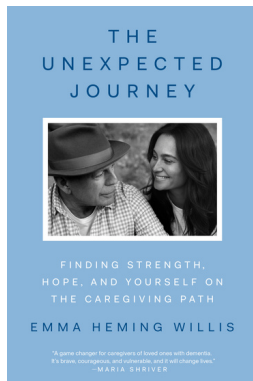


FALL 2025

NEWS FROM THE MGH FRONTEMPORAL DISORDERS UNIT

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The Unexpected Journey Book Discussion

After her husband, Bruce's diagnosis of frontotemporal dementia (FTD), Emma Heming Willis left the doctor's office with only a pamphlet, fear and uncertainty. After learning more about FTD, she wrote *The Unexpected Journey*, the book she wishes someone had placed in her hands that day.

Join the MGH FTD Unit for online discussion groups on November 10th and 17th about *The Unexpected Journey*. Discussion will be facilitated by MGH FTD Unit staff and discussion points will be distributed beforehand. Learn more and register at our [website](#).

Dear FTD Unit Community Members,



November is National Family Caregiver Month and we at the MGH FTD Unit recognize everything that family caregivers do. Not only do we care for the person diagnosed with FTD, we care for the caregiver through our Caregiver Support Services Program, staffed by Katie Brandt and Amy Almeida. We understand the crucial role of family caregivers to our patients' research participation and we value it so highly!

Once again, this November issue of *From Care to Cure* focuses on resources that can improve the quality of life for family caregivers. We share some greatest hits about caregiving from care partners featured in prior issues of *From Care to Cure*. We also have a new caregiving profile from Don Khouri about his experience caring for his father who lived with FTD.

On the community event front, we include some photos from last month's *A Night with the Arts for FTD*, our tenth fundraising gala benefiting the clinical care and research efforts of the MGH FTD Unit. We are excited to share a new community event, the A. Brandt Henderson Memorial Disc Golf Tournament. You can read more about it on page 6.

Finally, I want to draw attention to the last episode of the first season of our podcast which is also called *From Care to Cure*. In honor of National Family Caregiver Month, this month's episode is all about family caregivers. The episode will be released on November 20th so you have plenty of time to catch up with the first nine episodes before then. You can find *From Care to Cure* on [Apple Podcasts](#) and [Spotify](#).

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

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

Love Changes Everything: A Family's Journey Through FTD

By Don Khouri, Ph.D.

"I don't have time" really means "It's not a priority." Time is like a sponge – it absorbs what's important to us. And when something truly matters, we always find the time.

When to Say Yes: The 5 Steps to Protect Your Time (2021) by Don Khouri, Ph.D.

When my seventy-five-year-old father began exhibiting unusual behavior, I knew something wasn't right. Normally calm and easygoing, he suddenly became irritable, impatient, and impulsive. He started taking unexpected road trips when driving was no longer safe and even bought a bright red BMW convertible he didn't need. Beneath those choices, something deeper was changing – his judgment, his personality, and his ability to make sound decisions.

My mother was his steady anchor through it all. She noticed every small change, every shift in his mood or movement. Together, we went from doctor to doctor, searching for answers, only to meet more dead ends. Getting an accurate diagnosis felt impossible. When we finally learned it was frontotemporal dementia (FTD), one of his doctors told us, "This will be like riding a bronco for six months." What he meant was the unpredictable, sometimes unmanageable situations would be very rocky and difficult to stay centered. It turned out to be closer to two years.

As my father's executive functioning declined, his world – and ours – changed dramatically. Yet through it all, my mother became the embodiment of love in action. She cared for him twenty-four hours a day with patience and grace, even on the hardest days. I believe he knew it too; one day, he called her over, looked her straight in the eye, and said softly, "I wish I could help you." Being the primary caregiver was not an easy job, but Mom did it with a smile, and we all saw it – including Dad.

My sisters and I did what we could to give her a break. We rotated nights with Dad so she could rest. On those evenings, we'd order sushi, share dinner, and then play cards or watch one of his favorite shows. Looking back, those moments – small as they were – became gifts. We laughed, we reminisced, and we simply were together. I will always be grateful for that time.

The Boston-area FTD Support Group was like a reliable friend. It offered ideas, treatment insights, and encouragement from others who truly understood what we were living through. It reminded me that even in the most challenging seasons, we're never truly alone.

The doctors who cared for him had an extraordinary way of connecting with him—Dr. Press, Dr. Eldaief, and Dr. Dickerson. He was fortunate to have the best of the best, physicians who were there for us and for Dad, even beyond regular hours, helping us navigate some of the most challenging moments. They didn't just treat him; they cared for him as a person.

In the end, my father passed peacefully at home in his own bed – a blessing after such a long and unpredictable journey. I imagine for some families, this kind of journey could divide them – for us, it deepened our bond.

Andrew Lloyd Webber said it best: "Love changes everything – how we live and how we die." For us, that proved true in every way.



The Khouri family celebrates with Dr. Brad Dickerson at the inaugural *A Night with the Arts for FTD* gala in 2015

Caregiving Pearls of Wisdom

You do not have to travel this road alone. Seek help! Everything you can get help with frees you up to be your loved-one's companion and friend, not just a caregiver.

Bernie Metzger, Fall 2020

Every journey is better with a friend. If you are caregiving alone, reach out and make a connection. You will find that our bags are packed to travel with you.

Katie Brand, Fall 2014

If I could make one recommendation to my brother and sister caregivers, it is this – please be open to accepting change. It doesn't mean that it is easy, or that you like it, but try to open your heart and mind to the reality that things cannot stay as they have always been.

It is so important to build a care support team so that you can get the respite that you need. Sometimes it can be difficult to take that initial step. I guarantee that you will be happy when you do.

Gary Kent, Fall 2020

Stay in the moment—when you're with your loved one and when you're alone. Focusing on "right now" is never quite as scary as obsessing about the unknown future or fretting about the past.

Chris Boyer, Spring 2019

In support group, I learned from more experienced caregivers that the FTD journey is a series of phases. I've learned that if I'm frustrated by the phase we're in, it will eventually change.

Patty O'Keefe, Fall 2020

A Night with the Arts for FTD – October 24, 2025



A Night with the Arts for FTD – October 24, 2025



MGH FTD Unit in the Community



Amy Almeida and Katie Brandt held a discussion about *The Unexpected Journey* at the Ashby Free Public Library on November 8



A. Brandt Henderson Memorial Disc Golf Tournament



We are pleased to announce the inaugural **A. Brandt Henderson Memorial Disc Golf Tournament** benefitting the MGH FTD Unit. Taking place on Saturday November 29th at the beautiful Borderland State Park, this doubles tournament will honor the late Brandt Henderson, a devoted husband, father, grandfather, research participant in the Massachusetts General Hospital (MGH) Frontotemporal Disorders (FTD) Unit and advocate for people living with FTD.

A. Brandt Henderson was a lifelong learner, who loved the classics, philosophy and theology. In his mid-50s, Brandt and his family noticed that his high level of motivation had declined and turned into apathy. In addition, he began having difficulty meeting deadlines for work and completing household tasks, evidence of a drastic change in executive function. As an

MGH employee, Brandt began his journey to get an accurate diagnosis to understand what was causing these changes. He was ultimately diagnosed with frontotemporal degeneration and retired from his position with the MGH Development only to begin new roles, as research participant in the MGH FTD Unit and advocate for people living with FTD.

We are so excited that Sam Henderson, Brandt's son and professional disc golfer, has launched this exciting event! Marie Henderson, Brandt's wife and Sam's mom, states "The care team in the MGH FTD Unit was essential to our family in helping us understand what was happening with Brandt. Brandt also had questions and our care team was able to articulate answers for him. Because our family wants to support research to help others we have started this tournament."

You and a teammate can register to play in the tournament at https://www.discgolfsce.com/tournament/Brandt_Henderson_Memorial_Hollywood_Team_Challenge_2025.

You can make a donation in Brandt's memory at <https://because.massgeneral.org/discgolfforFTD>.

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 2025/6:

Tuesdays @ 10: 00 am	Tuesdays @ 7: 00 pm
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November 18	November 11, 25
December 2, 16	December 9, 23
January 6, 20	January 13, 27
February 3, 17	February 10, 24
March 3, 17, 24	March 10, 31
April 7, 21	April 14, 28
May 5, 19	May 12, 26
June 2, 16, 23	June 9, 30



From Care to Cure Podcast

The MGH FTD Unit has launched *From Care to Cure*, a podcast about frontotemporal disorders. The first season features 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.

The first six episodes are available now on [Spotify](#) and [Apple Music](#). New episodes will drop monthly. Please follow and share with family and friends.

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.

Subscribe to the MGH FTD Unit YouTube Channel today!

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