



WINTER 2022

NEWS FROM THE MGH FRONTOTEMPORAL DISORDERS UNIT

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LEARN, GROW  
AND CONNECT  
WITH US  
THIS SPRING!



MGH FTD Unit's Online *From Care to Cure* Education Day - April 1st  
Register: [Because.MassGeneral.org/FTDSupport](https://www.massgeneral.org/FTDSupport)

2022 AFTD Education Conference  
April 8th - Register: [theAFTD.org](https://www.theAFTD.org)



The Association for  
Frontotemporal Degeneration  
FIND HELP • SHARE HOPE



## Dear FTD Unit Community Members,



We appreciate the opportunity to connect with you through our first newsletter of 2022. The title of our newsletter, *From Care to Cure*, reflects our dedication to providing the highest quality of care while working tirelessly for a cure for Frontotemporal Dementia, Primary Progressive Aphasia, Posterior Cortical Atrophy, young-onset and atypical Alzheimer's Disease and related disorders. We recognize that families benefit from a wide net of support that includes medical care, educational opportunities, connections with community resources and access to research. Each person approaches the experience of a diagnosis with unique needs and goals of care. This inspires us to continue to create content and provide access to information on our website and our library of free online educational webinars through the [MGH FTD Unit YouTube Channel](#).

The new year brings a new calendar of webinars, online education and community events that we hope will reflect the diverse needs of our community of persons living with a diagnosis, their care partners and families. We understand that living life with a diagnosis can be overwhelming and isolating. Engage with our program and give us feedback about what is most helpful, as well as the areas where you have continued questions. We aim to harness the power of our network of clinicians, community experts and experienced families to find innovative ways to build bridges for care and support.

This issue spotlights some of the more sensitive issues including intimacy after a diagnosis of dementia, grief supports for children and families and understanding palliative care and hospice. Demystifying these topics is an important step to educating our community about ways to cope with challenges, connect for support and live the highest quality of life possible.

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

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



MASSACHUSETTS  
GENERAL HOSPITAL

FRONTOTEMPORAL  
DISORDERS UNIT

# MGH FTD Unit Online Educational Resources

[YouTube.com/MGHFTDUnit](https://www.youtube.com/MGHFTDUnit)

The MGH FTD Unit is committed to empowering our community of persons living with a diagnosis, family caregivers and community partners with information to navigate dementia care and support. Our team of clinicians have collaborated with community experts to create an extensive library of free online educational resources for you. You may find our full library by visiting: [YouTube.com/MGHFTDUnit](https://www.youtube.com/MGHFTDUnit). We look forward to connecting with you online, building community and knowledge together!

## *Understanding A Clinical Diagnosis*

### **An Overview of Frontotemporal Disorders, Alzheimer's Disease, and Related Disorders**

Presented by: Brad Dickerson, MD, Director, MGH FTD Unit

### **Cognitive Resilience: Brain Health Care Plan For Care Partners & Their Loved One**

Presented by: Bonnie Wong, PhD/ABPP-CN, Director Neuropsychology, MGH FTD Unit

### **Research to Develop Treatment: FTD, Alzheimer's & Dementia**

Presented by: Scott McGinnis, MD, MGH FTD Unit Neurologist

## *Understanding Primary Progressive Aphasia*

### **Understanding Primary Progressive Aphasia**

Presented by: Megan Quimby, MS, CCC-SLP, Director of Speech and Language Program, MGH FTD Unit

### **Connecting Through Communication**

Presented by: Clinical Team Members, Speech and Language Program, MGH FTD Unit

## *Tools and Techniques for Caregivers*

### **What I Learned From Support Group**

A Conversation with Jill Hovinasian LICSW, The Alzheimer's Association

### **Discussing Intimacy and Sexuality After a Diagnosis of Dementia**

A Conversation with Jennifer Pilcher, PhD, CMC, Founder, Clear Guidance

### **Understanding Hospice Care and Processing Grief**

A Conversation with Bernice Burkarth, MD, HMDC, FAAHPM, Chief Medical Officer of Home Health Foundations  
Susan Toleos, LMHC, Manager of Counseling For Spiritual and Bereavement Care

### **Understanding the Legal Landscape of Planning and FTD**

A Conversation with Attorney Patricia D'Agostino, Esq.

