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RARE DISEASE DAY®

[Rare Disease Day](#) is a worldwide event, occurring annually on the last day of February to raise awareness for the over 6,000 diseases that affect fewer than 1 in 2,000 people. FTD is a rare disease which enables companies to access a variety of incentives and financial safeguards that allow them to invest in the research and development of experimental drugs and therapies.

On Friday February 28, [MassBio](#) is hosting a [Rare Disease Forum](#) featuring patients, caregivers, advocates, and researchers to bring attention to advancements in the diagnosis and treatment of rare and ultra-rare diseases. Register now at the link above.

Dear FTD Unit Community Members,



We appreciate the opportunity to connect with you through our first newsletter of 2025. This issue is focused on Posterior Cortical Atrophy (PCA), an atypical form of Alzheimer's Disease, that we treat in the MGH FTD Unit. We're featuring an overview of PCA and an interview with Dr. Deepti Putcha, the director of the MGH PCA Program. We've also collected resources that may be helpful to those living with PCA.

I'm excited to share two upcoming educational efforts. The MGH FTD Unit has launched *From Care to Cure*, a podcast exploring care for a life lived with frontotemporal disorders, Alzheimer's disease and related dementias. Each month, Katie Brandt, our Director of Caregiver Support Services and Public Relations, and I will discuss a different aspect of living with FTD. See the article on page 5 for more information. Don't forget to subscribe and share with your friends and family.

Our second educational offering is a four-part webinar series about the Care Plan Trifecta (CPT) hosted by Katie Brandt. The CPT provides a framework for person-centered care planning. We've been using this framework in the FTD Unit's Caregiver Support Program with great success. Read more about it on page 6.

Finally, I want to recognize [Rare Disease Day](#), which will be celebrated globally on February 28th. This is a special day in our community because many of the patients we care for are living with a rare condition. We know that living with a rare diagnosis can increase feelings of isolation and loneliness and that is why we are committed to developing resources and events that build connections and support for persons living with a diagnosis, caregivers and family members. Remember that alone we are rare, but together we are strong.

We hope to see you at a community event, in clinic or online soon! Until then, take care and be well.

Bradford C. Dickerson, MD
Director, MGH Frontotemporal Disorders Unit

Spotlight on Posterior Cortical Atrophy

What is Posterior Cortical Atrophy?

Posterior cortical atrophy (PCA) is a progressive neurodegenerative condition that affects areas in the brain responsible for visual processing and spatial perception. Over time, other thinking skills such as memory, executive functions, and word retrieval may become affected.

What Causes PCA?

In the majority of PCA cases, the underlying cause is Alzheimer's disease. Lumbar punctures conducted in the clinic as well as specialized positron emission tomography (PET) scans can show abnormal accumulation of amyloid and tau proteins that form the plaques and tangles seen in Alzheimer's disease, thus confirming the diagnosis. Although PCA is usually caused by Alzheimer's disease, it can also result from other diseases including Lewy body disease and corticobasal degeneration, and the clinical features may be different in these cases. PCA is often under-recognized or misdiagnosed since patients and doctors can mistake visual cognitive decline (a problem with the brain) for a visual acuity impairment (a problem with the eyes).



The MGH FTD Unit PCA Program

Under the direction of Deepti Putcha, Ph.D., the [MGH FTD Unit PCA Program](#), offers a cross-disciplinary collaborative approach to caring for people living with PCA as well as for their families. Our patients receive a highly specialized clinical evaluation, which can diagnose or provide a second opinion confirmation of the PCA diagnosis. We also facilitate referrals to appropriate specialists and resources designed to optimize quality of life in line with evidence-based treatment guidelines. We are committed to supporting families through their whole journeys with this disease and as such, we offer comprehensive support and education about living with PCA and how to plan for the future. Our patients will also have the opportunity to participate in research designed to better understand and develop future treatments for those living with PCA. Our PCA program is also affiliated with the [Massachusetts Alzheimer's Disease Research Center](#) and the [MGH Memory Disorders Unit](#).

