



FTD- A Carer's Perspective

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27th May 2022
& 9th August 2023



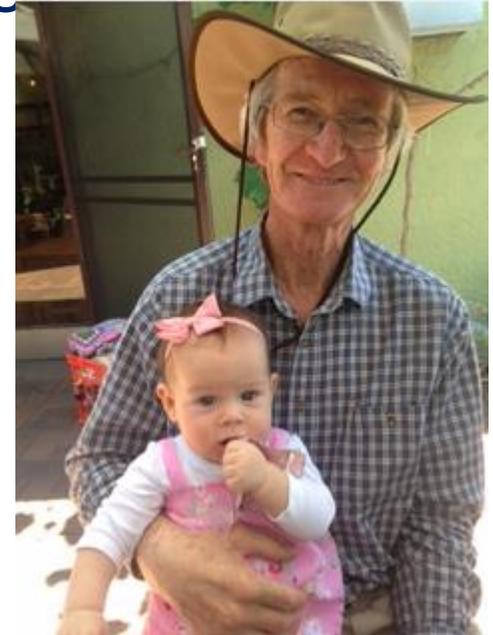
Michael Saladine- Our Journey

- Pre-diagnosis- January 2014



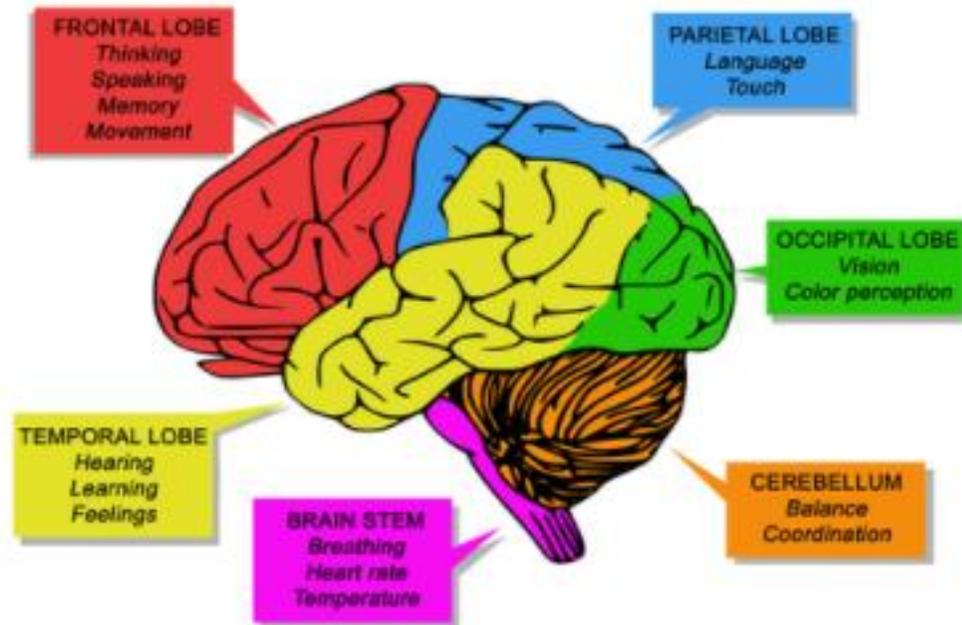
Frontal Temporal Lobe dementia

- Frontal Temporal Lobe dementia-FTD occurs in the Frontal & Temporal lobes of the brain.
- Less common than other forms of dementia (5-10%)
- Significant cause of dementia in young people- ie those under 65yrs.
- Diagnosed between ages 45-65
(Can be younger or older)
- Affects men & women equally.