### **Legal Planning After a Diagnosis of Young Onset Diagnosis of Alzheimer's or Related Condition**

A Conversation with Attorney Pam Greenfield, Esq.

Never miss a session from the MGH FTD Unit. Subscribe today!  
You may find our full library by visiting: [YouTube.com/MGHFTDUnit](https://www.youtube.com/MGHFTDUnit).

**SUBSCRIBE**





# MGH FTD Unit Winter 2022 Educational Webinar Series Join Us Fridays @ 10:00AM EST



Use this link to participate in each live broadcast: [mgh-ftd-events.girostudio.com](https://mgh-ftd-events.girostudio.com)

Our team of clinicians and staff are partnering with community experts to bring you relevant information to navigate life with a diagnosis, building skills for caregiving and strengthening connections with our MGH FTD Unit community.

We hope you will join us online for our upcoming sessions:

## *Community Forum Friday Webinar Series*

- Feb 11<sup>th</sup> @ 10AM EST** - **Dementia & The Law: Protecting Your Loved Ones**  
A Conversation with Dr. Judy Edersheim & Dr. Bruce Price,  
MGH Center for Law, Brain and Behavior
- Feb 25<sup>th</sup> @ 10AM EST** - **Connection, Care & Support: Navigating Life with Dementia**  
A Conversation with Susan Rowlett, Director of the  
MGH Dementia Care Collaborative
- Mar 11<sup>th</sup> @ 10AM EST** - **Intersection of Care & Innovation: Research Connections**  
Spotlight on the MGH Martinos Center for Biomedical Imaging
- Mar 25<sup>th</sup> @ 10AM EST** - **Access to Information, Education & Research for Dementia**  
Spotlight on the Massachusetts Alzheimer's Disease Research Center

## *From Care to Cure Educational Events*

- Apr 1<sup>st</sup> @ 10AM EST** - **After a Diagnosis: Education, Support & Clinical Care**  
When families receive a new diagnosis of a Frontotemporal disorder, Alzheimer's disease or a related dementia, they often have many questions. Join Brad Dickerson, MD, and clinicians in the MGH FTD Unit for a presentation geared towards the newly diagnosed.
- Apr 29<sup>th</sup> @ 10AM EST** - **Caregiver Coaching: Managing Challenging Behavioral Symptoms**  
Join staff and clinicians from the MGH FTD Unit Caregiver Support Services and the Speech and Language Program for tips and tools to manage behavioral symptoms related to dementia.

Can't make the livestream? No problem! All MGH FTD Unit Community Forum Friday episodes will be recorded and posted on our [MGH FTD Unit YouTube Channel](#).

# Spotlight on MGH FTD Unit Staff

Mike Brickhouse, BS, Data Analyst

## WORDS FROM THE MAN BEHIND THE SCANNER



I work as a data analyst in the Dickerson lab. That sounds super boring, but I promise it's a pretty good gig. Our lab is in a unique position where we can directly run the MRI scanner and collect our own data, and hoo boy have I collected a lot of data! Most of my work is in analysis however - we use some very specialized computer software to make all sorts of measurements on our MR and PET imaging data. I work mostly with "structural" MRI data, which means I'm looking very closely at the brains we've scanned and assessing how healthy different structures are.

I've been with the lab since I was fresh out of college over 10 years ago. It's safe to say that I enjoy working here! I do intend to further my education in the next few years to obtain a broader foundation in computational analysis. It's something I've put off because it's hard to compete with the truly brilliant people I'm surrounded by daily - you learn a shocking amount just by showing up and listening to co-workers like mine.

