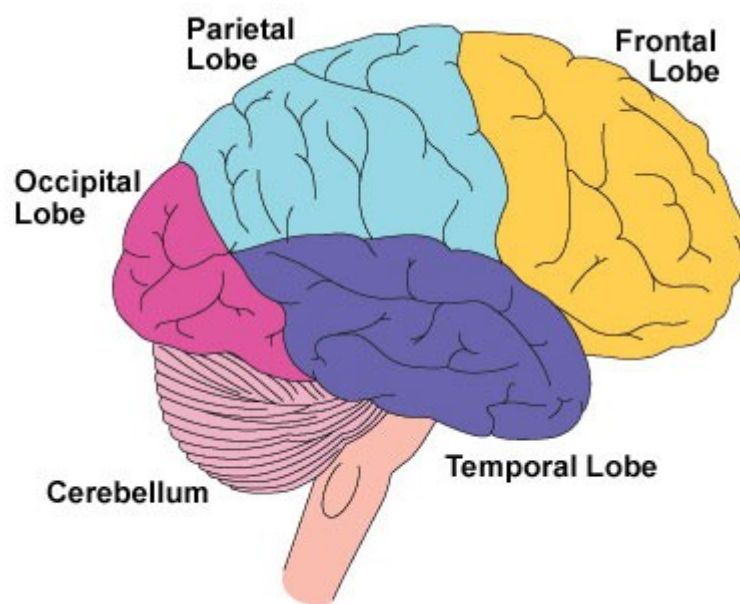


# Frontotemporal Dementia



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## Table of Contents

Introduction.....	3
Frontotemporal Dementia Basics.....	3
Research for a Cure.....	5
Research Around the World.....	7
Dementia: A World Problem.....	10
World Dementia Picture.....	12
Personal Experiences.....	13
Functional Part.....	13
Self-Evaluation.....	15
Works Cited.....	18

## **Introduction**

Frontotemporal Dementia, or FTD is a many-sided topic. Caregivers often see a person change personality and behavior, but still be perfectly healthy before their eyes. The hardest part isn't seeing the person change, the hardest part is remembering who the person used to be, energetic, positive, or vibrant. FTD is under the umbrella of dementia diseases and is a very specific type of dementia. The main reason that this type of dementia was chosen about for this project was because I have an aunt who has FTD. I wanted to learn more about the disease that she has. Neuroscience and dementia also fascinates me so doing research on FTD would hold my interest. FTD is the atrophy of the frontal and temporal lobes and a person with FTD usually sees great changes in behavior, language, and personality. There has no cure been found, but research is being done for FTD and for dementia in general all over the world. Dementia is truly a world problem with all countries affected by it and it is only expected to get worse as time goes on. Dementia affects everyone because it is not necessarily genetic and any close one could get it.

## **Frontotemporal Dementia Basics**

Frontotemporal dementia, frontotemporal lobar degeneration, otherwise known as FTD, are the names for a few diseases that are

characterized by the dying or shrinking of the frontal and temporal lobes of the brain. These lobes which are located in the front of the brain are usually the parts of the brain that control personality, language and speech. So because of that, the symptoms of FTD diseases differ depending on which part or lobe of the brain is experiencing the atrophy.

The most common ways that FTD expresses itself in the patient are in personality changes or language impairments and sometimes both. Usually as the disease progresses the two types of symptom groups blend into each other. If one has the personality and social skills changes, eventually one will get the language problems and those with language problems eventually have the personality changes as well. The two sides of the disease meld into one as the disease progresses and more of the frontal and temporal lobes degenerate.

If one has the personality changes as the most prominent symptom of FTD, a patient's personality is usually altered severely. The broadest change in a patient is differences and changes in a person's personality in general. This includes acting in ways that do not fit the situation and that can be very inappropriate. Another common symptom is the lack of being able to feel for other people, or having empathy. Often when a person with FTD hears something very sad or something tragic happens to someone close to them, they can't feel any sadness, happiness, or any true feelings over the matter.

However, sometimes they may feel the wrong emotion over the matter. They do not realize they are supposed to feel something for the situation and often say or do something inappropriate (1). This would be a very hard disease for anyone in the world to deal with if their family member had it. To have to watch as dear ones decline and become someone who is not who they once were would be heart-wrenching. This feeling of hopelessness when a family member has this disease affects everyone in the same way, no matter of where someone lives in a world. If someone's mother has a FTD in the middle of a poverty-stricken town in Africa or in an up-scale apartment in downtown New York the feelings for the family are still the same. No matter of money, class, country, or situation in life can affect the disease or make it any easier for the one affected or their family to bare. That is often how it is with devastating diseases with no cure, the field is level for all people throughout the entire world.

