, Alzheimer's disease or a related dementia.

www.madrc.org/community/

Get the Facts

Understanding the many different causes of dementia and their symptoms can be confusing. The MADRC team has created fact sheets on the various types of dementia diagnosis. These can be found in English and Spanish on the website here: madrc.org/news-events/get-the-facts/ Following are some examples of the fact sheets



MASSACHUSETTS Alzheimer's Disease Research Center **FACT SHEET**

Primary Progressive Aphasia

What is Primary Progressive Aphasia (PPA)?

Primary Progressive Aphasia (PPA) is a neurological disorder that involves a progressive loss of language functioning. Unlike a stroke or traumatic brain injury, PPA is a degenerative condition related to shrinkage in the parts of the brain responsible for speech and language. PPA most commonly originates from Alzheimer's Disease or Frontotemporal Lobar Degeneration pathology. Most people who develop this condition are in their 50s and 60s, however older individuals are also diagnosed with PPA.

What are the signs and symptoms of PPA?

In order to be classified as PPA, language must be the most prominent area of impairment when symptoms first begin. Other areas of cognition, such as memory and reasoning, are usually not affected in the early stages of the disease, but they often become impaired as the disease progresses.

PPA manifests gradually, with varying speech and language symptoms depending on the areas of the brain affected by the disease. Individuals with PPA may experience a variety of speech and language difficulties such as coming up with words, slow speech, problems with grammar, understanding others, and transforming thoughts into speech or writing.

What are the three subtypes of PPA?

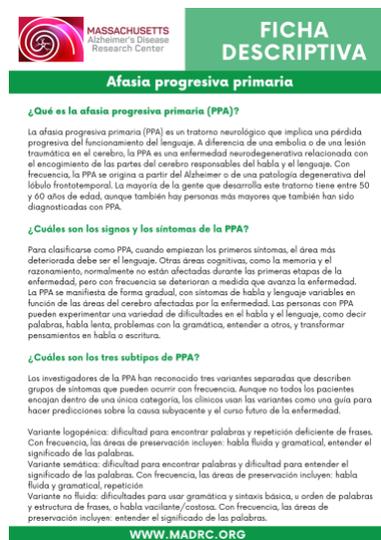
PPA researchers have recognized three separate variants that describe clusters of symptoms that often co-occur. Although not all patients clearly fit into a single category, clinicians use the variants as a guideline to make predictions about the underlying cause and future course of the disease.

Logopenic Variant: Word finding difficulty and impaired repetition of sentences and phrases. Areas of preservation often include: Fluent and grammatical speech, understanding the meaning of words.

Semantic Variant: Word finding difficulty and difficulty understanding meanings of words. Areas of preservation often include: Fluent and grammatical speech, repetition.

Non-fluent Variant: Difficulty with using basic grammar and syntax, or word order and sentence structure, or effortful/halting speech. Areas of preservation often include: understanding the meaning of words.

WWW.MADRC.ORG



MASSACHUSETTS Alzheimer's Disease Research Center **FICHA DESCRIPTIVA**

Afasia progresiva primaria

¿Qué es la afasia progresiva primaria (PPA)?

La afasia progresiva primaria (PPA) es un trastorno neurológico que implica una pérdida progresiva del funcionamiento del lenguaje. A diferencia de una embolia o de una lesión traumática en el cerebro, la PPA es una enfermedad neurodegenerativa relacionada con el encogimiento de las partes del cerebro responsables del habla y el lenguaje. Con frecuencia, la PPA se origina a partir del Alzheimer o de una patología degenerativa del lóbulo frontotemporal. La mayoría de la gente que desarrolla este trastorno tiene entre 50 y 60 años de edad, aunque también hay personas más mayores que también han sido diagnosticadas con PPA.

¿Cuáles son los signos y los síntomas de la PPA?