When I'm not working, I'm a pretty inert homebody. I play a good amount of video and board games online with friends. I like to cook; what I lack in talent I more than make up for with ambition. In that sense the science really follows me home to the kitchen (tonight I'm just going to see what happens if I air fry an entire wheel of brie.) I also enjoy playing music in my spare time, piano and violin, and while I'm not headlining the FTD Unit Gala playing gnarly Rush covers like Dr. Brad Dickerson, I still enjoy it as a way to decompress. Thanks for interviewing me!

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Amelia Jones, MS, CF-SLP, Speech Language Pathology Clinical Fellow

## CARVING A CAREER PATH



In July 2021, the MGH FTD Unit welcomed Amelia Jones to the Speech and Language Pathology team for a yearlong clinical fellowship. A graduate of Northeastern University, Amelia focuses her work on those living with a diagnosis of Primary Progressive Aphasia. As a part of her role in the FTD Unit Clinic, she conducts language evaluations.

### *What are your future career goals?*

I have enjoyed working with patients in the realm of cognitive communication and dementia in the FTD Unit this year. My career goals are to continue working as a Speech and Language Pathologist within a medical setting, specifically with adult populations. I am really interested in the area of aphasia, but I also think it would be interesting to explore other areas in the field of speech pathology such as rehabilitation services, and voice therapy as part of my career journey.

### *What are your current hobbies and interests outside of work?*

I really enjoy practicing yoga as it is such a positive outlet with many benefits. I also recently started to learn the unique art of crochet, and really enjoy that when I have free time as well.

## FROM CARE TO CURE PODCAST

The MGH FTD Unit is seeking more ways to provide education and information to our community. We welcome your feedback as we consider the development of a podcast! Email [MGHFTDUnit@mg.harvard.edu](mailto:MGHFTDUnit@mg.harvard.edu) with your ideas for topics and content.





# RESEARCH OPPORTUNITIES

## ALLFTD: ARTFL LEFFTDS LONGITUDINAL FTD STUDY

**You may be eligible if:** You have a diagnosis of bvFTD, PPA, PSP, CBD/ CBS, or bvFTD-ALS. You may also be eligible if you are from a family with a mutation in a gene known to cause FTD (such as C9orf72, MAPT, and GRN) or have a significant family history of FTD suggesting a familial genetic mutation. Participants from familial FTD families may or may not be identified with the mutation themselves, and may or may not be experiencing FTD symptoms.

**Goal:** To examine changes in brain functioning that may result from FTD and find factors that predict disease course in people who already have, or may later be diagnosed with FTD. To build a clinical research network that can support treatment and prevention studies, and better understand biomarkers of FTD.

**This study involves:** Annual study visits that include an MRI, cognitive testing, blood draw, optional lumbar puncture, and an optional skin biopsy.

## PRIMARY PROGRESSIVE APHASIA RESEARCH

**You may be eligible if:** You have a diagnosis of PPA or are cognitively normal.

**Goal:** To better understand the progression and symptoms of PPA and differentiate subtypes of PPA.

**This study involves:** Annual visits that include MRI, language and cognitive testing, and a blood draw.

## IMAGING TAU, AMYLOID, AND NEURODEGENERATION

**You may be eligible if:** You are age 40-90 and diagnosed with AD, PCA or PPA.

**Goal:** To better understand how the proteins tau and amyloid affect brain regions and relate to symptoms.

**This study involves:** Annual visits for MRI, amyloid and tau PET scans, and cognitive testing.

## FTD FAMILY STUDY

**You may be eligible if:** You are from a family with a mutation in a gene known to cause FTD (such as C9orf72, MAPT, and GRN) or have a significant family history of FTD suggesting a familial genetic mutation.

**Goal:** To see if there is a preclinical FTD stage where people at risk for FTD have brain changes but no symptoms.

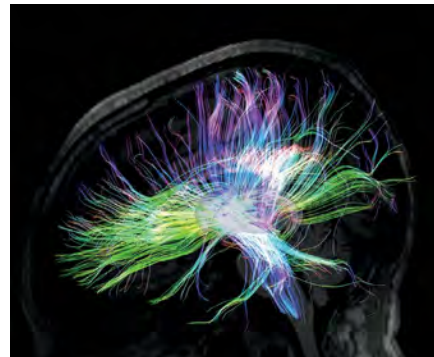
**This study involves:** Annual MRI and cognitive testing. People who cannot undergo MRI for medical reasons may still be able to participate in testing.

