MASSACHUSETTS GENERAL HOSPITAL

FRONTOTEMPORAL DISORDERS UNIT

FROM CARE TO CURE

SPRING 2026 NEWS FROM THE MGH FRONTEMPORAL DISORDERS UNIT

INSIDE THIS ISSUE

Have you ever wondered what the difference is between hospice and palliative care? Or how palliative care and hospice can be part of an FTD care plan? The latest episode of **Speaking of Alzheimer's**, the podcast from the New England Alzheimer's Association chapters, is great introduction to hospice and palliative care with guest Mary Crowe, Director of Professional and Community Education at **Care Dimensions**. Listen now on **Apple Podcasts** or **Spotify**.

Dear FTD Unit Community Members,

We welcome the opportunity to connect with you through our newsletter as spring finally seems to have vanquished winter in New England.

In this issue, we highlight Kanella Basilion and Sam Murdock, MGH FTD Unit team members who many of our research participants have gotten to meet over the years. I expect you will enjoy learning more about the people behind the research visits as I did.

This month, we also spotlight resources for children and teens dealing with dementia, especially young-onset dementia. Lorenzo's House, a dynamic non-profit based in Chicago that provides support to families living with younger-onset dementia (YOD) across the US and the world, will be hosting its annual summit on June 12th and 13th. We also include books about dementia and grief for children and teen, based on materials curated by Lorenzo's House and AFTD.

The MGH FTD Unit has two community events coming up in June. Please consider joining us for a verbal description tour at deCordova Sculpture Park exclusively for our FTD community or a night of music with the Concord Band. One of the guiding philosophies of our Unit is that not all care happens in the clinic. We recognize the benefits of the arts and gathering in community to a life lived alongside FTD, atypical Alzheimer's and related conditions and are committed to offering events that bring people together outside the clinic.

Continuing on the topic of care outside the clinic, if you are curious about the role that palliative and hospice care can play on the care team of someone living with FTD or a related condition, I urge you to listen to a recent episode of the Speaking of Alzheimer's podcast from our friends at the Alzheimer's Association New England Region. Details are to the left.

We appreciate your continued engagement with our clinic and research programs. We hope to see you at an event, in clinic or online soon! Until then, take care and be well.

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

Staff Profile: Kanella Basilion

Q: Kanella, can you introduce yourself and explain your role in the MGH FTD Unit?
A: I'm a Senior Clinical Research Coordinator at the Frontotemporal Disorders Unit and have been coordinating multiple studies since Fall 2023. About half of my position involves logistics such as regulatory upkeep, scheduling, and data analysis. The rest of the time, you can find me working with research participants through cognitive testing, neuroimaging, or physiological data collection. I also oversee operations in our FTD Clinic and am working to present a poster at this year's Alzheimer's Association International Conference under the guidance of Dr. Deepti Putcha.

Q: How does your role here fit in with your career goals?
A: I stepped into this role after obtaining my bachelor's degree at McGill University, where I studied Psychology and Behavioral Science. Through collaboration with the FTDU's team of neurologists, neuropsychologists, caregiver support specialists, and more, I've gained valuable insight into the diagnosis and management of neurodegenerative disorders. Most meaningfully, I've had the opportunity to work with the participants and families that have been impacted by them. Every fun fact and story shared during research visits stays with me long after study completion, and continues to remind me of how important this work truly is. I hope to continue it by pursuing a PhD in Clinical Psychology.

Q: What do you enjoy outside of work?
A: Outside of MGH, I try to keep things interesting. Something people may not know about me is that I'm fluent in French and teach at a French-speaking after-school program in my free time! I've been at it for years, but continue to be surprised at just how much the children teach me. My other interests include picking up new ones— right now, I'm focusing my energy on an outdoor vegetable garden and improving my jump rope skills.

Verbal Description Tour of deCordova Sculpture Park

Join MGH FTD Unit community and staff for a private verbal description of the **deCordova Sculpture Park** on Thursday June 4th at 10:30 am. Explore the outdoor sculptures and learn about the artists behind them.

Verbal description tours at deCordova Sculpture Park and Museum provide multisensory access to select sculptures and exhibitions through detailed verbal descriptions and tactile exploration. Led by trained museum educators, these tours invite participants to experience art through vivid narrative, touchable materials, and conversation, fostering a deeper understanding of the artworks and the environment of the Sculpture Park.

After the 45-minute tour, we'll gather for lunch. Bring your own lunch or order takeout from the **Twisted Tea Cafe** on the museum grounds.

Register at **https://www.eventbrite.com/e/verbal-description-tour-of-decordova-sculpture-park-tickets-1987947505503**.

Staff Profile: Sam Murdock

Q: Sam, can you introduce yourself and explain your role in the MGH FTD Unit?

