The Association for
Frontotemporal Degeneration
FIND HELP · SHARE HOPE

Walking with Grief:
Loss and the FTD Journey

Walking with Grief: Loss and the FTD Journey

2700 Horizon Drive, Suite 120
King of Prussia, PA 19406
267.514.7221 - Office, 866.507.7222 - HelpLine
www.theaftd.org

Photos courtesy of Unsplash.com, Pixabay.com and iStockphoto.com

Introduction

Grief, like the FTD journey itself, is intensely personal. Its impact is pervasive – both wide and deep – but there is no one-size-fits-all way to describe it. You've likely read or heard grief described as progressing through a series of stages. Other resources depict grief as a continuous journey that does not ever cleanly resolve.

You may find that the reality lies in between. What's clear is that grieving for the losses brought on by FTD can bring unique challenges. Loss can arise in multiple, compounded ways across this journey, from the struggles and isolation of the time prior to diagnosis, to the day-to-day challenges of navigating life with this disease, through to the death of the individual affected by FTD, and beyond.

In this resource, AFTD has drawn from interviews and discussions with dozens of people with FTD, care partners, and family members, to provide you with a guide to navigating the grief journey in FTD. Details have been condensed and changed in some instances to preserve the confidentiality of those who so kindly shared their perspectives with us.

These stories draw primarily from the experiences of primary care partners, referred to where appropriate as caregivers, but we have also sought to capture the perspective of persons with FTD where possible.

While the perspectives offered on FTD in this resource are likely to differ in some instances from your own, we believe that you will also be able to identify with much of what you read below. We hope that it will provide you with solace for this journey.

In the stories below, you'll read examples of people turning to AFTD and other resources for practical help on this journey. To learn more about information and support that can help you through this experience, contact AFTD's HelpLine by phone at **866-507-7222**, or email **info@theaftd.org**.

I.

Loss and the FTD Diagnosis

As FTD awareness grows, the amount of time it takes to obtain a timely FTD diagnosis will continue to shorten. Today, though, long years and months of confusion and uncertainty prior to diagnosis can chip away at a family's sense of overall well-being. As symptoms of the disease bring small loss after small loss, family members begin a new reality on uncertain footing, becoming care partners or caregivers without yet even knowing why.

Learning a diagnosis of FTD adds some clarity – but so often brings a new and profound sense of pending loss: that FTD is a terminal disease, and that today there are no ways to slow its course.

Feeling overwhelmed is a natural reaction. You may feel spread thin already, and likely now need to articulate what a diagnosis of FTD means to others around you. Family and friends are often ready to help when hearing of the diagnosis, but don't realize the difference between their own concept of dementia and the reality of FTD. This is often a time of learning for everyone – the individual diagnosed with FTD, you, family, friends and healthcare providers. The learning curve can be bumpy for everyone.

Still a Lot of Life Left: Kyle and Edna

Kyle's wife Edna was a successful real estate professional before her diagnosis of primary progressive aphasia (PPA). He found that anticipating the next phases of the disease can make an already overwhelming situation even more daunting. "The outcome is going to be that my wife will die," he said, "but when we first learned of the diagnosis, there was still a lot of life left."

He added: "The beginning phase of this disease can be confusing and overwhelming. The advice 'take things one step at a time' doesn't always feel practical -- there are a million shifting steps involved in this journey. Just remember that others have either been through this or are still going through it. Find them and reach out for support. I was grieving the loss of my wife, but also needed to figure out the parts that were still left, then balance my feelings so she could continue to live a good life for as long as she could. This was difficult; I had a hard time prioritizing and became overwhelmed quickly."

"The first step was learning about the disease," Kyle said, "wrapping our heads around what could come next." With two children still at home and one away at college, Kyle had to make sure he could provide the facts about FTD in a palatable way for their kids. He knew Edna had insights as well and they utilized

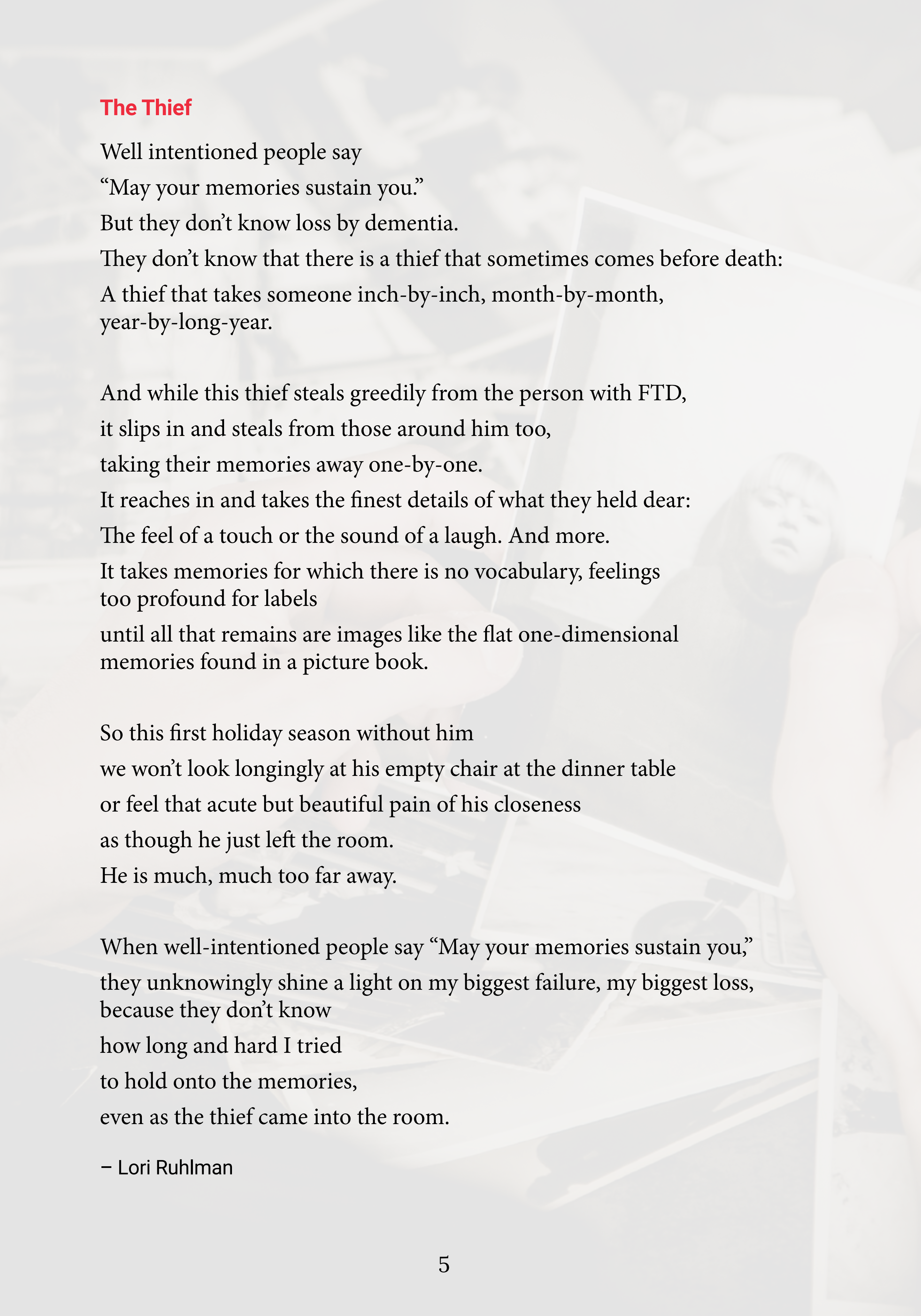
AFTD's "What about the Kids" booklet and AFTD Kids and Teens website for help. "These conversations were the most difficult," Kyle said. "With so much shifting there is nothing concrete, which is what our kids needed to help them understand." Kyle joined the phone-based support group for care partners who are also parents several months later to learn from others with children at home.