## LEADS: LONGITUDINAL EARLY- ONSET ALZHEIMER'S DISEASE STUDY

**You may be eligible if:** You have a diagnosis of young-onset Alzheimer's Disease

**Goal:** To better understand the progression and symptoms of young-onset Alzheimer's Disease.

**This study involves:** Regular visits that may include brain imaging, language, cognitive testing and potential blood or spinal fluid draws.



## CAREGIVER WELLBEING

**You may be eligible if:** You are caring for someone with Alzheimer's Disease, FTD, PCA, PPA, or dementia.

**Goal:** To gain better understanding from caregivers of how certain factors (caregiver personality, patient symptoms, relationship quality) effect mental health and the caregiver experience.

**This study involves:** Caregivers will fill out online surveys regarding their experience as caregivers every 6 months. Time commitment includes up to 1 hour per survey session.

## 4RTNI-2: FOUR REPEAT TAUOPATHY NEUROIMAGING INITIATIVE

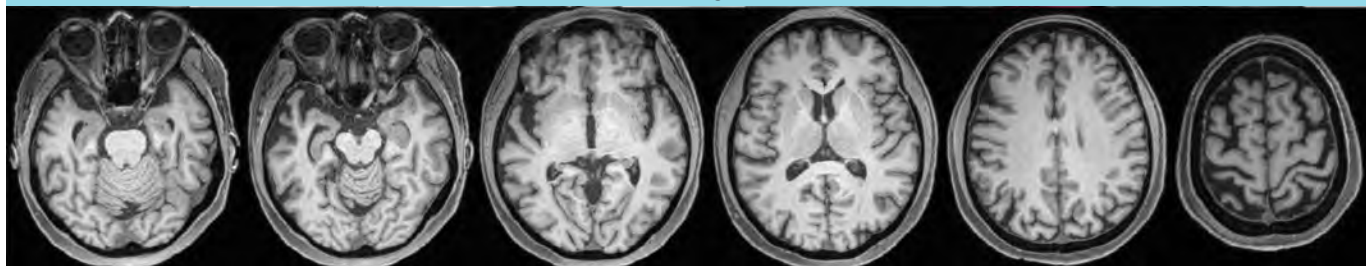
**You may be eligible if:** You are between 40-80 years old and are cognitively normal, or have probable PSP or CBS.

**Goal:** To better understand how the proteins tau and amyloid in the brain relate to PSP and CBS symptoms.

**This study involves:** 3-4 visits over 24 months including a combination of MRI, cognitive testing, blood draw, and tau and amyloid PET scans. Spinal fluid sample is optional.

To inquire about research, please contact our Research Coordinators at:

MGHFTDUNIT@mgh.harvard.edu



## 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](mailto:FTD.Boston@gmail.com) to register for this free resource.

### Upcoming Caregiver Groups:

#### Tuesdays @ 10:00AM

Feb 1st, 15th

March 1st, 15th, 22nd

April 5th, 19th

May 3rd, 17th, 24th

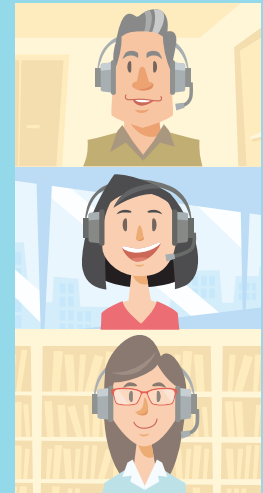
#### Tuesdays @ 7:00PM

Feb 8th, 22nd

March 8th, 29th

April 12th, 26th

May 10th, 31st



## CAREGIVER CONNECTION CORNER

We are excited to share community resources to provide additional learning experiences for caregivers and their loved ones. Please enjoy our recommendations for podcasts, books and websites. We'd love to hear your ideas and recommendations! Email us at [MGHFTDUnit@MGH.Harvard.edu](mailto:MGHFTDUnit@MGH.Harvard.edu).