### **Research for a Cure**

Looking into epidemiology has been significant in finding the the forecast for what a patient's disease of FTD will look like. "Epidemiology is the branch of medicine dealing with the incidence and prevalence of disease in large populations and with detection of the source and cause of epidemics and infectious disease(2)." Epidemiologic studies can help in

finding the origin of a disease in a person and can, in turn, contribute to curing the disease when the origin is known. So when FTD is studied in large groups of people, basic trends can be found. For example, when the Tau protein is found in patients some studies show that those patients decline faster, but some studies show that when the Tau protein is not found the patients decline faster. So the continuance of studying trends in large groups of people needs to be done to find the real trends and to find the pathology of the disease (3). Basic research into dementia in general assists in the long-run with the finding of a cure for FTD, but in the short-run the research is being done for dementia in general and doesn't affect FTD patients.. This is significant on an international level because there are thousands of people that suffer from a whole array of dementia type diseases. Because there has not been a cure found for the most popular one, the other diseases get left in the background to be not specifically researched. This is a justified practice, however, and does affect on the local level in Minnesota. The percentage of people affected by dementia has a majority that are affected by Alzheimer's so while there are still people that have FTD, it does make sense to research the disease that affects the most people and then it will assist in other dementia research down the road to help even more people.

## **Research Around the World**

With many different research agencies and studies going on and no definitive cure, studies can come out with different results, but recently researchers at the Mayo Clinic in Florida have found what appears to be the key gene that signifies that FTD and another disease, Amyotrophic Lateral Sclerosis, are present. The significance of finding the gene implicated in FTD is significant because future research has more of a path and a starting point where to direct research from. There has not been a cure found, but it provides a good starting point (4).

The major research institutes in the United States do research that includes research on FTD and other neurological diseases. The National Institute of Neurological Disorders and Stroke performs FTD research and there is also research being done in laboratories of the National Institute of Health. Current research on FTD is also funded by people and institutes that give grants to places of research and major medical centers (5). The fact that specific research on FTD is being done at institutes across America proves that FTD and dementia research is significant to America's interests. Considering America's and the world's aging population, people across America and across the world are interested and vested in seeing the progress made towards a cure or effective treatments for dementia.

There are no cures for FTD that actually reverse the progress of FTD

or grow brain back or stop its progress. There are only treatments that can help to either slow the brain degeneration in the frontal and temporal lobes or there are treatments that try to affect behavior positively. These treatments attempt to help the patient to be able to control their impulsive ways of speaking and behavior better. In other words the treatments that are in hospitals currently only try to cope with the symptoms, not change the course of the disease (6).

Dementia is becoming a more and more significant problem as the world's population is significantly aging. The percentage of the population that is old or is getting older is greater than it has ever been before. With that, the amount of people with all types of dementia will increase. So there will be more people getting all types of dementias including FTD. The disease is increasing in number of patients and therefore the need for finding effective FTD treatments and a cure. America has an aging population along with a lot of the world, and the fact that there is no cure or effective treatments is significant to us all. For the aging population who is aware that they could get dementia, it would be very hard to know that dementia percentages are only increasing and that there is really no way to keep yourself from getting the disease or help yourself if you get the disease.

There is a yearly conference held in different places around the world so



that experts, caregivers, researchers, doctors, and other professionals can meet and share ideas and thoughts on their personal research and findings. As more and more information is found out about FTD in the recent years the conferences are becoming larger and larger. As progress is made on finding out the biology of FTD, it can help in finding treatments for the FTD and dementia diseases. This year the conference is being held in Vancouver, Canada and the expectation is that there will be more than six hundred professionals coming from countries all over the world. The significance of this problem of FTD has brought international attention for many years. The first conference to discuss and share ideas was held in Lund, Sweden in 1986. The conference has steadily grown since then (7). The international attention, while small compared to some diseases, is significant because many countries in the world do have researchers looking into this disease because they know that many people are affected by it. On a local city level in Minnesota this is significant too. There are not professional researchers on FTD in every city because FTD is not a common enough disease for that, but because it is a big enough international problem, the levels all the way to the local level can be affected. The research done at top institutions can eventually trickle down to the FTD patient in one's hometown. Because this disease is so tragic to watch, I do wish that there would be more research being done on FTD.