"Then we had to assess my wife's declining capabilities, which was an ongoing process. Our approach to care changed constantly. We wanted Edna to have and to use her voice as long as she was able, but at first we didn't realize how much FTD was affecting her thought process. Medical appointments became difficult – she would simply agree with everything without truly processing what the doctors were telling her. I slowly realized that I needed to take a more active role and become her advocate.

"We worked to ensure that her needs were met, but had a hard time anticipating her needs and acting on them before they shifted. I turned to my faith and with reflection made the decision to accept that I knew I was doing the best I could for her, but needed to also start tending to my own needs. This took a long time, and no shortage of anguish, but in the end I realized that trusting my gut was the right thing to do – although I always remained open to adjustments along the way.

"Having one place where all my research lived was helpful. I maintained a document with links to all my online research, categorized by topic (financial considerations, housing, etc.). Keeping organized like this helped me to feel like I wasn't spinning my wheels, especially in the beginning, when I was poring over lots of new information. I needed this with all the kids schedules to also keep up with."

As FTD proceeds, the demands are constant. It may be difficult to remember that this is all very hard and very sad. Keep that in mind as you try to be patient with yourself and with the person who has FTD. Meanwhile, you will begin to grieve for the life you thought you would have, and all the things left undone and unsaid. "Staying present in the moment and embracing the new normal as I built coping skills worked for me, but it took time for me to get to that place," Kyle said.



The Thief

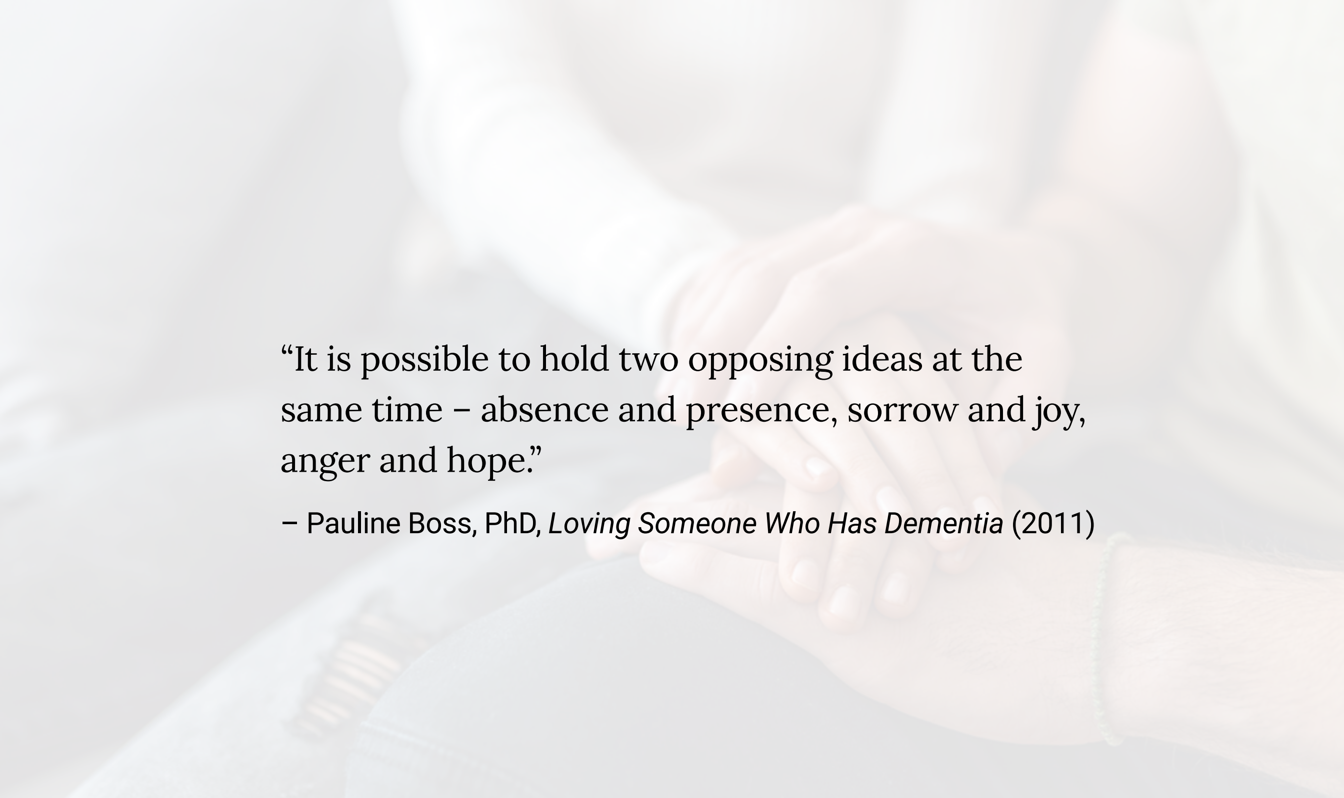
Well intentioned people say
“May your memories sustain you.”
But they don’t know loss by dementia.
They don’t know that there is a thief that sometimes comes before death:
A thief that takes someone inch-by-inch, month-by-month,
year-by-long-year.

And while this thief steals greedily from the person with FTD,
it slips in and steals from those around him too,
taking their memories away one-by-one.
It reaches in and takes the finest details of what they held dear:
The feel of a touch or the sound of a laugh. And more.
It takes memories for which there is no vocabulary, feelings
too profound for labels
until all that remains are images like the flat one-dimensional
memories found in a picture book.

So this first holiday season without him
we won’t look longingly at his empty chair at the dinner table
or feel that acute but beautiful pain of his closeness
as though he just left the room.
He is much, much too far away.

When well-intentioned people say “May your memories sustain you,”
they unknowingly shine a light on my biggest failure, my biggest loss,
because they don’t know
how long and hard I tried
to hold onto the memories,
even as the thief came into the room.

– Lori Ruhlman



> “It is possible to hold two opposing ideas at the same time – absence and presence, sorrow and joy, anger and hope.”
>
> – Pauline Boss, PhD, *Loving Someone Who Has Dementia* (2011)

Feelings Upon Diagnosis

Below is a list of common feelings care partners experience when they first learn that the FTD diagnosis is a terminal one, and start to consider life after the person diagnosed dies.

- Sadness for the loss of the future you had planned to share
- Emotional pain of watching a person you love decline and change as the disease progresses
- The anguish and stress of when and how to tell other family members, especially children
- Guilt at some of the things you’ve said to the person before realizing it was because of the symptoms of FTD that they acted the way they did
- Regret about your perceived failure to not notice and/or do enough to obtain a diagnosis
- Fear of what late stages of the disease will be like
- Anxiety about the inevitable death of the person with FTD

These things are all normal to feel on this journey, but they can be overwhelming. Seeking help and support during this time is important – even if doing so may be a little beyond your comfort zone.

A Rollercoaster Ride Every Day: Yvette and Burt

Yvette and her husband Burt received Burt's diagnosis of progressive supranuclear palsy (PSP) after three years of misdiagnosis. It was a relief to finally have a name for the strange things they'd been experiencing, but Yvette struggled to come to grips with FTD as a terminal diagnosis. Processing all of the changes to their lives made them feel like they were on a "rollercoaster ride every day."

No two days were the same.

Yvette reached out to their large extended family to address an area she knew they could help with: the logistics of caregiving. "When Burt was diagnosed, I reached out and created a schedule with times we needed help. He always hated to go to the dentist and this became more difficult with FTD symptoms. I would have those he liked best take him to these appointments and asked that they do something fun afterwards – whatever Burt wanted. He would always come back with a small complaint, but then tell me how much he enjoyed the cheeseburger, or the movie they went to see after."

"We worked together to stay on top of both Burt's care and our understanding of FTD. My daughter helped by researching PSP while my son would help with the heavy lifting and creating a safe environment for us to all live in. I'm proud of the supports my family provided and the system we built to keep everyone healthy and safe. Burt was a large, burly and healthy guy. At first, we had a hard time with so many people saying he doesn't look 'sick.' This disease is so misunderstood that it's hard to know how to articulate it."