### Listen to a New Podcast:



#### Bob's Last Marathon [bobsmarathon.com](http://bobsmarathon.com)

*Bob's Last Marathon* is a free podcast devoted to helping families, friends and caregivers create the best life possible for their loved ones living with Alzheimer's Disease. Episodes feature firsthand stories from family caregivers with guidance from professionals regarding common everyday challenges—while continuing to celebrate the essence of loved ones who bring light and joy to our lives.

*"We want listeners to know that they are not alone."*

– Lena Chow Kuhar, Founder

### Explore a New Website:



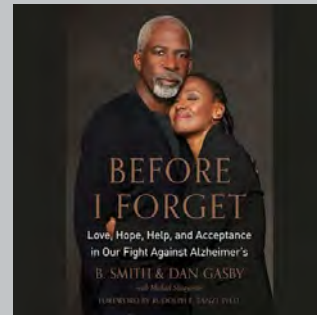
#### The Day After Yesterday [PortraitsOfDementia.com](http://PortraitsOfDementia.com)

Joe Wallace is a local photographer and the creator of *The Day After Yesterday: Portraits of Dementia*. This beautiful collection of portraits illustrates the multi-faceted aspects of dementia.

*"The goal of this book and traveling exhibit is to destigmatize those living with dementia. To use empathy as a means for connection and understanding. To tell a more complex and complete story of those living with the disease and it's effect on their families and loved ones."*

– Joe Wallace, Creator

### Dive into a New Book:



#### Before I Forget: Love, Hope, Help, and Acceptance in Our Fight Against Alzheimer's

*"Restaurateur, magazine publisher, celebrity chef, and nationally known lifestyle maven, B. Smith is struggling at 66 with a tag she never expected to add to that string: Alzheimer's patient.... B. and her husband, Dan, working with Vanity Fair contributing editor Michael Shnayerson, unstintingly share their unfolding story. Crafted in short chapters that interweave their narrative with practical and helpful advice, readers learn about dealing with Alzheimer's day-to-day challenges...At its heart, Before I Forget is a love story: illuminating a love of family, life, and hope."*

– from Penguin Random House

## Partnering for Resources and Support:

### Association for Frontotemporal Degeneration AFTD 2022 EDUCATION CONFERENCE

Connect, learn, and engage at the AFTD 2022 Education Conference. Persons with FTD, care partners, families, and health professionals will find the latest information, resources and support for the FTD journey. For this hybrid event, we will welcome up to 250 people to attend in person at the BWI Airport Marriott, in the Baltimore, MD area. The AFTD 2022 Education Conference will also be completely accessible online free of charge, for full participation.

Whether in person or online, all are encouraged to take part! In-person attendance will require a registration fee, which can be waived for people

and families affected by FTD. For the health and safety of all, proof of COVID-19 vaccination and masks will be required for all in-person attendees. As we continue to monitor the ongoing COVID-19 pandemic, we will keep you informed on any changes to the event format.

Registration for this hybrid event will open in early February: [www.theAFTD.org](http://www.theAFTD.org)



### Massachusetts Alzheimer's Disease Research Center STAY CONNECTED IN THE COMMONWEALTH

A graphic with a red border. At the top, it says 'STAY CONNECTED WITH MADRC!' in bold black text. Below this are three social media icons: Facebook with the handle '@MassADRC', Twitter with '@ADRCMass', and YouTube with 'ADRCMASS'. At the bottom left is the MADRC logo, which consists of a red circle with a white spiral and the text 'MASSACHUSETTS Alzheimer's Disease Research Center'. On the right side of the graphic is a blue smartphone displaying the MADRC website. The website shows 'MADRC.ORG' at the top, a 'Join a Study' button, and a 'Learn More' button. A stethoscope is draped over the phone.