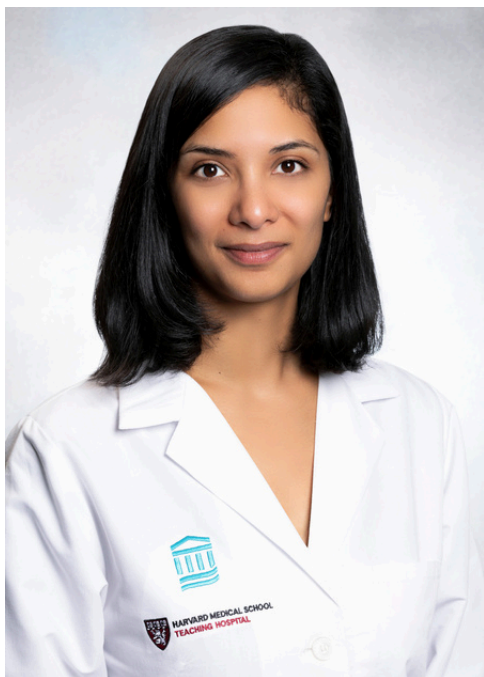
If you want to learn more about the MGH PCA program, you may email Dr. Putcha directly at DPutcha@MGH.Harvard.edu.



Clinical Evaluation

Our team has over a decade of experience in diagnosing and caring for individuals with PCA. At your initial clinic appointment, you will be evaluated by a team of neurologists, neuropsychologists, speech-language therapists, and caregiver support specialists. These evaluations will include a detailed clinical interview with patients and family members, as well as imaging and neurocognitive testing, with the aim of guiding diagnosis and treatment.

Q&A with Deepti Putcha, Ph.D.



Deepti Putcha earned her Ph.D. from Boston University in 2016 in Clinical Neuropsychology. She completed a clinical internship at the Brown University Alpert School of Medicine, and a postdoctoral fellowship in clinical neuropsychology and cognitive neuroscience in the MGH/BWH Harvard Partners Consortium and the MGH FTD Unit. Dr. Putcha has been an Associate Neuropsychologist in the MGH FTD Unit since 2018 and maintains a clinical practice at the BWH Center for Brain-Mind Medicine. She serves as the director of the MGH Posterior Cortical Atrophy Program. We sat down with her to learn more about the MGH FTD Unit's PCA Program and what makes it unique.

Q: Thanks for speaking with us today, Dr. Putcha. How did you become interested in PCA?

A: I'm glad I can let more people know about the PCA Program! As a neuropsychologist, I was always interested in examining how cognitive difficulty affects everyday life for our patients and families. When I learned that Alzheimer's disease does not only affect memory, I was driven to learn

what I could about other "atypical" forms of Alzheimer's disease. I realized that as a field, we have little knowledge about how to diagnose and treat individuals with the less well-known visual variant of AD, or PCA. I now dedicate myself to advocating for a better understanding of PCA to encourage earlier diagnosis and to develop more appropriate treatment strategies so we can make a meaningful difference in daily life for patients living with PCA.

Q: Why do you think that the MGH FTD Unit program is special for people diagnosed with PCA?

A: Our MGH FTD Unit PCA program takes a unique cross-disciplinary approach to helping diagnose, treat, and support people diagnosed with PCA and their families. Ours is one of just a handful of PCA-focused centers across the US and UK. Our clinicians, including not only neurologists and neuropsychologists, but also neuropsychiatrists and speech and language pathologists, social workers, caregiver support specialists, and geneticists, have all developed expertise about this syndrome, and all take an active role in contributing to clinical diagnosis and treatment planning for our patients. We also offer research participation opportunities that meaningfully contribute to the cutting edge of the scientific understanding of PCA. Because of the partnership between our patients and our researchers, we have published important work that serves to make PCA more visible to the international Alzheimer's disease scientific community, highlighting the need to study this variant of AD in more depth and design clinical trials that better serve these patients. We apply what we learn to the care we provide our patients.

Q: What can patients expect by receiving medical care in a specialty clinic like the MGH FTD Unit?