A: I am a Senior Clinical Research Coordinator in the Frontotemporal Disorders Unit. In this role, I facilitate some of the many research initiatives within the Dickerson Lab aimed at understanding and addressing FTD, Alzheimer's Disease, and related conditions. Day-to-day duties range from MRI scanning and blood draws to data analysis and regulatory upkeep. Currently, I am working with Dr. Bonnie Wong, our team's fantastic director of neuropsychology, to present some new research on the detection of cognitive symptoms using speech and language samples.

Q: How does your role here fit in with your career goals?

A: Prior to working at MGH, I was just across the river at Harvard College, where I studied neuroscience and philosophy. The FTD Unit has been an incredible place to watch expert clinicians and researchers translate cutting-edge knowledge in these fields to care for our patients. I have also had the great opportunity to work with dozens of participants and families, learning directly from them about how meaningful it can be to contribute to research efforts. In the future, I hope to complete graduate work in Psychology to further the mission of research and education.

Q: What do you enjoy outside of work?

A: Outside of the FTD Unit (and occasionally inside), I am an avid musician. While in undergrad, I was lucky enough to take courses in music theory and production at Berklee College through a joint studies program. I was also a Jazz Department DJ at WHRB, Harvard's student-run radio station. Nowadays, I work with local arts groups, such as the Mass General Brigham / Harvard Med School Arts & Humanities Initiative, to bring creative programming to staff, patients, and other members of our community.

FTD Community with the Concord Band

Join your friends from the Boston-area FTD community for a concert by the **Concord Band** at the **Performing Arts Center at 51 Walden** in Concord, MA on Thursday, June 25th. The concert will start at 7:15 pm.

The theme of the concert is "Born in the U.S.A." The pieces performed will feature American composers such as Leonard Bernstein, Aaron Copland, John Philip Sousa and John Williams.

Tickets are not necessary but donations are welcome with a suggested donation of $20 per person. Parking is available in municipal lots off Walden St. and Keyes Rd.

We hope to see you on June 25th!

Lorenzo’s House: A Resource for Families Living with Younger-Onset Dementia

In 2017, Diana Shulla Cose’s husband was diagnosed with younger-onset Alzheimer’s. Almost overnight, the entire family dynamic changed with Diana and her 11 and 14 year old sons taking on a new and difficult identity. Overwhelmed as a primary care partner, single mom and breadwinner, Diana recognized the connection and care gap for her family and understood that her family was not alone. Diana became determined to turn so much sorrow into something bright, imagining a place to sustain and heal her family and others like it. **Lorenzo’s House** was founded in 2021 with a motto, ‘We Bring Light’ representing its aim to shift the narrative from isolation and suffering to connection and joy. It is through the design and implementation of a holistic model including support, advocacy and education programs that Lorenzo’s House has created a place to belong – an alliance of families walking a younger-onset dementia diagnosis united – never alone.

What Is Lorenzo’s SUMMIT?

Lorenzo's SUMMIT is a free, virtual worldwide event that unites the daughters and sons of younger-onset dementia (ages 4-35+) on June 12th & 13th. Together, we create a space to heal in community and advocate for dementia justice. We share lived-experiences and build lifelong connections. We amplify our collective wisdom and create a more informed and empathetic world.

REGISTER NOW!

Lorenzo’s Light Club is a virtual hangout for young people (ages 4-35+) to connect, have fun, share common stories and build an alliance. Groups meet on the 1st Thursday, and the 2nd and 3rd Wednesday.

REGISTER NOW!

Shine On offers a safe space for children, teens and young adults experiencing grief and loss to find connection and community. Together participants share stories, empathize with those who understand and learn healthy expressions of grief and loss. Sessions are designed and facilitated with grief and loss professionals and trained youth leads.

REGISTER NOW!

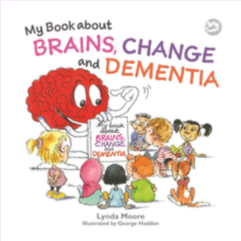
Lorenzo’s House NEXTGEN

NEXTGEN is a global advocacy movement at Lorenzo's House. It consists of a group of like-minded sons, daughters and children of parents with younger-onset dementia, alongside passionate allies, meeting dementia without silence, shame or invisibility. NEXTGEN is working to create a more just world for families of dementia. NEXTGEN is shifting the narrative for the over 28 million family carers worldwide affected by younger-onset dementia – who are unseen, misunderstood, undiagnosed, misdiagnosed, under-resourced and under-researched. Attend one of NEXTGEN’s **monthly meetings** to learn more and join the movement.

Helping Children Understand Dementia and Grief

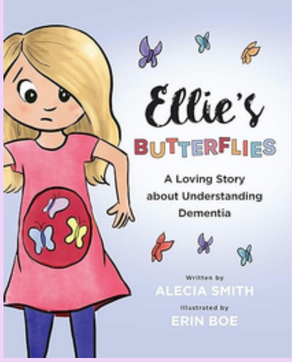
There are many resources available to help children understand FTD, dementia in general and grief. The following materials have been collected by the **Association for Frontotemporal Degeneration** and **Lorenzo's House**.