Activating help and support from her family freed Yvette up at times to process what she was learning. Her first experience of connecting with a support group was an intense one, and required her to step back for a period to assess what she was learning the journey could bring. But the group became another invaluable resource.

"I attended support group and made dates with family that kept me feeling engaged and grounded. Our family was very patient with Burt when he was being prickly or difficult. His siblings and cousins continued to come. They didn't always know what to talk about, but they had conversations in front of Burt they would always have. I turned our weekly Sunday dinner into a pot luck to make it sustainable for me, and to allow Burt the chance to connect as he wanted."

Yvette felt fortunate to have family rallying around her where they could. “I know from my time in group this type of family support isn’t always available. I felt lucky to have so many stick it out with us and it really helped me to not feel so alone. I knew I had others to call when things came up.” She adds: “It helped me be able to normalize this very unusual situation that FTD challenged us with. The roller coaster ride took us for loops, and the peaks and valleys felt worlds apart. My grief came out organically as I shared the decline of Burt’s strengths with family members who showed up and noticed the same decline.”

Not a Quitter: Diana

One of the hardest parts of being diagnosed with FTD for Diana was having to abandon the professional life she had thrived in. “My neurologist was worried about me hurting myself or clients with poor financial decisions, since that’s part of the disease… He told me to stop working right then.”

She added: “In some jobs I would have been OK to continue, but in my leadership position I had stop, just like that. My executive functioning was compromised and I completely lost the ability to multi-task; that’s FTD. After working 65-hour weeks for years, leaving my position was tremendously difficult. And if you don’t have a presence in the business world, people forget about you.”

The reactions of those around her were hard to process. “I had people look at me and go, ‘you’re fine,’ or I was faking it because the market had gone south,” she said.

“Well, I’m not fine,” she said. “I’d love to be back making money like I used do. Faking it is the last thing I’d do. I’m not a quitter. That part has been so hard for me to deal with…”

No Room for Perfectionism: Claudia and Jose

Claudia’s son Jose was diagnosed with FTD in his early 20s. She knew she needed to act quickly and decisively to put things in order. She quickly learned the chaos of the post-diagnosis to-do list can be relentless.

Claudia had to accept one thing up front: that “there is no room for perfectionism in this journey.” She added: “I knew the process would be about making decisions, and that some of them might not be the right ones. I gave myself permission to make the best decisions I could with the information I had at the time, then move on. I stayed as plugged in as I could with people who understand the disease, and constantly read about it to have the vocabulary to explain what was happening.

She quickly realized the need to become an advocate for Jose and focused on that being her role.

Claudia chose to find and embrace joyful times with Jose as well. “It’s okay to find happiness in the day-to-day. Laugher and enjoying the person that you have in the moment were the ways that I dealt with my grief. Dwelling on the negative would take away from the joy of the positive. In the beginning, I researched and made as many decisions as I could, so I could put all that aside and have time for meaningful interactions. I allowed my grief to manifest by making every moment count, making adjustments as declines happened. We planned a few trips while he could still enjoy them and indulged him with his favorite activities, food, etc.

“At the end, I adjusted our interaction with him according to his needs. I would just hold his hand, or he could put his head on my shoulder. He loved having his feet rubbed – even though he was non-verbal, I could see him enjoying these things. I lived in HIS world.

“I don’t have any regrets, and was happy to honor my son in this way. I allowed the process to unfold without holding back and know he had a good life despite his FTD. This profoundly helped with my grieving process as I was able to pour it all into these joyful moments.”

Understanding Grief: Anticipatory Grief

Anticipatory grief is the term given to the feelings of loss and dread that family members experience when imaging what life will be like after a loved one dies. It is a normal occurrence and can accompany scenarios unrelated to FTD. Anticipatory grief can manifest itself as: increasing concern for the person dying, and the anticipation of how life will change after a loved one is gone. In FTD, anticipatory grief can take on additional characteristics. Shortly after diagnosis, you may begin taking stock of just how long the journey has already been. During that time of uncertainty, you may have been in conflict with the person with FTD, spent money on therapy that produced no results, or have acted in a way that may cause you shame now that you know something was wrong. Even if FTD was diagnosed relatively quickly, you likely are still struggling to establish a solid plan.

Upon a diagnosis of FTD, doctors may tell you to get your affairs in order, and they aren’t wrong. Attending to your finances, insurance, benefits, wills, etc. is crucial, and should be done with input from the person diagnosed where possible. But that should never be the end of the conversation.

Families face a difficult but crucial transition: from searching for reasons for the uncharacteristic behavior of a person with FTD to living with the knowledge that their disease is the culprit. Obtaining a diagnosis that explains so much runs into the reality that there is no good roadmap. There are no formally defined or widely accepted stages of FTD. Nor is there a definitive timeline. FTD is both terminal *and* its course can run anywhere from 2 to 20 years.

Living with the uncertainty that accompanies FTD complicates how losses are experienced.

It is completely normal to have conflicting feelings. Hearing that a diagnosis is terminal, while feeling overwhelmed by what could lie ahead, can happen simultaneously with FTD. Find ways to acknowledge the emotions you're feeling. Reflect back on the incredibly hard work you've done: to salvage your relationship, to explain antisocial behaviors to strangers in public; all of the conversations, tests and logistics your family has endured to obtain the diagnosis. You've done so much important lifting already.

Advice Along the Way...

- I kept the book *Loving Someone Who Has Dementia* by Pauline Boss at my bedside. It taught me you can live with contradictory feelings.
- Know that you may grieve every day. I was never a crier, but I cried in the car all the time – it relieved some of the emotional pressure I felt.
- Meditation and prayer were my lifesavers. They helped me find my best, deepest self. Intuition, guidance, strength: These are the things you need.

Things to Try

- This is hard. Seek moments of peace and connection where you can.
- Hindsight is 20/20. You don't know what you don't know with FTD. Work on letting go of some of those things that happened before realizing it's FTD.
- Find support. This looks different for everyone. Here are a few we have heard can help:
    - FTD-specific support groups
    - Online forums, support-focused social media groups
    - Books (see recommended booklist)
    - Therapy and/or speaking with a spiritual leader

My Notes

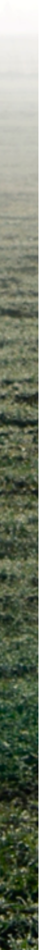
II.

Grief as FTD Progresses: A Difficult Balance

The progression of FTD brings growing needs as behavioral changes, loss of language, limitations grow; abilities decline. Whether you are the hands-on caregiver, caring from a distance, or living with this disease… whether FTD progresses gradually or at a faster or more erratic pace, whether the symptoms are primarily language-based or related to behavior… it is often said that FTD is a long goodbye with a thousand losses along the way.

Caregiving is often daunting and all-consuming. Grief can be just as demanding. But you can't only caregive, and you can't only grieve. Care partners may find that getting lost in thoughts of grief distracts from the daily demands FTD can impose, or that those demands limit the amount of time needed to understand and address the grief you're feeling.

Acknowledge your own strength. Care partners should try to find compassion for themselves and the person diagnosed, as you make your way through this complicated journey.



"It Can All Build Up:" Gloria and Jonathan

The day-to-day demands of caring for her husband Jonathan over five long years were wearing Gloria down. With the initial shock of his FTD diagnosis behind them, she was able to gain strength by looking back on the perspective she'd gained in navigating the difficulties his behaviors presented.

"Since this disease is progressive," she said, "I had to be ready for new behaviors that came along. Just when I thought I had a system going, things would change, and I had to go back to the drawing board."

"I had to learn that this is life in 'turtle time'," she said. "When I had to figure out how to help him shower and dress, I then just had to accept that these were things that were going to take time out of my day."

There were times when Gloria felt overwhelmed thinking about how their relationship had changed. "It was so hard witnessing his struggle, knowing that every day there was another loss, including the end of our relationship as we knew it. So many things left unsaid that ate at me. As the FTD progressed, he didn't want to be touched. He was scared, and I stayed alongside him as long as he let me. Losing both physical and verbal ways of communicating was hard. I didn't get to say goodbye. I was lonely and it was too much sometimes."