A: When patients living with PCA are seen in our clinic, they are stepping into an environment where they are surrounded by people who are experts in their rare disease. Our clinicians take the time to make sure our patients understand their diagnosis and their options for monitoring, treatment, and support over time. In our specialty clinic, patients have the knowledge that they are receiving care from professionals who are steeped in the latest science informing treatment of this illness. They also have the opportunity to participate in groundbreaking research that helps push the field forward to benefit people living with PCA world-wide. Lastly, our program offers a unique dyadic support group designed to welcome people living with PCA and their care partners, to learn adaptive strategies to optimize quality of life and benefit from being part of a community of people who share a similar journey.

(Q&A continued on page 4.)

Q&A with Deepti Putcha, Ph.D. (cont.)

Q: What kind of research on PCA is the MGH FTD Unit currently focusing on?

A: Our current research falls into two main branches. The first is to better understand the different kinds of cognitive difficulties that people with PCA experience. Our work studies the different aspects of cognition (visual-spatial decline, language difficulty, memory lapses) that emerge at different stages of the illness and how they impact daily life for PCA patients. We are also developing new tools that can measure these cognitive difficulties with greater precision than existing cognitive tests that are currently used in Alzheimer's clinical trials. With this work, we want to improve diagnostic accuracy and promote earlier diagnosis for patients around the world, as well as improve treatment trial design. The second branch of our work is understanding the actual disease mechanisms by which PCA starts and progresses. This work uses multimodal imaging tools (MRI and positron emission tomography (PET) scans) to look at where the disease starts in the brain, and to understand how it moves through the brain over time, impacting various types of thinking skills. The hope is that by understanding how the disease affects the brain over time, we can understand how to stop the spread of disease and slow its decline with newly developed interventions including the anti-amyloid therapies that have recently become available.

Q: Will this research help patients and their families in the shorter term, before disease-altering treatments are available?

A: Though we do not yet have a cure, there are several options for treating symptoms in PCA. Because of our research, we now understand that the difficulties that people living with PCA face are so different person-to-person. Being able to track cognitive function and brain health with our imaging tools at different time points is helpful to understanding a person-specific trajectory in this illness, and helps us predict and prepare for what may be down the road. For example, as we track cognitive function over time at frequent time points (every 6 months) in our detailed research study, we will be able to see how an individual progresses better than if they were seen in clinic only annually with less-detailed assessments. As a result, we may be able to differentiate slow progressors from fast progressors, and tailor treatment plans accordingly.

Q: What do you think is coming for the future for people living with PCA?

A: From a medical perspective, my hope is that as PCA syndrome is better understood and more easily diagnosed, we will be able to treat more people effectively with the disease-modifying therapies that continue to be developed. I am also hopeful that we can soon easily utilize smart technology to help support independence in daily life, such as utilizing voice recognition to support hobbies and communication, and fingerprint technology instead of keys for locks, for example, to reduce reliance on visual processing in navigating in and around the home.

Massachusetts Advocacy Day

Join MGH FTD Unit staff and Dawn O'Gara, AFTD Ambassador for the

state, at the Alzheimer's Association's MA Advocacy Day on Thursday, February 27th at the State House.



Join us to raise awareness of FTD, Alzheimer's Disease and other dementias while building relationships with our state legislators. You'll hear from legislative champions, be updated on bills supporting people living with dementia and their caregivers, and meet with your legislators to discuss our policy priorities. This is a great opportunity to make an impact!

Learn more and register now at <https://alz-ma.quorum.us/event/19806/>. Training will be provided. If you can't make it to the State House and still want to make a difference, please go to <https://alz-ma.quorum.us/campaign/107660/> to learn how to advocate from home.

Resources for People Living with PCA

Educational Resources:

[Roon](#) is an online platform dedicated to providing accurate medical information for a variety of conditions, including dementia. Built by an interdisciplinary team including doctors, patients, and caregivers, Roon is an easy to navigate source of expertise and features numerous videos about PCA, recorded by clinicians (including [Dr. Deepti Putcha](#)), researchers, people living with PCA and caregivers. Each video is 3-5 minutes so Roon is perfect when you have just a moment to learn.

[Rare Dementia Support](#) is a UK-based group supporting people affected by rare dementias including PCA. RDS offers social, emotional and practical support for those living with rare dementias. RDS' [resources about PCA](#) include two short films about PCA: [Living with PCA](#) and the animated [Do I See What You See](#).

