Caring for LTC Residents with Frontal Dementias… Hopes, Challenges and Strategies

Vicky Willis
Lived Experience Spouse

Dr. Lindy Kilik
Neuropsychologist
Providence Care Hospital and
Queens University

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Goals of this Webinar

- To familiarize the audience with FTD and other Dementias with frontal presentations from the clinical and lived experience perspectives, including:
  - What makes frontal dementias unique
  - Why care-providers need to address the unique aspects of frontal dementias
  - Strategies for caring for someone with a frontal dementia

What most common Dementias that include significant Frontal Pathology?

- Fronto-temporal Dementias (FTDs)
- Vascular Dementia with Frontal Involvement
- Atypical Alzheimer Disease

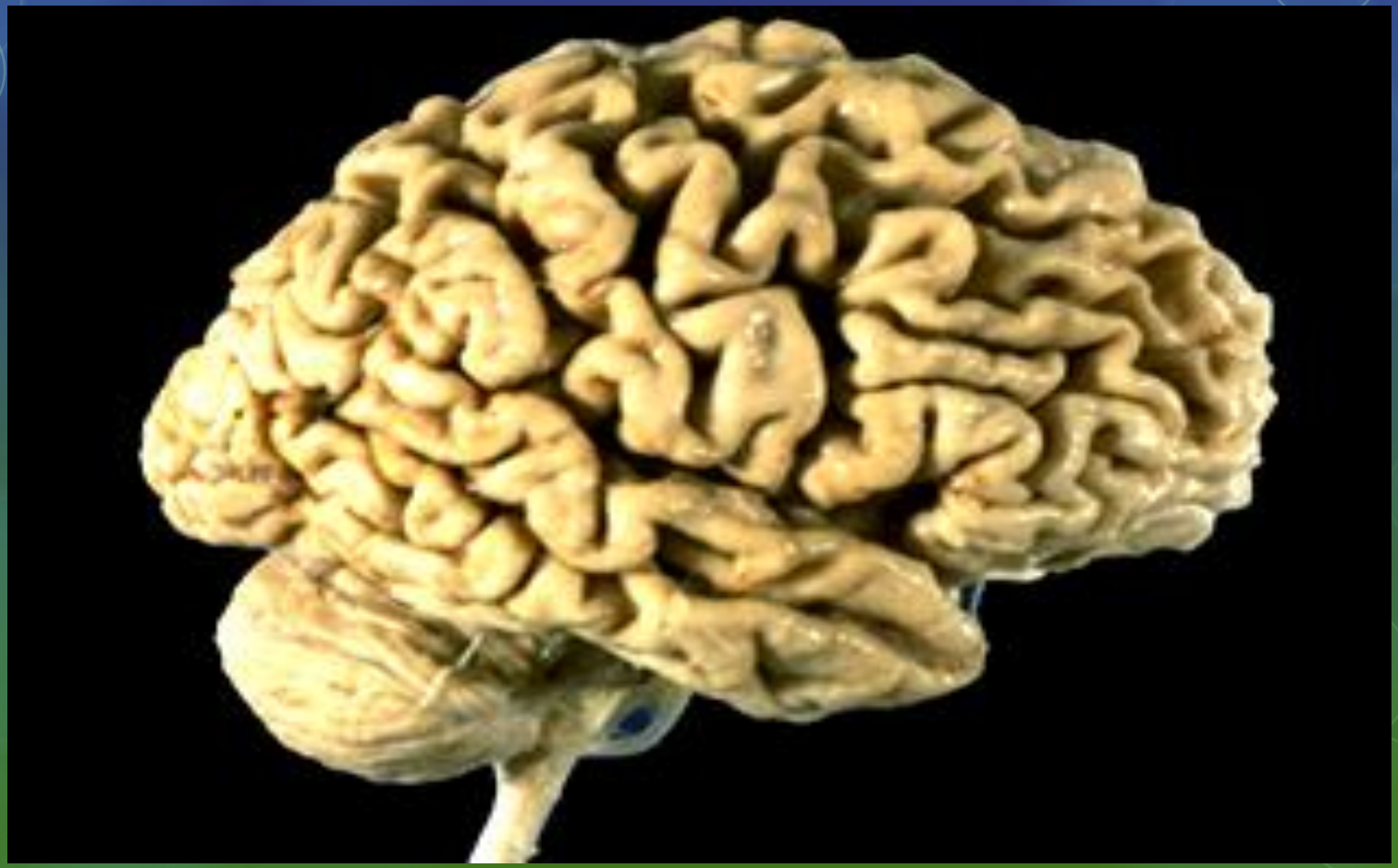
The Fronto-temporal Dementias

- Two main sub-types
  - **Language based** (Primary Progressive Aphasia) divided into two types (Semantic Aphasia and Progressive non-fluent aphasia)
  - **Behavioural Variant** , where behaviour change is the earliest symptom
- The subtypes become more similar in presentation as the disease progresses