Gloria found that Jonathan's family wanted distance. "I was surprised when it became clear that they would not stay in close contact with us. They told me they couldn't come to see him because they wanted to remember him as he was. But I wanted their support for HIS sake, not for mine. Do I harbor resentment? Yes. But I know this is my problem. That's how I process it."

Gloria focused on not feeling sorry for herself and trying to prepare mentally for stress. "You go through so many different aspects of change and grief it can all build up," she said. "I tried to have a balance between my needs and his needs, but it was hard. I never knew what each day would bring… In order to stay on my game and keep up with all the moving pieces, I had to get occasional distance."

Gloria urges giving oneself permission to remove yourself emotionally from the painful aspects of life with FTD. Some call it building a wall; or focusing on what priorities you need to set. Whatever you choose to label this strategy, it can help you be more present with the person living with FTD.

"To be successful, I had to let go of guilt and not let it color the decisions I had to make." Rather, she said, consider "what is best and wholeheartedly commit to balance…when you can."

Important to Keep Trying: Cindy

Whether the person diagnosed can express themselves clearly or not, the many losses at each stage can bring profound grief for the individual facing FTD.

"Most everyone is used to being independent and able to do things on their own," Cindy said.

"With FTD, it becomes more difficult as the FTD progresses. This can lead to the loss of 'self.' Not being able to do the things that we used to consider part of us is a feeling of loss, like part of us has died already. For me, it is my baking and my artwork. I have always made delicious, beautiful cookies. Each year, more people ask for me to give them a tray at Christmas. It was not unusual for me to make over 100 dozen in a holiday season. Making and decorating cakes was also something I did for my family and friends. I can still struggle through making the cake and the frosting, but my decorating abilities have gone by the wayside. I used to paint and was an award-winning ceramist, not anymore. I cannot begin to explain how painful it is to admit to myself that I cannot do it anymore."

She kept at it.

"I have learned tricks to still be able to do baking on a much smaller scale. The recommendation of copying the recipe and checking off the ingredients has helped quite a bit. Sometimes, though, that is not enough. I made a recent

attempt at making a cookie that I have made since I was about 10 years old. I had to throw out three batches of dough until one was adequate to use and it wasn't perfect either. This caused me a few days of deep depression. Here I was, 63 years old, not being able to do something I was doing as a child…"

But that didn't mean putting her practice away. "To me, it is still important that I keep trying. If that means only doing the easy cookies that maybe don't look so beautiful and I am not creating great works of art, I must continue to try doing things on my own to maintain a sense of worth."

Permission to be Human: Melissa & Christy

"There is nothing black and white about FTD. There are a zillion shades of grey," said Melissa, whose mother Christy is living with FTD. "You don't have a timeline. You might not even have the right diagnosis, and you can get lost in the rabbit hole. I just kept going forward and tried to get the family to understand that we had no control over anything except our reactions."

As Christy's FTD progressed, her dependence on Melissa grew, almost as if Christy knew her daughter was the one holding all the strings. As her capacity for language decreased, she did not want Melissa to leave her side. Christy followed Melissa around the house; if Melissa left, even to take out the trash or walk the dog, Christy would pace the whole time she was gone. This left Melissa feeling stressed and anxious herself. "It was palpable when I was in the room with my mom. The mom I knew my whole life was not this person that is following my every move and needing so much from me.

"There was a lot of anger to resist. I reminded myself that it's not her, it's the disease."

Melissa took steps to explore her grief and realized she needed to give herself permission to be human. She realized that her ability to care for Christy depended on balancing it with other relationships and aspects of her life. At first, it wasn't financially feasible for Melissa to explore options other than her caring for her mom alone. Eventually, she found an affordable adult day program, just 1-2 times per week, which removed her from 24/7 caregiving responsibilities.

The physical separation also gave Melissa deeper insights about how much her mom's abilities were deteriorating. When Christy was clinging to her, Melissa could only focus on not getting frustrated. With some distance, she had time and space to reflect on everything her mom could no longer do, and would often

Wiggle Room

“Obligation” is a rainy word,
out of date and dowdy and austere
as “duty,” unexpectedly severe,
and hardly ever, these past decades, heard

unless after the fact, to glue a label
on what preceded. Late, the realization:
do what you have to. Choice is not an option.
With little room, you cope as you are able.

That little room, that wiggle room, allows
at least a nod or headshake. Yes or no:
landscapes you discover as you go,
prairie, valley, swamp, a stand of trees

where darkness yields surprisingly to dawn
in the mind’s sky a hundred times a day.
Morning and evening, the old Q and A.
What should I wear? Oh, obligation.

– Rachel Hadas

become incredibly sad. “It’s hard to witness someone who had such a strong and outgoing personality turn into this person that has no confidence and is so reliant on me,” she said.

Little by little, it seemed that so many of the things Melissa loved about her mom weren’t there. By continuing to react with compassion as she grieved for those losses, Melissa created an environment for her mom that allowed her to have as much independence as possible while also remaining safe.

Melissa’s grief revealed itself at odd times. In the grocery store when she couldn’t remember that one ingredient for their family recipe, but also during those tough choices all caregivers need to make: taking away the keys, decreasing Christy’s independence, and adding safety measures to their house.

Melissa had a hard time differentiating between grief, stress and anger. She tried to sort through these feelings, but couldn’t find the time. She started making a checklist each day and crossing things off as small wins that made her feel successful so she did not feel like she was floundering all the time. This small routine, along with a mantra she would repeat to help herself stay calm, went a long way toward helping Melissa feel like she was balancing the right aspects of her life, while successfully caring for her mom.

Understanding Grief: Ambiguous Loss

The specter of death as the inevitable result of FTD today is challenging enough. The losses along the way can be even more difficult to address. In the 1970s, Pauline Boss, PhD, began to explore the impact of loss that could not be resolved so neatly, which she termed “ambiguous loss.”

Boss identified two types of situations that could lead to loss without closure. There are those situations in which a person is physically absent, but psychologically present in the minds of those they left behind, such as deployed military personal during wartime. Conversely, in situations involving dementia, the person is physically present but can be and/or can seem to be psychologically absent. In both types of ambiguous loss, families do not formally mourn, because there is no death to mourn.

The stress of living with the uncertainty of such losses can be significant. The person with FTD may appear healthy, normal or well, with the cognitive and emotional changes invisible. It can be confusing for things to look the same while the changes are so fundamental. Many care partners share that ambiguous loss is a defining characteristic of FTD. (“This is not the person I married.” “My wife would never have said or done the things she does now.”)

Resilience can play a huge role in the way individuals experience, think about and cope with ambiguous loss. Personal history and hereditary make-up can inform the way a care partner experiences the symptoms of FTD, and how they cope.

The lines between healthy and unhealthy coping are blurred – particularly in FTD, when a care partner's own needs are so often overshadowed.

FTD refuses easy resolutions. You maybe want to tell the person with FTD how you truly feel, both good and bad, but know that doing so is futile. You know the disease will be terminal, but may have no definitive sense of its progression. These are just a couple of ways that the anticipatory grief of an FTD diagnosis is particularly traumatic. The intensity of the symptoms can inflict on care partners a psychological wound that needs attention to heal properly. But due to the demands FTD puts on one's time and energy, most cannot attend to the healing process until after the person diagnosed dies.