Researchers at the University of Toronto have developed [Visual Dysfunction in Dementia: Home Safety Tips & Recommendations](#), a tip sheet for living with PCA. The document details ways to adapt the lived environment to accommodate the visual changes caused by PCA.

Science writer Jamie Talan has written [Atypical Dementias: Understanding Midlife Language, Visual, Behavioral and Cognitive Changes](#), telling the stories of midlife brain changes that atypical dementias cause and the effect on the lives of people living with these changes. Chapter 2 is about PCA.

[PCATips.org](#) offers many suggestions to improve functional independence in daily life.

Assistive Technology:

MGH FTD Unit patients living with PCA have found the following useful for navigating every day activities:

- [ViewClix](#): A tablet that allows for video calls, photo albums, and reminders without the need to navigate with the technology.
- [Speechify](#): A text-to-speech reader that will read you any text you input.
- [Be-my-eyes](#): A service that connects those with low vision with sighted representatives for visual assistance through a live video call.
- [ReadClear](#): A free app that facilitates reading for patients with PCA, developed by a neuropsychologist who specializing in PCA.

Talking clocks and watches, mobile telephones with simplified displays and cooking aids such as sensors which beep when a cup is nearly full can help those living with PCA maintain independence.

Support Resources

The MGH PCA Program offers a 10week online Skills & Support Group for patient/care partner pairs. Email DPutcha@MGH.Harvard.edu for more information.

The MGH FTD Unit Caregiver Support Program offers support to navigate every stage of PCA. Email MGHFTDUnit@MGH.Harvard.edu to learn more.

[PCA Support](#) is a private Facebook group for people living with PCA and their families/caretakers to talk and learn from other people.

The [Alzheimer's Association](#) hosts a weekly support group for caregivers of people living with PCA. Contact its helpline at (800) 272-3900 or via [live chat](#) on its website for more information.



Presented by  MASSACHUSETTS GENERAL HOSPITAL
Frontotemporal Dementia Unit

From Care to Cure Podcast Launches February 20th

The MGH FTD Unit is launching *From Care to Cure*, a podcast about frontotemporal disorders. The first season will feature Dr. Brad Dickerson, renowned neuroscientist and director of the MGH FTD Unit, introducing our clinical research program, explaining what FTD is and examining the process of diagnosis. The podcast will feature the voices of our clinical research team and community experts as they discuss key topics such as care

care planning, symptom management and available treatments. An introductory episode is available now on [Spotify](#) and [Apple Music](#). New episodes will drop monthly. Please follow and share with family and friends.

The Care Plan Trifecta

Do you have questions about care planning after an FTD diagnosis? The MGH FTD Unit is excited to offer a four-part webinar series about the Care Plan Trifecta (CPT), a framework to help you develop a person-centered care plan that centers on the person with a diagnosis and their care partner and community, unifying healthcare with personal values and goals of care. The CPT provides a framework for person-centered care planning that identifies specific needs of people living with a diagnosis and caregivers, prioritizes personhood and dignity, balances independence with safety, and recognizes goals of care at every stage. By focusing on three community-based domains, medical, home and patient advocacy, the CPT takes care out of the clinic and into people's lives at home. We hope to see you online for this informative series!



Katie Brandt, MGH FTD Unit Director of Caregiver Support Services and Public Relations, will lead the Care Plan Trifecta series, guiding individuals and families to set themselves up for success with a comprehensive care plan that respects their values, traditions and wishes for every stage of care. [Register now](#) to receive Zoom links for each session. All sessions will be recorded and posted on the [MGH FTD Unit YouTube Channel](#).