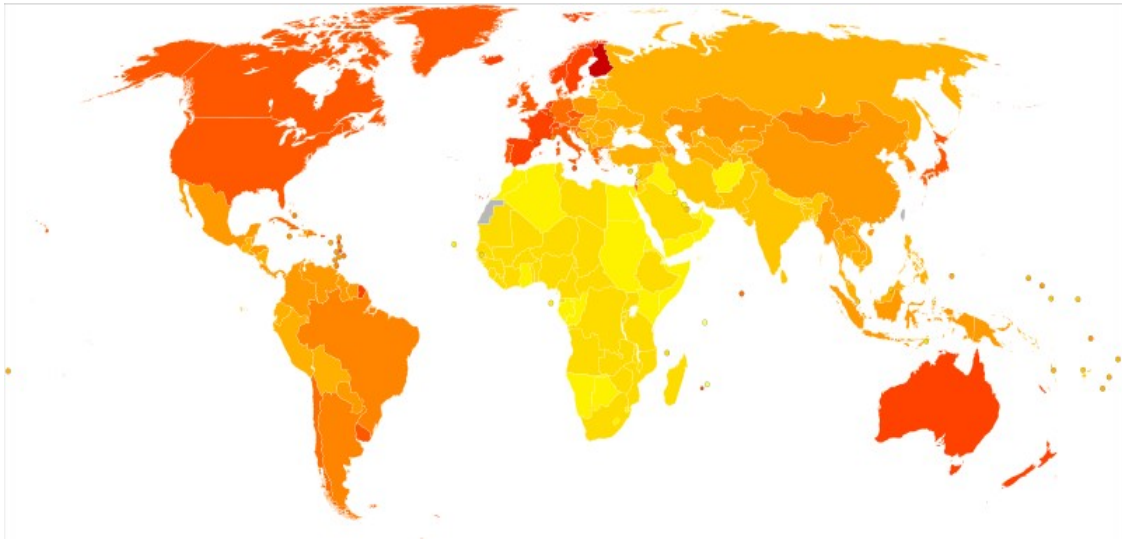
However, I do understand that bigger medical problems get the largest amount of research because they affect more people.

### **Dementia: A World Problem**

This is a significant problem in the world because of the increasing number of people who are aging and will potentially develop this type of dementia. All dementia diseases are becoming more significant and problematic in the world scientific discussions because of the increase in the number of aging people.

All over the world countries are affected by dementia and inside the umbrella of dementia is FTD. According to the map (see page 12), the darkest red colored countries are the countries with the greatest amount of people with Alzheimer and other dementias per 100,000 inhabitants and the lightest yellow colors have the least amount of people per 100,000 that have Alzheimer's disease and other dementias. Finland ranks number one as the country with the most people that die with dementia per 100,000 followed by Iceland, then the United States (8). In Finland, the rate is 34.9 die per 100,000 and the rate in Iceland and the United States is 25.1 and 24.8 respectively (9). There are many reasons for countries having high rates of dementia. On the one hand, Finland might have more people that die from dementia than other countries, but on the other hand, being a

developed country the modes of diagnosing Alzheimer's and dementia may be better than in less developed countries so that may account for the extreme differences in the dementia levels between developed and undeveloped countries. I don't believe that the modes of diagnosing being better in developed countries skew the data that much so I think that these numbers are probably for the most part accurate, at least in which countries have the most dementia and which countries have the least. With FTD being a part of the general studies on dementia, when research is done, the results are generally given in terms of dementia in general and not specific for FTD. So for this reason, the data here is about dementia in general. Some studies have found that dementia does not seem to be as prevalent as in the developing world, but the 10/66 research group has seen that increases in the next years in dementia in developing countries will be much steeper than that of developed countries, the percentages being 332% versus 103% respectively (10). That is a very interesting statistic for me. It is amazing that the dementia forecast can be so skewed to developing countries getting such a larger percentage than developed countries. It makes one wonder what the real reasons are behind it, or if the forecast is even true. However, some risk factors for dementia are more common in developing countries though, like low education, anemia, and more people in developing countries don't have as consistent access to food (11) .



