

Perspectives on Care & Support

Chuck Anastasia:
Spouse & care partner

Our family - 2012:
Starting the diagnostic
journey



Thank you. I'm here to honor my late wife, VJ, and to help others coping with FTD because I'm thankful for the families who shared their experience, which made our journey easier. I'm going to use notes because I could talk all day and we don't have time for that. Your FTD experience may be different from ours. I'm going to share a few snapshots from VJ's 7 year FTD journey, to convey my vision of Hope.

Summer
2013:
Diagnosis:
FTD –
probable
Cortical Basal
Syndrome
(atypical)



Our daughter, Emily finished college when VJ was diagnosed in 2013. I did a lot of research and took a free online “Living with Dementia” course offered by Johns Hopkins University that introduced me to person centered care which respects each patient as a unique individual.

We developed a 5 point care plan to:

1. Maintain routine,
2. Exercise as much as practical,
3. Eat healthy
4. Stay socially integrated & engaged
5. Manage symptoms with medications

This guided our decision making to maintain the best possible quality of life.

2014:
Enjoying
simple things
with a good
friend



This is VJ's loyal friend who visited often. VJ spent mornings at a Sr. center for an exercise program. I hired a home companion so she wouldn't be alone for hours when I was working. VJ started having urinary accidents, which ended her days at the Sr. center, because they require independence. She enrolled in an adult day program. I enlisted additional care providers at the early stages when was easier for VJ to accept assistance from others. This allowed me to take needed breaks from caregiving to re-charge.

August 2017:
Our
daughter's
wedding



Our daughters wedding was the highlight of 2017. We also recorded the VJ & Chuck awareness video that is available on the AFTD website. Please raise your hand if you have seen it. We lived in the same house for 34 years, but VJ was having trouble getting up and down the stairs. We sold our house and moved to a one-level home. Emily and her husband helped us move. Emily took VJ for the weekend while my son-in-law and I packed with the movers and set up the new place so it was ready when they returned. The move was smooth, and VJ adapted well to our new place for a time.

Nov 2018:
Sisters with
Oscar at
Steere House



In 2018, VJ was more agitated. She started pushing and shoving and she slapped her home companion. I worried that someone would get hurt, so I visited facilities and put her on waiting lists at skilled nursing homes. She fell several times. She was not injured, but I had to call rescue because I could not get her up. I was not sleeping enough and was becoming exhausted. When Steere house had an opening, I was given 24 hours to take the room or it would go to the next family. The day of admission, I cried, "What have I done?" but this was followed by a sense of relief, like a weight was lifted off me.

Dec 2018:
A new
grandson



I visited VJ at Steere house every day but her decline accelerated. The medical team made changes to her meds, and her agitation went out of control. They said it takes time to balance medications, but I met with their social workers, and advocated persistently when VJ's needs weren't being met. Her palliative care nurse recommended hospice, which provided a higher level of care. We also had uplifting experiences in the nursing home. Our grandson, Miles was born December 14th, 6 days before VJ's birthday. This is Miles with VJ celebrating her birthday. It was her best day in the nursing home. By the end of January, she was sleeping more and eating and drinking less. I asked our priest to anoint her.

Feb 2019:
1 week before
journey's end



VJ was peaceful at the end, but had to be sedated to manage her agitation. Her hospice team tried backing off the meds, to find a balance where she would be comfortable, and awake enough to eat and drink, but it just did not work. Five days before she died, I brought a chocolate milk shake from her favorite ice cream shop. She woke up enough to drink most of it. After that she took a small amounts of food and drink but not enough to sustain her. On the morning of February 13, the charge nurse called, telling me she was so sorry that VJ passed. I rushed to Steere House and was met by the hospice chaplain. I had a few minutes alone with her before her sister and our priest arrived. We prayed, saddened by our loss, but relieved that her journey was done.

Brain Donation: VJ's final generous act



MASSACHUSETTS
GENERAL HOSPITAL



BRAIN DONOR CARD

Valerie J. Anastasia

Name of Donor

In accordance with the General Laws of Massachusetts, I have indicated my wish to donate my brain upon death for research to advance the understanding, diagnosis, and treatment of brain disorders. I request that those present at my death contact:

MGH Brain Bank

Massachusetts General Hospital

617-726-1728 or 617-726-2000 and page Beeper #21300 (Neuropathology)

Valerie J. Anastasia 4/20/16

Signature of Donor

Date

Charles Anastasia

Name of Next of Kin or Legal Guardian

401 954 6057

Next of Kin Tel. #

This is VJ's brain donor card and my vision of Hope. VJ enrolled in a study at Mass General's FTD clinic in 2016. They did brain scans, and neuro-psych testing for 3 years. I wanted VJ to enroll in the brain donation program, but I didn't want to frighten her. I was reluctant to give her the consent forms but her reaction was positive. She said, "Yes, I'll donate my brain, it is important for the future and for our kids".

I'll end by comparing optimism with the power of hope, because brain donations give us hope.

Optimism is when you look out the window and you can see the storm clearing. A hint of bright sky looks good and you feel things will get better. Hope is when you look out the window and there is nothing but ugly black clouds swirling as far as they eye can see. It doesn't look good out there, but hope chooses to go beyond the evidence and create new possibilities based on vision and courage that become contagious allowing people to engage in heroic actions and find strength we didn't know we had, to do things we didn't think were possible. That is the power of hope.

Thank-you!

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VJ's journey lasted 7 years from the time something was obviously wrong and 6 years from diagnosis. She was on hospice within a month of admission to skilled nursing care. She spent 3 months and 5 days at the skilled care facility before she passed. I consider it a blessing that she was able to stay at home as long as she did.

Looking back, I think she may have benefited from hospice care sooner, but I don't beat myself up over that because hindsight is 20/20. I'm confident I did everything I could for her.

We set a goal to maintain the best possible quality of life for as long as possible, and I feel like we were successful at that.

I don't have any regrets.