Para clasificarse como PPA, cuando empiezan los primeros síntomas, el área más deteriorada debe ser el lenguaje. Otras áreas cognitivas, como la memoria y el razonamiento, normalmente no están afectadas durante los primeros etapas de la enfermedad, pero con frecuencia se deterioran a medida que avanza la enfermedad. La PPA se manifiesta de forma gradual, con síntomas de habla y lenguaje variables en función de las áreas del cerebro afectadas por la enfermedad. Las personas con PPA pueden experimentar una variedad de dificultades en el habla y el lenguaje, como decir palabras, habla lenta, problemas con la gramática, entender a otros, y transformar pensamientos en habla o escritura.

¿Cuáles son los tres subtipos de PPA?

Los investigadores de la PPA han reconocido tres variantes separadas que describen grupos de síntomas que pueden ocurrir con frecuencia. Aunque no todos los pacientes encajan dentro de una única categoría, los clínicos usan las variantes como una guía para hacer predicciones sobre la causa subyacente y el curso futuro de la enfermedad.

Variante logopéptica: dificultad para encontrar palabras y repetición deficiente de frases. Con frecuencia, las áreas de preservación incluyen: habla fluida y gramatical, entender el significado de las palabras.

Variante semántica: dificultad para encontrar palabras y dificultad para entender el significado de las palabras. Con frecuencia, las áreas de preservación incluyen: habla fluida y gramatical, repetición.

Variante no fluida: dificultades para usar gramática o sintaxis básica, u orden de palabras y estructura de frases, o habla vacilante/costosa. Con frecuencia, las áreas de preservación incluyen: entender el significado de las palabras.

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Research Participation Opportunities

The MADRC team, and affiliated Mass General Brigham partners, offer several research opportunities for Spanish speakers. The Center for Alzheimer's Research and Treatment (CART) has a clinical trial for Spanish speakers and English speakers called the AHEAD study.

The AHEAD study is a clinical trial for individuals who are cognitively normal:

The AHEAD A-3, 45: Alzheimer's Prevention Study is comprised of two different trials testing the same investigational drug (known as BAN2401). Study participants are enrolled in one of two AHEAD trials based on whether they have intermediate or elevated levels of amyloid in their brain:

Participants with intermediate amyloid levels take part in the AHEAD A-3 trial—the *first pre-preclinical Alzheimer's disease trial*. Participants with elevated amyloid levels take part in the AHEAD A-45 trial. Over the course of the study, the two different trial groups will receive intravenous (IV) infusions of BAN2401 or a placebo, an inactive substance designed to mimic the appearance of the drug. To learn more:

www.aheadstudy.org/

Additionally, there are several observational studies enrolling Spanish speaking participants. These studies are for people concerned about their memory or interested in learning about cognitive function and changes in their brain as they age.

Studies for individuals who are cognitively normal (no memory impairment):

Boston Latino Aging Study (BLAST) A study to assess Spanish speaking participant's cognitive function.

To learn more: [BLAST Flyer Spanish](#)

A study for individuals who are cognitively normal or who have problems with memory and thinking or a dementia diagnosis:

Memory & Aging Cohort Study (MAC) A study looking at the relationship between the substances in your blood and your memory and thinking abilities. **This study is also open to English speakers.**

To learn more: [MAC flyer](#)

A study for individuals facing memory and thinking concerns, a diagnosis of dementia:

Longitudinal Cohort Study (LC) Also known as a natural history study, the goal of the long-term study is to obtain a uniform set of data from individuals who have various types of dementia (e.g., Alzheimer's disease, frontotemporal degeneration, Lewy body dementia, etc.) and from healthy older individuals to understand how dementia develops in the human brain. Research findings from the 'LC' study can enable scientists to find effective treatments and an eventual cure for Alzheimer's disease and related forms of neurological diseases.

We have several additional clinical trials and observational studies at our center for your English-speaking patients and families. Please review the attached study information sheet to get the full list of open and enrolling studies. Study information is also on our website here: madrc.org/join-a-study/

Email us at: BWHBbehavioralNeurology@bwh.harvard.edu for additional study information and resources.

Contact Info

If you need additional information or have questions, contact:

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