## **Personal Experience**

Two years ago an aunt of mine was diagnosed with Frontotemporal Dementia. Her family and extended family all noticed many changes in her personality and social skills. At first everyone thought she was just changing, then the doctors thought she was depressed, and eventually the doctors took brain scans and after many tests and consideration, she was diagnosed with FTD. It was very hard to accept the fact that essentially my aunt's brain was dying in her frontal and temporal lobes. She is essentially becoming a different person. Her brain, the part that controls who she is, is literally degenerating. This matter of FTD and the number of people getting dementia increasing because the the population is aging is important to me because it affects my life, my family, and the quality of the world's future because I know first-hand the challenges that the families of those affected by FTD go through. They are not easy for anyone and I would hope that less and less people have to go through it, as more research and progress is being done.

## **Functional Part**

For the functional part of the project I decided on creating a poster. From the beginning I knew that I wanted to incorporate a large outline of a brain. I thought either to fill the large outline of the brain on the poster with words that relate to dementia or photographs. I liked the idea of pictures

slightly better because they can communicate to all people without a common language. However, when this project is focused on FTD and dementia, the selection of good, communicative pictures was not very plentiful. There were pictures of elders that I could find, but it does not present the feeling of the disease or the disease well. So I decided to make the brain a "wordle" or word bubble. I wrote the main words that appeared in my paper and the main words that relate to FTD and dementia in general in a list. The most important words, I decided, would be the largest size and the other words would be written in size according to importance. Then the words were written all over the brain outline in many directions and sizes. I picked three colors that were bold and looked good together and separated the words into three size groups and colored the words in accordingly. The quote on the poster, "seeing people change isn't what's hard, what's hard is remembering who they used to be" was very fitting for FTD. The disease changes a person's personality and how they relate to their close ones. The caregivers and family find it hard to see the person they are caring for and know how different and vibrant the person formerly was. The poster is effective in communicating to the local area, or the opisto, the main ideas and Effects of FTD because it draws the eye to the main words and they are easily and quickly read. The poster being in the shape of a brain makes people see right away that the poster has something to do with a brain. If a

person is interested they can read the smaller words and learn even more about the effects and main topics in dementia and FTD.

### **Self Evaluation**

In the beginning of international studies class I decided I was going to work on this project by myself. I decided this because in general I do not like doing group projects or writing papers together with another person. Trying to find a topic for the paper was very difficult for me. I wanted to do something that was important to me, that I was passionate about, and that was not a topic that gets chosen all of the time. I am very passionate about the brain and dementia diseases and I am considering studying them in the future so I decided that some dementia disease or Alzheimer's disease would be a good topic for me because I am so interested in the brain so it would sustain my attention the whole time. So I decided to write about Alzheimer's disease. I got a few weeks into research and writing when I decided it would be more interesting for me if I narrowed my focus from dementia in general and Alzheimer's disease to FTD. My aunt has FTD so that is where I knew about the disease and I wanted to learn everything about her situation so that I can understand her better and maybe help her family understand her situation better.

The weeks went by and I kept with the FTD and did a lot of research

on it in many different areas. With FTD being a type of dementia that goes under the general umbrella of dementia, there is not much information or data on FTD specifically internationally. So for the part where I researched international and national significance, I used information from dementia in general.

I had a very good feeling working on this project when I was finding fascinating articles on FTD and about specific cases of patients with FTD. Sometimes it was hard to actually sit down and write about it when I would rather just read the interesting articles. Also, I learned while doing this project that it is not easy to write a paper under these guidelines on a medical topic. It would have been easier to complete the paper if I had chosen some kind of current event. I had good feelings in this project when I actually was able to write things and my thoughts clearly. I like being able to just have a small piece of information and expand on it and bring it to the four levels and my own experience and not make the paper just full of facts without any analyzation. It was enjoyable to make the poster too. It made me think about FTD from a different perspective.

It was hard to write when I couldn't concentrate. I didn't have a good feeling while doing this project when I was having trouble finding specific information of FTD and not just dementia in general. Writing and keeping up with the journal wasn't always easy either. It was an easy thing to forget at



the end of class time. I did get quite a few journal entries written though. Main things that I learned from completing this maturity test was the complexity of FTD diseases and how many aspects there are to finding cures for specific diseases. Usually more information needs to be found on a broader scale on the umbrella disease in general before specific, smaller diseases can find cures. I learned that I do truly enjoy neuroscience and that the brain is something that truly interests me.

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