These are all expected feelings, but what can be done? In her 2011 book *Loving Someone Who Has Dementia*, Boss explains that if people can understand a problem, they are better able to cope with it. Understanding the role of ambiguous loss and how it factors into your own experience of FTD, with its unique symptoms and challenges, can be helpful. Boss writes:

> "Learn to manage stress… Let go of your need for certainty and absolute answers. Acknowledge your sadness as it ebbs and flows and talk about it with others. Grieve when you feel the need and know that there is no need for closure. The more you can embrace the ambiguity of dementia's loss, the less terrifying it is. Above all, remember to take care of yourself…
>
> If you are accustomed to solving problems, this experience can be especially stressful. The best way to make change and ease your stress lies in your own perceptions and the meaning you give to the situation. It is possible to hold two opposing ideas at the same time – absence and presence, sorrow and joy, anger and hope." – Pauline Boss, PhD, *Loving Someone Who Has Dementia* (2011)

How we see something is important. FTD can be a long haul, but it can also force one into a spontaneous, living-in-the-moment mindset. It can force you to see your true strength, and help you recognize your own resiliency. Focusing on the moments that bring joy, peace and laughter to you and your person with FTD, even if small or seemingly insignificant, can change the way you cope and deal with this disease.

This is not to suggest that the difficult aspects of FTD should be ignored – to the contrary, the challenges are often unignorably immense. The personal challenge for you as a care partner is to remain present enough to recognize the good moments, or to simply reflect with pride on all the love you are giving and hard work you are doing.

Maybe it's introducing a project that the individual with FTD really enjoys doing (and makes you feel good to see), or perhaps experiencing a "lightbulb moment" in a support group that really helps your situation. It can be as simple as gearing up for an inevitable fight about some aspect of caregiving, only to have it go smoothly, with no struggle.

Dr. Boss identifies resiliency as the best tool to make it through this experience. Taking in these small victories, and remembering them amid future challenges and difficulties, is what resiliency looks like.

Advice Along the Way…

- It's OK to not be in a good place – this is really hard. You still have as many needs as the person with FTD – we often ignore that. Find ways to get your needs met.
- The FTD journey is a marathon, not a sprint. It is not sustainable to put your life completely on hold for years at a time. Getting help is essential.
- I kept him home longer than I should have. I thought I had it handled until we had a couple big setbacks, and then I knew I had to move him to a residential care facility.

Things to Try

- While the person diagnosed is sleeping, take 5-10 minutes for a mental self-check-in. What people, routines, hobbies or forms of exercise do you most miss? Can you re-integrate those into your life, even if in a somewhat diminished form?
- Balance is so important. Living in the moment all the time is unrealistic, but staying in the moment with the person with FTD some of the time (even if it's scheduled in) can lend itself to joyful moments and connection points that are important for you both.
- Meditation and breathing exercises can help you to balance all the emotions, logistics and conflicts that arise.

My Notes

III.

The Last Goodbye: Hospice and Death

While death in FTD is inevitable, caregivers nevertheless find it to be complicated by exhaustion, guilt and the intensity of the losses along the way.

As the person with FTD enters their final decline, you may experience increased regret and anger, or these feelings may take a back seat to thoughts about keeping vigil, ensuring the person is comfortable and final arrangements.

The uncertainty surrounding hospice care (*When should it be considered? What does the term actually mean?*) can be frustrating. Palliative care teams are a great resource to consider having these kinds of conversations with. It helps to explore your choices and preferences regarding end-of-life care as early on as possible, so you can make decisions together prior to the decline, and free up your emotional bandwidth to be fully present as the life of the person with FTD comes to an end.

While those unfamiliar with the disease may consider it harsh, FTD caregivers often feel relief when anticipating the death of the person diagnosed – it means they will no longer have to focus daily on their ongoing loss and grief. Give yourself permission to anticipate the relief of setting down the drain of caregiving. Hearing how others have navigated this final passage is a gift that support groups and informal networks provide. Sharing your own story can also bring comfort.

Grief and the Loss of Friends With FTD: Teresa

“I loved my life,” said Teresa, who is living with FTD. “I felt I was living an exceptional life. I was living my best life. I had always wanted to be married, to have a child, to be a nurse – and I attained all three. I identified myself in society as a care provider, a nurturer, a nurse.”

But as her FTD slowly stripped away her ability to do what she loved, she grieved for her former self. When it became clear she could no longer work as a nurse, “I sat around for two years, trying to figure out – who am I now? It was hard. You’re not the same – nothing is the same.”

Teresa said her main strategy for dealing with grief is to simply stay as busy as possible, doing whatever is still possible. “If that means taking a nap, you take a nap. Sit outside and have coffee or tea -- or an adult beverage, in my case. I journal. I like to draw. I’ll garden.

"I have a jar on a bookcase at home, and a little chalkboard next to it that says 'Notes to Heaven.' So whenever I feel a loss, I'll type a little note, print it out, roll it up, put a little ribbon on it, and throw it in the jar. It doesn't matter if I'm grieving the loss of a friend or a function.

"This past year my jar got full really quick and I had to take some out. I don't read them again because I wrote them to heaven. So I burn them in our fire pit. It's freeing for me. I don't hang on to things and I don't hold grudges – those use energy, and I don't have that much brain energy to spend."

Teresa has become close to many other people living with FTD, and said she draws strength from those friendships.

Teresa said she was talking recently with a friend with FTD. One of their mutual friends who also had the disease had just died. "My friend said, 'Why bother? Why am I still making friends? It just hurts me over and over again.'

"And my response was, 'It's good we can still get hurt over and over again. Yes, it's sad, but we'll keep doing it – that's the life we have to live today.'"

Knowing He Was Comfortable: Fred & Jason

Fred knew there was no cure for his husband's diagnosis of behavioral variant FTD and subsequent PPA symptoms, but he pushed it out of his mind for years while caring for him. A few moments continued to stand out: the moment Jason was diagnosed, the day Fred realized their home environment was no longer safe, and the excruciating decision to move Jason into a care facility. Jason's symptoms led to many trying times through the years. Jason had anosognosia, and before diagnosis he wanted a divorce, was over-spending without Fred's knowledge and a few years later, Fred had to hospitalize Jason due to safety concerns. Fred had a lot of worry about Jason being at peace. Once in a locked, memory care unit, Fred visited him daily, always bringing his favorite things from the "outside" – new pajamas and blankets when the seasons changed, and sometimes treats from their favorite bakery. Jason asked every day for 3 years when he could go home. Fred tried to redirect at first, but it was more and more difficult.

A few years later, Fred faced another difficult decision. Jason could not walk, had to eat pureed food to accommodate his swallowing troubles, and had been non-verbal for years. The doctor recommended hospice care to ensure Jason's comfort as he neared end of life.

Fred found that the hospice staff at all levels and disciplines – nurses, CNAs, social workers, chaplains – were attentive and caring throughout Jason's last months. "They really helped to meet the needs of not only Jason, but of our whole family," he said. "Hospice provided a way to begin the healing process. Jason's illness was filled with many chaotic moments and tough decisions, but hospice helped us move into a space where we could all be with Jason in a different way. Knowing that he was comfortable and cared for leading to his death was a huge relief, and helped us grieve for the Jason we all loved."

Fred was surprised by how helpful he found the hospice chaplain. Having someone who came to see Jason in the facility consistently over a few months helped. Seeing Jason's decline, the chaplain offered Fred an opportunity to tell their story: how they met, more about Jason and how they lived a full life prior and up to Jason needing more care. Fred described the work he was doing with the chaplain and how it helped him open up about how painful this process has been. "He (the chaplain) really helped me see clearly how I have honored Jason throughout our relationship, then visualize the way to continue to do that through his death." Fred formulated a plan with the hospice team to ensure Jason was not alone in his final days. Part of this plan included non-medical things, like bringing in scented candles and singing to Jason, and reading his horoscope to him each day like they always had.

Fred was devastated when Jason was admitted to hospice, but realized the gift both he and Jason were given. The rituals and routines so important to them were reimagined in a way to help Fred give Jason the death he knows he would want. As a result, Fred was able to be at peace, knowing he continued to find ways of loving Jason even through death.

Grief for Mutation-Positive Families: Michael & Janet

Michael saw his mother, Janet, become a totally different person. He stayed by her as her illness progressed through its final phase, but became increasingly impatient for a resolution. "I didn't have the language for what I was feeling," he said. "You're not supposed to want your mother to die." With the help of hospice workers and other family members, he began to recognize that, in FTD, death is not entirely negative -- not necessarily something to celebrate, but nevertheless a release from a terminal neurological disease.