#### Resources are a Click Away!

Did you know the MADRC website has helpful resources on a variety of topics? Click on the links below for more information:

**Community Education Events:**  
[www.madrc.org/events/](http://www.madrc.org/events/)

**Research Studies:**  
[www.madrc.org/join-a-study/](http://www.madrc.org/join-a-study/)

**Support for Caregivers:**  
[www.madrc.org/resources-for-patients-caregivers/](http://www.madrc.org/resources-for-patients-caregivers/)

**Fact Sheets:**  
[www.madrc.org/news-events/get-the-facts/](http://www.madrc.org/news-events/get-the-facts/)

A graphic with a red border. On the left, the text 'BOOST YOUR BRAIN' is written in a large, bold, black, sans-serif font. On the right, there is a stylized illustration of a human brain in pink and red, with a blue stethoscope draped over it.

### NIH National Institute on Aging

#### KEEP IN THE KNOW FOR NATIONAL RESEARCH UPDATES

CLICK the images to the right to visit the National Institute on Aging website, Twitter or YouTube pages.





# Discussing Intimacy & Sexuality After a Diagnosis of Dementia: A Conversation with Dr. Jennifer Pilcher

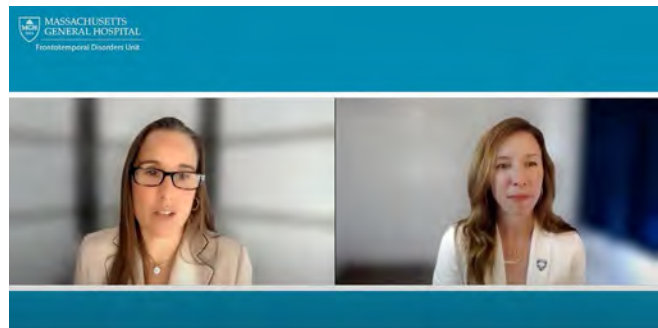
By Katie Brandt, MM, Director of Caregiver Support Services and Public Relations

The MGH FTD Unit Community Forum Friday webinar series aims to raise awareness about topics that impact persons living with a diagnosis, care partners and families. In our session, *Discussing Intimacy and Sexuality After a Diagnosis of Dementia*, Katie Brandt interviews Dr. Jennifer Pilcher, founder of Clear Guidance, expert in life care management and respected clinician in the dementia care community. Dr. Pilcher guided a discussion that demystifies a sensitive topic with respect and validation by recognizing that desires for love, belonging, and connection remain constant even when new approaches to physical expressions of emotions may be needed after a diagnosis of dementia.

*“It’s important to remember that this is not personal. The changes that occur with a diagnosis are a symptom of an illness which both of you in a partnership are experiencing”* – Dr. Jennifer Pilcher

Dr. Pilcher set the stage for the discussion by talking about the perspectives of both the person with the diagnosis and the care partner. She emphasizes, “There are quite a few things that both persons with the illness and their care partners have in common...a diagnosis impacts all areas of the marital experience, or the partner experience, including the most intimate ones. The goal of any intimate interaction is to express love for our partner and for many people sexual intimacy is at least part of the way they do this. For many, both the person with the illness and the care partner have a desire for a continued connection.” Dr. Pilcher acknowledged that there is the chance that both partners are dealing with the grief of the diagnosis but also of the potential loss of this side of their relationship. Getting support from trusted friends and family, a clinician or mental health provider can support navigation of this unique grief experience.

We know that cognitive decline can have different effects on sexual interest, desire and behavior. Some people with cognitive impairment will have diminished sexual interest or apathy while



*Dr. Pilcher acknowledges that discussing sexuality can be awkward but remembering to focus on the feelings being expressed – the desire for the connectedness with another human being – is a way to focus the conversation and make it meaningful.*

others will show increased interest and less sexual inhibition. For those who do maintain an interest in sexual activity, it may provide a way they can maintain their identity as a spouse or partner. For many, this sense of belonging is crucial to personhood. Caregivers may wish to continue these connections but worry when communication has changed. Dr. Pilcher recommends “I would encourage anyone who’s feeling like this is a difficult thing to communicate about to get a third party involved to help facilitate the conversation because sometimes it’s easier for a third party to open the discussion in a way that is looking at everybody’s feelings rather than one person in the couple imposing the conversation on another.” Dr. Pilcher also noted that it’s important to approach discussions with a focus on the relationship. Intimacy is one aspect of the relationship and discussions that have the “we perspective” can help couples discuss what is really important to them overall, not just in this one area.