Webinar Dates and Speakers:

- **February 25 at 10:00 am:** Introduction to the Care Plan Trifecta & Connecting With the Medical Community
- **April 1 at 7:00 pm:** Building from the Ground Up: Connecting With the Home Community (Part 1)
- **June 10 at 10:00 am:** Expert Guidance for Non-Medical Care Planning: Connecting With the Home Community (Part 2)
- **September 16 at 7:00 pm:** Education, Care & Support: Connecting With Your Patient Advocacy Community

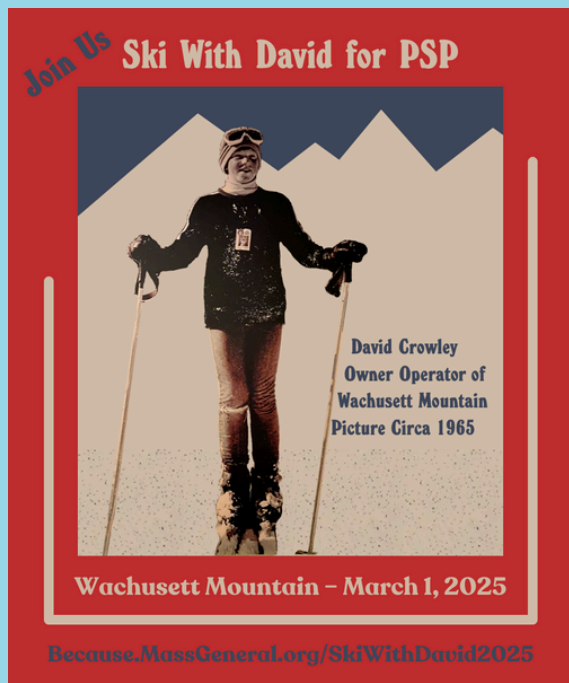
Wachusett Mountain

March 1, 2025

Join the Crowley family to honor the memory of David Crowley and support the MGH FTD Unit at the third annual **Ski with David for PSP** on March 1 at Wachusett Mountain in Westminister, MA. The **event** will feature a ski race, education about PSP and a raffle.

As the co-owner and operator of Wachusett Mountain, David's career and life mission was to share the joy of skiing with the world. Several years ago David Crowley was diagnosed with Progressive Supranuclear Palsy (PSP), a rare, degenerative, physically debilitating disease that affects all aspects of daily function. There is no known cure. David continued to ski using an adaptive sit-ski until his death in November 2024. The Crowley family hopes that all participants in *Ski with David for PSP* will share David's joy of skiing on March 1st.

Wachusett Mountain works to help people of all ages and abilities enjoy winter snow sports through its **Adaptive Program**. Email the program at Adaptive@Wachusett.com to learn how to participate in Ski with David.



Ski with David for PSP will benefit the clinical care and research programs at the MGH FTD Unit, bringing the cure of tomorrow closer to the care of today. Donate now at Because.MassGeneral.org/SkiWithDavid2025.

CAREGIVER SUPPORT GROUP TUESDAYS

Are you caring for a loved one living with Frontotemporal Dementia, atypical Alzheimer's Disease, or a related disorder? Our weekly online support groups meet for an hour over Zoom to provide care for the caregiver. Join us every week, or just once. You can attend on a schedule that works for you. We are here to offer support, resources and connections to our caregiver community at every stage of the journey with dementia.

We hope to see you soon.

Registration is required. Please email FTD.Boston@gmail.com to register for this free resource.

Upcoming Caregiver Support Groups in 2025: Tuesdays @ 10: 00 am Tuesdays @ 7: 00 pm

February 18	February 11, 25
March 4, 18	March 11, 25
April 1, 15, 22	April 8, 29
May 6, 20	May 13, 27
June 3, 17	June 10, 24
July 1, 15, 22	July 8, 29
August 5, 19	August 12, 26
September 2, 16, 23	September 9, 30
October 7, 21	October 14, 28
November 4, 18	November 11, 25
December 2, 16	December 9, 23



KNOWLEDGE AT YOUR FINGERTIPS: THE MGH FTD UNIT YOUTUBE CHANNEL

Our clinical research team is committed to empowering our community with information to navigate life lived with a dementia diagnosis. We know how busy your lives are. To make these educational resources easily accessible, we have launched an MGH FTD Unit YouTube Channel.

Subscription is free! We look forward to connecting with you online, building community and knowledge, together.



Subscribe to the MGH FTD Unit YouTube Channel today! [YouTube.com/@MGHFTDUnit](https://www.youtube.com/@MGHFTDUnit)



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