Michael, however, struggled with feelings of being inadequately focused on his mother as she declined. His family ensured that Janet was cared for and that she died without pain, but Michael admits that their conversations at this time were less about her and more about himself, his siblings and their children. They knew that Janet's own mother had had an undiagnosed dementia, and that her brother had died from ALS. During their mother's final days, Michael and his siblings spoke anxiously about genetic testing and the likelihood of one of them developing dementia. Such conversations dominated what was supposed to be a time devoted to bringing Janet's loved ones together to say goodbye.

Immediately after his mother's death, Michael was haunted by the fear that he, his siblings and/or their children were destined for the same fate. His anxiety was driven by uncertainty: while Janet had taken part in a research study that included genetic testing in an early phase of her FTD, she had never learned of the results.

Still struggling to process his mother's death (with help from counseling), Michael proceeded slowly and cautiously toward getting tested. He learned that people with known FTD mutations are likely to be the first to be eligible for emerging clinical trials, and that technology is available to prevent passing such mutations to future generations. Encouraged by this information, and with the support of his wife, he contacted his mother's physician and met with a genetic counselor at a nearby research center for testing. He waited another eight months before deciding to learn the results, at which point he found out he carried the *C9orf72* gene, which has been linked to both FTD and ALS.

About a year later, his older sister started undergoing noticeable, and worrying, changes. "When you are living in a family with an inherited FTD gene, you are always waiting for the other shoe to drop," Michael said. "When the first sibling goes through it, it becomes much more real for everyone."

Grief in FTD is ongoing – and for mutation-positive families, it is impossible to move beyond short of a cure. Michael decided to seek methods of support that worked for him, adopted healthier eating habits, started exercising, and encouraged other family members to participate in research, all while continuing to strive to live his best life.

Understanding Grief: Bereavement

Bereavement is a period of loss or mourning after someone has died. It's a normal and healthy reaction to death. Responses to loss will vary based on one's relationship to the deceased, the circumstances of their death, unique personality traits, and cultural influences, among other factors. The emotions that accompany bereavement can also vary greatly, and they can be confusing and unsettling for the survivor. The acute pain of bereavement lessens as people adjust to their loss over time, but grief is still an open, ongoing process.

The isolation and lack of understanding that make FTD so challenging during life can complicate one's experience of bereavement after death. While FTD is a terminal disease guaranteed to shorten a person's life expectancy, clinical presentations vary, and there is no "typical" way a person with FTD dies.

FTD's younger onset means that it is less likely persons diagnosed with FTD will die of concurrent age-related health issues, such as heart disease. On the other hand, impaired judgment, common in behavioral variant FTD in particular, can leave the person diagnosed vulnerable to dying of a tragic accident. As FTD reaches its late stages, it spreads to the parts of the brain that control basic functioning, potentially resulting in problems with mobility (including greater fall risk), swallowing, and a weakened immune system. Because of these physical problems, FTD generally leads to death by pneumonia or complications due to another acute debility, such as sepsis (an infection throughout the body) or pulmonary embolism (a blood clot that blocks a major blood vessel in the lung).

The physical decline associated with late-stage FTD can be very difficult for family caregivers who have spent years learning new ways of communicating with the person living with FTD: the subtle gestures, nuanced movements, other signals that they to indicate they have needs to be met. In FTD's late stages, these signals can become impossible for the person diagnosed to deliver, which caregivers can find alarming and even traumatizing. After death, former family caregivers may mentally process and replay the traumas of the past few years; their bereavement period may include sleep disturbances, changes in appetite, and wildly varying energy levels.

When the person with FTD has been in a facility, bereavement can present differently. Often, the caregiver has already had to develop a daily routine that is physically separate from the person diagnosed. Many therefore say they have felt initially "prepared" for death, since the hard goodbye took place when they moved the person with FTD into a facility, only to later realize that the actual loss of the individual with FTD provokes a new, and unexpected, sadness.

Immediately after the loss…

The start of the bereavement period coincides with the busy time of making arrangements for funerals, burials and/or whatever your customs and traditions dictate. Caregivers have shared some of these experiences:

- When my husband died, I was still in caregiving mode. I was running on adrenaline and could not slow down. The busy time of preparing for the funeral was good for me. It gave my energy a focus and a concrete task list at a time when I was feeling so lost.
- I had a difficult time making decisions about my mother's funeral service. By the end, she was not the same person she would have wanted everyone to remember. But it had been 12 years since her diagnosis, and it didn't feel right to ignore how she had changed. Even choosing a memorial picture for the service was a fight. All the siblings had different opinions, bringing more chaos than closure to this long goodbye.

- We decided to throw a party for my husband after he physically left us. He was so full of life before FTD struck; we wanted to celebrate his many accomplishments, recognizing that if not for the FTD, he would have been right there at his party – and would have loved to celebrate. I poured his favorite cocktail and left a glass of it on the table to honor him as we shared memories from his storied life.
- So many people disappointed us throughout our FTD journey. Once my wife died, it was really hard for me to know who I should reach out to before the service. I was so tired and just wanted someone else to spread the word – but we had lost touch with so many people that I didn't have updated contact information for most of them. I ended up with a list of email addresses based on my current contacts that should receive the obituary. I know that seems impersonal, but I just couldn't bring myself to have that conversation with people who did not acknowledge or support us during our "FTD years." Some ended up coming to the funeral, and even apologized for not being there for us. I am glad I spread the word in a way that was comfortable for me, as opposed to what was expected of me.

Advice Along the Way...

- Take advantage of all the services palliative care and hospice offers. It isn't just for the person who is dying, but for the whole family.
- When you want it all to be over with, but you feel guilt and shame about feeling that way… that is ambiguous loss, and is something many others also struggle with.
- Remain hopeful. You're not going to come out the same, but you will make it through.
- I'm not someone who thinks suffering is somehow good for us, but it does somehow cause a deep, soul-stretching transformation.

Things to Try

- Be patient with yourself through the different emotions, fluctuations in your energy level, lack of sleep (or too much sleep), and realize that your body, your mind and your psyche have been through a lot. Move at your own pace.
- You can and should use this period to refocus your time and attention back to yourself.
- Recognize that grief is a natural part of loss, and is not something that is bad, wrong, or shameful. Everyone grieves loss.

Signs You May Need More Help

Sometimes the loss is so difficult and all-encompassing that you may need seek outside resources for professionals. Here are some of these responses:

- Extreme weight gain or weight loss
- Significantly increased drug or alcohol use, or starting to drink and use drugs when you didn't before
- Extreme and prolonged sleep disruption (this can be tricky to judge because sleep disruption is often part of being a caregiver, especially if the person with FTD was at home with you until their passing. It may take time to achieve a normal schedule again – be sure to monitor your sleep)
- Intensified feelings of guilt that interfere with your ability to lead a normal life (i.e. making plans, going to work, raising your children, etc.)

IV.

Life After Life with FTD

Life as an FTD caregiver is filled with to-do lists and daily challenges. After death, things change dramatically. While reactions vary from family to family, life after life with FTD commonly involves looking back, revisiting (and reconsidering) decisions they made, taking stock of the support they did or didn't have.

Bereavement is an ongoing process, and those in it continue to mourn – both for the person who had FTD and for the unique relationship they had with them. But they also contemplate their future and, if they allow themselves, breathe a sigh of relief and embrace a new reality.

Slowly Letting Go: Claudia

Claudia was at peace about how she had cared for her son, Jose. She had devoted herself entirely to him and doggedly embraced the positive aspects of being his caregiver. "What I'm most proud of is that I was present every day for him, right up to the day he died," she said. "I stood in the abyss with him. It was hard, but I'm glad I loved him the way I did. I have no guilt. The whole time he was sick, I was slowly letting him go, gradually getting rid of his clothes and other possessions.

"Jose was gone way before he died," she said. "All my mourning was done gradually, over many years."