What does all this teach us about what we can do when we’re finding ourselves struggling as either a care partner or a person with the illness? Just like dealing with all the other aspects of the disease, it’s really important to employ strategies like flexibility, humor and acceptance of the diagnosis to navigate experiences together.

[View the full interview with Dr. Pilcher on our MGH FTD Unit YouTube Channel.](#)



## TIPS TO MAINTAIN LOVING CONNECTIONS

- Draw upon other levels of your relationship such as psychological, spiritual and emotional connections that are unique to you as a couple.
- Acknowledge the positives in your relationship. Sometimes receiving a diagnosis acknowledges the passage of time and brings focus to the gift of the present moment.
- Recognize small gestures and expressions of gratitude that both of you can have for one another.
- Focus on values, your commitment to one another and memories of the life you built together.
- Activities such as dancing, cuddling, kissing and hugging can reinforce a loving connection.



## Podcast Resources for Love and Connection



Through the beautiful art of storytelling, *Remember Me Podcast* takes the listener on a journey through darkness and back into the light. Family members who have a loved one diagnosed with early-onset dementia, including Frontotemporal Degeneration (FTD), share their experiences and who their loved one was before their disease.

Listen to 50+ episodes now on Apple Podcasts, Spotify, and on [RememberMeFTD.com](https://www.remembermeftd.com).



@remembermepodcast

## Ask A Matchmaker

PODCAST with Matchmaker Maria

#83 - Caregiving, Grief and Dating with Brooke James and Katie Brandt

Brooke James is a highly respected podcaster in the field of grief and loss based in New York City. She is a sought-out grief educator who consults with companies and organizations seeking to create empathetic and supportive work environments, particularly during this time of unprecedented loss. She currently works at Aidaly, a startup focused on paying family caregivers, and previously worked in management consulting.

Katie Brandt is the Director of Caregiver Support Services and Public Relations in the Frontotemporal Disorders (FTD) Unit at Massachusetts General Hospital. Katie provides leadership for research, education and community events aimed at supporting the caregiver experience for families impacted by Alzheimer's Disease, Frontotemporal Disorders, atypical and young-onset dementias.

[Listen Here](#)



# Supporting Children Through Grief and Loss

By Amy Marchesano, LMHC Caregiver Support Services Specialist,

An interview with Cammy Adler-Roth, LICSW, CCLS, Children's Program Manager, Care Dimensions



Cammy Adler-Roth, LICSW, CCLS  
Children's Program Manager

When a family member is living with a diagnosis of dementia, there are often mixed feelings of grief, loss, and uncertainty experienced not only by the person living with dementia and caregiver but also their children. Children and grandchildren care deeply for their loved one and are an integral part of the family unit.

As things change in their lives, children are often moving through a magnitude of strong emotions including grief related to their loved one's illness.

*"If you are old enough to love, you are old enough to grieve."*

*-Linda Goldman, Life & Loss*

To further support children and families of our FTD community, The MGH FTD Unit YouTube Channel aired a special Community Forum Friday Session, ***Grief Supports for Children and Families***. This informative session hosted by Katie Brandt, and facilitated by Amy Marchesano, featured an interview with community expert, Cammy Adler-Roth, Children's Program Manager at Care Dimensions, a local agency providing comprehensive and compassionate care for families coping with life-threatening illnesses.

In her heartfelt interview, Cammy emphasized the importance of providing children with emotional support in the wake of a loved one's diagnosis. She also discussed the importance of building connection around the child's own lived experience. She included important tips for understanding a child's developmental understanding of loss as they travel through different stages of grief, including anticipatory grief, ambiguous grief and loss. Cammy further explained that children in different developmental stages grieve uniquely as they process these strong emotions related to their loved one's illness within their own timeframe.

