# Ramblings; An FTD Journey for orchestra 

 "Frontotemporal Degeneration"

By
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Grace Episcopal Church, Newton, MA
The New Philharmonia Orchestra
Jorge Soto, Principal Conductor

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# Ramblings <br> an FTD "Frontotemporal Degeneration" Journey <br> for Orchestra <br> in 4 movements <br> In memory of Karen Zander, RN,BSN,MSN,PHD,CMAC,FAAN. 

Dedicated to

- Katie Brandt, \& Brad Dickerson who continue to help those who suffer and also to search for a cure
- All those who have made and those who continue to make "the journey"
- Jonathan Bass who recorded the original piano version and whose support gave me the inspiration to continue to compose
-David Stevens, my theory teacher, whose original guidance led me to write the piano piece.
I. Discovery - Andante (kind of)
II. Descent into Loss and Uncertainty - con fuoco - mostly just confusion
III. Ogni vita ha bisogno di un piccolo scherzo (every life needs a little joke) - Scherzo
IV. Disappearance into Death - Andante, Grave, Con fuoco - just plain bad stuff

This piece in four movements attempts to show the emotions associated with the FTD journey. For most of us it starts out with a vague awareness that something is just not right. It may be as innocuous as repeatedly listening the same song, or as in my wife's case playing up to 50 Words with Friends games. The search may start to indicate what is wrong. On average this can take $3-4$ years as FTD is frequently misdiagnosed as other mental health issues Many medical professionals have little awareness of this disease and may be confused by the fact that dementia in a 30 year old is not a normal consideration. The first movement portrays this part of the journey, ending in the diagnosis, which is a death sentence. Karen's theme is first introduced in the opening bars of the piece. The 2nd therem, Augmented 6 chords represents the disease.

The second movement portrays the middle part of the journey as the FTD sufferer continues to decline. This period can be particularly difficult for the partner/caregiver as their loved one engages in strange or illogical behaviors. Things can go from crazy to normal and back.

I put the third, scherzo, movement in as an after thought. This journey would be impossible without some humor... so here it is. However, even here, the unresolved German Aug 6 chord and Karen's theme show up. In the midst of joy, there is still sadness

The final, somewhat calmer movement speaks to the final stages of the disease. The patient becomes nonverbal, may lose the ability to walk or eat without help. Finally, at the end, as the brain continues to disintegrate, it loses its ability to run the body and death takes over. Karen's theme reappears, after the death knell,, to signify that love conquers all and that in the end, it is the spirit of the person that remains and the memory of the disease fades

You will experience many long silences which may make you uncomfortable or anxious. That has been done on purpose.

> Words that describe this piece:
> Anger, Confusion, Frustration, and Sadness.

## What is FTD?

FTD is also frequently referred to as frontotemporal dementia, frontotemporal lobar degeneration (FTLD), or Pick's disease.

FTD is the most common form of dementia for people under age 60.
It represents a group of brain disorders caused by degeneration of the frontal and/or temporal lobes of the brain. Each disorder can be identified according to the symptoms that appear first and most prominently, whether in behavior (behavioral variant FTD), changes in the ability to speak and understand language (primary progressive aphasia) or in movement (corticobasal syndrome, progressive supranuclear palsy). The clinical syndrome where FTD and ALS occur in the same person is referred to as ALSFrontotemporal Spectrum Disorder (ALS-FTSD).

Although age of onset ranges from 21 to 80, the majority of FTD cases occur between 45 and 64 . Therefore, FTD has a substantially greater impact on work, family, and the economic burden faced by families than Alzheimer's. It is less common and still far less known. FTD's estimated U.S. prevalence is around 60,000 cases and many in the medical community remain unfamiliar with it. FTD is frequently misdiagnosed as Alzheimer's, depression, Parkinson's disease, or a psychiatric condition. On average, it currently takes 3.6 years to get an accurate diagnosis.

The progression of symptoms - in behavior, language, and/or movement - varies by individual, but FTD brings an inevitable decline in functioning. The length of progression varies from 2 to over 20 years.

As the disease progresses, those affected may experience increasing difficulty in planning or organizing activities. They may behave inappropriately in social or work settings, and have trouble communicating with others, or relating to loved ones.

Over time, FTD predisposes an individual to physical complications such as pneumonia, infection, or injury from a fall. Average life expectancy is 7 to 13 years after the start of symptoms.

There is no cure for FTD. Unfortunately, no current treatments slow or stop the progression of the disease.

## Who was Karen Zander?

Karen Zander, RN, MS, CMAC, FAAN, PhD Hon. was my one true love and wife of nearly 44 years, mother of my two wonderful girls and was the prior owner and one of the original founders of The Center for Case Management. Her pioneering work with clinical case management and The CareMap(r) systems began at The New England Medical Center Hospital in Boston and is internationally recognized. She authored many articles and authored and co-authored many books. Her work touched hundreds of hospitals and had a major impact on nursing as it is currently practiced.