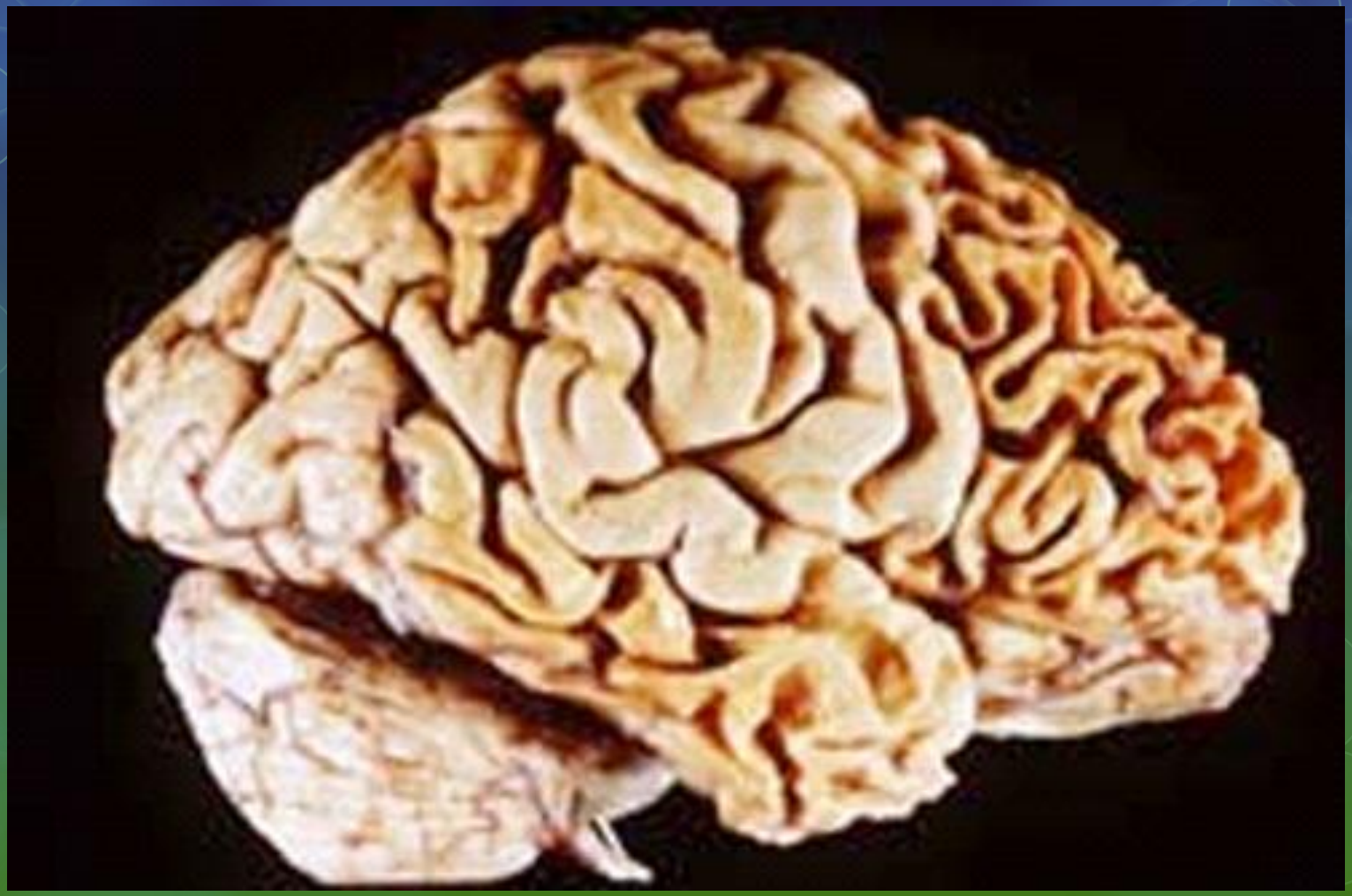
Why is it important to distinguish Frontal Dementias from others?

- **Different presentation** – not always what we expect from "dementia"; resident looks more capable than actually is.
- **Different needs**-related to the specific brain areas affected by the disease; different from more typical Alzheimer Disease
- **Different interventions**-tailor to brain areas affected:
  - You wouldn't use physiotherapy for an injured arm if it was your leg that was injured!