Cammy suggested supportive ways to validate children's concerns, as one navigates difficult conversations with children surrounding loss. She also discussed meaningful ways to respond to the concerns of children of all ages, from preschoolers to young adults, providing helpful examples.

Cammy described supports available through agencies such as Care Dimensions that include therapeutic supports through activities such as art therapy, support groups, individual therapy, therapeutic books, among others.

Cammy and Amy had a rich discussion about how parents can access these professional services, but also ways family members and other nonprofessionals can support a child as part of their daily life through compassion and understanding. She also highlights that although children may grieve differently than adults, it is important that we have the right tools to support them.

Cammy's interview informs us that because children have different needs than adults, focusing on understanding and recognition of a child's experience is very important for the adults in their lives. She provides an overview of resources and therapeutic resources such as books, art activities and supports like grief therapy and support groups for parents that can help children navigating loss and grief. It is because of professionals like Cammy at agencies like Care Dimensions that children have access to such rich supports in our community.

*"If we can keep the doors of communication open and invite people to walk through them when they are feeling ready, that sets the family up for honest conversations to move through this together."* –Cammy Adler-Roth



CareDimensions

HOSPICE | PALLIATIVE CARE | SUPPORT SERVICES

[www.CareDimensions.org](http://www.CareDimensions.org)

# Understanding Hospice and Processing Grief

By Amy Marchesano, LMHC, Caregiver Support Services Specialist



Amy Marchesano spoke with Dr. Bernice Burkarth and Susan Toleos, focusing on the core values of hospice care. Dr. Burkarth acknowledges that in life we do not always have many choices, and therefore it is important to have choices about how we live, especially when on the journey of living with dementia.

When a loved one enters the later stages of their journey with dementia, it can be overwhelming for family members to navigate comfort and supportive care. To help us answer some important questions about end-of-life care, the MGH FTD Unit Community Forum Friday session, “*Understanding Hospice Care and Processing Grief*” hosted by Katie Brant and Amy Marchesano, featured staff from Merrimack Valley Hospice, Bernice Burkarth MD, Chief Medical Director and Susan Toleos, LMHC, Counseling Services Manager for Bereavement and Spiritual Care. Dr. Burkarth and Ms. Toleos provided comprehensive information about hospice care.

*“Hospice is about living.”*  
– Susan Toleos, LMHC, Counseling Services Manager for Bereavement and Spiritual Care

This informational and compassionate conversation provided an overview of the importance that the support and care of hospice services can provide when faced with the late stage of dementia.

Guided by the principles of respect and dignity for individuals living with serious illness, Dr. Burkarth provided an overview of hospice and the interdisciplinary approach her team of professionals provides to individuals living with a diagnosis, caregivers and the entire family.

Dr. Burkarth provided information on hospice eligibility, expectations of care, and details of the types of support services available. She provided valuable insight regarding the continuum of palliative and hospice care and how families

can access these critical services when the time arrives. Dr. Burkarth reminds us that in life we do not always have many choices, and therefore it is important to have choices about how we live, especially when traveling the journey of living with dementia.

Dr. Burkarth’s multidisciplinary team includes counselors and chaplains supervised by Ms. Toleos. Her team of chaplains and therapists provide an array of person-centered support services such as music therapy, grief counseling, and mindfulness for family members and patients receiving hospice. Ms. Toleos provided a summary of the types of emotional and spiritual support that is available for family members and what value it can provide to families regardless of religious affiliation or spiritual beliefs.

In her interview, Ms. Toleos dispelled common myths of hospice care, and highlighted common fears and concerns that family members often have as they travel this journey together. She refers to the families she has worked with as “grief warriors” viewing them as bold and strong in the face of adversity.

Throughout the interview Ms. Toleos showed a compassionate and informed approach to palliative and hospice care, reminding us that people are often active on hospice, with autonomy to make their own health decisions. Ms. Toleos emphasizes that “Hospice is about living.”

*View the full session, “Understanding Hospice Care and Processing Grief” on our MGH FTD YouTube Channel*





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