Most of My Friends Disappeared: Melissa

Life with FTD changes you. You may find yourself surrounded by an entirely different community of people when the journey is over. "In interacting with my friends while my mom was sick, I noticed that everyone processes grief and trauma differently," she said. "And when denial was part of that process, I struggled."

"Most of my friends disappeared," she added. "Things changed. They're different now, and so am I. They can't comprehend what I have been through: Very few of them have had that kind of reality in their lives. Today I have a whole new community of friends."

Caregiving role reversals – when a child cares for a parent – are always difficult, but they are especially challenging when the caregiver is a young adult with no siblings to help. Melissa was barely 30 when her mother became ill, and she lived in an area with little health care support. She struggled to find the right care. “My mother was mistreated and prescribed with so many psychotropic drugs. I should have fought harder and spoken up more, but there were forces beyond my control, and I didn’t know where to turn for answers,” she said. “I could be angry at so many people now, but what is that going to do?

“I wasn’t always present when my mom was sick, and it’s hard to forgive myself for that,” Melissa continued. “I was always thinking about the next thing I had to do. When she died, my first reaction was relief, but that was accompanied by guilt. The stages of grief are different with dementia. With dementia, you grieve for years. To me, there are no stages.”

He Would Be Furious if I Dwelled on his Death: Fred

After a loved one’s death, many people find it necessary to join a grief-specific support group. Fred’s reflections following the death of his husband, Jason, bear that out:

“Going to group turned my grief around. In the year after Jason died, I only wanted to stay busy – wash floors, do housework. I needed that process. Then I joined a grief group. The leader suggested I write a letter from my husband to me. At first, I didn’t know how to approach it. But when I sat down to write, that letter poured out of me. It was him telling me that he was okay, and that I should move on and be happy. He said he would be furious with me if I dwelled on his death. That’s when I began to truly heal.”

Finding Your New Normal

After death, the landscape of your life will change – and so will you. You may find yourself feeling lost and alone, with no energy to figure out what comes next. You may be overwhelmed at the idea of re-engaging with a world that doesn’t acknowledge all you have been through. Your post-death mourning process is shaped by the long goodbye you have already lived. Healing is an ongoing process, with no actual finish line. In short, you may find your emotional life becoming even more complicated.

Give yourself time. The pace and process is yours to explore. Allow yourself to feel relief, and know that the best ending is a positive “new normal.” Remind yourself that you did your best, and that you can – and should – be hopeful about your future.

This can be a lonely process, and most people likely won’t understand it, nor will they be equipped to validate your complicated emotions. But you can seek support from a therapist and/or a spiritual resource like a rabbi, a pastor, or a faith-based resource such as the Stephen Ministries. This can be a good time to attend grief sessions, which typically run between six and eight weeks and can suggest activities to help you in your healing process.

Closure Through a Definitive Diagnosis

A clinical diagnosis of FTD is made based on symptom history, observations by a healthcare professional, and additional evaluations. But a definite diagnosis of disease pathology can only be made after death, via a brain autopsy. Results are usually returned between three and six months after death – and they can bring on new, complicated emotions. Autopsies are a necessary step to provide a definitive diagnosis. Studies show that as many as 20% of people clinically diagnosed with FTD have been found on autopsy to have had Alzheimer's disease or some other disease pathology.

If you find that to be the case, you may wonder if you could have done more to treat or care for the individual with FTD. You may feel less solace from your connections with others made along the way. You may feel confused and disoriented about having focused on the "wrong disease."

In still other cases, families may only become aware of FTD after the person who had it dies. As the term "FTD" enters their lives, families may begin to think about long- deceased relatives: Did they die of FTD also? Or, they may learn that a distant family member had had FTD. As families investigate further, additional revelations and questions may surface, complicating their grief even further.

Regardless of what new information a definitive post-death diagnosis brings, it is important that you be gentle with yourself. Recognize that you, the person with FTD, your family and friends, and the healthcare professionals involved were all working off the best knowledge available at the time, and that you did the best you could.

However you carve out your new routines and rituals and start figuring out life without the person with FTD, know that others have been on this journey before, and have been able to re-emerge as a happy, healthy person. Some found new skills and resources to help them shine a light on how they have changed. Others describe the journey as never-ending – and, while the process was often painful, they were still able to acknowledge and come to grips with their time as an FTD caregiver.

Disenfranchised Grief

Caregiver grief associated with dementia isn't well understood by those who have not directly experienced it.

The gerontology professor Ken Doka calls this grief "disenfranchised grief," and defines it as "a grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, socially sanctioned or publicly mourned."

You have the right to choose whether to talk about your experience when (or if) you want. Being one's own advocate in the aftermath of the FTD journey can feel like a daunting task. But there are others out there who understand.

While grief in this journey is an unfortunate constant, that doesn't meant the search for your "new normal" is hopeless. Allow yourself time to find it.

Understanding Grief: Post-Traumatic Growth

When FTD caregivers look back and process their journey after the person they were caring for dies, many realize for the first time just how much courage and determination they exhibited along the way. Indeed, they may recognize that they had tapped into formerly unknown reserves of strength within themselves. The idea that "in the midst of stress and sorrow, fear and grief, many discover inner strengths that had previously been hidden" (as described by writer Barbara McNally) is known as post-traumatic growth.

Post-traumatic growth can help turn the grieving process into a healing process; it embodies the phrase, "If I got through that, I can get through anything." After losing someone to FTD, former caregivers may experience growth by identifying and taking advantage of new opportunities that emerged from their journey. They may find that existing relationships have deepened along the way, and they may also feel greater connection and empathy with people who are suffering. Post-traumatic growth may manifest in an increased sense of one's own strength, or greater appreciation for life in general – some individuals report having more profound spiritual lives after their FTD journey. More information about post-traumatic growth can be found at the website of the Posttraumatic Growth Research Group at the University of North Carolina at Charlotte (ptgi.uncc.edu).

Thoughts on Moving On…

- After my mom died, life slowed down and the drama faded. I feel like I'm finally on the other side. Life as an FTD caregiver is a time of almost manic intensity. But life doesn't go back to what it was: You've changed.
- A message I am grateful for having received: You become a victim if you don't let go. Time does its thing. It's done and I'm moving forward.
- I gained advocacy and caregiving skills that I've continued to put to use in a positive way since his death by doing volunteer work. I feel proud for what I've done, and hope to share my hard-won abilities with others who can benefit.

My Notes

V.

Grief and Families

Confronting Familial Risk

One aspect of grief for many people facing FTD involves questioning whether FTD is inherited in the family. Approximately 40% of individuals with FTD do have a family history that includes at least one other relative diagnosed with a neurodegenerative disease.

If your family history raises some concerns, there are certain steps you can take to learn more. Knowledge is so important to this journey – and to better understanding and better navigating the grief that accompanies it. Gather as much family history as possible. Ask questions about the early symptoms of any family member affected with FTD or a related disease. Find out the age of onset for their symptoms.

Ask your neurologist for a referral to a genetic counselor, or another healthcare professional experienced in the genetics of adult neurological conditions. Genetic testing is available for the known FTD mutations, and counseling is a critical first step. The counselor will explain what the test can (and cannot) tell you, provide information on insurance, and go over next steps. Genetic counseling is valuable both for answering important questions about familial risk and for raising new and potentially urgent ones.

More information about the genetics of FTD can be found at AFTD's website: Visit **theaftd.org/what-is-ftd/genetics-of-ftd** and download *Understanding the Genetics of FTD*, a booklet produced by the University of Pennsylvania with AFTD's support.

Need for Companionship: The Changed Marital Relationship

The cognitive, emotional, and behavioral changes that come with FTD significantly change the relationship between spouses. The loss of empathy and language ability and the increasingly impulsive and disinhibited behaviors displayed by the person diagnosed may lead their spouse to think, "This is not the person I married," in a form of ambiguous loss common in FTD.