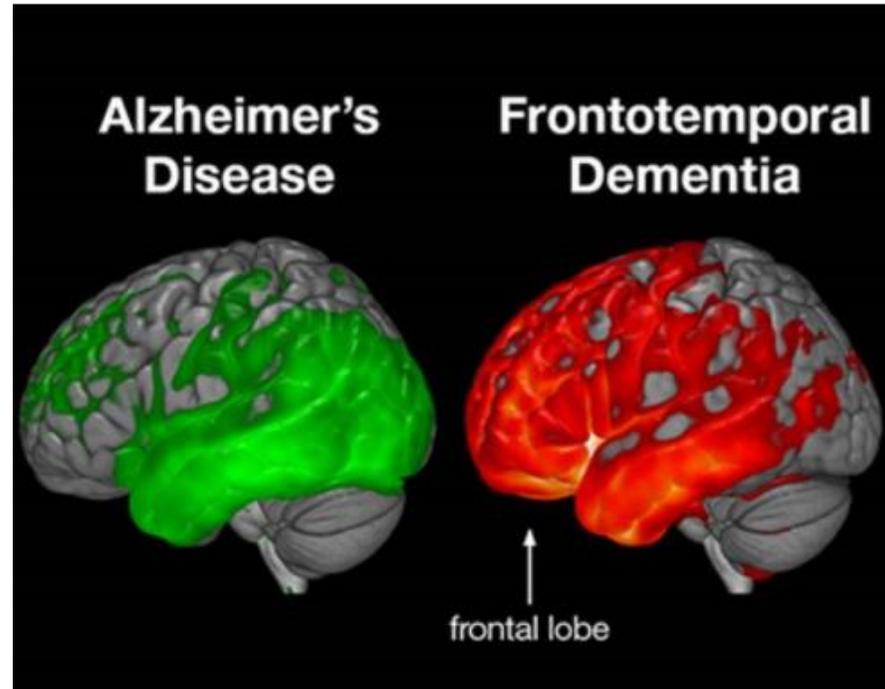


Frontal Temporal Lobe dementia

- Affects the areas of the Frontal & Temporal lobe.
- These are the areas for thinking, speech, feelings etc...



Alzheimers Disease vs FTD



Types of FTD

- 2 main subtypes:
- **Behavioural Variant FTD** or bvFTD
- Primary progressive aphasia or PPA
- PPA split further (Semantic & progressive aphasia)
- Usually affects people in 50's or 60's (younger or older) Can be linked to **MND** (or other conditions).
- A third can be **genetic**



Diagnosis-2016

- Always done by a Neurologist or specialist
- Often not recognised by GP (score well in Mini Mental)
- Huge difficulty in getting diagnosis -6mths
- Other carers state can be up to 6 years+
- GP may think spouse is one with problem.
- ↑ Divorce rate
- MRI required.



Neurologist:

- Changes on brain for MRI (seen by Neurologist not radiologist)
- Classic signs (Neurologist)-
- Does he clock watch?
- Preference for sweet foods?
- Continually use catch phrases? (Blows me away)
- Struggle to find the correct word (Pillowcases/bananas)
- Repetitive movements (Tapping)



Were to from diagnosis:

- Became part of research projects with the Frontier group- Forefront. Testing, access to other Neurologists, Carer's Day's & access to leaders in the world in FTD.
- NDIS (under 65- carer's while I'm at work)
- Speech Pathologist, Dietician, Occupational Therapist etc..



Signs & Symptoms- Behaviours:

- Behave inappropriately ('She's got heaps of tatt's, fat')
- Loss of inhibitions
- Talking to strangers (Barnaby)
- Fixed mood & behaviour (Very fixed in thinking-cutting things up for compost very small)
- Difficulty concentrating (2 minutes jigsaw puzzle)
- Distractibility & impulsiveness (Unable to drive)
- Obsessive or repetitive behaviour (Clothes drying on line, paranoid+++)



More Symptoms:

- Appear selfish- less interested in others
- Lack empathy
- Lack insight (There is nothing wrong with me)
- Decline in self care & personal hygiene (Same clothes day after day)
- Apathetic +++
(Except if I had clothes on the line)



- Changes in eating patterns, craving sweet foods (Packet of Tim Tams), overeating or unusual food preferences. (Hide sweets)



- Food fads- Eat one specific food type (McDonalds soft serve ice-cream. Michael Coffee)
- Increased consumption of wine or cigarettes (Watered down wine)
- Eating very quickly
(What are table manners?)