Books about Dementia



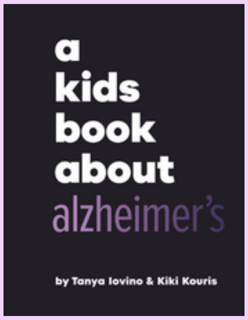
My Book about Brains, Change and Dementia by Lynda Moore and George Haddon discusses dementia in a non-age specific manner.

Big Bear, Little Bear and Dementia by Katie Faulkner and Iain Welch explores the thoughts and feelings experienced when a loved one is living with dementia.

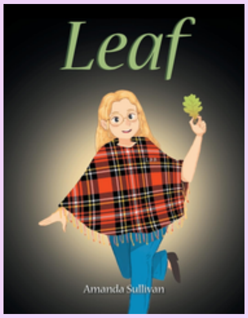


Ellie's Butterflies: A Loving Story about Understanding Dementia by Alecia Smith (an FTD caregiver) and Erin Boe features an honest approach to the complicated feelings surrounding an FTD diagnosis and offers a support guide for parents.

My Forever Super Hero by Fatima Devine, LICSW and Cynthia Laroche, told from the perspective of an adolescent son, describes the feelings and day to day experiences of a family's journey with early onset Alzheimer's disease.



A Kids Book About Alzheimer's by Tanya Iovino and Kiki Kouris lets kids know what Alzheimer's is and what it can look like, as well as offers support and encouragement for kids (and grownups) who love someone with Alzheimer's.



Leaf by Amanda Sullivan illustrates how frontotemporal dementia can present, the devastation it causes, and how a family learns to cope with this difficult illness and loss.

Books about Grief

The Memory Box*: *A Book About Grief by Joanna Rowland and Thea Baker can help start the grieving process and support discussions about their loved one in a normal, healthy way.

After a Death: An Activity Book for Children by the Dougy Center is easy-to-use workbook for children ages 5 to 12 who have experienced the death of a family member or friend.

Something Very Sad Happened A Toddler's Guide to Understanding Death by Dr. Bonnie Zucker and Kim Fleming explains death in developmentally appropriate terms for two- and three-year-old children.

Welcome to the Grief Club Because You Don't Have to Go Through It Alone by Janine Kwoh uses lighthearted approach to cover powerful topics about the wide range of emotions and experiences that grief can encompass.

MGH FTD Unit in the Community

Katie Brandt attends a legislative breakfast in Providence, RI with advocates from the Rhode Island Chapter of the Alzheimer's Association with Representative Gabe Amo

Katie Brandt joins Alzheimer's Association staff members, Brooke Patterson and Jill Hovanasian, at Advocacy Day at the Massachusetts State House

Katie Brandt, Amy Almeida, Dawn O'Gara (AFTD Ambassador for MA) and Gina Biskupic represent the FTD community at Advocacy Day at the Massachusetts State House

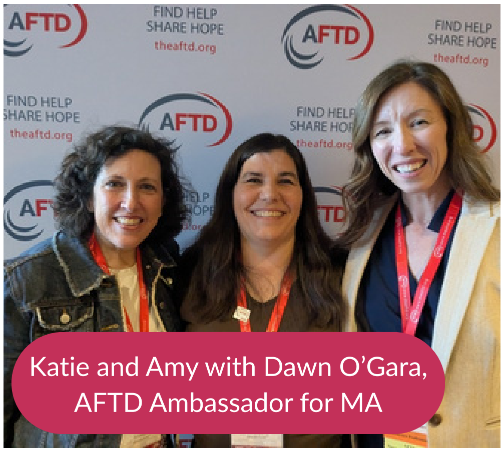
Amy Almeida and other advocates meet with Jamie Nathan of Sen. Joan Lovely's office at Advocacy Day at the Massachusetts State House

MGH FTD Unit at the AFTD Education Conference

Boston-area FTD caregiver support group facilitators, Katie, Norm and Amy enjoy some fresh air and Lake Washington

Katie and Amy with Genevieve Wanucha, former MGH FTD Unit team member now with UW Memory and Brain Wellness Center

Katie and Amy thank Emma Heming Willis for her FTD advocacy and her book *The Unexpected Journey*



Katie and Amy with Dawn O'Gara, AFTD Ambassador for MA

Katie and Amy with Dr. Hilary Heuer, ALLFTD researcher from UCSF

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.

Upcoming Caregiver Support Groups in 2026:

Tuesdays @ 10: 00 am	**Tuesdays @ 7: 00 pm**
May 19	May 12, 26
June 2, 16, 23	June 9, 30
July 7, 21	July 14, 28
August 4, 18	August 11, 25
September 1, 15, 22	September 8, 29
October 6, 20	October 13, 27
November 3, 17	November 10, 24
December 1, 15	December 8, 22

We hope to see you soon.

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

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 season is available now on **Spotify** and **Apple Music**. Season 2 launched in February 2026 and new episodes 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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