Other circumstances can further complicate grieving for a spouse living with FTD. If facility care becomes necessary, the caregiver faces a risk of isolation and depression as they adjust to life without their spouse by their side. With FTD's progression difficult to predict, this period can be lengthy and especially challenging for people in midlife.

Some caregivers find that the loss of emotional and physical intimacy with their spouse to be detrimental to their own health. They may seek friendly companionship outside their marriage, or they may choose to begin dating while still caring for their spouse. They do not feel they are cheating – to the contrary, devotion to their spouse may remain strong. Sometimes caregivers who date while still married find that their new relationship expands the circle of care for their spouse.

Caregivers face countless profoundly difficult decisions as a result of a loved one's FTD. Determining the "right path" is a complex individual decision. Caregivers deserve support that does not judge, but extends understanding, compassion, and grace.

Kids and Grief in FTD

When a parent gets FTD, the kids may be confused at changes in the parenting partnership, as the well parent becomes a solo parent. In behavioral variant FTD, the parent may use poor judgment or act in immature and inappropriate ways. The parent diagnosed with FTD may not understand when play is unsafe or when play is too rough. Changes in the parent's behavior that can be acutely embarrassing to pre-teens and teens may shape many decisions.

Children are able to help to a point, but may feel that they have too much responsibility around the home. You can explain that everyone simply has to pitch in more since the FTD parent no longer does some of the chores they used to do. Respect too, that children need to have regular involvement with peer activities for their overall growth and well-being. Mutual respect and shared problem-solving can foster coping and new strength in the family.

Even when given lots of support, many children who have a parent with FTD feel different from their peers. Children often feel very isolated and that others do not understand. As the main caregiver for the parent with FTD you simply will not be as available to your children. They will miss the attention of their parent with FTD, too.

Reach out to a trusted relative or friend as a mentor to nurture and support each child. Take a break with the kids from the FTD parent—anything from a brief outing to the park to a vacation to reinforce your relationship.

All kids need a way to work off anger and frustration in their lives, so physical activity from sports and time outside is probably more important than ever for your kids. Creative arts such as painting, music and dance allow for the expression of feelings not easily put into words.

Let your child share how they feel. According to an NIMH study (Sandler, et al), of all the parenting behaviors that can negatively affect a child's adaptation after a loss, the one with the largest negative impact is actively inhibiting the child from talking about what he or she feels the desire to talk about.

My Notes

VI.

Questions for Reflection

- What type of coping mechanisms were helpful for you as an active care partner/caregiver?
- What are the barriers preventing you from taking respite time for yourself?
- Who around you is the greatest support during this time?
- Are you giving yourself permission to take time to grieve? Are there ways to acknowledge all the changes in your life while honoring your feelings about all the losses?
- What type of rituals or routines were important to you before FTD came into your life? Can you re-engage in any of the activities while caregiving and/or after the death of the person who had FTD?
- Do you seek out support from others?
- Do you feel like you are doing the best you can? Can you imagine that being enough?
- What small steps, if any, did you take to leave space for grief and/or start your new normal?
- Have you spent time remembering or jotting down your own proud moments of strength, resilience, etc.?

My Notes

My Notes

Resources and Suggested Reading

As you navigate an FTD journey, AFTD is here to offer guidance, support, and to listen. You can reach our HelpLine by calling **(866) 507-7222**, or by **emailing info@theaftd.org**.

We mention several suggestions throughout this resource. Here are a few follow up web pages for more information:

- Palliative care in dementia: www.capc.org/documents/114/
- How to talk to kids about FTD: www.aftdkidsandteens.org
- Bereavement camp for children: elunanetwork.org/camps-programs/camp-erin/

Over the years, many have shared with us books and other resources that have helped them. These recommendations come from members of our community, and we share them with you for your own exploration:

- *A Loving Approach to Dementia Care: Making Meaningful Connections with the Person Who Has Alzheimer's Disease or Other Dementia or Memory Loss* by Laura Wayman
- *Ambiguous Loss: Learning to Live with Unresolved Grief* by Pauline Boss, PhD
- *Dementia Reimagined: Building a Life of Joy and Dignity from Beginning to End* by Tia Powell
- *Final Gifts: Understanding Special Awareness, Needs, and Communications of the Dying* by Maggie Callanan and Patricia Kelley
- *Grief Works: Stories of Life, Death and Surviving* by Julia Samuel
- *It's OK That You're Not OK: Meeting Grief and Loss in a Culture That Doesn't Understand* by Megan Devine
- *Loving Someone that has Dementia: How to Find Hope While Coping with Stress and Grief* by Pauline Boss, PhD
- *The Caregiver's Path to Compassionate Decisions Making: Making Choices for Those Who Can't* by Viki Kind, MA
- *The Grief Recovery Handbook: The Action Program for Moving Beyond Death, Divorce, and Other Losses including Health, Career, and Faith* by John W. James and Russell Friedman

- *The Journey Back to Self: Life After Caregiving* by Margo Ewing Woodacre, MSW
- The RAIN Approach to Mindfulness (Recognize, Allow, Investigate, Nurture): a theory by Tara Brach that has been adopted in many online and written works.
- *A Three Dog Life* by Abigail Thomas
- *Griefwriting,* by Joan Zlotnick
- *Widow to Widow: Thoughtful, Practical Ideas For Rebuilding Your Life* by Genevieve Davis Ginsburg

Glossary

Ambiguous loss – A loss that occurs without closure or clear understanding, as defined by the groundbreaking researcher Dr. Pauline Boss.

Anticipatory grief – Feelings of loss and dread that family members experience when they imagine what life will be like upon the death of a loved one.

Bereavement – The emotional state following the death of a close relation or friend.

Complicated grief – For some people, feelings of loss are debilitating and don't improve even after time passes. This is known as complicated grief (sometimes called persistent complex bereavement disorder). In complicated grief, painful emotions are so long-lasting and severe that you have trouble recovering from the loss and resuming your own life.

Disenfranchised grief – Grief that is not usually openly acknowledged, socially accepted or publically mourned, as defined by gerontology professor Dr. Ken Doka.

Post-traumatic growth – "Positive change experienced as a result of the struggle with a major life crisis or a traumatic event, or this idea that humans can be changed by their encounters with life challenges, sometimes in radically positive ways." Source: Posttraumatic Growth Research Group, University of North Carolina at Charlotte

Traumatic grief – A pathological response to a loss of a significant other that is distinct from depression, anxiety and post-traumatic stress disorder. Traumatic grief centers on two components: the separation distress of losing an attachment figure, and the traumatic distress of adjusting to life without that figure.

Dedication

This work is dedicated to the thousands of families who have shared their time, energy, and resources to advancing AFTD's mission – bringing hope for a world with compassionate care, effective support, and a future free of this disease. We owe special gratitude to the care partners, family members, and persons diagnosed who lent their stories and their voices to this effort.

Lori Ruhlman and Rachel Hadas kindly allowed us to reprint their poems here. Rachel's poem "Wiggle Room" was included in STRANGE RELATION (Paul Dry Books, 2011), a moving account of losing her husband George to FTD. Ms. Hadas further reflects on grief and her family's journey in additional works THE GOLDEN ROAD (2012) and QUESTIONS IN THE VESTIBULE (2016).

Diana Winoker, Cindy Odell, and Teresa Webb -- advocates living with FTD -- agreed to share their own reflections on grief with us for attribution. Diana's were adapted from a 2012 Forbes article, "*The Disease That Stole My Career...*" Cindy's were adapted from an AFTD resource she authored, "*Coping with FTD.*"

Last but not least, Elaine Rose contributed much of the writing for this resource. In addition to this work, Elaine has been a long-time AFTD volunteer who brought her own experiences with FTD to this task. We thank her for her work and her ongoing commitment to AFTD's mission.

AFTD
The Association for
Frontotemporal Degeneration
FIND HELP·SHARE HOPE

My Notes

My Notes

My Notes

2700 Horizon Drive, Suite 120
King of Prussia, PA 19406
267.514.7221 - Office, 866.507.7222 - HelpLine
www.theaftd.org