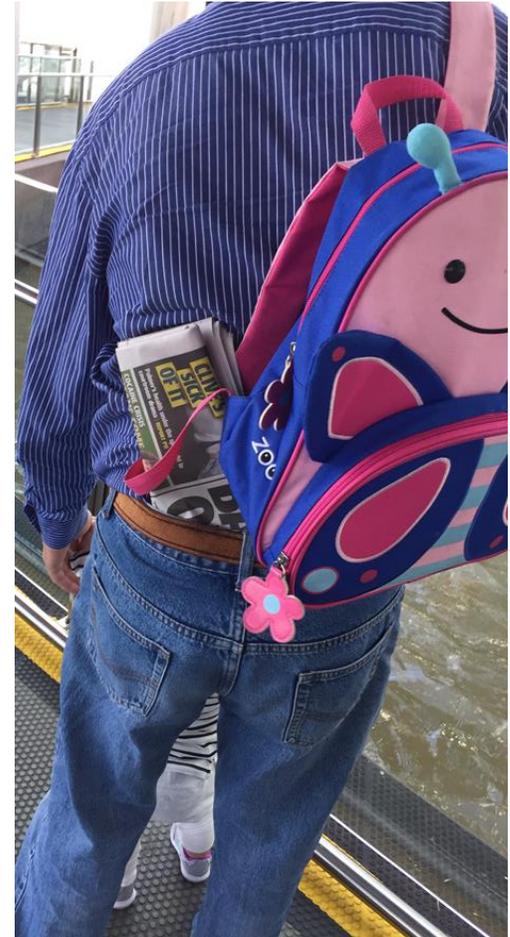
Homemade Muesli-example of behaviours:

- Could only eat muesli in the morning (Rigid thinking)
- Absolute flap if no muesli, couldn't eat toast.
- Would eat all muesli & leave x2 pieces of oatmeal for me (Selfish)
- Couldn't make it himself (Despite recipe-loss of executive thinking)
- Study by Rebeka Ahmed.
(Over eating sweet things & rigid thinking in eating)



Difficulties in behaviours-leading to care

- Behaviours became more difficult to manage
- Hiding/running away on carer's
- Hallucinating (Hunny Buns)
- Suspicious of everyone
(Clothes on the line)
- Poor sleeping (Noises at night)
- Etc.....
- I was exhausted!!!!



Ningana dementia specific unit- Sept 2020

- It would be excellent to have dementia unit for younger adults- none available in country NSW
- Angel when first moved in 😊 (Approx.1 month)
- Behaviours more difficult to manage:
- Alpha Male (Young, fit resident with dementia)
- Escaping (Over the fence, tried to sneak out to races)
- Suspicious of everyone (punching, kicking etc- coffee too expensive!)
- Required 'clinical nurse specialist consultant' reviews- No idea about FTD

Settled: From about November 2021

- Very frail
- Walks with 2 carers
- Not orientated to time & place etc...
- Unable to swallow properly-
(Pureed food, thickened drinks & feed by staff)
- 48kgs- high calorie/high protein diet (Lost 25kgs+)
- Loves watching footy/movies, & sing-a-long.



What to do?



- Continue to deteriorate
- Keep him comfortable
- Continue the nutrition as best as possible
- Try to ensure he is enjoying his life as much as possible. (Loves hand/foot/shoulder massages. Loves having his finger nails painted-beautiful pink colour)
- Keep him interacting & enjoying the things he likes (Movies/footy, sing-a-long etc..)

Passed away
12th June
2022- 65
years old



Questions:

