

FALL 2024

NEWS FROM THE MGH FRONTEMPORAL DISORDERS UNIT

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FTD AND THE HOLIDAYS

The holidays can be a challenging time to be a caregiver. The changes brought on by an FTD diagnosis can make it difficult to navigate the holidays. We step away from our routines and that can lead to unsuccessful holiday experiences. These resources may help.

AFTD is hosting "Navigating the Holidays with an FTD Diagnosis" as part of its Care Partner Learning Series on Thursday November 19th. Register [here](#).

The Alzheimer's Association has put together a [website](#) on navigating the holidays. It has a lot of good tips about how to approach and potentially modify your holiday celebrations to accommodate changes in your loved one.

Katie Brandt discusses grief and loss, the uninvited guests that might be at your holiday celebrations after a diagnosis of FTD, in a [video](#) for AviadoBio.

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. As those of you who attended our [A Night with the Arts for FTD](#) gala last month know, we also conduct research into educational interventions that can improve the quality of life for FTD caregivers.



This issue of *From Care to Cure* focuses on resources that can improve quality of life for family caregivers. We share some books, apps and podcasts that caregivers have told us they find useful. We also highlight special podcast episodes and upcoming webinars in honor of National Family Caregiver Month. Knowing the financial burden of caregiving, we feature opportunities for respite grants as well.

Finally, befitting National Family Caregiver Month, we profile a family caregiver. Chris talks about his husband Shawn's participation in the *Sermos Memorial Art Show* at the gala last month and how the experience demonstrated that someone's personhood does not have to be diminished with a diagnosis of a frontotemporal disorder. I thought Shawn's bird carvings were exquisite and I look forward to seeing what he creates next! If you would like to be a featured caregiver in future newsletters, please contact Katie Brandt at Katherine.Brandt@MGH.Harvard.edu or Amy Almeida at AAlmeida9@MGH.Harvard.edu.

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.

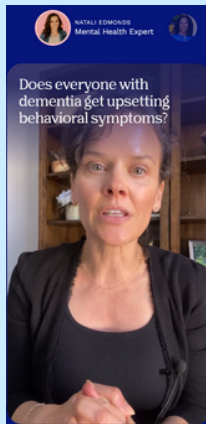


Bradford C. Dickerson, MD
Director, MGH Frontotemporal Disorders Unit

Caregiver Resources for National Family Caregiver Month

ROON

[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. Users can ask about a specific topic such as “Behavioral Symptoms” and a variety of videos will appear on that topic. Users can also browse topics (e.g., basics about dementia, FTD, home life) or experts, including Teepa Snow, Dr. Bruce Miller and Katie Brandt. Each video is 3-5 minutes so Roon is perfect when you have just a moment to learn.



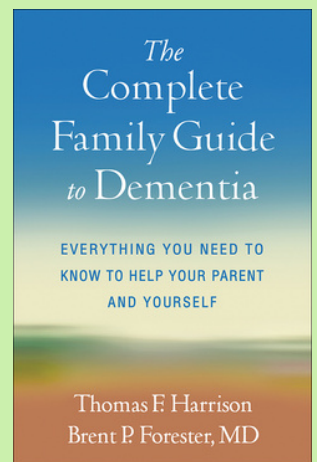
willGather PODCAST

[willGather](#) is a podcast about navigating the world with an aging loved one hosted by Nicole Will, a gerontologist with experience in senior living and as a family caregiver. Ms. Will and her guests discuss all aspects of elder care, from dementia and art to grief to the challenges of rural caregiving. As a bonus, willGather is committed to donating a portion of its proceeds to organizations that enhance the lives of older adults, families, and the eldercare community.

[willGather](#) interviewed Maria Kent Beers, host of the Remember Me podcast and member of the Boston-area FTD community in March 2024.

The Complete Family Guide to Dementia: Everything You Need to Know to Help Your Parent and Yourself

[The Complete Family Guide to Dementia: Everything You Need to Know to Help Your Parent and Yourself](#) by Thomas Harrison and Dr. Brent Forester, has been recommended by many Boston-area FTD caregiver support group members. Although geared toward children caring for a parent with Alzheimer's Disease, it is an incredible, straightforward approach to caregiving with lessons for caring for all types of dementia. One admirable idea is setting caregiving goals. "I'll fix what I can, and as for what I can't, I'll sympathize" is an important context for both caregiving and caregivers' attitudes towards themselves.