An Alzheimer Brain



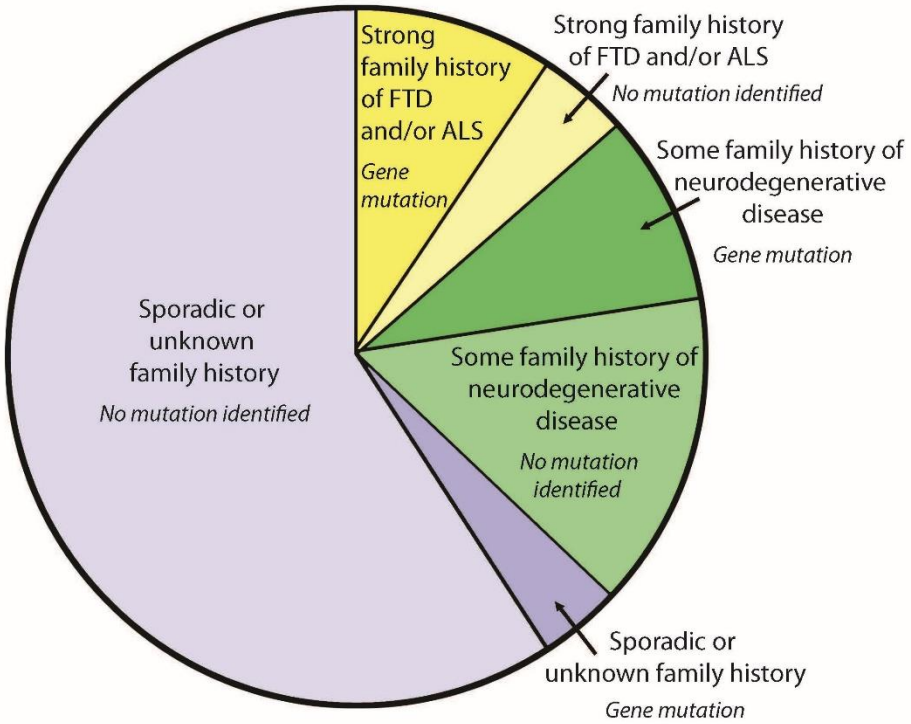
A Fronto-Temporal Brain



FTD Quick-Facts

- FTDs are the 3rd most common type of dementia (A.D.= #1, L.B.D. =#2)
- Represents up to 20% of all dementias
- Age of onset:
  - more often < 65
  - peaks around age 55, but onset can occur from 30 - 75 years of age
- Duration of FTD
  - range = 3 - 17 years
  - average = 8 years

Genetics and FTD



Strong family history of FTD and/or ALS: Accounts for about 10-15% of FTD.
The majority, but not all, can be explained by a mutation in a known FTD gene.

Some family history of neurodegenerative disease: Accounts for about 20-25% of FTD.
Less than half have a mutation in a known FTD gene.

Sporadic or unknown family history: Accounts for about 60% of FTD.
Only a small percentage (less than 10%) have a mutation in a known FTD gene.

Understanding the **impact** of FTD… The importance of **CONTEXT**

Without context, a piece of information is just a dot. It floats in your brain with a lot of other dots and doesn't mean a damn thing. Knowledge is information-in-context ... connecting the dots.

- Michael Ventura

The context of FTD

Cognition in FTD

Common Questions…

- How can this patient have a Dementia, and remember who I am and where his room is?

Cognitive Functioning: areas remaining relatively INTACT

- **MEMORY**
  - can recall much of past and present (I.e., much better than AD patients)
- Orientation (person, time, place)
- Visuospatial abilities
- Normal Intelligence remains

Common Questions…

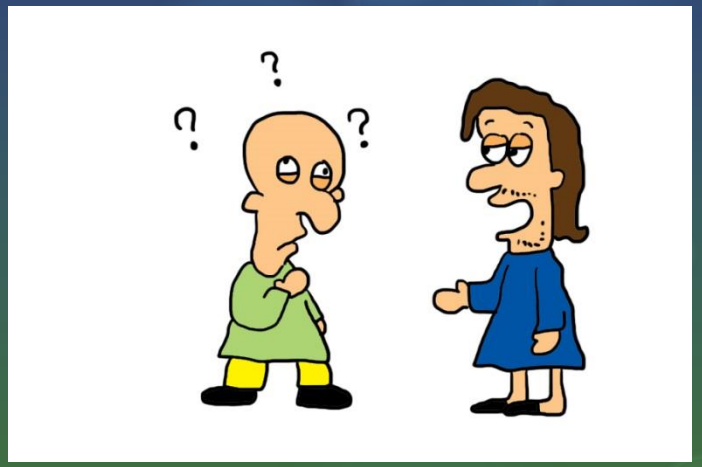
- How can the patient remember so much information but keep asking the same question over and over again to the point of annoyance?