Even after becoming paralyzed in 2007 (unrelated to dementia), she continued to travel the world with her family, make plenty of time for friends, and worked passionately in healthcare until selling her company in 2018. The beauty and joy that this world had to offer was never lost on her and she never took it for granted. She also understood the pains of this life for both humans and animals and made charitable giving a large priority. Her commitment to giving continues posthumously, as her brain has been donated to Massachusetts General Hospital Dept. of Neurology, FTD to further the study of this terrible disease in search for a cure. It will be used in many studies worldwide.

She felt deeply connected to the people and the world around her and often said that it was her relationships with others that made her happiest. If you knew Karen, you could truly feel this. She gave everyone the love and acceptance they might need.

Karen was diagnosed with FTD in March of 2018 and died from its insidious effects on Aug 30, 2020.
"Ramblings, an FTD Journey" is my way of handling the grief this disease created for me as it does so for many others. It is, at times, an angry piece, at times disjoint and strange. Make it yours as you can.

# Performance Notes 

## Instrumentation

2 Flutes (1 doubling Piccolo)<br>2 Oboes<br>2 Clarinets in Bb<br>2 Bassoons<br>4 Horns in F<br>2 Trumpets in C<br>2 Trombones

1 Bass Trombone<br>1 Tuba<br>1 Timpani<br>1 Percussion (Large Gong, triangle, bass drum, crash cymbals, Chimes ( 1 in $\mathrm{F} \#$ ))<br>Strings (Violin,Viola,Cello, 2 basses)

## Performance Notes

Words that describe this piece: Anger, Confusion, Frustration, and Sadness. All Parts: only page turns they have are after I, II. There are two musical themes in the piece. The first, in bars 1-4, played by the oboe in mvt I represents the person diagnosed with FTD, in my case, my wife Karen. You will find this theme sprinkled throughout. Snippets of it appear at the end of each movement to indicate, that in the end, the memory of the patient is what remains. There are a number of delayed entrances, these are important to bring out.

Tbe second theme, introduced in bar 5 by the timpani and viola, shows up in two forms, a French Augmented 6 in C and German augmented 6, also in C. Generally the sequence will be French up and German Down. This chord represents the disease itself. In general usage this chord resolves to the dominant, but as FTD allows little resolution, so this chord does not resolve in the piece, leaving one hanging.

## MVT I

The oboe introduction should not be conducted and played freely. The time signature is a suggestion only but clearly this is the introduction of the first important theme.

There is also a rhythmic theme that appears in the first movement as what seems to be a 5:4. However, if you look closely, you will see that the notes in the bass should be played as though they are written in $2: 2$ time with a constant meter. The melodic theme, is the 6 note series of the two augmented 6 ths which takes 5 measures to complete a full cycle. On top of this is the $5: 4$, first with the theme in 5 , then the base in 5 . This should create 6 against 5 against 4 against 2 against and if you don't get dizzy, it's not correct. The result of all this, is to create an off balance effect which one experiences during the 2-3 years it can take to get a diagnosis;

There are a number of empty measures. these are for tension. Also note that you will find a number of notes that appear to be mistakes. They are not. FTD creates cognitive decision making issues, these mistakes represent those issues.

## MVT II.

At mm12 The forth beat is delayed by $1 / 16$ ths on purpose to create and out of rhythm feeling.
At mm 31 the horns have a Bmaj 7 but the bass trombone has a B-flat. This just sounds wrong mixing a b-flat aug 7 th with the bfmajor. It is supposed to sound wrong.
72-73 - this represents everything falling apart
At mm 73 - bass drum just needs to be a little behind the beat

## MVT III

This is basically to lighten the mood. the next movement starts at the end of this movement.

## MVT IV

At the end of the last movement, there is an obvious reference to the Moonlight Sonata which was the first piece of music Karen heard me play. I continued to play it for her up to the end,. There is also a reference to the first Prelude from the Well-tempered clavier. I put it in as a remembrance to the time Karen played a piece which i recognized but realized there was something wrong with it. It turned out that she had transposed it up a fifth, something she did not know how to do. That was FTD.

The build up to the fortississimo at mm 101 should start at 87 and build subtly so that the audience is barely aware of the build up. The oboe at the end doesn't need to be conducted. just cut off the chimes and bring in the timpani sometime after the final $G$ is sounded in the oboe. mm 101-105 are tied in the winds/brass, I just want a continuous sound, players should breath when they need, just at different times.
Wait a really a long time at the end. You may want to consider asking the violins/violas to keep their instruments up after their last note as to not distract from the calming sounds.

Approximate playing times:
mvt I - $2^{\prime} 22^{\prime \prime}$
mvt II - $2^{\prime} 40^{\prime \prime}$
mvt III - $0^{\prime} 47^{\prime \prime}$
mvt IV - $4^{\prime} 39^{\prime \prime}$

17.2.188 (FINAL)






2. II. Descent into Loss and Uncertainty


*The delayed 4th note should sound like a late entrance





17.2.188 (FINAL)


17.2.188 (FINAL)


71 Larghetto $d=60$


17.2.188 (FINAL)


3. III. Ogni vita ha bisogno di un piccolo scherzo (every life needs a little joke)






4. IV. Disappearance into Death

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17.2.188 (FINAL)


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17.2.188 (FINAL)