This month, there are opportunities to hear more from the authors. They appeared on the [Speaking of Alzheimer's](#) podcast, presented by the MA/NH chapter of the Alzheimer's Association. The authors discussed caring smarter, not harder to help maintain the best possible quality of life for their loved ones affected by dementia. The two discuss why caregiving for a loved one with Alzheimer's disease is challenging, strategies for caregivers, the importance of planning ahead of a crisis, and more.

The Alzheimer's Association will host "[Navigating the Dementia Care Journey](#)" with the authors on Wednesday November 13 at 6:00 pm. They will discuss how families and professional caregivers can work together more smoothly to improve outcomes for all involved. Register [here](#).

Caregiver Perspective: Love through the Lens of Art

A Conversation with Chris Milliken

Chris Milliken's husband Shawn Caron is a retired veterinarian and avid carver with a specialty in birds. Shawn was recently a Featured Artist at the *Sermos Memorial Art Show* as part of *A Night with the Arts for FTD* gala. To highlight National Family Caregiver Month, we sat down with Chris to hear about Shawn's involvement in the Sermos Memorial Art Show and how it may have impacted their family.

Q: How did it feel to watch Shawn go through the experience of being a Featured Artist since this was the first time he exhibited his art?



Shawn and Dr. Brad Dickerson

A: In the week leading up to the Gala, Shawn was busy building a display stand for his work. His complete focus and dedication, a standard with which he approaches every task, was a clear reminder that the Shawn I love is still there in so many ways. The preparation brought a lightness to his affect which resonated throughout our home.

Q: What did the experience as a Featured Artist bring out about Shawn's personality that you love?

A: Shawn possesses a grace that is subtle and deep. Watching him

admire his contemporaries' artworks and seek them out for conversation was so in keeping with his character. Also, Shawn has always been generous with his carvings, choosing to give them away. The way he mentioned to people that he wanted to carve a bird for the benefit of FTD research was his way of building community.

Q: What is a new memory of joy that you and Shawn are taking from the experience of being a part of A Night with the Arts for FTD?

A: There is one photo of Shawn standing behind his birds, smiling from ear to ear that is a joyful moment for us. Shawn has never exposed his emotions to the eyes of the world. Even true joy has often been kept inside. Validation of his art form, something he might identify with even more than being a veterinarian, is a true and lasting memory.



Shawn's art work



Shawn, Chris and family celebrate at the gala



A joyful moment!

Caregiver Respite Grants



The Association for
Frontotemporal Degeneration
FIND HELP · SHARE HOPE

Recognizing the financial burden that families living with FTD face, AFTD offers **Comstock Grants** as direct assistance to people in the FTD community.

- Respite Grants (up to \$500/year) are available for full-time, unpaid care partners to meet their own needs while caring for a loved one at home.
- Quality of Life Grants (\$500/year) are available for persons living with FTD to access services or supports to improve their quality of life.
- Travel Grants (up to \$500/year per family) are available for persons living with FTD and their family care partners for use in attending the AFTD Education Conference or other FTD educational event approved by AFTD.

HFC respite grants cover the cost of professional, in-home care so you can feel confident about the care being provided while you take time for you.



HFC grants two types of awards:

- Recharge Grant – 50 hours total of respite care to be used within 3 months of being awarded
- Extended Relief Grant – 25 hours of respite care per week for six months (24 weeks)

Respite grants provide in-home, professional care and have no cash value. HFC partners with **Home Instead** and other licensed providers to coordinate the in-home care awarded through HFC's respite grant program. If care cannot be provided by a licensed provider within 60 days of the award for any reason, the grant will become void.

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.

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

UPCOMING CAREGIVER SUPPORT GROUPS

Tuesdays @ 10 am	Tuesdays @ 7 pm
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November 19

November 12, 26

December 3, 17

December 10

January 7, 21

January 14, 28

February 4, 18

February 11, 25

March 4, 18

March 11, 25



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