Cognitive Symptoms

- **Attention**
  - Short attention span – "hummingbird phenomenon"
  - mental rigidity, difficulty with set-shifting-leads to getting stuck on something and going over and over it, like a needle stuck in a groove (**Perseveration** of action or speech).
- **Language**: decreased spontaneous speech, word-finding, etc.
- **Abstract reasoning** – concrete thinking, inability to appreciate subtleties such as humour
- **Slowed mental processing**-takes a longer time to make sense of the message, figure out a response and deliver the response
- **Executive Functioning-including insight**

Cognitive Strategies: Communication

- **Verbal strategies**
  - Speak in short, focussed phrases
  - Use the person's name



- **Non-verbal strategies**
  - Speak in a friendly, pleasant tone
  - Smile when you speak
  - Allow for a long processing time where the person may just stare at you without responding – don't get impatient and jump in!

Behavioural Change in FTD

- Common misperceptions of FTD

Behavioural Symptoms…1

- **Disinhibition**-loss of mental "brakes"
  - Reacting to stimuli without considering first… "See the cupcake-want the cupcake-take the cupcake"
  - What would the automatic response be to a stimulus?

  - **Eating**
    - Non-edibles (e.g., Styrofoam cups)
    - Over-eating
    - Hot cookies right off the baking sheet
    - other people's food at mealtime

  - **SEXUAL disinhibition** – "you are the cupcake"

Behavioural Strategies: Disinhibition

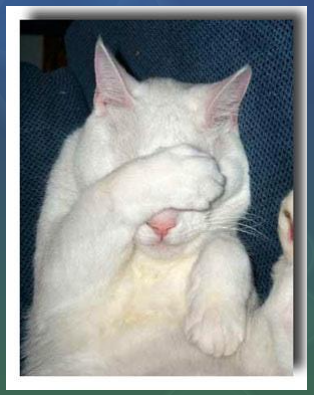
- Be mindful of "releasing Stimuli"- what will capture this person's attention?
  - Where is the resident situated at meals? At Activities?
  - What are you wearing?
  - Where are you standing?
- Carry out cares efficiently
  - Your pace may need to match the person's attention span
  - Choose clothing that limits access if the person is incontinent and disempacting"
- Use foods as an enjoyable, perseverative activity
  - If safe, use finger-food snacks that can be consumed over a longer period of time – e.g., a bowl of Cheezies

Behavioural Symptoms…2

- Loss of Social Judgment
  - Making inappropriate social comments/humour
  - Staring
  - Intrusion into personal space
  - Peering into another person's room: is there something in this room for me?
- Emotional blunting
  - Apathy
  - Lack of empathy

Behavioural Strategies: Poor Social Judgment

- **Don’t take it personally!**
  - Don’t be embarrassed by a comment
  - Don’t think you’re being “targeted’ or that it was done on purpose.
  - Don’t get angry – step away/have someone sub-in for the moment to re-compose



- Redirect
  - Use redirection to move a patient from an inappropriate/unsafe activity to a new activity
  - Can be a favourite conversation topic, something to look at, something to do – have a go-to list of things on your “**redirection strategies list**”

Behavioural Symptoms…3

- Being constantly on –the-move/restless, can't stay on task for long (attention)

Behavioural Strategies: Short Attention/Restlessness

- Identify list of enjoyable activities
  - What are **currently enjoyed** activities?
  - **How long** can the person engage in these?
  - **How much support** does the person need to engage in these activities?
  - How can **current cognitive and behavioural status** be utilized to client's advantage?
  - What does the person's **typical week** look like?
    - Is there a variety of activities?
    - Are there enough activities to make days meaningful and interesting?

When a family member makes the decision to place someone in LTC

- What caring for someone with FTD at home looks like… and making the transition

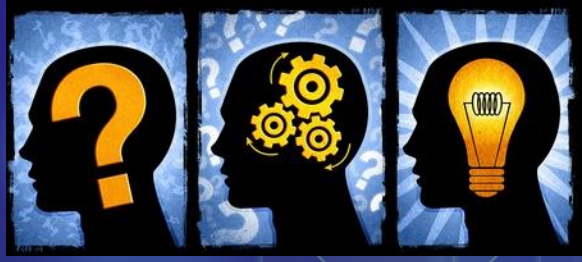
- A brief Video

https://www.youtube.com/watch?v=v_OFfqw_dFw

Caregivers' Hopes in LTC

- Don't give up on this person!
- Try doing things "in the moment" – even 5 minutes of doing an activity that brings out joy is so meaningful!

Final thoughts



- The person with a Frontal Dementia is much more than their diagnosis. Utilize all their information in your treatment planning.
- Be mindful of your non-verbal responses.
- Remember that FTD is a brain disorder - the behaviours that may catch you off guard, are the result of the disease - check your own feelings and responses
- The family is an important team member with hopes for their loved one who is now in your care.
- Remember to tailor your care strategies and programming to the needs of the person including those needs resulting from FTD.

Thank you -

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Questions?